

# **Review of Respite Services and Short-Term Breaks for Carers for People with Dementia**

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***Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)***

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## **Executive Summary**

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### **Background**

It is estimated that dementia currently affects approximately 600 000 people in the UK, a figure that is increasing. The majority of older people with dementia are cared for at home by a relative or friend. The emotional and psychological impact that dementia has on patients suffering from the condition leads in turn to stress on carers, whose practical needs for support and alleviation of emotional stress are especially high. Respite care and short-term breaks are widely regarded as a key intervention to reduce the stress of caring. The Carers Special Grant, first introduced in 1999 as part of the national strategy for carers, makes ring-fenced monies available to local authorities for the enhancement of services to allow carers to take a break from caring. Given the rising numbers of dementia sufferers, the key role of respite services and the policy emphasis on improving services, the identification of service models that benefit carers of people with dementia, and care recipients themselves, is essential.

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### **Objectives of the study**

The study aimed to establish the current state of knowledge about the effectiveness and cost-effectiveness of respite services and short breaks for carers for people with dementia. The overall aim encompassed six objectives:

- to identify the range of services available for carers,
- to examine evidence from national and international published and grey (unpublished) literature about effectiveness and cost-effectiveness of respite services for carers of people with dementia,
- to develop existing conceptualisations of 'effectiveness' and 'cost-effectiveness',
- to ensure the views of key stakeholders were central to the literature review,
- to identify examples of good practice,
- to advise on areas of priority for further research.

The report presents the findings from the literature review and consultation with representatives from national statutory and voluntary organisations, and carers.

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### **Research methods: literature review**

The aim of the literature review was to identify all studies published since 1985 that could help answer the central review question: what is known from

the existing literature about the effectiveness and cost-effectiveness of respite services and short-term breaks for carers for people with dementia? 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 2287; 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 a Microsoft 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.

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## Research methods: consultation

Key individuals from 20 statutory and voluntary organisations contributed to the consultation. The information they provided helped to identify four areas of the country with respite services providing examples of good practice. Focus groups and telephone interviews were then conducted with carers who were current or recent users of respite services in these four locations. The consultation aimed:

- to set the context for examining gaps in the literature,
- to help indicate the relevance of the literature-review findings to current policy and practice in the NHS,
- to examine whether the outcomes that carers and carers' representatives value are the same as, or similar to, those used in the research literature,
- to help identify respite services and projects that are regarded as innovative.

At key points in the review process, the research team benefited from the advice of members of an Expert Reference Group, comprising professionals and 'key informant' carers.

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## Key findings: literature review

The evidence from the studies included in the review was mixed and at times contradictory. Overall, however, the review found that on the basis of the outcome measures used and on the service that was offered, evidence of the effectiveness and cost-effectiveness of respite care and short-term breaks is limited. In contrast, there was considerable qualitative evidence from carers (and some from care recipients) of the perceived benefits of the use of respite services. It would be wrong to assume that lack of evidence of effectiveness should be interpreted as evidence that respite is ineffective. This is a very complex area; methodologically, undertaking studies of respite services is

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particularly challenging. The review identified the following key points in respect of the different types of respite care available.

### ***Day care***

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, problems relating to day-care attendance acted as barriers to usage for some carers.
- 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 the activities provided.
- The 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, yet others showed no change.
- The evidence about the impact on people with dementia of day-care attendance was unclear. Some studies showed improvements or stabilisation, whereas others showed no positive effects.
- The mixed results are likely to reflect issues such as: weaknesses/differences in study design, the wide range of outcome measured used, study timescales, differences and/or deterioration in disease severity and differences in the frequency and amount of day care used.
- 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 be cost-saving whereas two suggested that day care might provide greater benefits but at a higher cost as compared to standard care. All four studies suggested that the benefits of day care might be similar to, or greater than, those achieved through standard care.

### ***In-home respite***

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

- Carers reported high levels of satisfaction with in-home respite services; satisfaction appeared to be closely linked to their perceptions of the benefits that the service bought to their relative, and the quality of care provided.
- Carers reported that they would have liked the service more often, and liked visits to last longer as the relatively short periods of respite constrained the type of activities they could undertake.

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- None of the studies were able to demonstrate statistically significant positive effects of in-home respite on a range of measures.
- The evidence suggested that in-home respite could assist in maintaining family routines, and roles, and the dementia sufferer's sense of self.
- It is difficult to separate the impact of in-home respite on the demand for other types of respite care, or in reducing or delaying entry into long-term care as most carers in these studies were accessing a range of different services.
- No evidence was retrieved in relation to cost-effectiveness of in-home respite.

### ***Host-family respite***

Host-family respite gives 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 host-family respite was effective in addressing the needs of carers and care recipients.
- Carers reported positive 'outcomes', 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.
- Host-family respite is a means of meeting the needs of those carers and care recipients who want to spend time together.

### ***Institutional/overnight respite***

Institutional/overnight respite 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 institutional/overnight services.
- Institutional and overnight services were seen to help in some way, but other short-term breaks were seen as more beneficial to the care recipient.
- Standards of care and quality of service influence use of services. There was some evidence that care recipients returned home in a worse state, but also that medical conditions could be diagnosed during breaks.
- Although some carers experienced guilt in using services, others reported that services helped them to continue in their caring role.
- There appeared to be a major benefit to sleep, with increased and better-quality sleep.
- There was mixed evidence on the impact of services in relation to activities of daily living, behaviour and dependency, but it is difficult to unravel the potentially negative effects of respite from the natural progression of the disease.

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- There was little evidence that services reduced the demand for long-term placements.

### **Respite programmes**

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

- Respite programmes might reduce carer burden, depression and carers' reported health problems.
- There might be differential impact of respite care reflecting the characteristics of the person with dementia.
- Time freed up was likely to be spent catching up on chores rather than leisure activities.
- Patients were as likely to maintain or improve in physical and cognitive functioning as to decline.

### **Multi-dimensional carer-support packages**

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

- A common thread was that there were no demonstrable lasting improvements carers' health and well-being.
- Whereas some carers believed they themselves had benefited, they were less positive about gains for people with dementia.
- The 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 institutional care.
- Only a single economic evaluation had been conducted in this field. The cost per quality-adjusted life year (QALY)<sup>1</sup> of the support package was reported to compare favourably with other health-care interventions and might therefore present value for money.

### **Video respite**

Video respite uses a tailored video to occupy the care recipient's attention, thus freeing up the carer's time for a mini-break.

- The tape was well received by carers and care recipients, and was used regularly to create respite time.
- There was greater participation in video respite when it was watched alone by individuals, rather than in a group setting.

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<sup>1</sup>The QALY is a measure of health outcome that simultaneously captures changes in mortality (a quantity issue) and changes in morbidity (a quality issue), aggregating them into a single, numeric measure.

## Key findings: consultation

There was little divergence between the views of representatives from national bodies and carers; many of the issues raised in the national interviews were illustrated by the carers' experiences.

In terms of the overall state of respite care and short-term breaks, many carers still have only limited access to a break from caring, although the picture varies significantly across the country. There was felt to be a need 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.

Many contributors felt that more innovative services were being developed in some areas of the country, in part due to recent government policy in relation to carers. The Health Act 'flexibilities', and the emergence of Care Trusts and Partnership Trusts, were perceived to be leading to some interesting innovations, as was the requirement in the National Service Framework (NSF) for Mental Health 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 and the 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. Finally, the introduction of direct payments and voucher schemes was welcomed as a way of increasing the flexibility of respite provision.

The consultation highlighted many of the barriers faced by providers delivering respite care. These included major difficulties in recruiting and retaining staff with the right skills, knowledge and attitude. The significant cost constraints which many services work within were also felt to affect their ability to respond to carers' needs in a flexible and individualised manner. There was concern that the Best Value tendering process could stifle innovation by insisting that services fit into social services' categories and, in general, contributors called for better co-ordination between commissioners and providers.

The consultation also explored contributors' views about the ways in which the effectiveness and cost-effectiveness of respite service could be measured. There was agreement that respite is complex and that a range of measures are needed which would encompass the following.

- 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.

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- Quantitative measures based on long-term cost-effectiveness analysis of the impact of respite care on service usage by both carer and care recipient.

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 focus groups and interviews with carers revealed much about the factors or characteristics which are important in delivering effective respite services. These can be grouped together into the following seven 'underpinning' factors:

- knowledgeable and supportive doctors,
- appropriate management of the condition,
- responsive social services,
- fair and understandable benefits/charging systems,
- supportive carers' networks,
- helpful family, friends and neighbours,
- well-coordinated services.

The consultation also suggested that for short-term breaks to be effective, they not only need to be underpinned by these seven factors but also need to display a number of key characteristics, which are in effect drivers (rather than measures) of effectiveness. These characteristics indicate that the most effective respite service is likely to 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.

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## **Policy implications**

- The 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, for instance 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 into service provision.
- Quality standards may need strengthening in order to reduce variability in the quality of, and access to, services.



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- 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 on-going training and development, is important.
- 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.
- If the new Carers (Equal Opportunities) Bill becomes law, this will have implications for the development and promotion of respite services for carers of 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.

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## Recommendations for further research on respite services

- *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 the regional availability, quality and appropriateness of short-term breaks for carers for younger people with dementia, black and ethnic-minority carers and carers of people with Down's syndrome and dementia.
- *Organisational context.* Research into the organisational context and service configurations of respite-care provision.

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## Recommendations for improving research methods

- *Outcome measures.* Research to establish the appropriateness of different outcome measures to help gauge whether or not a service is effective.

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- *Pluralistic evaluations.* Evaluation studies that adopt multiple methods, take account of a broad range of potential outcomes and reflect the views of all key stakeholders.
- *Views of carers and people with dementia.* Studies that not only use outcome measures to collect quantitative data, but also collect qualitative data that provides in-depth information about the experiences and views of carers and people with dementia who use, and do not use, respite care and short-term breaks.
- *Comparative studies.* Comparative data exploring: cost-effectiveness; variations in different types of respite care provision for different groups of carers and care recipients between different geographical areas; which different types of short-term break best meet the needs of black and ethnic-minority carers, carers supporting younger people with dementia and carers of people with Down's syndrome and dementia; spouse carers and adult children caring for elderly parents; the impact of rural and urban settings on access to, and provision of, respite.
- *Longitudinal studies.* Longitudinal studies to help determine the medium- to long-term effects of respite on carers and care recipients.
- *Reporting of studies.* Studies that report much greater detail about the context of the service, including information about the amount of respite received (frequency and duration), staffing issues, accommodation, facilities provided and available activities.
- *Primary research.* Studies that are powered to detect a true difference in costs and effects across comparator interventions would provide more-robust information to policy-makers. Also, in order to include appropriate outcome measures within studies more clarity is needed as to what constitutes *effective respite care*. If policy-makers are interested in obtaining information on the cost-effectiveness of interventions then it would be useful to conduct more economic evaluations along side effectiveness studies in this field.
- *Modelling.* The reporting of summary statistics of patient-level data in primary studies would enhance the potential to undertake secondary analysis of the data.

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## Dissemination and implementation of research findings

It is important that continued efforts are made to improve the dissemination and implementation of existing and future research evidence, particularly the publication and wide distribution of 'reader-friendly' summaries of research.

**Disclaimer**

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health

**Addendum**

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