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# **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)***

***July 2004***

prepared by

Hilary Arksey\*

Karen Jackson\*

Karen Croucher†

Helen Weatherly‡

Su Golder§

Philippa Hare¶

Elizabeth Newbronner¶

Sally Baldwin\*\*

\* Social Policy Research Unit, †Centre for Housing Policy, ‡Centre for Health Economics, §Centre for Reviews and Dissemination, ¶Acton.Shapiro, \*\* Department of Social Policy and Social Work

Address for correspondence

Hilary Arksey

Social Policy Research Unit, University of York, Heslington, York, YO10 5DD

E-mail: [ha4@york.ac.uk](mailto:ha4@york.ac.uk)

Telephone: 01904 321950

## Contents

<b>Acknowledgements</b>	<b>6</b>
 <b>Executive Summary</b>	
<i>Background</i>	7
<i>Objectives of the study</i>	7
<i>Research methods: literature review</i>	7
<i>Research methods: consultation</i>	8
<i>Key findings: literature review</i>	8
<i>Key findings: consultation</i>	12
<i>Policy implications</i>	13
<i>Recommendations for further research on respite services</i>	14
<i>Recommendations for improving research methods</i>	14
<i>Dissemination and implementation of research findings</i>	15
 <b>The Report</b>	
<b>Section 1 Introduction</b>	<b>16</b>
1.1 <i>Introduction</i>	16
1.2 <i>Background</i>	16
1.3 <i>Aims and objectives of the study</i>	19
1.4 <i>Challenges</i>	20
1.5 <i>Structure of report</i>	23
1.6 <i>Terminology and definitions</i>	23
<b>Section 2 Research methods</b>	<b>24</b>
2.1 <i>Introduction</i>	24
2.2 <i>The review question</i>	24
2.3 <i>Generic literature review</i>	24
2.3.1 <i>Search strategy</i>	24
2.3.2 <i>Study selection</i>	26
2.3.3 <i>Strength of evidence</i>	28
2.3.4 <i>References retrieved in generic literature review</i>	31
2.4 <i>Economic-evaluation literature review</i>	34
2.4.1 <i>Study selection</i>	34
2.4.2 <i>Economic-evaluation references retrieved</i>	34
2.5 <i>Consultation</i>	36
2.5.1 <i>Interviews with national organisations</i>	37
2.5.2 <i>Local consultation with carers</i>	37
2.6 <i>Expert reference group and workshop</i>	39
2.7 <i>Reporting the findings</i>	39
<b>Section 3 Scoping the field: initial mapping</b>	<b>42</b>
3.1 <i>Introduction</i>	42
3.2 <i>Geographical distribution of evaluation studies</i>	42
3.3 <i>Types of respite service and short-term break</i>	43
3.4 <i>Geographical distribution of evaluation studies according to type</i>	44
3.5 <i>Distribution of studies according to characteristics of care recipients and carers</i>	45
3.6 <i>Type of research design used</i>	45

## **Review of respite services for carers for people with dementia**

3.7 Measures of effectiveness and cost-effectiveness	47
3.8 Summary of characteristics of available research	48

### **Section 4 Evidence from the literature review about the effectiveness and cost-effectiveness of respite services and short-term breaks 49**

4.1 Introduction	49
4.2 Day-care services	50
4.2.1 Introduction	50
4.2.2 Overview of studies	50
4.2.3 Evidence on the effectiveness and cost-effectiveness of day-care services	52
4.3 In-home respite services	62
4.3.1 Introduction	62
4.3.2 Overview of studies	62
4.3.3 Evidence on the effectiveness and cost-effectiveness of in-home respite	63
4.4 Host-family respite	68
4.4.1 Introduction	68
4.4.2 Overview of studies	69
4.4.3 Evidence on the effectiveness of host-family respite	69
4.5 Institutional/overnight respite services	71
4.5.1 Introduction	71
4.5.2 Overview of studies	71
4.5.3 Evidence on the effectiveness of institutional/overnight services	72
4.6 Respite programmes	79
4.6.1 Introduction	79
4.6.2 Overview of studies	79
4.6.3 Evidence on the effectiveness and cost-effectiveness of respite programmes	79
4.7 Multi-dimensional carer-support packages	82
4.7.1 Introduction	82
4.7.2 Overview of studies	82
4.7.3 Evidence on the effectiveness and cost-effectiveness of multi-dimensional carer-support packages	83
4.8 Video respite	86
4.8.1 Introduction	86
4.8.2 Overview of studies	86
4.8.3 Evidence on the effectiveness of video respite	87

### **Section 5 Findings from the consultation about respite services and short-term breaks 89**

5.1 Introduction	89
5.2 The overall state of respite services and short-term breaks for carers	90
5.3 The impact of recent policy developments	91
5.4 The barriers faced by providers	92
5.5 Measuring effectiveness and cost-effectiveness	93
5.6 What underpins an effective respite service and short-term break?	95
5.7 What are the characteristics of an effective respite service and short-term break?	100
5.7.1 Recognising the importance of assessment and on-going review	100
5.7.2 Meeting the needs and circumstances of the carer	101

## **Review of respite services for carers for people with dementia**

5.7.3	<i>Ensuring services are tailored to the age, culture, condition and stage of illness of the care recipient</i>	104
5.7.4	<i>Maintaining or improving the well-being of the care recipient</i>	105
5.7.5	<i>Recognising the importance of appropriately trained and caring staff</i>	105
5.7.6	<i>Understanding the significance of 'affordable' services</i>	106

## **Section 6 Review summary, implications for policy and recommendations for further research and improving research designs**

		<b>108</b>
6.1	<i>Introduction</i>	108
6.2	<i>Overview of results</i>	108
6.2.1	<i>Benefits to carers</i>	109
6.2.2	<i>Benefits to care recipients</i>	113
6.2.3	<i>Impact on use of other services</i>	116
6.2.4	<i>Cost-effectiveness of respite services</i>	118
6.3	<i>Gaps and weaknesses in the evidence base</i>	119
6.3.1	<i>Gaps</i>	119
6.3.2	<i>Methodological and quality issues</i>	120
6.4	<i>Policy implications</i>	122
6.5	<i>Recommendations for further research on respite services</i>	124
6.5.1	<i>New respite services and short-term breaks</i>	124
6.5.2	<i>Alternative forms of respite service and short-term break</i>	125
6.5.3	<i>Respite care and other community care services</i>	125
6.5.4	<i>Amount of respite care</i>	126
6.5.5	<i>Respite services for specific groups of carers of people with dementia</i>	126
6.5.6	<i>Organisational context</i>	126
6.6	<i>Recommendations for improving research methods</i>	126
6.6.1	<i>Outcome measures</i>	126
6.6.2	<i>Pluralistic evaluations</i>	127
6.6.3	<i>Views of carers and people with dementia</i>	127
6.6.4	<i>Comparative studies</i>	127
6.6.5	<i>Longitudinal studies</i>	127
6.6.6	<i>Reporting of studies</i>	128
6.6.7	<i>Primary research</i>	128
6.6.8	<i>Modelling</i>	128
6.7	<i>Dissemination and implementation of research findings</i>	128
	<b>References</b>	<b>129</b>

## **Appendices**

<b>Appendix 1 Search strategy for generic and economic literature reviews</b>	<b>136</b>
<b>Appendix 2 Databases searched</b>	<b>139</b>
<b>Appendix 3 Data-extraction form</b>	<b>140</b>
<b>Appendix 4a Summary of studies/ articles included in the generic review</b>	<b>143</b>
<b>Appendix 4b Economic evaluations of support services for carers for people with dementia</b>	<b>160</b>
<b>Appendix 5 Representatives of national organisations consulted</b>	<b>163</b>
<b>Appendix 6 Telephone interview schedule: consultation with national bodies</b>	<b>165</b>
<b>Appendix 7 Topic guide for carers' groups</b>	<b>166</b>
<b>Appendix 8 Telephone interview schedule: consultation with carers</b>	<b>167</b>

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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

## ***Review of respite services for carers for people with dementia***

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 brought 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.

## ***Review of respite services for carers for people with dementia***

- 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.

## ***Review of respite services for carers for people with dementia***

- 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.

## ***Review of respite services for carers for people with dementia***

- 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.

## ***Review of respite services for carers for people with dementia***

- 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.

## **Review of respite services for carers for people with dementia**

- *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.



# The Report

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## Section 1 Introduction

### 1.1 Introduction

This review of respite services and short-term breaks for carers for people with dementia builds on an earlier scoping study undertaken for the NHS Service Delivery and Organisation (SDO) Research and Development Programme (Arksey *et al.*, 2002a, b; Newbronner and Hare, 2002). The scoping study mapped the literature relating to the effectiveness and cost-effectiveness of services to support carers of people with mental health problems. Eighteen per cent (36 out of 204) of the studies included in the scoping review focused on breaks from caring of one sort or another. Of these, nearly three-quarters involved breaks for carers for people with dementia.

Given that a major component of a scoping study is to 'map' or identify the literature that currently exists in the field of interest (Mays *et al.*, 2001) rather than address the issue of quality of individual studies, the review did not seek the 'best evidence' (Slavin, 1995). The analysis did suggest, however, that the evidence on the effectiveness and cost-effectiveness of services was inconclusive, and sometimes contradictory (Arksey *et al.*, 2002a, b). The scoping study also indicated that outcome measures commonly adopted in evaluations, such as changes in carers' psychological health (for example levels of distress, burden or strain), did not capture the levels of satisfaction with services reported by carers. Current thinking recognises the need for a wider methodological approach to evaluating the effectiveness of services (Moriarty, 1999; Arksey *et al.*, 2002a, b; Ryan *et al.*, 2002).

The present study was commissioned to take forward this earlier work; our specific remit was to examine the evidence for the effectiveness and cost-effectiveness of respite care and short-term breaks for carers for people with dementia. This report presents the findings.

### 1.2 Background

Dementia is estimated to affect about 600 000 people in the UK (Department of Health (DH), 2001). This represents five per cent of the total population aged 65 and over, rising to 20 per cent of the population aged 80 and over. By 2026, the number of sufferers is expected to grow to 840 000, and to have reached 1.2 million by 2050. The prevalence of dementia increases with age. It is 0.1 per cent for people aged 40–60, around two per cent for the 65–70 age group, and up to 20 per cent for people over the age of 70 (Melzer *et al.*, 1994). Alzheimer's disease is the most common form of dementia, causing up to 60 per cent of cases of dementia (DH, 2001). Vascular dementia and dementia with Lewy bodies causes up to 20 per cent and 15 per cent of dementia cases respectively. The prevalence of dementia is much higher among older adults with learning disabilities than in the general population

## **Review of respite services for carers for people with dementia**

(21.6 per cent as opposed to 5.7 per cent; reported in Elliott *et al.*, 2003). People with Down's syndrome are at a particularly high risk of developing dementia, with an age of onset some 30–40 years earlier than the general population.

The majority of older dementia sufferers are cared for at home by a relative or friend (Watkins and Redfern, 1997). The average age of informal (unpaid) carers is between 60 and 65 years, and many are much older. Caring for someone with dementia is different from caring for people affected by other types of disability. This is because of the complex, unpredictable and progressive nature of the illness (Alzheimer Scotland, Action on Dementia, 1995). Dementia has a profound emotional and psychological impact on sufferers themselves, leading in turn to stress on carers. Carers of people with dementia are likely to have higher than normal levels of stress and burden, and report higher levels of depression (Wills and Soliman, 2001). Consequently, carers' practical needs for support, as well as needs in relation to relieving the emotional stress of caring, are especially high (DH, 1999a).

A number of policy initiatives, including the National Strategy for Carers (DH, 1999a), the Carers and Disabled Children Act 2000 and the National Service Frameworks (NSFs) for Mental Health (DH, 1999b) and for Older People (DH, 2001), aim to support carers and improve carers' services. The national strategy document, *Caring about Carers*, sets out the government's aims to help carers take a break from caring (DH, 1999a). An accompanying document, *A Real Break*, provides a guide for good practice in the provision of breaks for carers (Weightman, 1999).

Breaks can be provided in the home or in other settings. Care at home may include day and night sitting services, or input from a support worker or nursing assistant. Care away from home may include day centres, weekend respite schemes, mobile centres in rural areas, holiday respite care or short-term respite care in residential or nursing homes, hospital or specialist short-stay units or family break schemes. Some schemes enable the carer and care recipient to have a break away or a night out together. Service providers include health and social services, and the voluntary and independent sectors.

There is no consensus regarding the overall aim of respite care and short-term breaks. In the past, such services have served different purposes including to give carers a break from caregiving, to prepare carers and care recipients for the latter's entry to long-term care and to prevent institutionalisation. In the UK, the government endorses the view that the primary objectives of respite care are to relieve carers of caring responsibilities in the short-term, while offering a positive experience for the care recipient (Weightman, 1999). Carers are now entitled to an assessment of their needs (even if the person they care for refuses an assessment themselves) under the Carers and Disabled Children Act 2000. This offers the opportunity for respite care and short-term breaks to be used as a preventive measure rather than being not provided until a crisis situation has developed (Jewson *et al.*, 2003).

## **Review of respite services for carers for people with dementia**

As part of the national strategy for carers, the government introduced the Carers Special Grant in efforts to promote independence through the prevention of illness, disability or disease (DH, 1999c). The Carers Special Grant made ring-fenced monies available to local authorities for the enhancement of services to allow carers to take a break from caring. The grant totalled £140 million for England over three years (£20 million in 1999/2000; £50 million in 2000/2001; £70 million in 2001/2002), and has since been renewed on a regular basis. The current extension is up to 2006, and the level of funding has been increased to £185 million. However, the ring-fencing element was removed in April 2004.

The Carers Special Grant was designed to stimulate diversity and flexible provision to meet individual needs, and in this way provide supportive services to help carers maintain their health and relieve stress. However, studies from the King's Fund (2001), Carers UK<sup>2</sup> (Macgregor, 2000) and Crossroads – Caring for Carers (2000) suggested that the Carers Grant did not lead to a significant increase in the range and quality of breaks provided in its first two years of operation. Whereas the Grant went some way towards promoting and realising flexible breaks for carers, local implementation varied and relatively few carers were benefiting compared with the probable unmet need (King's Fund, 2001). Furthermore, research showed there was a particular gap in relation to developments for respite services targeting carers from black and ethnic-minority communities (Hepworth, 2001).

At the time of the present review, the Carers Special Grant has been available for over three years. The Community Dementia Support Service in Sheffield (Ryan *et al.*, 2002) is an example of a new respite care development that reflects the requirement for person-centred care, as set out in the NSF for Older People (DH, 2001) and the new government standards for respite provision (DH, 2000).

Under the provisions of the Carers and Disabled Children Act 2000, local authorities were given the power to develop voucher schemes from October 2001. The intention was that local authorities could issue vouchers so that carers, care recipients and those with parental responsibility for disabled children could have short-term breaks. Vouchers can have either a time or monetary value to allow maximum flexibility, and are seen as being halfway between direct payments and direct services provided by or on behalf of the local authority (DH, 2003). As yet, voucher schemes are not fully developed in many social services departments, and pilot schemes are reported to be running into difficulties due to a lack of services against which vouchers can be redeemed (Revans, 2001).

Respite care is regarded as one of the key formal support interventions to alleviate the stress of caring (Rudin, 1994; Strang and Haughey, 1998); it is also a service that carers have identified as critical to their caring efforts (Cotrell and Engell, 1998). Contradictorily, respite and short-term breaks are known to have low utilisation rates (Cohen-Mansfield *et al.*, 1994; Toseland *et al.*, 2002). This might reflect the fact that carers and care recipients often feel

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<sup>2</sup>Formerly the Carers National Association.

## **Review of respite services for carers for people with dementia**

they have little choice in what is available (Social Services Inspectorate, 2000). Furthermore, some carers see conventional respite services as ill-suited to the needs of the care recipients (Frost, 1990; Katbamna *et al.*, 1998; Jewson *et al.*, 2003).

Given the growing numbers of people with dementia, the important role of respite services and the policy emphasis on improving these services, the identification of service models that provide beneficial breaks from caring for carers of people with dementia is essential.

### **1.3 Aims and objectives of the study**

The overall aim of the present review is to establish the current state of knowledge about the effectiveness and cost-effectiveness of respite services or short-term breaks for carers for people with dementia. Within this overall aim, the study has six key objectives.

- To identify the full range of respite services for carers for people with Alzheimer's disease and other forms of dementia, including younger people with dementia.
- To examine the evidence from published and grey literature (both national and international) about effective and cost-effective respite services for carers for people with dementia.
- To ensure that the views of key stakeholders are central to the literature-review element of the study and inform its findings and recommendations.
- To further develop existing conceptualisations of 'effectiveness' and 'cost-effectiveness' specifically in relation to respite services for carers for people with dementia.
- To identify examples of good practice of respite care and short-term breaks in health and social services, as well as the voluntary and independent sectors, for carers for people with dementia.
- To advise the SDO which areas should be a priority for further research, having identified key gaps in the evidence base.

This report documents the findings from the literature review and the consultation. The review is based on evidence from 45 studies, reported in a total of 52 different articles and/or books (see Section 3 for an explanation of the discrepancy in the figures). Based on the evidence from the review and the accounts collected during the consultation with professionals and focus groups with carers, the report provides an in-depth analysis of available evidence on respite care and short-term breaks, as well as identifying areas of good practice and areas where further research is required and how these areas may be addressed. The findings will provide substantive knowledge that can be disseminated within the UK, and in particular to those working in health and social care services, and the voluntary sector.

## **1.4 Challenges**

Undertaking evaluation studies of the effectiveness and cost-effectiveness of respite care and short-term breaks for carers for people with dementia is challenging. At this point, it is useful to identify some of the complexities involved. In particular, contextual issues relating to service provision, carers and care recipients, and the disease itself present a myriad of challenges that need to be kept in mind when assessing the evidence base on respite support for the carer.

As noted above, respite services often lack clearly defined objectives, making evaluation difficult, and it is not always clear whether the service is intended to benefit carers and/or care recipients or indeed other stakeholders. Carers themselves are very different, and it is erroneous to talk about 'carers' as if they were one homogeneous group with similar needs and living in similar circumstances. Generally, they comprise the care recipient's relatives and/or friends, so the outcomes of any form of support need to be assessed in the light of these relationships. As Mason (2003) states 'the relationship between carer and patient is a close one, reflected by the terminology for the partnership, the (carer-patient) 'dyad'. Dementia can impair people's ability to judge what is in their own best interests, so choices about preferred care can be problematic to elicit. As a result of the carer-patient dyad, the values and interests of the two parties may be interdependent. Deciding what works best for whom is not clear-cut.

There are a number of different types of dementia, as pointed out earlier, and the clinical picture on dementia is complicated by the fact that the disease process is varied. Different care recipients are likely to be at different stages of the disease trajectory, and service provision for the person with dementia should reflect this. What is certain though, is that dementia is a chronic condition and, at this point in time, irreversible. No effective treatments exist and pharmaceutical approaches do not present a panacea; however, the effects of medication may impact on the effectiveness of social care support in this population.

In the absence of definitive evidence on the benefits of medications, non-pharmaceutical approaches, including the quality of the environment in which people with dementia live, gain more importance (Keen, 1992). Potentially, respite care and short-term breaks have a key role to play in sustaining the health, well-being and quality of life for the carer and the care recipient. However, outcomes of respite care (and other support services) may be influenced not only by the intervention itself, but also by the way in which it is delivered. The relationship between interventions and outcomes is rarely based on well-specified pathways, and instead can be more like a 'black box'. Moreover, respite care is often just one component part of a comprehensive support package, so potentially the impact of the service on the carer and/or the care recipient is open to yet more confounding influences.

As well as challenges reflecting the context within which short-term breaks are provided, there are also a number of methodological difficulties for researchers trying to assess the impact of short-term breaks on carers and care recipients. Previous reviews of respite programmes and/or individual

## **Review of respite services for carers for people with dementia**

respite services report that the results of studies are ambiguous, or that they do not consistently show positive effects relating to carers' health or well-being (Deimling, 1991; Flint, 1995; Zarit *et al.*, 1998; Roberts *et al.*, 2000). However, it is acknowledged that not being able to demonstrate that respite can help carers may be a reflection of weaknesses in the research design and/or measurement (Zarit *et al.*, 1998). A detailed critique focusing on evaluations of respite services and short-term breaks is provided by Zarit *et al.* (1998), points that are all reflected extensively in the wider literature. Criticisms by Zarit and colleagues (1998), and other commentators, relate to the following methodological issues, elaborated below: outcome measures; control groups; study sample; baseline measurements; prior/other service use.

*Outcome measures.* Instruments are not always sensitive enough to detect the psychological effects of respite care, and/or changes in effects over time. A related point is that the range of outcome measures used might not be broad enough to capture all the effects of respite care. For instance, some studies may employ only instruments that measure carer stress, whereas others may use ones that measure psychological well-being, and yet others may employ both types.

*Control groups.* If no control groups are included in an evaluation, then studies are not able to assess changes in, say, carers' levels or stress and well-being that could have occurred without the treatment. When control groups are included, however, it is sometimes the case that carers in the control group are in receipt of services similar to those used by the study group. To give an example, in Lawton *et al.*'s (1991) study of the Multi-Service Respite Service Demonstration Project based at the Philadelphia Geriatric Center, designed specifically for families caring for people with Alzheimer's disease and related disorders, some carers in the control group were using respite services under their own initiative in amounts very similar to those being used by carers in the study group.<sup>3</sup> The resulting comparison between the study group and the control group was then diluted in terms of showing large differences in stress and well-being.

*Study sample.* If sample numbers are low, they may be too small to detect any statistically significant findings or to make meaningful sub-sample comparisons. Samples may be prone to selection bias, for example white carers, female carers, highly educated carers, carers linked into particular support networks, such as national or local Alzheimer's groups, or carers from one geographical area. There can be high attrition rates in longitudinal studies due to carers stopping using the service, institutionalisation or the death of the care recipient.

*Baseline measurements.* Studies may not assess carers' stress, well-being and other psychological states before the start of the use of respite services and short-term breaks. Consequently, there is no baseline measurement against which to determine the amount of change that has occurred as a

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<sup>3</sup>Carers in the study group averaged ten days of day care over the 12-month study period, 63 hours of in-home respite and 11 days of nursing home respite. A substantial number of families did not use respite services at all.

## **Review of respite services for carers for people with dementia**

result of using respite care. Furthermore, studies may not include patient measures such as their illness severity stage.

*Prior/other service use.* Some studies do not take into account the level of services used by carers (or people with dementia) prior to participation in the respite service under evaluation. This means that the effects of service use might have already got underway, and it is hard to disentangle the effects of the different services. Likewise, respite care is often just one component in a comprehensive package of community care and studies may not necessarily try to disentangle the impact of the different elements making up the support package.

Clearly, the challenges of undertaking evaluation studies are considerable, yet that is not to say that they should no longer be commissioned. Here, it is worth drawing on the scoping study on services to support carers of people with mental health problems (Arksey *et al.*, 2002a). This literature-review report discussed key points about effectiveness and cost-effectiveness that had a bearing on future research commissioning, and which have relevance when applied to the narrow field of dementia. We do not intend to rehearse those issues in detail again, suffice to say that the analysis highlighted the complexity of both defining and operationalising these two concepts in evaluation research.<sup>4</sup> Briefly, the scoping study came to the conclusion that questions to be considered when designing (cost-)effectiveness studies include:

- *whose perspective is to be prioritised:* multiple stakeholders are involved – carers, care recipients, health and social care professionals – and views about effectiveness are likely to differ accordingly. This feeds back into the related question of whose perspectives should be included in the design of interventions themselves.
- *which specific aspects of service delivery are to be evaluated:* a concentration of the final outcomes of services can be at the expense of learning more about the positive and negative features of the structure and process and of the intervention.
- *what is the duration of follow-up for the study:* carers, and care recipients, have different and/or changing needs that may or may not be met, depending on timescales.
- *whether the intervention adopts a needs-based approach:* the effectiveness of a 'generalised' service is determined by the individual characteristics and circumstances of the carer and/or care recipient.
- *whether the intervention provides value for money:* resources used and costed, as well as relevant effects, differ according to the perspective of the analysis. Sound methodological principles on which to base new economic evaluations were provided in the scoping study.

We return to these complex issues in the final section of this report (Section 6), where we draw on the findings from the present review to make

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<sup>4</sup>For readers who are interested in the issues raised and ideas discussed, see Section 6 of the literature-review report (Arksey *et al.*, 2002a) and also Mason (2003).

suggestions for improving research designs specifically examining respite services and short-term breaks for carers for people with dementia.

## **1.5 Structure of report**

The report is organised as follows:

- Section 2 discusses the methods adopted for the literature review and consultation.
- Section 3 contains a breakdown of the studies/articles reviewed in terms of geographical distribution, range of respite care and short-term breaks, characteristics of carers and care recipients, research designs adopted and measures of effectiveness and cost-effectiveness.
- Section 4 reports the evidence on the effectiveness and cost-effectiveness of different types of short-term break as follows: day-care services, in-home respite, host-family respite, institutional/overnight respite, respite programmes, multi-dimensional carer-support packages and video respite.
- Section 5 presents data from the consultation, including both interviews with representatives of national organisations and focus groups with carers.
- Section 6 includes an overview of key findings from the literature review and consultation, as well as recommendations for further research and improvements to research designs.

## **1.6 Terminology and definitions**

For the purposes of the report, we use the terms 'respite' and 'short-term breaks' interchangeably; however, our preference is to talk about breaks from caring rather than respite. This is consistent with terminology used in the National Strategy for Carers (DH, 1999a) and its parallel document, *A Real Break* (Weightman, 1999). It recognises the fact that many carers and disabled people now feel that the label 'respite' is too negative a term, with its suggestions of 'burden' from the carer's point of view and dependency from the care-recipient's point of view. In contrast, the label 'short-term breaks' implies aspirations towards a positive experience for both the carer and the care recipient in order to enhance their lives and support their relationship (Nocon and Qureshi, 1996).



## Section 2 Research methods

### **2.1 Introduction**

A thorough literature review was conducted with advance decisions made about how the literature would be found, appraised and collated. A protocol guided the review process, which aimed to minimise bias in the presentation of the findings and ensure that our intentions were transparent and explicit. This section sets out how studies were chosen for inclusion in the two complementary reviews that were undertaken, namely:

- 1 a review of the literature focusing on general issues related to the effectiveness of respite care for carers for people with dementia. For the purposes of the present report, we call this the 'generic' literature review;
- 2 a review of what we call the economic-evaluation literature which relates to the cost-effectiveness of respite care for carers for people with dementia.

In what follows, we report on the various stages of the process, from defining the question, searching for evidence, applying the inclusion and exclusion criteria, appraising the strength of the evidence and reporting the findings of the final selection of studies. The section also describes how the accompanying consultation exercise was conducted.

### **2.2 The review question**

The review question was: 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? We spent time developing our understanding of the question as it informed each stage of the generic and economic-evaluation review processes. The focus was on all unpaid or 'informal' carers of people with dementia-type illnesses.

The emphasis on research evidence in the literature reviews aimed to establish what the available best evidence could tell us about issues related to effectiveness in general, and cost-effectiveness, of respite care for carers for people with dementia, compared to the experiential and anecdotal knowledge of the representatives of national organisations and carers consulted in the field. Gaps and weaknesses in the evidence base could thus be identified.

### **2.3 Generic literature review**

#### **2.3.1 Search strategy**

Research evidence about general issues related to effectiveness was identified using a number of channels, shown in Table 2.1.

**Table 2.1 Identifying research**

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- Searches of appropriate electronic databases
  - Reference checking of articles retrieved
  - Searching for publications of key authors
  - Citation searching on the Social Science Citation Index (SSCI)
  - Checking relevant Internet sites
  - Consultation with national organisations and carers
  - Contact with key researchers in the field
  - Contacting lead researchers identified from the National Research Register
  - Hand searching of journals (*Journal of Dementia Care*, *Dementia* and the *International Journal of Social Research and Practice*)
- 

The review team included an information scientist from the Centre for Reviews and Dissemination (CRD), who developed and conducted the electronic search strategies. Appendix 1 shows the master search strategy used for MEDLINE searches that was then adapted for use in each subsequent database. For reasons of space, the full search for each database is not presented but is available on request from the authors. Appendix 2 lists the electronic databases searched, which aimed to represent literature from both the health and social care domains. Databases were also chosen to provide evidence from published journals, grey literature and on-going research projects. All the searches were carried out in March 2003 and a date restriction was placed of 1985 onwards. No language restrictions were placed on the literature searches. The intention was to capture documents leading up to the introduction of the National Health Service and Community Care Act 1990 in the UK. We realise this Act has no significance in the international literature, but felt that 18 years was also sufficient to locate studies relating to current policy, practices and societal norms.

Relevant Internet sites, displayed in Table 2.2, were searched and provided empirical material and reports that served as useful background information. The references of all literature received were checked for citations that had not appeared in our initial reference set. Key researchers in the field and the representatives of national organisations contacted in the consultation exercise were asked to identify relevant research reports. This proved useful in identifying some additional studies, especially local evaluations of projects, and aided the identification of possible fieldwork sites for the consultation with carers.

Reference Manager (Adept Scientific) was used to administer the reference set and record decisions made regarding each publication.

**Table 2.2 Internet sites searched**

<b>Website</b>	<b>URL</b>
Age Concern	<a href="http://www.ace.org.uk/">www.ace.org.uk/</a>
Alzheimer Scotland – Action on Dementia	<a href="http://www.alzscot.org.uk/">www.alzscot.org.uk/</a>
Alzheimer’s Society	<a href="http://www.alzheimers.org.uk/">www.alzheimers.org.uk/</a>
ARCH National Respite Network (USA)	<a href="http://www.chtop.com/archbroc.htm">www.chtop.com/archbroc.htm</a>
Audit Commission	<a href="http://www.audit-commission.gov.uk/">www.audit-commission.gov.uk/</a>
Blue Care (Australia)	<a href="http://www.bluecare.org.au/home.cfm">www.bluecare.org.au/home.cfm</a>
Carers UK	<a href="http://www.carersonline.org.uk/">www.carersonline.org.uk/</a>
Centre for Social Research on Dementia, University of Stirling	<a href="http://www.stir.ac.uk/Departments/HumanSciences/AppSocSci/CSRD/index.HTM">www.stir.ac.uk/Departments/HumanSciences AppSocSci/CSRD/index.HTM</a>
Clive Project Supporting Younger People with Dementia	<a href="http://www.thecliveproject.demon.co.uk/">www.thecliveproject.demon.co.uk/</a>
Crossroads	<a href="http://www.crossroads.org.uk">www.crossroads.org.uk</a>
Dementia Services Development Centres Network	<a href="http://www.dementia-voice.org.uk/SiteIndex.htm">www.dementia-voice.org.uk/SiteIndex.htm</a>
Department of Health, Carers website	<a href="http://www.carers.gov.uk/">www.carers.gov.uk/</a>
Help the Aged	<a href="http://www.helptheaged.org.uk">www.helptheaged.org.uk</a>
Holiday Care	<a href="http://www.holidaycare.org.uk/">www.holidaycare.org.uk/</a>
Kingshill Research Centre	<a href="http://www.kingshill-research.org/">www.kingshill-research.org/</a>
Mental Health Foundation	<a href="http://www.mhf.org.uk">www.mhf.org.uk</a>
Princess Royal Trust for Carers	<a href="http://www.carers.org.uk">www.carers.org.uk</a>
Royal College of Physicians of London	<a href="http://www.rcplondon.ac.uk/">www.rcplondon.ac.uk/</a>
Royal College of Psychiatrists	<a href="http://www.rcpsych.ac.uk/search.htm">www.rcpsych.ac.uk/search.htm</a>
Scottish Executive	<a href="http://www.scotland.gov.uk">www.scotland.gov.uk</a>
Shared Care, Scotland	<a href="http://sharedcarescotland.com">http://sharedcarescotland.com</a>
Welsh Assembly	<a href="http://www.wales.gov.uk/">www.wales.gov.uk/</a>
Winged Fellowship Trust	<a href="http://www.wft.org.uk/">www.wft.org.uk/</a>

### **2.3.2 Study selection**

There were three stages for a study to go through in the generic literature search before it was included in the final literature review:

- a check for potential relevance, so that only articles were ordered that had the potential to answer the review question,
- a check that the review inclusion criteria had been met, so that the study provided direct evidence to address the questions posed,
- a check for quality, to ensure that the research findings were generally valid.

Two reviewers scanned all references to check for potential relevance, double-checking the initial 30 per cent to ensure consistency in decision-making.

## ***Review of respite services for carers for people with dementia***

Where the abstract or title indicated that it related broadly to respite, effectiveness and dementia, the report was obtained. If it was not possible to ascertain the study's potential value to the review from the title or abstract, the article was still retrieved and decisions made on the full text. Many references were clearly not appropriate and had been brought forward because of the soft nature of the terms used in social care, but the quality of abstracting on some databases was poor, meaning additional resources were employed in obtaining studies when structured abstracts would have produced more accurate initial decisions.

Two reviewers then checked all of the retrieved studies against the inclusion criteria presented in Table 2.3. Of these decisions, 50 per cent were double-checked to ensure that the research studies were eligible for inclusion. The criteria were useful in that they placed boundaries around literature that helped answer the central review question, and ensured consistent application across the members of the team. Any disagreements regarding decisions about inclusion were resolved consensually in the wider team.

International studies were retrieved and assessed for relevance to the UK. Studies that addressed universal issues of respite care in developed countries were put forward for review. Whereas no restrictions were placed on the search, translating non-English-language studies was beyond the scope of this review. We are aware of the bias that this may introduce into the reported findings. However, most of the research in this field is from the UK or North America, and many European studies are published in English (very few foreign-language references were retrieved in the search). Consequently, we do not feel that the language restriction significantly limited the scope of the study.

Once the initial inclusion criteria had been established, the studies had to be evaluated in terms of research quality. The review team established the strength of the evidence after examining the research design and the conduct of the methods as outlined in the next section.

**Table 2.3 Study selection criteria**

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<i>Language</i>	
Studies written in English	Non- English-language study reports
<i>Period of interest</i>	
Studies published since 1985	Studies published prior to 1985
<i>Populations of interest</i>	
<ol style="list-style-type: none"> <li>1 All 'informal' carers of people with dementia - type illnesses regardless of carer age, ethnicity, gender, length of time as carer, relationship to care recipient.</li> <li>2 All care recipients with dementia - type illnesses, regardless of age, ethnicity, gender, relationship to carer.</li> </ol>	<ol style="list-style-type: none"> <li>1 Paid carers</li> <li>2 Care recipients with non-dementia type illnesses</li> </ol>
<i>Intervention of interest</i>	
Studies must relate to interventions directed at carers of people with dementia, where the carer is relieved of their caring duty. Interventions may take place in any setting.	Interventions not intended primarily to relieve carers of their caring duty such as interventions to develop caring skills or understanding of dementia or to offer 'support' to carers (for example, support groups, counselling or educational programmes)
<i>Study design</i>	
Studies must include empirical evidence from experimental or observational research including qualitative research. It may be published or unpublished work.	Literature reviews, book reviews and discursive/opinion pieces will be excluded. In addition, in cases where there are multiple publications from a single study only the base report or findings will be used.
<i>Quality appraisal</i>	
Included studies must meet all five essential elements of the quality-appraisal criteria (Table 2.4, below) to secure internal validity of the study and trustworthy findings.	Studies that do not meet the essential elements of the quality appraisal criteria, and so may not have trustworthy findings.
<i>Outcomes</i>	
Studies that consider effectiveness, and/or cost-effectiveness and/or perceived benefits of respite services or short-term breaks.	Studies that are descriptive, and do not report outcomes.

### **2.3.3 Strength of evidence**

It is important that the conclusions and recommendations of the final report to the SDO programme are based on the best evidence available, but this does not mean reporting only 'ideal-type' research. Empirical studies were selected in which the research design and its conduct could be assumed to offer a reasonable level of confidence in the results. These decisions ensured that the studies met a basic quality threshold, and that the studies were designed in such a way as to represent good research inquiry.

## Review of respite services for carers for people with dementia

A quality criteria tool developed by Croucher *et al.* (2003) was chosen to establish whether a study met the quality threshold. There is little consensus over the use of appraisal tools in reviews, and this tool was adopted as reviewers and readers alike can readily understand it; it includes guidance on its practical application and is not resource-intensive. The set of criteria is presented in Table 2.4. For the generic effectiveness review, one reviewer applied these criteria to each study that met the inclusion criteria, and those that met the essential elements were put forward for the final review. A second reviewer checked 20 per cent of these decisions. The cost-effectiveness literature was quality-appraised by one reviewer (see below).

**Table 2.4 Quality-criteria appraisal tool**

1	Question	Is the research question clear?	E
2	Theoretical perspective	Is the theoretical or ideological perspective of the author (or funder) explicit, and has this influenced the study design, methods or research findings?	D
3	Study design	Is the study design appropriate to answer the question?	E
4	Context	Is the context or setting adequately described?	D
5	Sampling	(Qualitative) Is the sample adequate to explore the range of subjects and settings, and has it been drawn from an appropriate population?	E
		(Quantitative) Is the sample size adequate for the analysis used and has it been drawn from an appropriate population?	
6	Data collection	Was the data collection adequately described and conducted rigorously to ensure confidence in the findings?	E
7	Data analysis	Is there evidence that the data analysis was conducted rigorously to ensure confidence in the findings?	E
8	Reflexivity	Are the findings substantiated by the data and has consideration been given to any limitations of the methods or data that may have affected the results?	D
9	Generalisability	Do any claims to generalisability follow logically, theoretically and statistically from the data?	D
10	Ethics	Have ethical issues been addressed and confidentiality respected?	D*

Source: adapted from Croucher *et al.* (2003).

E, essential; D, desirable.

\*May be essential in some (sensitive) fields of study.

All research studies that entered the review were then classified using a typology of study design (Table 2.5) adapted from that used in the NSF for Older People (DH, 2001). This provided an indication of what type of evidence informed the findings presented. It was intended that research from categories A and B would be included in the final reviewed articles as they

## **Review of respite services for carers for people with dementia**

were the most rigorous studies, unless other studies were able to fill gaps found in the evidence base. The use of C1-type evidence, for example, was to be used mainly to explore gaps where there was a lack of more rigorous research.

**Table 2.5 Typology of study designs**

<b>Evidence from empirical research and other professional literature</b>	
<b>Evidence type code</b>	<b>Examples of study type</b>
A1	Systematic reviews that include at least one RCT (e.g. Systematic Reviews from Cochrane or Centre for Reviews and Dissemination)
A2	Other systematic and high-quality reviews that synthesise references
B1	Individual RCTs
B2	Individual experimental/intervention non-randomised studies
B3	Individual non-experimental studies, controlled statistically if appropriate; includes studies using case-control, longitudinal, cohort, matched pairs or cross-sectional random-sample methodologies, and sound qualitative studies; analytical studies including secondary analysis
C1	Descriptive and other research or evaluation not in B
<b>Evidence from expert opinion (in the absence of empirical research evidence)</b>	
C2	Case studies and examples of good practice
D	Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified
E	Professional opinion based on practice, or reports of committees
U	User opinion from carers or carers' organisations

Source: *adapted from NSF for Older People (DH, 2001).*

*RCT, randomised controlled trial.*

We felt it was reasonable to draw on a range of research designs if the evidence the study presented addressed the central review question. The strength that a certain study design can offer also relates to the particular question and line of inquiry. Studies perceived to hold greater internal validity may have less external validity, so reducing their utility to the review. For example, treatment groups in some studies may be in receipt of experimental forms of service provision other than that available in 'natural' or everyday settings. Conclusions from these studies, although precise, do not tell us how the new service compares with current practice. Also the transferability of the studies from an experimental setting to a natural one may pose problems. There can be instances where the level or volume of the intervention (respite care in the present case) received by the study group and the control group appear to be quite similar. Studies with large convenience samples comprising members of, say, disease-specific organisations, may be wholly appropriate when the cost and time taken to glean a random sample of carers from

## ***Review of respite services for carers for people with dementia***

general omnibus surveys is taken into account, providing the researchers reflect upon this issue and how any bias may relate to the research question. The classification of study designs was therefore used as a typology rather than a hierarchy. To make it easier to operationalise, and to ensure consistency, two reviewers independently checked the study code of all research that entered the final review.

A Microsoft Access database was used to manage data-extraction forms, presented in Appendix 3. The database recorded a uniform set of information for each study that met the inclusion criteria. All reviewers used the data-extraction form to ensure consistency and ease of comparison between studies. The extraction of the substantive content of the studies was based around the structure, process, outcomes, impact and effectiveness of the short-term break.

### **2.3.4 References retrieved in the generic literature review**

Table 2.6 shows the number of studies retrieved at each stage of the generic review, broken down by source of reference. The searches were all conducted between 6 and 25 March 2003. A note of caution needs to be sounded in that it is difficult to compare bibliographic databases. This reflects their variation in size and quality, the different interfaces not allowing for the same search strategy to be used on each database, the differing topic areas covered by the databases and the order in which duplication took place.

The search process produced 2213 references. Once duplicate references were removed, 1351 studies remained. Of these, 261 were found to be generally relevant to the review. Some 65 of these passed the inclusion criteria, of which 47 met the quality threshold. Forty-five and two studies respectively were categorised as presenting B-type and C-type evidence. There were no studies containing A-type evidence.

Eighteen studies, initially thought to be potentially relevant, were excluded from the final review as they did not meet the quality threshold:

- two were not dementia-specific,
- two did not define the respite intervention being evaluated,
- eight had an insufficient sample size for the type of analysis attempted,
- four gave insufficient methodological detail,
- two reported case studies, with no analytical content.

When a reviewer decided that a study was not to be included in the review, the decision was double-checked by another member of the review team. Some of the studies excluded on quality grounds nonetheless proved useful in terms of background material.

Appendix 4a contains a summary table of the 47 articles from the generic search included in the final review.



**Table 2.6 Source of reference per each stage of the generic literature review**

Database/ source	Total hits	After de-duplication	Potentially relevant	Passed inclusion criteria	Passed quality criteria	Categorisation		
						A	B	C
<b>Peer-reviewed journal databases</b>								
CDSR completed reviews (Issue 1, 2003)	44	0	0	0	0	0	0	0
CDSR protocols (Issue 1, 2003)	12	0	0	0	0	0	0	0
<b>Bibliographic databases</b>								
<i>Health</i>								
AMED (1985–Feb 2003)	43	8	2	1	1	0	1	0
BNI (1994–Feb 2003)	31	11	5	0	0	0	0	0
CCTR (Issue 1: 2003)	48	12	1	0	0	0	0	0
CINAHL (1982–week 3, Feb 2003)	260	117	28	2	0	0	0	0
DARE (1994–Mar 2003)	18	16	2	0	0	0	0	0
DSDC (24 Mar 2003)	52	38	5	0	0	0	0	0
EMBASE (1980–week 9, 2003)	435	268	52	11	11	0	11	0
HTA (Mar 2003)	2	2	0	0	0	0	0	0
HMIC Kings Fund database HELMIS and DHdata (1979–Jan 2003)	148	99	20	4	3	0	3	0
MEDLINE (1966–week 3, Feb 2003)	403	377	66	28	18	0	17	1
PREMEDLINE (4 Mar 2003)	10	3	0	0	0	0	0	0

**Table 2.6 continued**

Database/ source	Total hits	After de-duplication	Potentially relevant	Passed inclusion criteria	Passed quality criteria	Categorisation		
						A	B	C
<i>Social care</i>								
Caredata (13 Mar 2003)	72	43	13	3	1	0	1	0
IBSS (1985–11 Mar 2003)	10	8	1	0	0	0	0	0
SocAbs (1963–Dec 2002)	85	35	3	0	0	0	0	0
SSCI (1985–2003)	145	54	13	1	0	0	0	0
SPECTR (21 Mar 2003)	30	24	0	0	0	0	0	0
<i>Grey literature databases</i>								
PLANEX (1994–20 Mar 2003)	17	14	0	0	0	0	0	0
SIGLE (1980–Dec 2002)	8	5	1	0	0	0	0	0
WoSP- ISTEP (1990–14 Mar 2003)	12	5	0	0	0	0	0	0
<i>Research registers (on-going research)</i>								
Controlled-trials.com (25 Mar 2003)	20	20	0	0	0	0	0	0
NRR (Issue 1, 2003)	38	38	0	0	0	0	0	0
<i>Other sources</i>								
Hand- searching named journals			0	0	0	0	0	0
Personal communication			10	6	6	0	5	1
Reference checking			19	4	3	0	3	0
Organisational Internet sites			0	0	0	0	0	0
Specialist libraries			0	0	0	0	0	0
<b>Totals</b>	<b>2213</b>	<b>1351</b>	<b>261</b>	<b>65</b>	<b>47</b>	<b>0</b>	<b>45</b>	<b>2</b>

*Categorisation (A, B, C) is according to the typology of study designs (see Table 2.5).*

## **2.4 Economic-evaluation literature review**

### **2.4.1 Study selection**

In addition to sifting the results of the generic search results for economic literature, a separate rigorous search of the economics literature was conducted on the databases listed in Appendix 2. To be included in the cost-effectiveness review, studies had to meet the study selection criteria shown in Table 2.3. Importantly, the outcomes section of the inclusion criteria specified that the study should be a cost-effectiveness study. Cost-effectiveness analysis can be seen as an umbrella term to include all studies in which two or more appropriate interventions are compared in terms of both their associated costs and consequences (effects; Drummond *et al.*, 1997). Such analysis examines the extent to which the balance between input (the costs of resources used) and outputs (effects/benefits/outcomes/consequences) of interventions represent value for money. It seeks answers to such questions as: is the intervention worth implementing compared with other interventions that could be implemented with the same resources and/or are we satisfied that the resources used to provide the intervention should be spent on intervention *x* as compared to intervention *y*?

### **2.4.2 Economic-evaluation references retrieved**

Table 2.7 shows the number of economic-evaluation-focused references retrieved at each stage of the review, similar to Table 2.6. Four specialist databases were searched for economic literature. This resulted in 70 references, of which 14 were deemed to be potentially relevant. A further 19 papers retrieved via the generic searches (see Section 2.3) were also thought to be potentially relevant when reviewing the title and abstract of these papers. Nine potentially relevant papers were found via reference checking. The full text of these 42 papers (14 from the economic searches, 19 from the generic searches and nine from reference checking) were all ordered through the interlibrary loans process at CRD.

**Table 2.7 Sources of references per each stage of the economic evaluation focused literature review**

Database/ source	Received	After de-duplication	Potentially relevant	Passed inclusion criteria	Passed quality criteria	Categorisation		
						A	B	C
<b><i>Bibliographic databases</i></b>								
<i>Economic</i>								
EconLit Silver Platter (1969–Mar 2003)	2	2	2	0	0	0	0	0
HEED CD-ROM (Mar 2003)	30	30	8	1	1	0	1	0
IDEAS Internet (25 Mar 2003)	25	25	0	0	0	0	0	0
NHS EED Internet (1994–Mar 2003)	17	13	4	0	0	0	0	0
<i>Health</i>								
CINAHL* (1982–week 3, Feb 2003)	260	12	2	0	0	0	0	0
EMBASE* (1980–week 9, 2003)	435	268	5	0	0	0	0	0
HMIC* (1979–Jan 2003)	148	99	4	0	0	0	0	0
HTA* (Mar 2003)	2	2	1	0	0	0	0	0
MEDLINE* (1966–week 3, Feb 2003)	403	377	3	2	2	0	1	1
<i>Social care</i>								
PsychINFO* (1994–20 Mar 2003)	270	154	3	1	1	0	1	0
SSCI* (1985–2003)	145	62	1	0	0	0	0	0

**Table 2.7 continued**

Database/ source	Received	After de-duplication	Potentially relevant	Passed inclusion criteria	Passed quality criteria	Categorisation		
						A	B	C
<b>Other sources</b>								
Hand-searching named journals								
Personal communication								
Reference checking			9	1	1	0	1	0
Organisational Internet sites								
Specialist libraries								
<b>Totals</b>	1737	1044	42	5	5	0	4	1

*Categorisation (A, B, C) is according to the typology of study designs (see Table 2.5).*

*\* The references in these rows were generated by the generic literature search. All the results from the generic searches were sifted for economic-evaluation literature; only those that produced potentially relevant papers are shown here. For other databases that were searched, see Table 2.6.*

Of the 42 studies thought to be potentially relevant, five met both the inclusion and quality criteria thresholds and were included in the full review. The reasons for rejection of the 37 studies then excluded from the economic evaluation literature review were based on the following justifications:

- four studies were not dementia-specific,
- 14 did not assess respite support services, including one that focused on pharmaceutical interventions,
- ten provided a review or an overview of respite support services in dementia,
- four did not include a review of the consequences associated with interventions (that is, they focused on cost alone),
- three did not compare interventions,
- two did not assess costs associated with interventions.

A summary table of the five economic studies included in the final review is presented in Appendix 4b.

## **2.5 Consultation**

The consultation was designed to set the context for examining the gaps in the literature, and to help indicate the relevance of the findings of the literature review to current policy and practice in the NHS. It was used to examine whether the outcomes that carers/carers' representatives value are the same as, or similar to, those used in the research literature. Lastly, the

## ***Review of respite services for carers for people with dementia***

consultation helped direct the research team to grey literature relevant to the review and assisted with the identification of respite services and projects that are regarded as innovative.

### **2.5.1 Interviews with national organisations**

The first stage of the consultation involved telephone interviews with key individuals from 20 national statutory and voluntary organisations, with an interest in carers and/or mental health. Appendix 5 gives full details of the organisations and individuals who took part in this stage of the consultation. During the interviews, we sought the interviewees' views and perspectives on the following key topics.

- The current state of respite/short-break services for carers of people with dementia.
- How services do or should meet the needs of different groups of carers, carers at different stages in their 'caring career' and the needs of the cared-for person.
- The characteristics of effective respite/short breaks and how effectiveness and cost-effectiveness could be measured.
- The difficulties or barriers faced by providers of respite services and the impact of recent policy developments.

Appendix 6 shows the topic guide used to structure the interviews. The interview usually lasted for between 30 minutes and one hour. Detailed notes were taken during the interview and typed up using a common template, to facilitate analysis. The findings from the national interviews were used to identify key themes and issues and these are discussed in detail in Section 5.

### **2.5.2 Local consultation with carers**

The national interviewees were also asked to suggest areas of the country which they regarded as having either a good range or mix of respite services, or individual respite services which were perceived as examples of 'good practice'. The primary reason for seeking this information from the national interviewees was to enable the research team to identify four areas in which to conduct the direct consultation with carers. We chose to work in areas of perceived 'good practice' because we judged that in these areas we were more likely to find carers who had had good experiences of respite services and therefore might be more able to identify aspects of an effective respite service.

The four areas chosen for the second stage of the evaluation were Redbridge/Ilford, Nottingham, Ealing and Swindon. We should stress that it was not the intention of the review to evaluate these areas or services, and so it would be inappropriate to hold them up as specific examples of good practice. However, in selecting the areas/services to be used in the second stage of the consultation, we looked for areas in which:

- respite services were being provided in a range of settings (for example, in-home, day centre, residential), and/or

## ***Review of respite services for carers for people with dementia***

- respite services were being provided by a range of organisations, and/or
- respite services had been developed to meet the needs of specific groups within the population (for example, younger people with dementia, carers/care recipients from minority ethnic communities), and/or
- aspects of service delivery or organisation were regarded by the national interviewees as particularly innovative.

In July 2003, three focus groups with carers of people with dementia were held in Redbridge/Ilford, Nottingham and Ealing. A fourth focus group of carers of younger people with dementia was planned for Swindon. However, we were advised by local workers that telephone interviews would be more convenient for this group of carers, who are perhaps more likely to have work and family commitments constraining their time. Our aim was to interview up to six carers in Swindon but despite vigorous efforts to recruit participants, we were only able to conduct three telephone interviews. In addition to the focus groups and interviews with carers, five telephone interviews with local managers of respite/short-break services were conducted. The main purpose of these interviews was to further our understanding of the local context. However, it also provided a useful opportunity to explore managers' perceptions of what constitutes effectiveness in the provision of respite services in their local situation.

In each area, the research team worked with local respite and carers services managers to make contact with carers who were using local respite services. The managers wrote to the carers using their services inviting them to take part in the consultation. With the letter they enclosed an information sheet about the project, and a consent form, which carers interested in participating were asked to return to the research team in a prepaid envelope. We then wrote to the carers who returned a consent form giving them details of where and when the focus groups were being held (or how the telephone interviews were to be arranged), and asked them to confirm whether they were able to attend. No attempt was made to 'select' carers and all those who were willing and able to attend the groups or take part in an interview were offered the opportunity to be involved in the consultation.

In total, 24 carers confirmed that they would be attending the focus groups but only 17 actually attended. Three carers agreed to be interviewed. Of the 20 carers involved (16 women and four men), five were from black and minority ethnic communities. Four were of working age but none were actually working. Most were caring for their husband or wife but five were caring for a parent or parent-in-law. They were all primary carers, and the majority lived in the same household as the care recipient. None were 'distance' carers. Whereas most of the carers were caring for someone with Alzheimer's disease (including five carers of people with the early-onset form), other conditions were represented, including Pick's disease and vascular dementia.

The groups were held in local venues (for example, day centre or carers' centre) and generally lasted for about one-and-a-half hours. The discussion was recorded on a minidisk and then transcribed in 'notes and quotes' form. The telephone interviews were conducted at a pre-arranged time, convenient

to the carer, and usually lasted for 45 minutes to an hour. During the interview the researchers took detailed notes which were then written up in full. Copies of the topic guides used in the groups and interviews are shown in Appendices 7 and 8.

The methods and instruments used in the consultation (including topic guides, information sheets, consent forms and letters to carers) were all approved through the Multi-Centre Research Ethics Committee system.

## ***2.6 Expert reference group and workshop***

The research team was advised by members (professionals and 'key-informant' carers) of an expert reference group at key points in the review process. Communication was generally by e-mail and/or post. However, members were brought together for a one-day Workshop held in Social Policy Research Unit (SPRU) at the University of York to discuss material presented in a specially prepared work-in-progress report. Topic areas discussed at the workshop included how best to structure the final report, the implications of the preliminary findings and suggestions for policy, practice and further research.

## ***2.7 Reporting the findings***

Together, the 52 articles included in the review comprised a large and unwieldy literature. It was a very heterogeneous body of research in terms of: the multiplicity of services that were evaluated; the type of research designs and quality of the evaluations; the variability in the delivery of the respite intervention; the composition of the study groups; and the type and range of outcome measures used to assess effectiveness and cost-effectiveness. Furthermore, the research was in some ways imperfect, reflecting weaknesses in the methodologies adopted in some of the studies (see Section 1).

Pulling together such a complex literature for the purposes of the review was a challenging task. A meta-analysis was not appropriate since the data were sparse and the studies were too heterogeneous to be sensibly combined (CRD, 2001). Instead, we chose to follow principles more akin to a narrative synthesis approach. However, there is no established canon of methodological rigour for synthesising,<sup>5</sup> and we approached the task of reporting the findings with caution – especially given the nature of the literature where dominant themes were rare and it could even have been misguided to focus on commonalities.

The approach the review team adopted was as follows. Our starting point was to narrow down and reduce the heterogeneity of the review studies by linking together similar types of respite service and short-term break. We did this on

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<sup>5</sup>The project Developing methods for the narrative synthesis of quantitative and qualitative data in systematic reviews of effectiveness for the ESRC Research Methods Programme by Popay, Sowden, Roberts, Petticrew and Baldwin should rectify situation in the future. See [www.ccsr.ac.uk/methods/projects/posters/popay.shtml](http://www.ccsr.ac.uk/methods/projects/posters/popay.shtml)



## ***Review of respite services for carers for people with dementia***

the basis of different models of respite service delivery, commonly found in this country and/or North America and Europe:

- day-care services,
- in-home services,
- host-family respite,
- institutional/overnight respite,
- respite programmes, offering multiple forms of respite care,
- multi-dimensional carer-support packages, where respite care is one option,
- video respite.

It is known that 'effectiveness' means different things to different people (Newbrunner and Hare, 2002). Likewise, there are many alternative domains or mechanisms whereby respite can operate; this diversity was reflected in the wide range of outcomes that researchers chose to focus on in their evaluations. Consequently, our next step was to attempt to define what we felt would be useful concepts or organising categories by which to document relevant evidence from the studies included in the review. We were keen to present evidence in a way that would be helpful to policy-makers and practitioners who might be involved in decision-making in this area. After considerable debate within the research team, we eventually decided to organise the evidence around issues and outcomes that were relevant to the key stakeholder groups, namely carers, care recipients and service providers. The four categories that we chose to report evidence under are:

- effectiveness in relation to carers' health and well-being,
- effectiveness in relation to care recipients' health, well-being and dementia-related symptoms,
- impact on the use of other services,
- cost-effectiveness in relation to carers' and care recipients' health and well-being.

The first category, the effectiveness in relation to carers' health and well-being, presents evidence under two different sub-headings. The first, Perceptions of services, contains carers' and professionals' subjective views about the benefits, advantages (including use of time freed up by respite care) and disadvantages of respite services. Carers' views in particular are not always prioritised, yet they are the very people the services are aiming to support.

The second part of this category, called Health status and well-being, concentrates on evidence relating to changes in carers' physical and emotional health status, which researchers have tended to capture using some type of outcome measure or instrument.

The second category, effectiveness in relation to care recipients' health, well-being and dementia-related symptoms, uses a similar format. Again, there is a section on Perceptions of services that includes the views of people with dementia, carers and professionals on the impact of respite on care recipients. The following section, called Health status, well-being and dementia-related

## ***Review of respite services for carers for people with dementia***

symptoms, contains evidence about respite and any associated changes relating to care recipients' health, activities of daily living (ADL) and behavioural problems.

Some respite services aim to prevent or delay entry to long-term care. Likewise, using respite services has the potential to impact on usage of other formal support arrangements. The third main category, impact on use of other services, taps into these issues. It reports evidence about respite and entry to long-term care, as well as what is known about changes in carers' usage of other community care services.

The final category, cost-effectiveness in relation to carers' and care recipients' health and well-being, looks at the findings of the economic evaluations and describes the literature on the costs of competing interventions and how these relate to effects.

Our narrative account of the effectiveness and cost-effectiveness of respite care and short-term breaks is presented in Section 4. The accounts of contributors to the consultation and carers taking part in the focus groups are presented separately in Section 5; cross-references are made as appropriate. An overview, pulling together key themes, similarities and contrasts from the literature, is presented in Section 6.

As a preliminary to reporting the evidence, the next section maps out the studies included in the final review.

## Section 3 Scoping the field: initial mapping

### **3.1 Introduction**

This section of the report maps the number and type of the studies included in the review in terms of:

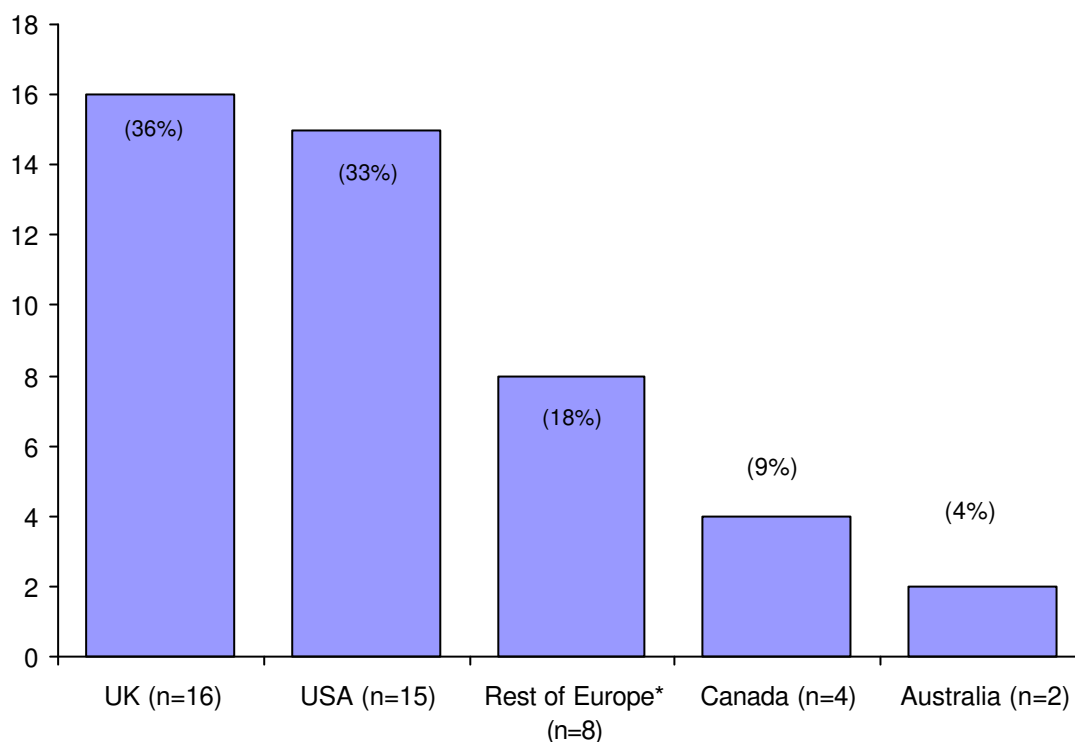
- geographical distribution,
- type of respite care and short-term break,
- geographical distribution according to type of service,
- characteristics of care recipients and carers,
- research methods adopted,
- measures of effectiveness and cost-effectiveness.

As stated in the last section, 52 articles met the inclusion criteria, comprising 47 generic effectiveness research reports and five economic evaluation research reports. The 52 articles discussed a total of 45 studies. The discrepancy in numbers reflects two issues. First, multiple papers were written drawing on the data collected in a single study (the Adult Day Care Collaborative Study). We decided to include the primary or 'parent' analysis (Zarit *et al.*, 1998) as well as the five related articles because they report on different elements of the research. Second, three of the economic evaluations report on studies whose primary analysis is also included in a second article in the main review (this applies to the Adult Day Care Collaborative Study, for example). The two remaining economic evaluations, however, do not have any accompanying parent analysis retrieved as part of the generic review.

### **3.2 Geographical distribution of evaluation studies**

Figure 3.1 shows the number and proportion of studies that evaluated respite services and short-term breaks for carers for people with dementia according to the country in which the service was implemented. A slightly larger proportion of evaluations were carried out in the UK (36 per cent;  $n=16$ ) compared with the USA (33 per cent;  $n=15$ ). Eighteen per cent ( $n=8$ ) of the studies were conducted in European countries other than the UK. Studies from Canada (9 per cent;  $n=4$ ) and Australia (4 per cent;  $n=2$ ) accounted for the remainder.

Figure 3.1 Distribution of studies of respite care and short-term breaks for carers for people with dementia, by country (n= 45)



The y-axis represents the number of studies that were found for a particular region. Percentages show the proportions that studies from a given region contribute to this review.

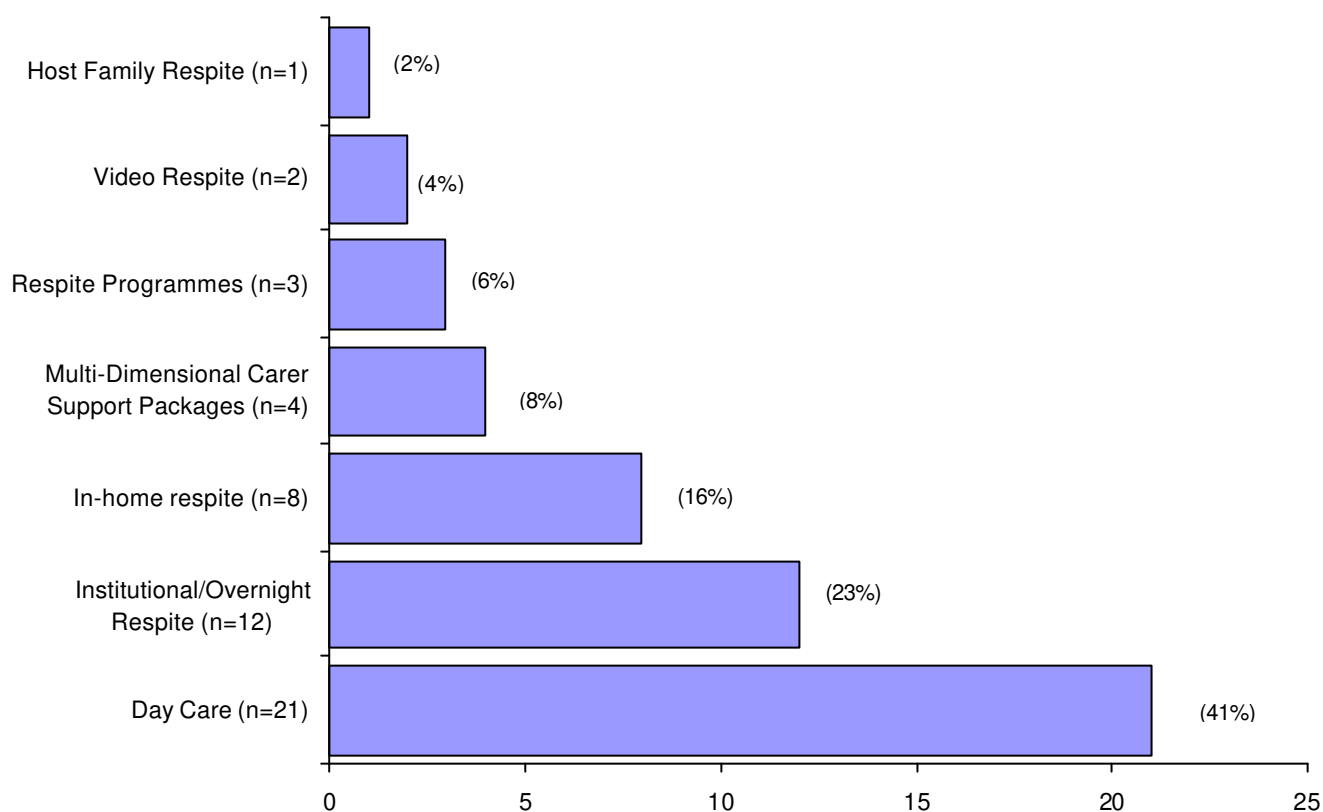
\* Comprising Sweden (3); The Netherlands (2); Norway (1); Germany (1); European-wide study covering Germany, Denmark, Belgium, Spain, Sweden and France (1)

### 3.3 Types of respite service and short-term break

As noted in the introduction to this report, different forms of respite service and short-term break have been developed to help support carers and care recipients. In our discussion about the challenges of reporting the findings in the last section, we emphasised the multiplicity of research studies included in this review and explained how we had narrowed down this heterogeneity by grouping together similar types of service. Figure 3.2 shows the number of studies evaluating respite services according to the classification scheme presented above (Section 2).

The majority of studies (41 per cent;  $n=21$ ) evaluated day care. Residential/overnight respite and in-home respite accounted for 24 per cent ( $n=12$ ) and 16 per cent ( $n=8$ ) respectively. In comparison, studies of multi-dimensional carer-support packages, respite programmes, video respite and host-family respite were much less frequent. Fuller descriptions of the different types of respite service and short-term break are provided in the next section.

**Figure 3.2 Number of studies according to type of respite care and short-term break for carers for people with dementia (n= 51)**



*The x-axis represents the number of studies that were found for a particular type of respite care. Percentages show the proportions that studies on a given type of care contribute to this review.*

*Numbers add up to 51 instead of 45 because five studies in the review evaluated two or more forms of respite service.*

### **3.4 Geographical distribution of evaluation studies according to type**

Table 3.1 shows the number and proportion of studies by country for each of the seven categories of short-term break. The majority of studies examining day care, residential/overnight respite and in-home services have been conducted in the UK. In comparison, evaluations of respite programmes and video respite have been conducted solely in the USA. Most studies conducted in Europe have focused on day care.

**Table 3.1 Geographical distribution of studies according to type of respite service and short-term break (*n* = 51)**

	Number of studies (% of total number of that type)						
	Day care	Institutional / overnight respite	In-home respite	Multi-dimensional carer-support packages	Respite programmes	Video respite	Host-family respite
UK	9 (43%)	5 (42%)	5 (62%)				1 (100%)
USA	4 (19%)	4 (33%)	2 (25%)	1 (25%)	3 (100%)	2 (100%)	
Canada		2 (17%)		2 (50%)			
Australia	2 (10%)						
Rest of Europe	6* (28%)	1† (8%)	1‡ (13%)	1§ (25%)			
<i>Total</i>	21	12	8	4	3	2	1

\* Comprising Germany (2); Sweden (2); The Netherlands (1); Norway (1).

† France.

‡ Sweden.

§ The Netherlands.

### **3.5 Distribution of studies according to characteristics of care recipients and carers**

The majority (78 per cent; *n* = 35) of the 45 studies included in the review examined respite services and short-term breaks for carers for people with Alzheimer's disease or other forms of dementia. Of these, just one looked at service provision for younger people with dementia (that is, people under 65 years of age). The remaining evaluations (22 per cent; *n* = 10) focused specifically on services for carers for people with Alzheimer's disease. Of these, two concentrated on short-term breaks for people with early-stage Alzheimer's.

Two studies investigated short-term breaks aimed at spouse carers, and one looked at services for rural carers. Whereas study participants did include carers and/or care recipients from ethnic-minority communities, none of the studies evaluated services specifically targeting ethnic-minority carers and/or care recipients. Exceptionally, the two study groups in one comparative study comprised African-American carers and white carers.

### **3.6 Type of research design used**

Table 3.2 shows the breakdown of types of respite care and short-term break service according to research design. As the table indicates, over half the studies in the review collected quantitative data (*n* = 31, 61 per cent of all

## Review of respite services for carers for people with dementia

studies), through randomised controlled trials (RCTs), quasi-experimental studies, before-and-after studies, and surveys or post-intervention studies. In comparison, there was only a handful of qualitative research designs. Nearly one-third of researchers used mixed methods such as interviews, focus groups, observations and survey work, in which they collected both quantitative and qualitative data. Researchers examining the effectiveness of day care used a broad spectrum of research designs. In contrast, researchers examining multi-dimensional carer-support packages and respite programmes used experimental and quasi-experimental approaches of evaluation.

**Table 3.2 Numbers of studies according to research design and type of respite care and short-term break for carers for people with dementia (n= 51)**

	Quantitative				Qualitative interviews	Mixed methods	Other
	RCTs	Quasi-experimental	Before-and-after	Survey/ post-respite intervention			
Day care	2	3	2	7		7	
Institutional/over night respite			5	1		6	
In-home respite		1		3	2	2	
Multi-dimensional carer-support packages	3	1					
Respite programmes		1	2				
Host-family respite					1		
Video respite						1	1*
<b>Totals</b>	<b>5</b>	<b>6</b>	<b>9</b>	<b>11</b>	<b>3</b>	<b>16</b>	<b>1</b>

*Numbers add up to 51 instead of 45 because five studies in the review evaluated two or more forms of respite services.*

*\* Content analysis of video tape recordings*

All the studies apart from two were rated as presenting B-type evidence according to the typology of study designs shown in Table 2.5 in the last section. The two remaining studies that presented C-type evidence were both cross-sectional; one collected quantitative data and the other quantitative and qualitative data.

Generally speaking, those studies undertaken in North America and also the economic evaluation studies were more likely to comprise RCTs or quasi-experimental research designs to assess (cost-)effectiveness. In contrast, studies set in the UK were more likely to use multiple methods collecting both quantitative and qualitative data, from a wide range of stakeholders. Some UK studies included qualitative interviews with people with dementia, and two included Dementia Care Mapping.

Many studies employed longitudinal research designs that followed up participants over a period of time. Generally, these varied from three to 12 months, thus providing the opportunity to examine the medium-term effects of respite care and short-term breaks. Exceptionally, one study was a five-year follow-up of a cohort of subjects. Very few of the studies included in the review were comparative studies that compared the efficacy of one type of respite care against another. Often, studies evaluated existing respite and short-term breaks in their natural or everyday settings, rather than services set up for experimental purposes.

### **3.7 Measures of effectiveness and cost-effectiveness**

The large majority of studies included in the review examined (cost-)effectiveness issues from the point of view of carers and/or care recipients, rather than investigating the perspectives of, say, service providers. Consequently, the vast majority of studies included in the review used batteries of outcome measures as a way to evaluate the (cost-)effectiveness of respite care and short-term breaks in relation to carers and care recipients. However, the costs included in the evaluation studies tended to reflect those incurred on the public purse, reflecting the government provider interests.

Appendices 4a and 4b give fuller details of the outcomes measured in each study.

For carers, outcomes most commonly measured were (changes in) levels of carer burden, strain, depression, physical health and health-related quality of life. The outcome measures used were mainly 'standard' or 'off-the-shelf' instruments, for instance the General Health Questionnaire, the Burden Interview, the Beck Depression Inventory, the Strain Scale and the Center for Epidemiological Studies Depression Scale. The economic evaluation studies included also tended to use the same or similar off-the-shelf instruments to evaluate effectiveness. Quality-adjusted life years<sup>6</sup> (QALYs) were calculated, a standard outcome measure commonly used by health economists.

If, however, researchers felt existing standard measures were not fully appropriate for their particular focus of interest, they took subsets of different measures and combined them into a new pool of items. Very occasionally, researchers developed their own scales, tailor-made for the purpose. For example, in one economic evaluation study caring professionals were asked their opinion about the well-being of the patient they cared for and these data were transformed into a modified 'well-year' form.

For the care recipient, researchers frequently measured behaviour and cognitive functioning with instruments such as the Special Behaviour Assessment Schedule, the Clifton Assessment Procedures for the Elderly and the Mini Mental State Examination. Carers' perceptions of behavioural

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<sup>6</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.



## ***Review of respite services for carers for people with dementia***

problems, to identify what were viewed as the care recipient's most troublesome behaviours, were assessed using, for example, the Memory and Behaviour Checklist or the Problem and Burden Checklist.

In terms of the cost-effectiveness studies, one cost-utility analysis, three cost-effectiveness analyses and one cost-consequence analysis were undertaken. Whereas all the economic evaluation studies included costs, the effectiveness measure of choice differed with QALYs being used in the utility part of the cost-utility analysis, natural units of effectiveness being used in the effectiveness part of the cost-effectiveness analyses and multiple consequences being provided in a disaggregated way in the cost-consequence analysis.

Alternative, and/or additional, ways to assess the effectiveness of short-term breaks included semi-structured interviews or focus groups where study participants were asked their opinion about perceived benefits, disadvantages and barriers to using short-term breaks. Some studies also conducted satisfaction surveys with carers and/or care recipients.

Based on the economic evaluation studies, data on resource use were collected according to the perspective of the analysis. In all the studies reviewed, the perspective was that of the health and social care sector with three studies also including carer costs. Resource-use information tended to be collected prospectively from databases; however, interviews were used also. Costing was based on a mixture of local- and national-level unit costs.

All resources used to provide services are limited and inevitably choices have to be made about how to allocate resources. Economic evaluation evidence can be used as one input into health and social care programme decisions, along side other decision-making inputs such as equity arguments and practical considerations.

### ***3.8 Summary of characteristics of available research***

The mapping exercise of the studies of respite care and short-term breaks for carers included in the review shows that:

- over one-third of studies were conducted in the UK,
- day-care services were most commonly studied, followed by institutional/overnight respite and then in-home respite,
- studies were mainly of breaks for carers for people with Alzheimer's disease or a related dementia, rather than specifically for Alzheimer's patients,
- few studies focused on respite care for specific groups of carers,
- the vast majority of studies used standard outcome measures to assess the effectiveness of breaks,
- around ten per cent of the studies reviewed were economic evaluations,
- about half the studies addressed medium-term effects, collecting data for three to 12 months; only one study looked at long-term effects, collecting data for five years.

## Section 4 Evidence from the literature review about the effectiveness and cost-effectiveness of respite services and short-term breaks

### **4.1 Introduction**

This section analyses the evidence reported in the studies included in the review, categorised into the seven different types of respite care and short-term break as follows:

- day-care services (Section 4.2),
- in-home services (Section 4.3),
- host-family respite (Section 4.4),
- institutional/overnight respite (Section 4.5),
- respite programmes offering multiple forms of respite care (Section 4.6),
- multi-dimensional carer-support packages where respite care is one option (Section 4.7),
- video respite (Section 4.8).

Each of the above forms of break has been written up so that it can stand on its own, for readers who have a special interest in one particular type of service. A small number of the studies evaluated more than one type of respite service or short-term break. In those instances, we have documented the relevant data under the appropriate short-term-break category. This means that evidence from the same study may appear in two or even three of the above sections; cross-references have been made, if appropriate.

We have devised a template to help report the findings for each type of respite. The layout of the template is as follows. It starts with an introduction describing the particular form of short-term break under discussion. This is followed by a short overview of the studies under review, together with an accompanying table detailing the author(s) and the aim of each study (see Appendices 4a and 4b for fuller summary details of all the studies, including sample sizes and methods). The material that follows is the core of each sub-section. It documents substantive issues about the effectiveness and cost-effectiveness of the short-term break under investigation, broken down into the four categories first outlined in Section 2.7:

- effectiveness in relation to carers' health and well-being,
- effectiveness in relation to care recipients' health, well-being and dementia-related symptoms,
- impact on use of other services,
- cost-effectiveness in relation to carers' and care recipients' health and well-being.

The remainder of this section goes on to present relevant evidence about the effectiveness and cost-effectiveness of respite care and short-term breaks for carers for people with dementia. As indicated above, we start with studies of

day-care services. This was the model of respite-service delivery that generated the highest number of evaluations.

## **4.2 Day-care services**

### **4.2.1 Introduction**

In recent years, day care has become one of the main sources of community-based care for older people with physical and mental disabilities, both in this country and overseas. Day-care services are 'planned' and not intended to be an emergency response where there is a crisis. Day care embraces a range of services provided outside the home in day centres, day hospitals and residential facilities. Who provides the service influences the nature of provision.

In the UK, for example, local authorities and voluntary organisations are the main providers of day care in 'social' day centres. Ideally, this type of service aims to provide social care: stimulating, interesting and purposeful activities, and company for people with dementia. The number of day centres specialising in dementia care is growing (Walker *et al.*, 2001) which is important since there is evidence that many social day centres refuse admission to people with dementia, citing behavioural problems associated with severe dementia (Dabbs, 1999; quoted in Walker *et al.*, 2001).

In contrast, NHS day care is provided by day hospitals often based in geriatric psychiatric units. Here, the medical model is prevalent, and the emphasis in the short-term is on assessment, treatment and rehabilitation of the person with dementia. In some instances, however, the person with dementia may continue attending this type of day care if there is a lack of alternative day-care facilities.

### **4.2.2 Overview of studies**

The 27 articles reporting on day-care services for carers for people with dementia discuss 21 different studies set in the UK and overseas (see Table 4.1). Researchers evaluated a wide range of services, located in different settings including day centres, special dementia-specific day centres and psychogeriatric day hospitals using a mix of research designs collecting both quantitative and qualitative data. Service providers included both statutory sector (health and social services) and the voluntary sector. Six of the articles, one of which is an economic evaluation, draw on data from the same (USA) study: the Adult Day Care Collaborative Study.

**Table 4.1 Studies of day-care services included in the review**

<b>Authors</b>	<b>Study</b>
Beisecker <i>et al.</i> (1996)	Examination of carers' views of day care
Berry <i>et al.</i> (1991)	Comparison of carers' use of time using either day care or in-home respite
Colvez <i>et al.</i> (2002)	Europe-wide examination of the work burden and health of carers; components included day care and a respite hospitalisation programme
Curran (1996)	Examination of the effects of day-care attendance on people with dementia
Diesfeldt (1992)	Examination of day care in relation to institutionalisation
Engedal (1989)	Economic evaluation of day care compared to standard care
Gaugler <i>et al.</i> (2003a)	Examination of interaction between day care and time spent caring in relation to stress and mental health (Adult Day Care Collaborative Study)
Gaugler <i>et al.</i> (2003b)	Economic evaluation of day care (Adult Day Care Collaborative Study) compared to standard care
Gibson (1996)	Evaluation of the Rural Action on Dementia Project
Gilleard (1987)	Evaluation of psychogeriatric day care
Jarrott <i>et al.</i> (1999)	Evaluation of carers' satisfaction with day care (Adult Day Care Collaborative Study)
Jarrott <i>et al.</i> (2000)	Evaluation of time use of employed and non-employed carers using day care (Adult Day Care Collaborative Study)
Leitsch <i>et al.</i> (2001)	Comparison of medical and social day-care models (Adult Day Care Collaborative Study)
Levin <i>et al.</i> (1989)	Examination of day care and short-term 'relief' breaks
Levin <i>et al.</i> (1994)	Evaluation of day care, in-home respite and institutional/overnight respite
Lorensini and Bates (1997)	Comparison of the health of carers who use day care, carers who do not use day care and non-carers
Melzer (1990)	Evaluation of respite care unit with day places and beds for overnight respite using a new framework for service evaluation
Pritchard and Dewing (1999)	Evaluation of the Specialised Early Care for Alzheimer's (SPECAL) project
Quayhagen <i>et al.</i> (2000)	Comparison of four non-pharmacological interventions, including early-stage day care
Reid <i>et al.</i> (2001)	Exploration of views of people with dementia on day-care attendance
Walker <i>et al.</i> (2001)	Evaluation of day care provided in a day centre and a day hospital
Wells <i>et al.</i> (1990)	Examination of the effects on carers of special day-care programmes for people with dementia

**Table 4.1 continued**

<b>Authors</b>	<b>Study</b>
Wimo <i>et al.</i> (1990)	Economic evaluation of day care compared to standard care
Wimo <i>et al.</i> (1993)	Examination of the effects of day care on the symptoms and behaviour of people with dementia
Wimo <i>et al.</i> (1994)	Economic evaluation of day care compared to standard care
Zank and Schacke (2002)	Evaluation of the effects of geriatric day care on people with dementia and caregivers
Zarit <i>et al.</i> (1998)	Evaluation of the effectiveness of day care on carers' stress and well-being (Adult Day Care Collaborative Study)

### **4.2.3 Evidence on the effectiveness and cost-effectiveness of day-care services**

The box below pulls together the main findings of this sub-set of the research evidence.

- 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; 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.
- Half (two) of the economic evaluations suggested that day care might be cost-saving whereas the other half 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 or greater than those achieved through standard care.

## **Review of respite services for carers for people with dementia**

### **Effectiveness of day-care services in relation to carers' health and well-being**

#### **Perceptions of services**

Many of the studies report evidence from carers illustrating the perceived benefits of day-care services for themselves.

Day care was particularly praised, for example, in the two longitudinal studies undertaken by researchers from the (UK's) National Institute of Social Work (NISW; Levin *et al.*, 1989, 1994). In the first study, all the carers who used day care ( $n \sim 60$ ) regarded it as helpful to them personally; three-quarters of them considered it 'a lot' of help (Levin *et al.*, 1989). The proportion of carers placing a very high value on day care was far higher than the comparable proportions for other standard services such as institutional 'relief' care. Carers valued day care because it: linked them with professionals involved in the care of their relative; gave them more time; helped those carers who also undertook paid work. Some carers claimed that day care was the one service that enabled them to continue to care, a view confirmed by some studies in the review (Gibson, 1996).

Equally positive results were found in the second NISW study (Levin *et al.*, 1994). The vast majority (92 per cent) of carers with day care ( $n = 193$ ) considered the service had brought some improvements to their lives. Benefits reported included a sense of freedom, more choice about how to spend the time and having a longer break in any one day than that provided by, say, sitting services.

Many of the above advantages were cited by carers taking part in other studies that we reviewed, as well as additional ones such as: preservation of physical health; emotional relief; a safe environment for the person with dementia; peace of mind knowing their relative was being well cared for; stimulation; an opportunity for shared-responsibility support; a decrease in social isolation; improved communication and interaction (Wells *et al.*, 1990; Beisecker *et al.*, 1996; Jarrott *et al.*, 1999; Pritchard and Dewing, 1999; Quayhagen *et al.*, 2000; Walker *et al.*, 2001; Colvez *et al.*, 2002).

As noted at the start of this section, there are different models of day-care provision. Walker and colleagues' (2001) study examined respite care provided for people with dementia attending a day centre and a day hospital. Day-centre staff were of the opinion that the service benefited carers by providing: emotional support; information and advice; an opportunity to meet with other carers; a safe and enjoyable environment for their relative; stimulation that tired their relative so that they came home calm and ready to sleep; a break; flexibility (if a carer phoned one morning in desperate need of respite they could usually find a place); and the provision of personal services when required, like washing hair, shaving and bathing. In contrast, day hospital staff identified far fewer advantages for carers, namely the provision of respite, support and advice, and a safe environment for the care recipient.

Carers taking part in another study in the review showed a similar preference (Leitsch *et al.*, 2001). Leitsch *et al.* (2001) drew on data from the Adult Day Care Collaborative Study to compare medical and social adult day-care

## **Review of respite services for carers for people with dementia**

models. Carers using social programmes ( $n=154$ ) rated these as having higher-quality interactions between staff and clients, a more home-like and familiar atmosphere and fewer institutional elements than medical programmes.

Common sense suggests that carers' levels of satisfaction regarding day-care services will influence their perceptions of the effectiveness of day-care services (and other types of short-term break). Carers ( $n=19$ ) using a new respite care unit with both day places and overnight beds spoke highly of it, commenting on the helpfulness and caring attitude of the staff (Melzer, 1990). In his evaluation of the unit (which did not distinguish between the two type of respite care) Melzer (1990) noted that the unit's staff placed considerable emphasis on quality of care, which was interpreted predominantly as relative luxuriousness of physical inputs to the unit, achieved partly by maintaining a low occupancy. Melzer made the point that relative luxury and a high staff ratio were unreasonable, if it resulted in ignoring the needs of potential clients outside the unit.

Jarrott *et al.* (1999) assessed carers' satisfaction with specific aspects of day care related to the Adult Day Care Collaborative Study, and the potential benefits and drawbacks of usage. The evidence showed that carers in the study group at three months ( $n=175$ ) were highly satisfied with aspects of programming (staff skills, competence, friendliness, concern, activities, meals, programme setting), programme logistics (opening days and times, location) and cost. The study addressed change in carer experiences between three and 12 months, and found that carers who still used day care ( $n=90$ ) continued to report high levels of benefits at the 12-month assessment. The only significant change over time among those carers who used day care for 12 months related to satisfaction with programming aspects, which declined significantly (the authors give no reasons for this shift). Analysis of the interviews with carers who discontinued programme use before the three-month interview ( $n=80$ ) data suggested that some carers were dissatisfied with the times and number of days that day care was available, transportation and the cost of the programme (Jarrott *et al.*, 1999).

There was further evidence of carers' concerns or criticisms about day-care services. Difficulties relating to the availability of day care, lack of choice and transportation were reported in other studies in the review (Levin *et al.*, 1989; Quayhagen *et al.*, 2000; Walker *et al.*, 2001). Carers ( $n=19$ ) taking part in Melzer's (1990) evaluation gave various reasons for non-use of the new respite unit, including: the experience, or belief, that the patient became more confused when moved from home; existing successful arrangements or respite-type arrangements with other family members; serious physical illness of the patient; some carers feeling unable to continue to cope and preferring residential options.

As indicated above, a number of studies included in the review reported that carers welcomed the time freed up by the use of day care. The issue of how carers actually used this additional time was explored in a handful of studies. One study compared the use of time by female carers of dementia patients who used day care ( $n=20$ ) with those who used home care ( $n=20$ ; Berry *et al.*, 1991). The findings revealed that women who used day-care services

## **Review of respite services for carers for people with dementia**

spent more time performing caregiving activities on respite days than they did on non-respite days. One possible explanation suggested by the researchers is that preparations for the out-of-home visit increased their caregiving time on respite days. Berry *et al.* (1991) concluded that respite provides relief from care demands and frees blocks of time that can then be used to participate in other activities, but at the same time it does not necessarily reduce the amount of time spent on caregiving tasks.

Beisecker *et al.*'s (1996) study of day care for people with Alzheimer's disease prompted similar propositions. The evidence suggested that carers who used day-care services ( $n=52$ ) perceived physical and psychological benefits to themselves. In contrast, carers who did not use day-care services ( $n=52$ ) theorised benefits to themselves as a means to provide more time for activities – both tasks related to caregiving and those that were not. The authors speculate that day-care use could be seen as a route to ever-expanding work rather than providing relief from caring responsibilities, a view supported by other studies in the review (Gibson, 1996).

Finally, Jarrott *et al.* (2000) used data from the Adult Day Care Collaborative Study to investigate the time spent on caregiving activities specifically among employed carers ( $n=40$ ) and non-employed carers ( $n=82$ ) of relatives with dementia who attended day care for three months. Having started day care, both employed and non-employed carers reported spending significantly less time dealing with the care recipient's behavioural problems (slightly less than one hour per day). There was no change, though, in the time spent assisting relatives with ADL dependencies or memory problems. Non-employed carers experienced a greater increase in the time spent away from their relative than employed carers. For employed carers, day-care services provided additional supervision for the care recipient while they were at work, and it further reduced the carers' time of responsibility.

### **Health status and well-being**

Nearly half the studies in this section commented on the effectiveness of day-care services in relation to carers' health and well-being, examining a whole range of physical and psychological states including stress, strain, distress, depression, well-being and burden.

Gilleard's (1987) study looked specifically at levels of strain and emotional distress in carers ( $n=129$ ) of people with dementia using psychogeriatric day hospital care over a seven-month period. The results indicated that day hospital care is associated with a significant reduction in carers' emotional distress, particularly during the first three months of attendance, while having no obvious reduction on the range and extent of problems presented by the care recipient.

In comparison, Levin *et al.*'s (1989) research showed that the psychological health of carers using day-care services ( $n \sim 60$ ) at the time of their first interview was, on average, much the same at the follow-up interview some 12 months later. In contrast, the psychological health of those without day care showed signs of changes for the worse at follow-up, although the difference was not significant. On this basis, day care appeared to stabilise carers' psychological health.



## **Review of respite services for carers for people with dementia**

Wells *et al.* (1990) assessed the psychological symptoms and behaviour problems of two groups of carers: those using special dementia day care ( $n=155$ ) and those about to begin using it ( $n=64$ ). Their main finding was that over three months, the day-care programmes investigated did not produce a reduction in carers' psychological distress. The initial psychological symptom scores of those who had dropped out by three months tended to be higher than the scores of those still attending.

More recently, Zarit and colleagues' (1998) evaluation of the Adult Day Care Collaborative Study investigated the psychological benefits of day care for carers of people with dementia. The results showed that carers who used day care at least two days a week for a period of three months or more experienced reductions in role overload, worry, depression and anger. Advantages from day-care use were found, even though carers in the study group ( $n=121$ ) were initially more stressed and distressed than those in the control group ( $n=203$ ) who did not use day care for their relative at any time during the study. The findings at 12 months showed that the study group ( $n=73$ ) continued to have significantly lower scores on overload and depression than the control group ( $n=120$ ).

A newly published article (Gaugler *et al.*, 2003a) used three-month longitudinal data from the same study to determine whether day care use interacted with decreases in caregiving hours (time spent on ADL dependencies, behaviour problems or memory problems) to alleviate carer stress and improve psychological well-being. The findings reinforced the positive results of the parent analysis just discussed (Zarit *et al.*, 1998), in that they indicated that decreases in hours spent dealing with memory problems by carers using day care ( $n=169$ ) were associated with reduced feelings of role overload. Non-users of day-care services ( $n=231$ ) who reported decreases in time spent dealing with ADL dependencies indicated greater reductions in feelings of worry and strain when compared to carers who did use day-care services. The authors speculate that carers using day-care services may experience greater difficulty preparing the care recipient for day-care attendance.

In their comparison of medical and social day-care programmes, again drawing on data from the Adult Day Care Collaborative Study, Leitsch *et al.* (2001) found evidence of benefits for carers. In common with the findings of the main analysis (Zarit *et al.*, 1998), depression, anger, role overload and worry all decreased over the three-month period of study. However, carers using medical day-care programmes ( $n=106$ ), which cost more than social programmes for private-pay clients, experienced significantly more financial strain.

One of the treatments in a three-month comparative study (Quayhagen *et al.*, 2000) to evaluate four non-pharmacologic interventions was early-stage day care (which also included just two sessions for carers offering education/training opportunities). Analysis of the relevant data sub-set revealed a significant decrease in symptoms of hostility for the carers with relatives in the early-stage day-care group ( $n=16$ ), but no change in levels of depression.

## **Review of respite services for carers for people with dementia**

Zank and Schacke's (2002) undertook a study of geriatric day care units where just under 80 per cent of patients suffered from dementia. Results concerning the effects on carers ( $n=20$ ) were unclear. The quantitative data showed no positive effects of day care on either carer well-being or burden over the nine-month study period. However, in semi-structured interviews, carers in the study group reported substantial benefits due to the use of day care. These gains included reductions in perceived burden, positive changes in role conflicts, better recreation and more social activities.

Finally, Lorensini and Bates (1997) undertook a comparative study looking at the health, psychological and social consequences of caring for a person with dementia, and the impact on the care recipient of attending a day care centre. There were three study groups: carers of elderly people with dementia attending day care ( $n=45$ ), carers of elderly people with dementia not attending day care ( $n=40$ ) and non-carers ( $n=47$ ). The results showed that carers experienced more negative consequences when compared with non-carers. Negative consequences were related to symptoms (depression, and self-reported stress and arousal), life satisfaction and social interaction, but not physical health. Carers providing full-time care suffered more negative consequences than those whose relative attended day care. Carers who used day care experienced less depression and arousal, and were more satisfied with their life.

### ***Effectiveness of day-care services in relation to care recipients' health, well-being and dementia-related symptoms***

#### **Perceptions of services**

Some studies of day-care services included in the review reported the views of people with dementia. Reid *et al.* (2001), for example, interviewed 19 people with dementia as part of a study into unmet needs for respite care. A number highlighted the advantages of being part of a group, for instance meeting other people, new friendships, gaining confidence, a sense of interdependence and solidarity. Other sources of satisfaction included the different activities and physical activities. Initial experiences generated feelings of insecurity, uncertainty and anxiety for some people; however, these fears and misgivings dissipated over time.

The data collected from people with dementia in Walker and colleagues' (2001) study of a day centre and a day hospital shed light on differences in how they perceived the two types of day care. The interviews with care recipients attending the day centre ( $n=5$ ) indicated that they valued the service, particularly the company and social aspects. Attending the day centre had made a difference to their quality of life in that they felt less isolated or alone, spent less time thinking about negative things and had less time on their own to become low in mood or bored. In contrast, data from care recipients attending the day hospital ( $n=5$ ) were much less positive insofar as they commented on feeling like a failure, feeling alone or left out, a perceived lack of stimulation and valued activity and little choice.

The findings of other studies in the review endorsed the above positive views of day-care attendance. Examples of benefits reported by people with

## **Review of respite services for carers for people with dementia**

dementia included the meals, the outings, friendships, a sense of belonging, activities, identity, safety, relaxation and being able to help (Levin *et al.*, 1989; Pritchard and Dewing, 1999).

Studies documented evidence about carers' views of the impact of day care of their relative. For example, four in ten carers taking part in Levin *et al.*'s (1989) study ( $n = \sim 60$ ) believed that day care was very effective. Over five in ten carers considered that it was some help; the remainder thought that it was probably not helpful or made little difference to their relative. Benefits included: getting out of the house; being in company; being occupied; having a meal, and even a bath; having an outside interest which provided a talking point.

The evidence from the later NISW study (Levin *et al.*, 1994) was similar. Nearly one in three carers using day care ( $n = 193$ ) thought their relative had benefited greatly, describing relatives as happier, more relaxed, more confident, more talkative and showing more interest in people and events.

Other studies reporting evidence about carers' perceptions of benefits from day care for people with dementia cited phenomenon such as stimulation, socialisation, safety, help with mental functioning, sleeping better and being less agitated (Beisecker *et al.*, 1996; Jarrott *et al.*, 1999).

Finally, Beisecker *et al.*'s (1996) study of day care for people with Alzheimer's disease found that carers who used day care ( $n = 52$ ) were more likely to feel that the service benefited both themselves and the care recipient. In contrast, carers who had never used day care ( $n = 52$ ) were more likely to see it as benefiting the carer only, prompting the authors to suggest that carers may be less motivated to use a service if they see no benefit to the care recipient.

### **Health status, well-being and dementia-related symptoms**

Some studies included in the review evaluated the effects of day-care provision on the symptoms and behaviour of demented patients. The results of the study by Wimo *et al.* (1993) showed that over a 12-month study period participants in both the day-care group ( $n = 55$ ) and the control group ( $n = 44$ ) deteriorated in terms of ADL functions. Day care had no positive effect on cognitive function. There was a tendency towards more-severe behavioural disturbances in the control group during the first six months of the study, but during the last six months the day-care group deteriorated more than the control group.

In contrast, Zank and Schacke's (2002) results revealed an improvement or stabilisation in the subjective well-being and dementia symptoms in the study group ( $n = 43$ ) in comparison with the control group ( $n = 40$ ), even though the study group had worse scores at the beginning of the study. The results also showed a decrease in symptoms of agitation in day-care patients (not through medication) and an increase in the control group. The authors suggest that the results also indicate that partial cognitive abilities can be improved by general day-care attendance even in participants with reduced capacity. Follow-up data from carers suggested a significant decline in health in the control group in comparison with the day care users, and the authors

## **Review of respite services for carers for people with dementia**

speculate that this could have been due to the higher morbidity at the outset of the control group or alternatively a long-term effect of day care.

A smaller-scale study produced mixed results (Curran, 1996). Of the 19 people with dementia, eight showed marked improvements in mood and/or behaviour – attributed by their carers to attendance at day care – and which was maintained in most cases for at least nine months. Of the 11 people who did not respond, eight showed no real change in levels of activity, mood or sociability as observed by carers. A further three showed a temporary improvement in mood and sociability but these changes were confined to one or two days post-attendance, and did not endure throughout the week.

The Specialised Early Care of Alzheimer's (SPECAL) dementia care service is a particular approach to dementia care centred around maintaining a person with dementia in a state of positive well-being as far as is possible, via the development of SPECAL care, ahead of potential crises (Pritchard and Dewing, 1999). Professionals ( $n=23$ ) taking part in the evaluation of the SPECAL service for people with dementia claimed a general increase in the well-being experienced by patients. Communication was believed to have increased, as had self-esteem and interaction with others. There was also a reduction in confusion, fear, agitation and anxiety. The disease process seemed to slow down and there were periods of 'plateau'.

### **Impact of day-care services on use of other services**

No evidence was retrieved on the impact of day-care services on the use of other community care services. However, some of the studies included in the review examined the relationship between the provision of day-care services and entry to long-term care. Wimo *et al.* (1993) concluded that day care seemed to have a preventative effect on institutionalisation: after one year, the number of permanently institutionalised patients was 24 per cent in the day-care group ( $n=55$ ) compared with 44 per cent in the control group ( $n=44$ ). The authors speculated that day care might have a stress-reducing impact and act as a buffer, creating a space of freedom and offering a chance for carers to regain their strength.

A five-year longitudinal follow up of a cohort of 224 patients in receipt of psychogeriatric day care examined long-term outcomes (Diesfeldt, 1992). The results showed that at one year after admission to day care, 44 per cent of patients were still resided in the community, 42 per cent were admitted to a nursing home or (psychiatric) hospital and 14 per cent had died. At five years, only four per cent of patients still lived in the community, 29 per cent were in long-term institutional care and 67 per cent had died. Severity of cognitive impairment was associated with increased risk of becoming institutionalised.

In their study, Levin *et al.* (1989) found that, overall, people with dementia in receipt of day care were equally likely to have entered residential care between the two sets of interviews (12 months apart) as those without day care.

***Cost-effectiveness of day-care services in relation to carers' and care recipients' health and well-being***

Four economic evaluations (abstracted in Appendix 4b) assessed day-care services compared to standard care (Engedal, 1989; Gaugler *et al.*, 2003b;<sup>7</sup> Wimo *et al.*, 1990, 1994), all of which were non-UK based (Norway, USA and two Swedish studies respectively). Each of these studies conducted the analyses from multiple perspectives, including the social-services perspective. Additionally the carer perspective was considered in three of the studies (Gaugler *et al.*, 2003b; Wimo *et al.*, 1990, 1994) and the care recipient and the health-care perspective was examined in three studies (Engedal, 1989; Wimo *et al.*, 1990, 1994).

In those studies that included the carer perspective, carer costs that were calculated included loss of carer earnings<sup>8</sup> (Gaugler *et al.*, 2003b) and remuneration to families (Wimo *et al.*, 1990, 1994). The latter studies included a financial allowance paid to relatives by the Swedish municipality. The remuneration was regarded as a payment to the relatives since less help from staff was needed. Accordingly, if the help needed increased, the payments made to family members increased.

The consequences identified and measured also reflected the study perspectives taken. Three out of the four studies included a battery of standard outcome measures, similar to those used in the effectiveness studies (Engedal, 1989; Gaugler *et al.*, 2003b; Wimo *et al.*, 1994) and the fourth study asked carers and staff on behalf of the care recipients to assess their own well-being (Wimo *et al.*, 1990).

From the carer perspective, instruments such as the seven-item Role Overload Scale to measure stress and the 20-item Center for Epidemiological Studies for Depression Scale to measure depression were used. In one study (Wimo *et al.*, 1994) relatives/carers were asked to assess the effects of day care on their own situation.

In contrast, the patient became the focus when instruments such as the Mini-Mental Status Examination were used (Engedal, 1989; Wimo *et al.*, 1994) or when caring professionals were asked to judge the well-being of the patients (Wimo *et al.*, 1990).

In terms of study design, one study was based on an RCT (Engedal, 1989), two studies on quasi-experimental studies (Wimo *et al.*, 1994; Gaugler *et al.*, 2003b) and one on a pre- and post-intervention study (Wimo *et al.*, 1990). Where stated, all studies were publicly funded (Engedal, 1989; Gaugler *et al.*, 2003b) and services were government provided (Engedal, 1989; Wimo *et al.*, 1990, 1994). Initial numbers enrolled in the studies varied from 38 to 231. All studies were based on a 12-month-long follow-up, apart from the Wimo *et al.* (1990) study that took place over a six-month period.

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<sup>7</sup>The letter 'b' after the date of the publication denotes that the study relates to an effectiveness study, cited above.

<sup>8</sup>Measured taking the human capital approach in which the shadow price of lost earnings is calculated.

## **Review of respite services for carers for people with dementia**

In the Gaugler *et al.* (2003b) study, higher costs and consequences were reported in terms of the alleviation of carer depression and role overload in the day-care user group compared to the standard-care control group. To alleviate depression by one unit on the 20-item Center for Epidemiological Studies for Depression Scale, day care cost \$2.20 more than standard care (1993 US \$). To alleviate role overload by one unit on the seven-item Role Overload Scale, day care cost \$4.51 more than standard care.

The core findings were similar in the Wimo *et al.* (1990) study where it was also suggested that day care was associated with higher costs and consequences, compared to the standard-care group. The additional cost per well year for the carers in the intervention group was calculated at SEK 43 931 (£3922) (1985 Swedish krona, SEK).

The Wimo *et al.* (1990) study also assessed the impact of day care on the care recipients as well as the carer. Caring professionals were asked to judge the well-being of the care recipients. Fifty-four per cent of care recipients were reported to have improved well-being when receiving day care; however, there were additional costs associated with receiving day care. Based on staff opinion, the cost per well year for the care recipient was SEK 48 076 (£4293).

In summary, study findings in Gaugler *et al.* (2003b) and Wimo *et al.* (1990) suggest that day care can provide more benefits at greater cost than standard care and if this were the case the funder would need to decide whether they were willing to pay the additional cost of gaining potentially greater benefits.

In contrast, the Engedal (1989) study and the Wimo *et al.* (1994) study reported that day care might be potentially cost-saving since both studies reported lower costs and similar/better consequences when comparing day-care to standard-care groups.

The consequences measured in the Engedal (1989) study reported similar levels of deterioration in the mental capacity of the care recipient across day-care and standard-care groups whereas day care was observed to be less costly than standard care; however, no statistically significant differences in costs or consequences were found. Lower costs for the day-care group were related to less time spent in acute care in that group.

On the other hand, the Wimo *et al.* (1994) study reported less deterioration in the utility indices (satisfaction), from the care-recipient perspective and lower costs in the day-care group as compared to the standard-care group. As the authors state, 'Although the trend..indicated that day care was cheaper and improved quality of life, the main result was that differences were not significant and the assumption that day care is more cost-effective than a caring organisation without day care was not confirmed.'

## **4.3 In-home respite services**

### **4.3.1 Introduction**

In-home respite, where a care worker comes to the family home and 'sits' with the dementia sufferer, seems to offer potential advantages to some carers and some dementia sufferers. As noted in Section 4.2 above, it can be onerous for a carer to prepare the care recipient to go out to a day centre. Some dementia sufferers may be reluctant to attend day centres, or they may be too frail, or their behaviour too challenging. Some carers may have concerns about institutional settings for day care, or concerns about the distress and confusion for the dementia sufferer when taken out of their own familiar surroundings. In-home respite services provide the carer with an opportunity for a break from caring without 'removing' the dementia sufferer from their home. Ryan *et al.* (2002) suggest that in-home respite can be designed to facilitate the 'rhythms of family life'.

Levin *et al.* (1994), in a longitudinal study of respite services undertaken in the early 1990s, observed that all in-home respite services in the study areas were provided by voluntary-sector organisations or privately arranged by carers. They were used in addition to other respite services. Very few carers were getting in-home respite, and services were often limited to a given number of hours in a month, rarely more than a few hours a week, and usually in working hours. All those using the service would have liked the service more often, and the visits to last longer. One-third of those carers who did not have access to in-home respite said they would like to have access to this service, suggesting that at the time of Levin *et al.*'s study there were considerable unmet needs.

### **4.3.2 Overview of studies**

Eight studies addressed in-home respite services (see Table 4.2 below). Five were conducted in the UK (Turvey *et al.*, 1991; Milne *et al.*, 1993; Levin *et al.*, 1994; Parahoo *et al.* 2002; Ryan *et al.*, 2002), two in the USA (Berry *et al.*, 1991; Grant *et al.*, 2003), and one in Sweden (Jansson *et al.*, 1998). The two respite interventions evaluated by Jansson *et al.* (1998) and Grant *et al.* (2003) were experimental and delivered for the study period only. All the other studies evaluated 'natural' services. The studies employed a variety of different methods and considered different types of outcomes. Only two studies (Berry *et al.*, 1991; Levin *et al.*, 1994) compared in-home respite with other types of respite service.

**Table 4.2 Studies of in-home respite included in the review**

<b>Authors</b>	<b>Study</b>
Berry <i>et al.</i> (1991)	Comparison of carers' use of time using either day care or in-home respite
Grant <i>et al.</i> (2003)	Impact on carers' of an experimental two-week period of in-home respite
Jansson <i>et al.</i> (1998)	Evaluation of the Circle Model of in-home respite
Levin <i>et al.</i> (1994)	Evaluation of day care, in-home respite and institutional/overnight respite
Milne <i>et al.</i> (1993)	Evaluation of Age Concern Carer Support Scheme (in-home respite)
Parahoo <i>et al.</i> (2002)	Evaluation of carers' views of in-home respite to younger dementia sufferers
Ryan <i>et al.</i> (2002)	Evaluation of Community Dementia Support Service (CDSS)
Turvey <i>et al.</i> (1991)	Survey of carers' satisfaction with in-home respite

### **4.3.3 Evidence on the effectiveness and cost-effectiveness of in-home respite**

The box below pulls together the main findings of this sub-set of the research evidence.

- 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 brought 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 activity that could be undertaken.
- 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 the cost-effectiveness of in-home respite.

#### ***Effectiveness of in-home respite in relation to carers' health and well-being***

##### **Perceptions of services**

One of the difficulties noted by all authors in isolating the benefits that carers derived from in-home respite was that most carers in these studies were



## **Review of respite services for carers for people with dementia**

accessing a package of formal and informal support services. Nevertheless, where carers' were asked about their perceptions of in-home respite (all studies, with the exception of Grant *et al.*, 2003), high levels of satisfaction were reported. Carers reported that the services did them good and enabled them to continue caring for their relative. In those studies which sought to understand *why* carers were satisfied (Parahoo *et al.*, 2002; Ryan *et al.*, 2002; Levin *et al.*, 1994; Jansson *et al.*, 1998), carers' satisfaction appeared to be closely linked to their perceptions of the benefits that the service brought to their relative, and the confidence carers had in the care staff and the quality of care provided.

The Community Dementia Support Service (CDSS) evaluated by Ryan *et al.* (2002) was designed to be flexible, operating seven days a week between 7.00 a.m. and 9.00 p.m. Sessions lasted between three and four hours, and carers were allowed up to 15 hours respite per week. The service aimed to allow carers a break, and at the same time enable people with dementia to participate in appropriate activities whether in or outside the home. Interviews with a sub-group of carers using the service suggested that CDSS had assisted them in being able to continue to face the demands of caring at both a psychological and practical/logistical level. They gained a break from caring and had the opportunity to pursue different activities. Carers felt that they themselves had a significant role in defining the nature of the intervention. Carers felt it provided a quality break, but that effectiveness of the service was limited by the amount of respite time available, and the timing of the sessions that did not always accommodate carers' preferences.

In a qualitative study conducted in rural Northern Ireland, Parahoo *et al.* (2002) carried out a series of in-depth interviews with carers ( $n=8$ ) to assess their satisfaction with an in-home respite service for dementia sufferers under 65. Carers reported that initial responses to the service were cautious; they had reservations about letting a 'stranger' into their home, and felt guilty about leaving their relative. At follow up, however, carers were unanimous about the benefits of the services and were highly satisfied. Carers who had used other types of respite reported that they were unsuitable for younger people with dementia, causing distress to both carer and care recipient. There were also difficulties in preparing, transporting and collecting their relative. Providing respite in the home helped to maintain family cohesion and the status and dignity of the person with dementia in the family; the family's usual cultural and traditional activities could continue, and household routines kept as 'normal' as possible so the service not only caused little disruption to the household, but positively contributed to promoting the status quo. Carers were highly satisfied with the service. Care workers were considered to be experienced, friendly and helpful. Carers reported that without the service they would not have been able to continue to care at home.

The 85 carers who were receiving in-home respite care in the large sample of carers participating in the longitudinal study conducted by Levin *et al.* (1994) appreciated the time off from caring; however, the respite was typically only a few hours per week, limiting what carers could do during their break.

Jansson *et al.* (1998) reported on the development and evaluation of the Circle Model where carers and volunteers were trained together in study

## **Review of respite services for carers for people with dementia**

circles, and the volunteers then replaced the family caregivers in their homes providing up to four hours care per week on a regular basis over a four-month period. Many of the relatives appreciated the regular respite from caregiving, whereas others felt a sense of security knowing that they could rely on a new and understanding friend who was willing to help when needed. As much as they appreciated the respite, carers also appreciated having contact with other carers.

The studies by Milne *et al.* (1993) and Turvey *et al.* (1991) both report surveys of carer satisfaction; thus they are relatively limited in what they tell us about carers' own perceptions of effectiveness. Both surveys report high levels of satisfaction with in-home respite services; however, survey respondents in both studies did not include those carers who had chosen not to use, or had discontinued using, in-home services. Milne *et al.* (1993) reported that 98 per cent of carers ( $n=78$ ) perceived the service to be the 'right type of help', and 'provided by competent staff' (96 per cent); 69 per cent of carers thought the service was very good, and good by the remainder; 59 per cent were very satisfied and 19 per cent quite satisfied, but seven per cent were very dissatisfied. Despite these apparently high levels of carer satisfaction, there were no apparent changes in various outcome measures (see below).

Turvey *et al.*'s survey indicated that at six months follow up 73.5 per cent of carers ( $n=132$ ) felt the service had a 'great deal of good effect' on them, a further 7.6 per cent felt it had 'some good effect'. Although no carers reported a bad effect, 18.9 per cent made no response to the question. Sixty-eight per cent of carers felt the dementia sufferer was 'happy' with the service, three per cent said 'not happy' and 28.8 per cent made no comment.

Berry *et al.*'s (1991) comparison of two groups of carers using either in-home respite or day care did not identify any significant difference on levels of satisfaction between programme users. Both groups were highly satisfied. There was no difference between the groups in willingness to continue caring.

In all these studies, in-home respite visits typically lasted three to four hours at most; the maximum number of hours given in any week was 19 (most services provided fewer hours than this), and services were usually, although not always, confined to working hours on weekdays. Unsurprisingly, a consistent criticism of in-home respite – which might also be read as an endorsement for these services – was the limited time they were available. 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 carers could undertake.

Three of the studies indicated how carers used their time during periods of in-home respite (Berry *et al.*, 1991; Parahoo *et al.*, 2002; Ryan *et al.*, 2002). These studies provide little evidence that carers used the 'break' to engage in social or recreational activities. The carers interviewed by Parahoo *et al.* (2002) usually did shopping or other chores; men often used the free hours to do paid work; some carers used the respite time for additional help with caring tasks such as lifting, bathing and other personal hygiene tasks. The carers using CDSS (Ryan *et al.*, 2002) welcomed the opportunity to have time

## **Review of respite services for carers for people with dementia**

away from the care recipient; however, some carers adopted a mid-way approach, doing something on their own one week, and going with care recipient and support worker on outings/trips the following week so as to participate together in social activity.

The study by Berry *et al.* (1991) compared how carers using in-home respite and day care used their time. For in-home respite carers, time spent on caregiving with their relative was less on respite days than on non-respite days, compared to day-care users who spent more time caregiving on respite days than on non-respite days, probably preparing their relative for going to the centre (see Section 4.2.3 above). In-home respite workers took on some of the regular personal care tasks usually undertaken by carers. Much of the respite time for both in-home and day-centre respite users was used to undertake paid employment, household tasks and errands, with very little time spent on social activities with friends or relatives.

Ryan *et al.* (2002) attempted to gauge the attitudes of in-home respite staff regarding the effectiveness of services. The CDSS staff felt their work was positive and rewarding as they were encouraged to develop personal relationships with both carers and care recipients. They felt satisfied that they provided activity, stimulation and company, and an improved quality of life to carer and care recipients. Staff invested great efforts in building a rapport with people, and encouraged people to participate in normal activities both in and out of the home environment. Staff also reported some tensions between meeting the needs of carers and those of care recipients.

### **Health status and well being**

Milne *et al.* (1993), Ryan *et al.* (2002) and Grant *et al.* (2003) employed various different quantitative measures of health and well-being to provide a profile of the carers participating in the studies and also to measure the impact of in-home respite on carers' health, ability to cope with the demands of caring, and stress levels. None of these studies were able to demonstrate statistically significant positive effects of in-home respite on a range of measures, although there is weak evidence (Grant *et al.*, 2003) that vulnerable carers in particular may gain some advantage.

Milne *et al.* (1993) report that the use of the Age Concern Carer Support Scheme did not influence the levels of stress, coping or strain of the carers group. There were no significant differences at three-month follow-up between the control group (15 carers who had elected not to use the service) and 78 carers who had used the in-home service. The authors note, however, that there was no significant deterioration in levels of stress, coping or strain among the carers using the service, but a slight and non-statistically significant increase in strain in the control group.

Two-thirds of carer respondents taking part in the evaluation of CDSS (Ryan *et al.*, 2002) experienced a reduction in GHQ-28 scores at six-month follow-up, but these changes were not statistically significant. Median scores decreased on all but one of the GHQ-28 sub scales (social dysfunction), but again these changes were not statistically significant.

## **Review of respite services for carers for people with dementia**

Grant *et al.* (2003) measured psychological and physiological indicators of stress in carers receiving an experimental two-week programme of in-home respite. Vulnerable carers (defined as those who had experienced a severe mismatch between caregiving demand and help received in the previous six months) experienced a reduction in circulating plasma epinephrine (adrenaline) concentration following an intensive two-week period of in-home respite compared to a group of vulnerable carers who were waiting to receive the intervention who experienced an increase in circulating epinephrine. No blood-pressure or heart-rate changes were observed. The study failed to detect improvements in mood measures related to the intervention for vulnerable and non-vulnerable caregivers. The authors suggest that in-home respite may reduce sympathetic-adrenal-medullary activation independent of psychological symptoms. Given that sympathetic activation mediates pathophysiological events, the authors suggest these preliminary results may indicate that in-home respite may reduce morbidity and mortality in certain caregivers.

### ***Effectiveness of in-home respite in relation to care recipients' health, well-being and dementia-related symptoms***

#### **Perceptions of services**

Only two studies, by Ryan *et al.* (2002) and Parahoo *et al.* (2002), provide any indication of the perceptions of dementia sufferers regarding in-home respite services and this evidence is minimal. Ryan *et al.* (2002) interviewed six in-home respite-care recipients. It was not clear how they benefited from the service, although some were able to express their pleasure at being able to go out accompanied by their support worker, and visit different places. The researchers observed an increased participation in social activities, and considerable efforts made by support workers to involve dementia sufferers in decision-making. Parahoo *et al.* (2002) interviewed one care recipient who reported looking forward to the care worker's visits, as it enabled him to do odd jobs around the house, including gardening, which he was unable to do without supervision.

As noted above, carers' satisfaction with the service appeared to be closely linked to whether they perceived their relative to have benefited from their respite experience. Carers perceived that the stimulation of different company, and outings to undertake activities or visit places of interest, were beneficial to their relatives, and helped reduce wandering and problematic behaviour and improve mood (Levin *et al.*, 1994, Ryan *et al.*, 2002). Similarly, when Ryan *et al.* (2002) interviewed support workers they noted how much care recipients enjoyed going out to do things they had always enjoyed. They also noted that there was sometimes tension between the wishes of the carer and the care recipient, when the carer wanted the support worker to take the care recipient out of the house even when the care recipient had no real interest in an outing. The carers in Parahoo *et al.*'s (2002) study valued the way that in-home respite could assist in maintaining family routines, and roles, and the dementia sufferer's sense of self.

## **Review of respite services for carers for people with dementia**

The survey of Turvey *et al.* (1991) reports (again, noted above) that 68 per cent of carers thought the service was 'good' for their relative, although a small percentage of carers thought the service had been harmful.

In comparison to other respite services, 60 per cent of those using in-home respite ( $n=85$ ) in Levin *et al.*'s (1994) study thought the service had benefited their relative, whereas only 30 per cent of carers using day care ( $n=193$ ) thought day care benefited the care recipient. A higher proportion of carers using relief care (that is, short stays away from the home in a respite facility) felt it did not bring any benefits to the care recipient, but recognised that they could not continue caring without this type of support.

Four studies (Berry *et al.*, 1991; Milne *et al.*, 1993; Jansson *et al.*, 1998; Grant *et al.*, 2003) made no comment about the impact of the in-home respite service on care recipients.

### ***Impact of in-home respite on use of other services***

As noted above, most carers in these studies were accessing a range of different services. Thus 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. The study by Levin *et al.* (1994) identified that those dementia sufferers who had in-home respite or day care ( $n=85$ ) were more likely to have remained in the community than those who were using these services in conjunction with relief care (short stays away from home). Other studies did not attempt to investigate the complex relationships between different types of service provision.

A further study (Milne *et al.*, 1993) asked health-care professionals who had referred carers to the in-home respite service about their levels of satisfaction with the service. Referrers expressed high levels of satisfaction with the scheme (75 per cent reported they were 'very satisfied'), and all believed that without the service demands for other services would have increased. All referrers saw the scheme as providing the 'right type of help', and 62 per cent judged the quality of scheme as 'very good'. Referrers expressed less satisfaction with the amount of support available.

### ***Cost-effectiveness of in-home respite in relation to carers' and care recipients' health and well-being***

No evidence was retrieved in relation to cost-effectiveness.

## **4.4 Host-family respite**

### **4.4.1 Introduction**

There appears to be very little evidence as to the effectiveness of breaks that enable the carer and care recipient to stay together, but relieve the carer of their usual caring tasks, and it seems highly likely that these services are rarely provided as part of mainstream respite services. Nevertheless, in the same way that in-home respite services are intended not to disturb family

## **Review of respite services for carers for people with dementia**

routines and lifestyles, being able to take a break together may provide an opportunity for carers and care recipients to sustain their identity as a couple.

### **4.4.2 Overview of studies**

Only one recent study (Robertson, 2002) evaluated a service offering spouse carers and their partners the opportunity to take a short-term break together, staying with a host family (Table 4.3). The scheme was organised jointly by health and social services. Couples went to stay with the host family, for a few days or longer in some cases.

**Table 4.3 Studies of host-family respite included in the review**

<b>Author</b>	<b>Study</b>
Robertson (2002)	Assessment of the impact of host-family respite for couples for dementia care

### **4.4.3 Evidence on the effectiveness of host-family respite**

The box below pulls together the main findings of this sub-set of the research evidence.

- 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.

#### ***Effectiveness of host-family respite in relation to carers' health and well-being***

##### **Perceptions of services**

The evidence from this qualitative study suggests that this type of short-term break was effective in meeting the needs of carers. The carers ( $n=6$ ), particularly women, appreciated being away from household routines and chores. All participants said they felt relaxed during the break, and went home feeling refreshed and better able to deal with coming challenges. Although carers felt the effects of the break were short-lived, knowing they were coming back for another break gave them something to look forward to.

Carers also valued the opportunity to have an experience that could provide happy memories, and enabled both carer and care recipient to look forward to something together. The homely, family environment was valued as it allowed some flexibility in meeting individual needs and requirements. Carers and care recipients reported they felt comfortable with the service providers and their

## **Review of respite services for carers for people with dementia**

families, enjoying the different company, which they felt helped stimulate more talking between themselves.

Carers felt it was important to be able to have a break together. Some couples had always done everything together over 40 years or more, and it was important for them to continue to be together as a couple and integral to their quality of life. The short-term break allowed them to continue in their existing family roles. They appreciated having a 'normal break' with the opportunity to do the usual holiday activities. The carers did not expressly talk about a break from caring itself, and looking after their partner appeared to be an expected and valued part of their relationship.

People could not identify ways in which the service could be improved, but the author notes that often people are simply grateful and cannot evaluate services critically.

### **Health status and well-being**

This study did not attempt to measure in any quantitative way the impact of host-family respite on health and well-being of carers.

### ***Effectiveness of host-family respite in relation to care recipients' health, well-being and dementia-related symptoms***

#### **Perceptions of services**

People with dementia ( $n=4$ ) had difficulty explaining how the service affected them in the longer term. Nevertheless they appeared to enjoy the homely atmosphere of the family environment and preferred it to that of a residential care home. The homely setting helped people with dementia adapt more quickly to the change. They valued being around people who understood dementia and were patient, and consequently felt more able to talk and be sociable. They appreciated being offered a choice of things to do, whereas for their carers it was more important that the dementia sufferers had stimulating things to do.

#### **Health status, well-being and dementia-related symptoms**

No evidence was retrieved regarding the impact of host-family respite on health status or dementia-related symptoms.

### ***Impact of host-family respite on use of other services***

No evidence was retrieved on the impact of host-family respite on the use of other community care services, or entry to long-term care.

### ***Cost-effectiveness of host-family respite in relation to carers' and care recipients' health and well-being***

No evidence was retrieved in relation to cost-effectiveness.

## **4.5 Institutional/ overnight respite services**

### **4.5.1 Introduction**

The 12 studies in this section refer to institutional/overnight services. These are breaks away from the care recipient's home, including at least one night away from the carer. Whereas day care provides short-term breaks from caring, institutional/overnight services provide longer periods of relief. Covering longer time periods also means relief at those times in the day when care might be more difficult, for example during evenings and night time when care recipients may become more agitated and restless and therefore disruptive to carers' sleep (Watkins and Redfern, 1997). An oft-stated aim is relief from caring duties for people caring for someone with dementia (Adler *et al.*, 1993; Hirsch *et al.*, 1993; Watkins and Redfern, 1997).

Although a generic aim may be relief, as noted with day-care services, institutional/overnight services offer interventions with differing emphases on health and social aspects for the care recipient. Institutional and overnight services include activities such as walking, maintenance of personal routines (Perry and Bontinen, 2001), recreational and occupational therapy facilities, or opportunities to treat other illnesses and to re-adjust medication (Seltzer *et al.*, 1988), whereas others contain no special programmes (Adler *et al.*, 1993).

Institutional/overnight services may occur in a variety of settings and are provided by a range of organisations, such as health trusts, social services, voluntary organisations and private agencies. Settings include places such as private facilities, nursing homes and hospital wards.

### **4.5.2 Overview of studies**

The 12 studies reporting on institutional/overnight services were scattered across North America and Europe; two were conducted in Canada, four in the USA, one in Europe and five in the UK (Table 4.4). The majority of the studies were in natural settings and covered a range of dementia diagnoses. Four of the studies (Levin *et al.*, 1989, 1994; Melzer, 1990; Colvez *et al.*, 2002) are also reported elsewhere in this section, as they cover different kinds of short-term break.

The studies reviewed reported on institutional and overnight respite, in medical facilities and nursing homes, of various durations and frequencies ranging from an overnight stay to two weeks.



**Table 4.4 Studies of institutional/ overnight respite included in the review**

<b>Authors</b>	<b>Study</b>
Adler <i>et al.</i> (1993)	Examination of responses to a two-week hospital admission to a veterans' medical centre
Burdz and Eaton (1988)	Assessment of the impact of in-patient respite care in a nursing home
Colvez <i>et al.</i> (2002)	Europe-wide examination of the work burden and health of carers; components included day care and a respite hospitalisation programme
Hirsch <i>et al.</i> (1993)	Evaluation of the effect of an in-patient respite break at a veterans' medical centre
Larkin and Hopcroft (1993)	Examination of the influence of an in-patient respite break at a veterans' hospital on a dementia study unit
Levin <i>et al.</i> (1989)	Examination of day and short-term 'relief' breaks
Levin <i>et al.</i> (1994)	Evaluation of day care, in-home respite and institutional/overnight respite
Melzer (1990)	Evaluation of a respite care unit with day places and beds for overnight respite using a new framework for service evaluation
Pearson (1988)	Establishing the benefits and disadvantages of in-hospital relief admissions to psychogeriatric unit
Perry and Bontinen (2001)	Exploration of the experiences of an Adult Day Program extended to include weekend care offering an overnight respite service
Seltzer <i>et al.</i> (1988)	Assessment of the short-term effects of an in-hospital respite program
Watkins and Redfern (1997)	Collection of data on an overnight in-patient respite service.

### **4.5.3 Evidence on the effectiveness of institutional/ overnight services**

The box below pulls together the main findings of this sub-set of the research evidence.

- 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 carers experiencing increased and better-quality sleep.
- There was mixed evidence on the impact of services in relation to ADL, behaviour and dependency, but it is difficult to unravel the potentially negative effects of respite from the natural progression of the disease.
- There was little evidence that services reduced the demand for long-term placements.

***Effectiveness of institutional/ overnight services in relation to carers' health and well-being***

**Perceptions of services**

Four of the studies relating to institutional/overnight respite reported on carers' perceptions of services.

Carers ( $n=19$ ) using overnight weekend respite in Perry and Bontinen's study (2001) felt that the benefit to themselves and the physical and emotional benefit to the care recipient was worthwhile when set against the costs and difficulties of organising the care recipient for respite care. This was especially so for carers who were multiple programme users.

Physical and emotional benefits for carers were also found by Watkins and Redfern (1997). In an evaluation of a night hospital nursing service (Care and Respite for Elderly People with Support and Treatment, CREST), carers ( $n=27$ ) reported feeling happy, pleased and relieved about the care recipient attending the service. These positive feelings stemmed from physical benefits: carers were experiencing increased sleep, and better sleep because the care recipient slept better at home when not at CREST; the carer was able to rest more and home was more peaceful, and they also appreciated having help with care.

The majority of carers using relief care ( $n=167$ ) in Levin *et al.*'s (1994) study said that the service had made life better in some way; for example, increased patience in dealing with the care recipient and feeling more able to cope with caring. Daughters were especially positive about relief care. The amount of relief received affected perceptions, with carers using regular relief programmes feeling more satisfied with the amount of relief care that they received than occasional users.

Watkins and Redfern (1997) found that those people who remained emotionally attached to their relative generally valued the institutional/overnight service because it allowed them to go on caring. However, some users of the service felt unhappy or guilty about using the service for a variety of reasons: because they felt that they could no longer cope; because the care recipient had not wanted to go for respite; because they felt relieved to receive respite; and because they felt that they had let their friend or relative down.

In Pearson's (1988) study, just under half of the sample ( $n=25$ ) reported no drawbacks to relief care, but others experienced difficulties in visiting the patient in hospital or reported an adverse change in the patient (for example,

## **Review of respite services for carers for people with dementia**

a change of sleep routine). Over half felt sad or lonely while the patient was in hospital, and one-fifth felt guilty, whereas a similar proportion reported criticism from friends and relatives for allowing relief admission in the first place.

Levin *et al.* (1994) found that a drawback identified by carers in terms of taking up relief care was a concern about standards of care. It was sometimes the case that this concern outweighed carers' preferences for taking up more regular breaks. Ten per cent of Levin *et al.*'s (1994) sample ( $n=167$ ) who tried institutional/overnight breaks decided not to use the service again. This decision was based on the quality of the service, and their perceiving no difference for themselves or the care recipient in using the service. Indeed, for some carers using institutional/overnight breaks there was an increase in short-term workload because the care recipient's continence worsened on return home, whereas other carers reported a loss of mobility for the care recipient because wheelchair use by the services had created a dependency.

Many carers in Levin *et al.*'s (1994) study believed that overnight/residential services (relief care) were less beneficial to the care recipient than other forms of short-term break. Thirty per cent of carers felt that the care recipient had benefited from institutional/overnight care, through changes to their medication and improved sleeping patterns. Overall, opinions in Levin *et al.*'s (1994) study were divided about the effect of care relief. A higher proportion of carers using this service ( $n=167$ ), as opposed to sitting and day-care services, suggested that although the service did not benefit the care recipient, they were able to continue caring because of the break.

Five studies (Pearson, 1988; Larkin and Hopcroft, 1993; Levin *et al.*, 1994; Watkins and Redfern, 1997; Perry and Bontinen, 2001) briefly reported on use of the time away from caring created by institutional/overnight respite breaks. Perhaps unsurprisingly, Watkins and Redfern's (1997) carers found they had more time for themselves, thus allowing more time for housework and cooking. Pearson's (1988) sample also reported more free time, and over half used this time to catch up on domestic jobs. Carers in Levin *et al.*'s (1989, 1994) two studies also reported using the break to spring clean or decorate.

Some carers also used this 'free' time to maintain family relationships, and to maintain and expand social relationships (Pearson, 1988; Perry and Bontinen, 2001), a point echoed by Levin *et al.* (1989) who found that carers used the time for other family members and to get out and about. The time away from the care recipient was also used to pursue different and pleasurable activities (Larkin and Hopcroft, 1993; Perry and Bontinen, 2001), including going on holiday and outings (Pearson, 1988; Levin *et al.*, 1989, 1994).

### **Health status and well-being**

Eight of the studies looking at institutional/overnight respite services report findings related to carers' physical and psychological health and well-being.

Sleep and rest are discussed in four studies (Pearson, 1988; Larkin and Hopcroft, 1993; Watkins and Redfern, 1997; Perry and Bontinen, 2001). Respite allowed carers to catch up on sleep and rest (Perry and Bontinen,

## **Review of respite services for carers for people with dementia**

2001) and carers reported feeling better after a good night's sleep and being able to cope more generally (Watkins and Redfern, 1997). Larkin and Hopcroft's (1993) study reported that carers' sleep behaviour had improved while the care recipient was in respite and that this was a major benefit of respite. Pearson (1988) also reported better sleep (64 per cent) and increased relaxation (92 per cent) for carers while the care recipient was in relief hospital admission.

Themes relating to psychosocial health included stress, coping, anxiety, breakdown and burden, and depression. Larkin and Hopcroft (1993) and Perry and Bontinen (2001) found that respite care lowered stress. Three days prior to respite discharge, carers were reported to have significant reductions in psychological distress (Larkin and Hopcroft, 1993). However, symptom relief was short-lived and relief of respite was not sustained beyond two weeks after respite. Perry and Bontinen (2001) reported that the lowering of stress was found to be a short-term effect for their sample ( $n=19$ ), and the authors suggest that carer stress may be attenuated by institutional respite. Levin *et al.* (1989) found that institutional/overnight care acted as a palliative for carers who were already stressed, rather than preventing them from becoming stressed.

Institutional respite appears to have had a positive effect on burden in some of the studies. Adler *et al.* (1993), looking at the effect on carers' burden of a two-week admission to respite care, found a decrease in mean burden between two weeks prior to respite and the time of discharge. Burdz and Eaton (1988), examining the short-term effects of inpatient respite, found that overall the respite break had a positive effect on perceived burden.

Colvez *et al.* (2002) found that carers whose care recipient was temporarily hospitalised ( $n=37$ ) did not fare that well in terms of burden compared with those who cared for the care recipient at home or by group living and who reported lower burden. The authors suggested that this might be due partly to the lack of follow up after institutional/overnight care, thus emphasising the importance of constant support.

With regard to coping and anxiety, Watkins and Redfern found (1997), while conducting a service evaluation of CREST, an NHS-run night service for elderly people with dementia, that carers' rating on coping and anxiety subscales showed no significant differences between time periods. However, in relation to depression Adler *et al.* (1993) found a transient improvement in depression, although by two weeks post-respite depression scores returned to pre-respite values. This study also found an improvement in carers' mood during the period of respite care.

Over half of Pearson's (1988) sample ( $n=25$ ) said they could not go on without respite, and one-third expressed the belief that the relief admission prevented a nervous breakdown; over three-quarters of the sample perceived the benefit as the relief of strain.

## **Review of respite services for carers for people with dementia**

### **Effectiveness of institutional/ overnight services in relation to care recipients' health, well-being and dementia-related symptoms**

#### **Perceptions of services**

Larkin and Hopcroft's (1993) study of the moderating effects of in-patient stays on carer stress found that family carers' judgements of the effect of institutional/overnight services on the care recipient were mixed. According to family carers, two care recipients had improved, four were unchanged, and eight had declined in relation to ADL functions.

#### **Health status, well-being and dementia related symptoms**

As far as impacts on care recipients were concerned, the studies reviewed report on behaviour, ADL, cognitive and functional status, and the physical effects of institutional/overnight respite.

ADL, behaviour and dependency are discussed in four studies (Burdz and Eaton, 1988; Adler *et al.*, 1993; Hirsch *et al.*, 1993; Watkins and Redfern, 1997). Findings from these studies present a mixed picture of the effects of institutional/overnight respite breaks.

Hirsch *et al.* (1993) looked at the effect of an inpatient admission on care recipients' ( $n=39$ ) behaviour and ADL. Care recipients with actual or potential wandering behaviour in their sample received up to two weeks respite care every three months at a Veteran's Affairs Medical Center. The mean ADL and behavioural scores demonstrated a small but statistically significant deterioration between admission and two days after returning home, but reverted to pre-admission values by week two. Twelve out of 39 patients showed improvement in their total ADL and behaviour score from admission to two days after discharge, and all patients worsened in at least two categories. Among the 26 who worsened, 19 subsequently improved and seven continued to deteriorate. There was significant deterioration in bladder and bowel continence, and grooming. Thirty-eight out of 39 patients were reported, by their carer, to have worse behavioural problems. The most severely impaired patients tended to deteriorate the least. Hirsch *et al.* (1993) suggested that their results 'provide preliminary evidence that inpatient respite for patients with severe dementia may be associated with a short-term decline in both functional status and behaviour following the patient's return home' (p.526).

Rather mixed effects are reported by Adler *et al.* (1993), but these, it is suggested, are related in part to disease progression. Adler *et al.* (1993) found that respite care had little sustained effect on patient behaviour and ADL. There was a strong trend towards fewer behavioural problems after respite care (but the study does not indicate how long this lasted for) and a trend towards greater dependence in ADL; this latter finding could be due to disease progression. The results of the study show little change in dementia patients receiving respite care beyond that expected from normal disease progression.

Watkins and Redfern (1997) found carers recorded no significant differences in dependency of the care recipient between one week, after six weeks, 12 weeks, or six months attendance of the night hospital nursing service they

## **Review of respite services for carers for people with dementia**

evaluated. Patients who attended the service for six months did not become significantly more or less dependent. They concluded that this could mean that either the service had no deleterious effects or that it had positive effects as patients would be expected to deteriorate with disease progression. There was no difference between admission and patient outcome in the scale used to measure patients' ability with ADL and behavioural problems. No trends emerged between care recipient diagnosis and outcome. Watkins and Redfern (1997) suggest, though, that the service facilitated independence and minimised preventable deterioration. Burdz and Eaton (1988), however, found that respite patients showed significant improvements in their reported problems relative to their waiting-list counterparts, regardless of diagnosis.

Focusing on cognitive and functioning status, Seltzer *et al.* (1988) found that overall there was no significant change in a sample of 37 patients admitted for two week's respite between the time of respite admission and the time of discharge. Patients with lower functional levels at the time of admission were likely to improve during respite, whereas those patients functioning at higher levels on admission were likely to deteriorate during the respite. When the initial severity of dementia was taken into account, patients with scores indicating the most severe dementia tended to show improvement on some of the measures after two weeks in hospital. In contrast, patients with higher levels of performance, suggesting milder dementia, showed a decline on some of the measures at the conclusion of respite. All of the changes were small and largely restricted to tests using ADL. No significant changes in cognitive status were found.

Finally, Larkin and Hopcroft (1993) reported on the negative health consequences of institutional/overnight respite breaks. They found that at least eight patients experienced an untoward event or negative health consequence during their respite (for example, pneumonia or a fall). However, this figure included two patients who were excluded from all other data analysis because they did not complete the study protocol. Levin *et al.* (1989) reported that one-fifth of carers with at least one relief break in their sample ( $n=167$ ) thought that an institutional/overnight break had adversely affected the care recipient. There were suggestions that care recipients had arrived home in a generally worse state than they had left, or specific changes occurred, such as the onset of incontinence due to changes in routine, or increased anxiousness. However 25 per cent of carers thought that respite had benefited the care recipient for a variety of reasons, among which was that an illness had been diagnosed and treated. Eleven per cent of Levin *et al.*'s (1994) sample of carers reported deterioration in the care recipient after a relief break, deterioration included increased confusion and increased sleep.

### ***Impact of institutional/ overnight services on use of other services***

No evidence was retrieved on the impact of institutional/overnight respite care on the use of other community care services. However, six studies relating to institutional/overnight respite did report on the impact of service use in relation to entry to long-term residential care. A number of factors appear to impact on the care recipient being admitted to long-term care: emotional attachment, burden, use and availability of other services.

## **Review of respite services for carers for people with dementia**

Emotional attachment and burden are factors explored in Watkins and Redfern's (1997) study. They found that there appeared to be an association between carers' lack of emotional attachment and requests for long-term care, and between admission to long-term care and carers reporting their role in terms of burden. For some, using the institutional/overnight service appeared to be a catalyst for giving up caring; half the patients in their sample were admitted to long-term care.

Exposure to institutional/overnight respite may also impact on decisions about long-term residential placements. For some carers in Watkins and Redfern's (1997) study, their relative's attendance for overnight in-patient respite enabled them to make the decision to give up caring and did little to prevent patients from being admitted to long-term care once carers decided that they wanted to give up. Larkin and Hopcroft (1993) reported that the number of carers receptive to a long-term care placement increased as respite drew to a close; this was also true of receptivity to a nursing home placement. They also found that within two weeks of their respite stay, six patients had been admitted to a hospital or a nursing home for long-term care. Upon examination of these six people for admission predictors, no significant associations were found. The rate of long-term institutional placement was reported as being: within 30 days of respite, eight patients had been admitted for long-term in-patient care; within a year, 20 patients had also been admitted for long-term care (seven other patients had died). Levin *et al.* (1989) also suggested that regular institutional/overnight breaks might facilitate, rather than prevent, take up of long-term residential care.

Melzer (1990) suggested that the evidence from his evaluation of a respite unit with both day places and overnight beds indicated that take up of institutional/overnight care did not avoid admission to long-term institutional care. As noted in the section on day care (Section 4.2), it is not obvious which of Meltzer's comments apply to day care or institutional/overnight respite.

A difference between the type of services being used appears to affect long-term institutionalisation. Levin *et al.* (1994) found that elderly people using day care and sitting services in conjunction with institutional/overnight respite were more likely than those using day care and sitting services, but not institutional/overnight respite, to have entered residential care. They suggested that this might be due to the fact that carers utilising relief care were approaching the limits of their capacity to continue caring.

However, institutional and overnight respite breaks were also reported to enable carers to continue caring. Pearson (1988) reported that two-thirds of the carers in a study sample of 25 thought that relief admission had made looking after the care recipient easier. Eight carers, in Watkins and Redfern's (1997) sample of 26 carers, continued looking after the care recipient at home until shortly before the care recipient died, suggesting the service enabled a proportion of carers to keep relatives at home for longer than might otherwise have been possible. However, other community services also have a role to play. Watkins and Redfern (1997) report that people in their sample used a range of community care services and suggest that night care facilities are rarely sufficient without supplementary services.

***Cost-effectiveness of host-family respite in relation to carers' and care recipients' health and well-being***

No evidence was retrieved regarding the cost-effectiveness of institutional/overnight services.

## **4.6 Respite programmes**

### **4.6.1 Introduction**

Respite programmes comprise multiple forms of respite and short-term break within a single programme. This means that carers can be provided with a variety of choices to better accommodate their particular preferences and the specific needs of the care recipient. Most programmes explicitly acknowledge that their primary aim is to provide carers with temporary relief from the burdens of caregiving (Deimling, 1991; Kosloski and Montgomery, 1993). Having said that, some programmes also target the care recipient and have goals related to their rehabilitation or improved psychosocial functioning. Whereas respite programmes are pervasive in North America, we found no references to similar service provision in any other country.

### **4.6.2 Overview of studies**

Table 4.5 outlines the respite programmes evaluated in the three studies reviewed. The TOPS (Time Off Promotes Strength) programme offered respite care specifically for people with Alzheimer's disease through in-home services from a home health aide, day care and short-stay institutional care at a nursing home (Deimling, 1991). The same three types of respite were available in the Maryland Alzheimer's Demonstration Grant (Cox, 1998). In contrast, the Michigan Model Respite Programs (Kosloski and Montgomery, 1993) funded six model programmes on seven sites providing different mixes of day-care and in-home respite, but not short-stay institutional care.

**Table 4.5 Studies of respite programmes included in the review**

<b>Authors</b>	<b>Study</b>
Cox (1998)	Comparison of the use of respite by African-American and white carers taking part in the Maryland Alzheimer's Demonstration Grant project
Deimling (1991)	Examination of the impact of respite on carers taking part in the TOPS programme
Kosloski and Montgomery (1993)	Evaluation of the impact of respite care on carers taking part in the Michigan Model Respite Programs

### **4.6.3 Evidence on the effectiveness and cost-effectiveness of respite programmes**

The box below pulls together the main findings of this sub-set of the research evidence.



## **Review of respite services for carers for people with dementia**

- 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.

### ***Effectiveness of respite programmes in relation to carers' health and well-being***

#### **Perceptions of services**

No evidence was retrieved regarding carers' and/or professionals subjective views about respite programmes. However, two of the studies looked at issues relating to respite care and time usage. Deimling's (1991) analysis suggested that the modest amounts of respite delivered by the TOPS programme did not provide sufficient time for carers ( $n=78$ ) to take part in social or recreational activities. In most cases, respite provided time to 'catch up' on other chores or responsibilities, to undertake paid work or to rest.

Kosloski and Montgomery's (1993) study of the Michigan Model Respite Programs found there was no discernible impact on respite use on carers' ( $n=47$ ) use of time or objective burden. Similarly, this prompted the authors to suggest that respite might enable carers to catch up on housework work and other chores, or other neglected tasks, rather than take part in (additional) recreational activities.

#### **Health status and well-being**

All three studies discussed issues relating to carers' health problems, and levels of depression and burden. Results were mixed, as shown below.

Analysis of the data collected from the full sample of 78 carers taking part in the TOPS programme showed no significant differences for carers between initial assessment and follow-up at four to six months for any of the outcome measures: depression, symptoms of health problems and care-related strain (Deimling, 1991). However, sub-group analysis revealed a slightly different picture, one of apparent benefit for carers. For example, carers of patients with stable ADL and cognitive functioning exhibited (statistically significant) reduced depression scores between assessment and follow-up. Levels of depression for carers of patients with declining physical functioning or declining cognitive ability were stabilised.

As far as carers' health problems were concerned, analysis of the full TOPS sample indicated that carers' health problems declined slightly but not significantly over time, regardless of the patient's functioning (Deimling, 1991). Sub-group analysis again showed a somewhat different picture. Carers of patients with stable cognition experienced a greater and statistically significant decline in health problems compared with the group as a whole,

## **Review of respite services for carers for people with dementia**

whereas carers of patients experiencing rapid cognitive decline reported significant increases in health problems.

The Michigan Model Respite Programs assessed carers' subjective burden and objective burden, together with morale (Kosloski and Montgomery, 1993). At the six-month follow up, carers who had used respite ( $n=47$ ) exhibited a significantly lower level of subjective burden than carers in the comparison group ( $n=25$ ). After (statistically) exploring alternative explanations, the researchers concluded that the change was indeed due to respite use. Analysis of the data relating to morale, or psychological well-being, showed a statistically significant difference between the two groups at the six-month follow up, indicating that respite use increased carer morale.

The findings from the first year of the Maryland Alzheimer's Demonstration Grant project showed that neither the African-American carers ( $n=61$ ) nor the white carers ( $n=62$ ) reported any changes relating to anxiety or depression after six months of service use (Cox, 1998). However, both groups reported significant reductions in their feelings of burden. Whereas exhaustion declined among the African-American carers, it did not change for the white carers.

### ***Effectiveness of respite programmes in relation to care recipients' health, well-being and dementia-related symptoms***

#### **Perceptions of services**

No evidence was retrieved regarding carers', care recipients and/or professionals' subjective views about respite programmes.

#### **Health status, well-being and dementia-related symptoms**

Two of the three evaluations of respite programmes investigated the impact of respite on care recipients. Carer reports in Deimling's (1991) study of the TOPS programme showed that 59 per cent of care recipients ( $n=78$ ) were stable or improved in overall physical and cognitive functioning, whereas 41 per cent declined. Patients' physical functioning declined. In terms of cognitive ability, 23 per cent of patients were stable, 38 per cent improved and 39 per cent declined. Deimling (1991) concluded that because the average decline was small and approximately as many patients improved as declined, it was unlikely that the apparent benefit of respite care for carers was at the expense of the person they looked after.

The measures of patient status in the Maryland Alzheimer's Demonstration Grant project showed a strong decline in ADL functioning for the white group ( $n=62$ ) after six months of respite use, but no deterioration for the African-American group ( $n=61$ ) (Cox, 1998). Both groups deteriorated in cognitive status. Patients' behavioural problems were also assessed. The behavioural status of the African-American patients strongly improved, but did not change for white patients.

### ***Impact of respite programmes on use of other services***

No evidence was retrieved regarding the impact of respite programmes on the use of other services or entry to long-term care.

***Cost-effectiveness of respite programmes in relation to carers' and care recipients' health and well-being***

No evidence was retrieved regarding the cost-effectiveness of respite programmes.

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

### **4.7.1 Introduction**

The label 'multi-dimensional carer-support package' is being used to refer to interventions that consist of a set of support services. In addition to (alternative forms of) respite care, other services that might be incorporated into such a package include, for example, education about dementia-related issues, training in lifting and handling techniques, a support group or individual counselling. This sort of comprehensive service is designed to address the multi-dimensional problems and needs that carers are likely to experience and to provide practical community-based services; the package gives carers choice about what mix of formal and informal services to use. Some researchers evaluating respite care argue that to be fully effective respite must be closely linked to other available services, and preferably must be a component of a comprehensive system of (long-term) care services, hence they strongly endorse the value of multi-dimensional carer-support packages (Lawton *et al.*, 1991).

### **4.7.2 Overview of studies**

Four studies included in the review evaluated multi-dimensional carer-support packages (see Table 4.6). The range of respite and other service options offered as part of the respective multi-dimensional carer-support packages included in the review is shown in Appendix 4a. Two studies, one set in the USA and the other in The Netherlands, concentrated on evidence relating to the effectiveness of respite care rather than distinguishing between the impact of different elements of the experimental carer-support packages (Lawton *et al.*, 1991; Drees *et al.*, 2000). In contrast, the remaining two studies – both Canadian – focused on the overall support packages, and did not tease out the specific effects of the respite option (Mohide *et al.*, 1990; Chu *et al.*, 2000).

**Table 4.6 Studies of multi-dimensional carer-support packages included in the review**

<b>Authors</b>	<b>Study</b>
Chu <i>et al.</i> (2000)	Evaluation of the Early Home Care Program
Droes <i>et al.</i> (2000)	Evaluation of an integrated family support programme provided through the Amsterdam Meeting Centers
Drummond <i>et al.</i> (1991)	Economic evaluation of the Caregiver Support Program for caregivers of demented elderly versus conventional community nursing care
Lawton <i>et al.</i> (1991)	Evaluation of the Philadelphia Geriatric Center's Multi-Service Respite Demonstration Project
Mohide <i>et al.</i> (1990)	Evaluation of the effectiveness of the Caregiver Support Program in reducing carer burden

### **4.7.3 Evidence on the effectiveness and cost-effectiveness of multi-dimensional carer-support packages**

The box below pulls together the main findings of this sub-set of the research evidence.

- A common thread in all four studies 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 QALY of the support package was reported to compare favourably with other health-care interventions.

#### ***Effectiveness of multi-dimensional carer-support packages in relation to carers' health and well-being***

##### **Perceptions of services**

Two studies looked at consumer satisfaction with multi-dimensional carer-support packages. Carers in receipt of the Caregiver Support Program ( $n=30$ ), and also those in the control group ( $n=30$ ) accessing conventional (existing) community nursing care, were asked to rank the three services perceived as most helpful (Mohide *et al.*, 1990). The respite worker was ranked fourth (out of six) by carers who completed the trial in the study group ( $n=22$ ), and fifth by carers in the control group ( $n=20$ ).

The Multi-Service Respite Demonstration Project based at the Philadelphia Geriatric Center reported on carers' evaluations of the quality of the respite received and the impact of the respite on their quality of life (Lawton *et al.*, 1991). Over three-quarters of carers in the study group ( $n=315$ ) reported

## **Review of respite services for carers for people with dementia**

that they were very satisfied with the respite care offered. It provided substitute helpers when carers were ill or hospitalised, as well as giving them time off for leisure or family events, shopping, household chores and the like. In-home respite was a more popular form of respite than day care and institutional respite. Respite was named the most helpful and most wished for service by carers in both the study group and the control group ( $n=317$ ).

### **Health status and well-being**

Three studies looked at what effect the support packages had on carers' health and well-being. Mohide *et al.* (1990) evaluated the effectiveness of the Caregiver Support Program in reducing burden on family carers of older people suffering from moderate to severe dementia. At baseline, carers in both the study group ( $n=30$ ) and the control group ( $n=30$ ) were suffering from above-average levels of depression and anxiety. After the six-month intervention period, effectiveness analyses showed that neither the study group nor the control group had improved in either of these two areas. In spite of this lack of impact, carers' quality of life increased in the study group, while it decreased in the control group.

Lawton *et al.* (1991) tested change in caregiving attitudes and self-assessed physical and mental health from baseline to follow-up at 12 months as part of the Multi-Service Respite Service Demonstration Project (Lawton *et al.*, 1991).<sup>9</sup> The findings showed that there was no evidence that respite care provided through the experimental programme (or respite obtained by the families on their own) was effective in relation to carer well-being, carer burden or the more general indicators of physical and mental health. There was a lack of effect even among those carers who were originally the most stressed or disadvantaged. Services delivered by the experimental programme did not contribute to any change in depression, negative or positive effect.

Chu and colleagues (2000) investigated the impact of the Early Home Care Program for persons with early-stage Alzheimer's disease on carer burden. The results indicated that at six months carers in receipt of the experimental programme ( $n=37$ ) felt less burdened than at the start of the study, and less burdened than carers in the control group ( $n=38$ ). However, this improvement appeared to be only temporary and was not maintained over the 18 months of the study. When the study ended, the difference in carer burden between the two groups was slight.

### **Effectiveness of multi-dimensional carer-support packages in relation to care recipients' health, well-being and dementia-related symptoms**

#### **Perceptions of services**

The Multi-Service Respite Service Demonstration Project (Lawton *et al.*, 1991) was the only study to provide evidence in this area, and this was limited to

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<sup>9</sup>This was the study mentioned in Section 1 where not all the carers who were offered the experimental service actually used it. At the same time, substantial use was made of respite services by members of the control group acting on their own initiative.

## **Review of respite services for carers for people with dementia**

commenting that carers' judgements as to how care recipients seemed to assess the respite programme were less favourable in comparison with carers' own views.

### **Health status, well-being and dementia-related symptoms**

Results regarding the effects of respite on care recipients were mixed. Respite care had no meaningful measured effect on the psychological state of people with dementia taking part in the Multi-Service Respite Service Demonstration Project (Lawton *et al.*, 1991).

In contrast, the results of Drees and colleagues' (2000) study were more positive. These researchers compared an integrated family support programme provided through the Amsterdam Meeting Centers with psychogeriatric day care only. During the seven-month period of study, the experimental support programme showed a large significant positive effect on patients' behaviour problems, and specifically on the degree of inactivity and non-social behaviour. Behaviour problems of participants in the study group ( $n=33$ ) increased less than those in demented persons in the control group ( $n=23$ ) using regular psychogeriatric day care. The effects occurred especially after a period of seven months, which the authors suggested was an argument in favour of long-term support. No effect on mood was found.

### **Impact of multi-dimensional carer-support packages on use of other services**

Mohide *et al.* (1990) investigated the number of visits to family doctors during the six months of the Caregiver Support Program. The mean number of visits to doctors did not differ between the study group ( $n=30$ ) and the control group ( $n=30$ ), but more visits about caregiving were made by carers in the study group. There was a trend towards delayed long-term residential or nursing care. Care recipients in receipt of the support programme who entered long-term care during the study period remained in the community slightly longer than did those in the control group: an average of 17 weeks compared with an average of ten weeks.

Both the study group ( $n=315$ ) and the control group ( $n=317$ ) increased the amount of formal services of different types they used (and the help they themselves provided) over the 12 months of the Multi-Service Respite Service Demonstration Project (Lawton *et al.*, 1991). This probably reflected the downward trajectory in the functional capacities of Alzheimer's patients. There was a small but measurably greater increase in formal service use for the study group as contrasted with the control group. Using survival analysis techniques, Lawton *et al.* (1991) found that over 12 months, families with respite care maintained their relative significantly longer in the community – an additional 22 days.

Chu and colleagues (2000) also carried out a survival analysis in their study of the Early Home Care Program. This revealed no significant difference between the study group ( $n=37$ ) and the control group ( $n=38$ ) in the number of days patients remained in the community. However, sub-group analysis showed there was a much higher likelihood of patients with mild to moderate impairment in the control group being placed in long-term institutional care.

## **Review of respite services for carers for people with dementia**

Patients with mild to moderate impairments in the study group remained in the community an average of 52 days longer than patients in the control group. Over the 18-month study period, the researchers found no significant difference between the study group and the control group regarding the number of community services used. The only significant difference between the two groups was the use of case management: the study group utilised an average of 17 hours per month compared with an average of nine hours for the control group.

### ***Cost-effectiveness of multi-dimensional carer-support packages in relation to carers' and care recipients' health and well-being***

Drummond *et al.* (1991) provided the only economic evaluation of multi-dimensional carer-support packages as compared to standard, community care nursing. The study was conducted in Canada and was undertaken from the health and social care perspective and this influenced the types of resource use data that were collected and costed. The consequences were measured from the carer perspective and included the Caregiver Quality of Life Instrument to value health states and QALYs.

The study was based on an RCT and a small sample size ( $n=30$  in either group) and the attrition rates over the duration of the study (six months) were high (27 per cent in the day-care group and 33 per cent in the standard-care group).

Although no statistically significant differences in costs or consequences were found across the groups, observed differences suggested that the costs and consequences associated with the support package were higher than for standard care. The additional (incremental) cost per QALY gained from providing day care as opposed to standard care was Canadian \$20 000 or £12 400 (1991 Canadian \$). The authors of the study report that the result compares favourably with other health-care interventions. However, as the authors say 'this study alone cannot demonstrate that caregiver support programs represent good value for the money'.

## **4.8 Video respite**

### **4.8.1 Introduction**

Video respite was developed in the early 1990s primarily to create opportunities for carers to have a short-term break by maintaining the attention of people with Alzheimer's disease and occupying them in meaningful activities. What began as the development of an in-home resource for carers has since expanded to applications in a variety of settings, including long-term care facilities, throughout the USA and Canada.

### **4.8.2 Overview of studies**

Details of the two studies about video respite included in the review are given in Table 4.7. Both were small exploratory pieces of work undertaken by the same researchers. The first study documents early findings relating to the use

## **Review of respite services for carers for people with dementia**

of videotapes in the home environment (Lund *et al.*, 1995); the second study looks at the use of the tapes in an institutional environment (Caserta and Lund *et al.*, 2002). The video respite evaluations present C.1 type evidence, in other words their quality is somewhat less robust than other studies included in the review. However, they are useful in terms of filling a gap in the review about a novel and innovative form of respite.

**Table 4.7 Studies of video respite included in the review**

<b>Authors</b>	<b>Study</b>
Caserta and Lund (2002)	Comparison of the impact of the videotape <i>Remembering When</i> with people with dementia in a group setting and a solitary setting
Lund <i>et al.</i> (1995)	Comparison of the impact of the videotape <i>Favorite Things</i> and a television programme (Lawrence Welk) on people with dementia

### **4.8.3 Evidence on the effectiveness of video respite**

The box below pulls together the main findings of this sub-set of the research evidence.

- 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.

#### ***Effectiveness of video respite in relation to carers' health and well-being***

##### **Perceptions of services**

Carers ( $n=31$ ) using the *Favorite Things* generic videotape at home appeared to appreciate having the tape (Lund *et al.*, 1995). They used it on average 14 times during the one-month study period. Nearly three-quarters of carers reported that they used the videotape for respite time, rather than sitting and watching it with their relative.

##### **Health status and well-being**

No evidence was retrieved regarding health status and well-being.

#### ***Effectiveness of video respite in relation to care recipients' health, well-being and dementia-related symptoms***

##### **Perceptions of services**

No evidence was retrieved regarding perceptions of service in relation to care recipient's health and well-being.

##### **Health status, well-being and dementia-related symptoms**

The preliminary trends reported in Lund and colleagues' (1995) study showed that most of the people with dementia ( $n=31$ ) remained seated throughout the entire 33 minutes of the *Favorite Things* videotape, and were paying attention and verbally responding throughout the viewing time.



## ***Review of respite services for carers for people with dementia***

The later study looked at whether or not there was a difference in how Alzheimer's patients ( $n=12$ ) watched the video-respite videotape *Remembering When* in a group setting or when each viewed it alone (Caserta and Lund, 2002). Irrespective of the setting, patients demonstrated at least moderate levels of interest, enjoyment, ease of responding and eye contact throughout the video. The videotape tended to hold people's attention for the 20 minutes it lasted, and there was little occurrence of problematic behaviours interfering with patients' ability to pay attention and respond to 'requests' made on the tape. The findings overall suggested that there was greater participation with the video-respite tape in a solitary setting than a group setting, further endorsing its use by family carers in the home environment.

### ***Impact of video respite on use of other services***

No evidence was retrieved on the impact of video respite on the use of other community care services or entry to long-term care.

### ***Cost-effectiveness of host-family respite in relation to carers' and care recipients' health and well-being***

No evidence was retrieved in relation to cost-effectiveness.

This section completes the summary of the (cost-)effectiveness review of the published literature. The following section summarises the findings from the consultation.

## Section 5 Findings from the consultation about respite services and short-term breaks

### **5.1 Introduction**

This section describes the key issues that emerged from the telephone interviews with representatives from national bodies and the consultation with carers in four areas of the country with respite services that were regarded as being examples of 'good practice'. The first four sub-sections of the section are largely based on the contributions from the national interviews, and focus on the following issues.

- The overall state of respite services and short-term breaks for carers (Section 5.2).
- The impact of recent policy developments (Section 5.3).
- The barriers faced by providers (Section 5.4).
- Measuring effectiveness and cost-effectiveness (Section 5.5).

The remaining two sections draw on both the national interviews and the focus groups and telephone interviews with carers, to discuss:

- what underpins an effective respite service and short-term break? (Section 5.6).
- what are the characteristics of an effective respite service and short-term break? (Section 5.7).

Both of these sections include illustrations based on the experiences of the carers who took part in the focus groups and interviews. However, some details (for example, gender and first name/initials) have been changed in order to maintain confidentiality.

Perhaps not surprisingly, given the roles of many of those involved in the national interviews, there was little divergence between their views and those of the carers. Many of the issues raised in the national interviews were reflected in, or brought into sharp relief by, the experiences of the carers.

However, before discussing these issues in more depth, it may be helpful to consider what contributors said about the purpose and meaning of respite. Several contributors to the national interviews suggested that a fairly broad definition of respite was needed, so that it encompassed services such as emergency/crisis breaks, support sessions attended by the carer and care recipient, and perhaps even home care, none of which are designed to offer the carer a 'break' in the true sense of the word. The carers involved also saw respite in very broad terms, focusing much more on what it achieved for them and the care recipient (that is, on outcomes), than on the precise 'type' of respite or short-term break offered. Therefore, throughout this section a broad definition of respite care has been adopted. By and large, we have also taken an unashamedly 'carer's eye view' of respite services. Comments on the effectiveness of respite services in relation to the care recipient or those

providing services are based on what the carers and the national interviewees (many of whom work with carers) said, rather than on direct or formal consultation with these groups.

## **5.2 The overall state of respite services and short-term breaks for carers**

The majority of contributors to the national interviews felt that the availability of short-term breaks varied significantly across the country. The overall perception was that there were still many carers who had no break at all, or only a very limited break, from caring. The research team were told about an on-going survey by the Princess Royal Trust for Carers (unpublished). Preliminary findings from this survey suggest that, on average, carers received four hours' respite per week, two of which they paid for themselves and two of which were 'free'. Ideally, most carers wanted an average of nine hours per week. Overall, the survey suggests that, although many more carers are receiving respite care, they are still not getting the 'amount' they would ideally like.

Many contributors also noted the need for a broader range of services. There was a view that, although non-residential respite services were improving, in many areas there was still an over-reliance on residential respite. Short-term breaks in residential homes were regarded as having an important place, especially for carers of people in the later stages of their illness, but contributors emphasised the value of homes having a 'dementia wing' or, at the very least, staff trained in caring for people with dementia.

There was also a strong view that the quality and appropriateness of services was very variable. In some cases this was put down to funding constraints, but the knowledge of providers about caring for people with dementia was also felt to be important, as was their ability to recruit staff with appropriate experience and understanding of dementia. Many contributors noted that, if respite care was poor or inappropriate, it disrupted the care recipient and could actually worsen the situation for the carer, making them reluctant to use respite services again.

The problem of inappropriate respite care was seen as particularly acute for certain groups of people with dementia. It was suggested that carers of younger people experienced particular problems in finding appropriate respite care, especially where the dementia was caused by a disability or illness that was associated with old age, such as stroke. Options available were often limited to inappropriate residential settings such as older person's homes or hospital wards. Home-based services for this group were seen as a rarity.

More generally, it was felt that carers of people with challenging behaviour, or those with multiple problems, such as stroke and dementia or Down's syndrome and dementia, were most likely to find it difficult to get appropriate short-term breaks. With regard to the latter group, there was concern that, where the NHS reduced its role in learning-disability services, it would be harder for the social care sector to deal with some of the symptoms of dementia such as incontinence and challenging behaviour. It was also noted

that respite services for people with a learning disability were often designed to help younger people to increase their independence rather than for those who were starting to require more support, such as people with Down's syndrome who were developing dementia. A different model of respite provision might well be required for the latter group.

Finally, there was a strong view that service providers need to move away from the 'one size fits all' approach and to recognise that dementia is a very varied condition, affecting people in different ways at different times. On the positive side, many contributors did note that more-innovative services were being developed in some areas of the country. Although the power of the carers' lobby was thought to be significant, as was the impact of government policy (see below), much still appeared to depend on local priorities and resources.

### **5.3 The impact of recent policy developments**

On the whole, there was a consensus that NHS policies had led to a greater awareness of carers' needs and to more innovative services. Contributors to the national interviews accepted for example that the emphasis on person-centred care was beginning to change the mindset of both practitioners and policy-makers, and to raise the profile of respite as an integral part of supporting carers. The Health Act 'flexibilities', and the emergence of Care Trusts and Partnership Trusts, were also leading to some interesting innovations and beginning to effect cultural changes. The requirement in the NSF for Mental Health (DH, 1999b) to recognise and address the needs of younger people with dementia by 2004 was felt to be having some impact, although it was regretted that the NSF for Older People (DH, 2001) did not have a specific standard for carers similar to Standard 6 of the NSF for Mental Health.

There were concerns, however, that the implementation of new policies was hindered by the lack of qualified staff in the field of dementia care, including old-age psychiatrists and psychologists, nurses, social workers and care staff. The continuing organisational barriers between health and social care were seen as an additional problem. In particular, there were fears that Primary Care Trusts (PCTs) would start to ration services when they had to fund the nursing-care element of nursing-home care, and that the artificial divide between respite care and continuing care could be used by the NHS to avoid paying for respite care.

In general, contributors spoke positively of the Carers Special Grant, feeling that it had allowed providers and commissioners to think more broadly and had also ensured greater transparency to carers. The combination of ring-fenced monies to pump-prime projects and the good-practice guidelines in the Carers and Disabled Children's Act 2000 had resulted in greater diversity, encouraging providers to offer a wider range of services, rather than 'just more of the same'. In some regions, the grant had resulted in highly innovative responses, including equipment and adaptations, labour-saving devices such as washing machines and mobile phones, and escorts for a holiday – in fact, anything that relieved the carer. On the other hand, there

## ***Review of respite services for carers for people with dementia***

were some concerns as to how the Carers Special Grant had been used in some areas. It was also felt that there was still much unmet need, and that many of the innovations associated with the grant had been small-scale and limited to a few carers.

The introduction of direct payments and voucher schemes was welcomed as a way of increasing the flexibility of respite provision, and there was support for greater use of these options. It was felt that, if more people had access to these, service delivery would change because people would buy what they wanted rather than accept what they were given. The schemes were considered perfectly appropriate for people with dementia, as they themselves could articulate what they wanted in the early stages and, later on, decisions could move to the carer if they had power of attorney.

It was generally accepted that the promotion of carers' assessments had been a positive policy development, although there were concerns at the lack of reassessment and at the potential link between assessment and charging. It was also noted that very few young carers were receiving an assessment, even when the parent fell within the remit of the Care Programme Approach.

### ***5.4 The barriers faced by providers***

The contributors to the national interviews highlighted the low profile and general under-valuing of care services, although the new national regulatory framework was generally seen as a positive development. The relationship between commissioners and providers was seen as causing some barriers to the development of flexible and effective services. Independent services were generally funded by social services, and could therefore only take people who had been assessed – a process that could take weeks. The Best Value tendering process could stifle innovation: for example, the Crossroads Care model did not fit into social service categories. Care-home providers would in future have to contract with PCTs for the nursing element of care, and there were concerns that PCTs would be overwhelmed by the numbers needing help. In general, contributors called for better co-ordination between commissioners and providers – in other words, a more integrated approach to services that cut across the boundaries (both structural and attitudinal) of health, social care, housing and even leisure services.

One of the key issues facing providers was how to staff services adequately. Most found it hard to recruit and retain staff with the right skills and knowledge, both of dementia (with its physical and behavioural problems) and of carers' needs. Few had experience of dealing with challenging behaviour. Job satisfaction for care workers was not helped by low wages, irregular hours and a lack of continuity and regular clients. Consequently, staff turnover in both domiciliary care and residential/nursing homes tended to be high, and many staff were very young.

Another criticism was that services tended to lack imagination. Although non-residential services were felt to be improving, residential services were still seen as very traditional and sometimes culturally inappropriate. Carers were not always made to feel included as partners. This was felt to be at least in part related to financial constraints: it was not easy to provide an

## **Review of respite services for carers for people with dementia**

individualised service within the resources available, and home-based services were perceived as particularly costly. To meet the fluctuating demand for respite and to retain flexibility for clients, service providers would ideally have to operate with excess capacity. However, this of course had significant cost implications and created a tension between the financial and quality objectives of the service.

An additional perceived barrier was that services lacked awareness of the particular needs of younger people with dementia. Indeed, it was suggested that commissioners did not always know how many there were in their area, in spite of recent research on prevalence.<sup>10</sup> Services were often targeted at people in the later stages of their illness, but contributors pointed out that support was needed in the early stages too, especially for the carer.

For young carers, eligibility criteria could represent an additional problem, as it was often the case that families were just below the threshold, even though the young person was undertaking a good deal of caregiving.

Finally, it was pointed out that confidentiality protocols could prevent social care staff from accessing 'medical' information from health colleagues that would help them in the caring situation.

### **5.5 Measuring effectiveness and cost-effectiveness**

In general, the contributors to the national interviews felt that respite was too complex to be based on one or two measures of effectiveness. They proposed a range of indicators, both qualitative and quantitative, against which they felt the effectiveness of respite services should be measured. There was a strong view that the former at least should be identified by carers themselves (including young carers) through consultation and assessment, and also that they should be measured by carers. There was considerable consensus that the key measure should be the outcome that the carer wanted, not the tasks or functions carried out by the service. The importance of measuring not just health benefits, but also quality of life and social benefits, was stressed.

The qualitative measures proposed included the following.

- The appropriateness of the service to the assessed need (including its timeliness and availability).
- The degree of readiness with which care recipients and carers accepted the service (for those who were in the later stages of the illness, these could be passive measures; for example, did they agree to go or did they resist strongly?).
- The degree of enjoyment/stimulation the care recipients gained from the respite service.

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<sup>10</sup>For further details, see

[www.alzheimers.org.uk/Younger\\_People\\_with\\_Dementia/Numbers\\_of\\_younger\\_people\\_with\\_dementia/index.htm](http://www.alzheimers.org.uk/Younger_People_with_Dementia/Numbers_of_younger_people_with_dementia/index.htm)

## ***Review of respite services for carers for people with dementia***

- The level of confidence of the carers in the service.
- The outcomes for the carers; did the respite service reduce or increase the 'burden of care' for the carers? Did it protect them from inappropriate levels of caring? Did the families feel supported? Did they feel that staff communicated well with them?
- The outcomes for the care recipients; did they have a positive experience? Were they kept safe? Was their quality of life at home (supported by respite) better than in residential care?

It was also suggested that the 'person-centredness' of the service should be tested against Standard 2 of the NSF for Older People (DH, 2001). In addition, it was stressed that respite services should not be evaluated in isolation, but within the context of a whole package of support, which might well include community support (such as leisure activities, or attending special-interest clubs) as well as formal services.

Contributors accepted that more quantitative measures should also be applied, in order to ensure that the socio-economic arguments for respite care, as well as the moral/quality-of-life arguments, were addressed. For many contributors, an effective and cost-effective service was felt to be one that allowed people with dementia to remain in the community for as long as possible. Although this was perhaps primarily a quality-of-life or 'human rights' issue, respite care was also seen as saving money in the long-term, both by avoiding crisis admissions due to 'carer breakdowns' and by staving off premature entry into permanent care. Longer-term savings might also relate to a reduction in carer ill-health or mental breakdown, and, in the case of young carers, to future use of social care and health services, and impact on educational attainment and employment prospects.

Contributors proposed that some more quantifiable measures of individual respite services might include:

- a comparison of the care recipient's health (both physical and mental) on admission and discharge, within the context of clear individual health goals;
- a similar assessment of the health of the carer;
- the impact of activities/stimulation on the care recipient's behaviour, sleep patterns, ADL and the like.

Contributors recognised that measuring the longer-term economic impact of respite, including the opportunity costs of caring, was also important, though fraught with difficulties, not least because it required a whole-systems approach. However they did suggest that measures should include broader, long-term outcomes through, for example:

- a comparison of trends in admission to long-term care against additional investment in respite care;
- a comparison of costs of health care (for care recipients or carers) against additional investment in respite care;
- investigating the impact of introducing respite care earlier as opposed to later in the stages of the illness.

## **Review of respite services for carers for people with dementia**

Although carers who took part in the focus groups and interviews were not asked explicitly about 'measures of effectiveness', the issues raised during the discussions do seem to endorse the measures suggested above. In particular, carers felt very strongly that respite services helped to maintain their health and, in the long run, may lead to carers making fewer demands on both primary and secondary health-care services. Carers also felt that respite 'enabled them to go on caring'. They frequently used phrases like 'I don't think I could cope if he didn't go the day centre', or 'The two week's respite I get enables me to care for the other six weeks'.

In summary, contributors to the consultation proposed three main types of measure against which the effectiveness and cost-effectiveness of respite services should be evaluated:

- 1 qualitative measures based on the carer's (and where possible the care recipient's) own perceptions of the impact of respite care on their quality of life;
- 2 qualitative and quantitative measures based on the impact of respite care on the health and well-being of the carer and care recipient;
- 3 quantitative measures based on long-term cost-effectiveness analysis of the impact of respite care on service usage by both care recipient and carer.

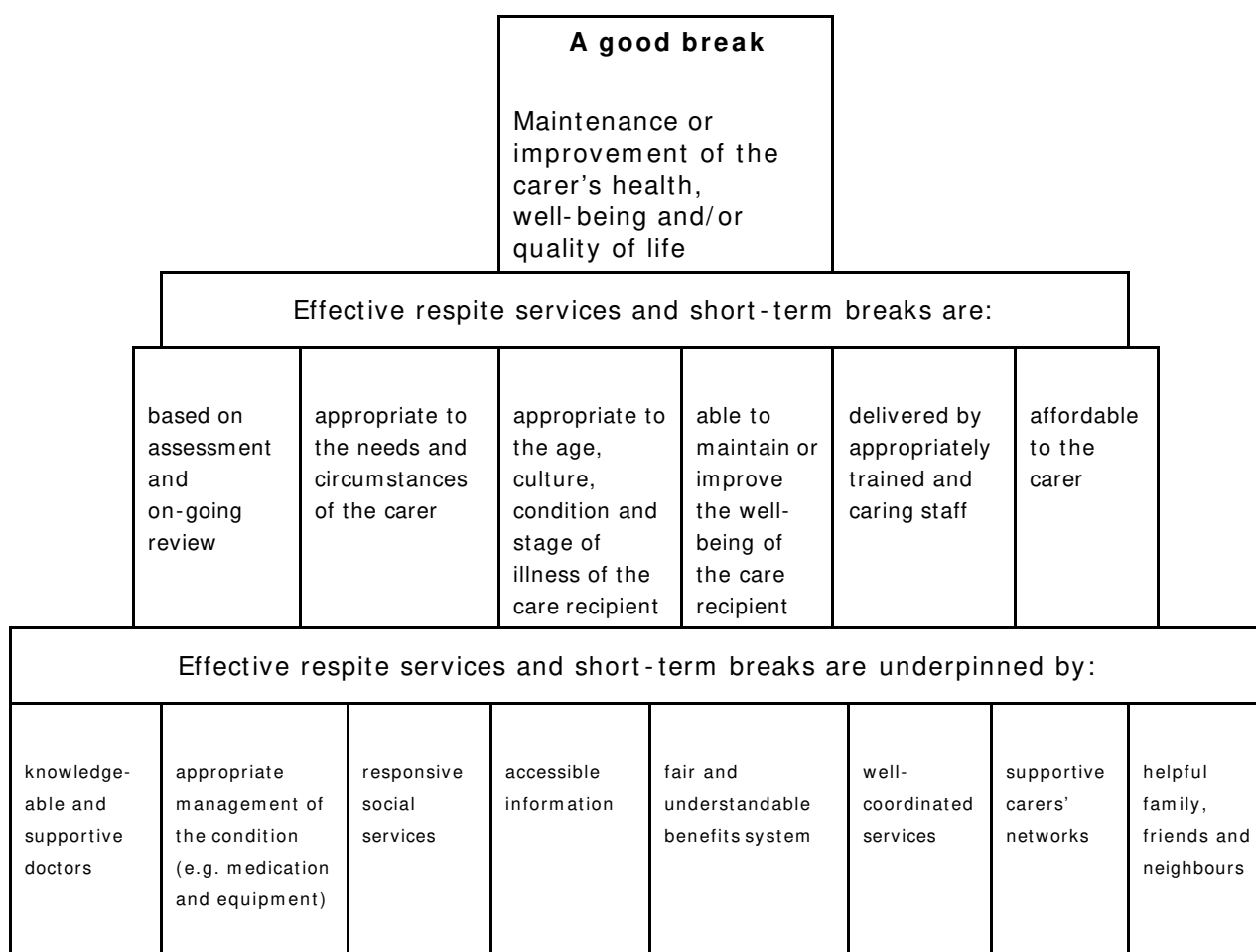
### **5.6 What underpins an effective respite service and short-term break?**

With the above-described concepts and measures of effectiveness in mind, the data from the focus groups and interviews with carers were examined with the aim of trying to understand what factors or characteristics are important in delivering effective respite services. The discussions with the carers re-emphasised one of the key points made by the contributors to the national interviews, namely that respite care does not exist in isolation from other services to support carers and care recipients. If they are to be effective, they have to be underpinned by a range of other services and systems. Much has been written elsewhere (Perring *et al.*, 1990; Arksey *et al.*, 2002b) about what constitutes an effective pattern of services to support carers, and so we do not intend to cover this topic in detail here. However, a number of factors did emerge which, if present, were perceived as facilitating access to, and take up of, respite, and generally enabling carers to get the most out of the respite services that existed in their area.

To illustrate this point, the research team developed a simple diagram, the effective-respite pyramid (see Figure 5.1). These underpinning factors form the base tier, supporting the pyramid. The second tier shows the key characteristics or 'drivers' of an effective respite service (described in Section 5.7). The consultation suggests that where both tiers of the pyramid exist, carers are more likely to receive respite or a short break which maintains or improves their health, well-being or quality of life (the top tier of the pyramid).



Figure 5.1 The effective-respite pyramid



The underpinning factors identified and shown in the base tier of the respite pyramid are described below, and illustrated with brief examples from the focus groups and interviews.

*Knowledgeable and supportive doctors.* Among those consulted, there were a number of examples of carers who had been unable to access services such as short-term breaks because they had not been given an accurate diagnosis or because it had taken months or even years to receive a firm diagnosis. In some cases this appeared to relate to a lack of expertise on behalf of the GP, or to their unwillingness to refer the patient to a specialist. Second, carers felt strongly that medical staff should direct them to other sources of support, about which they themselves may be totally unaware. This should be done at an early stage to prevent crises and breakdowns. Third, if appropriate, doctors could play a role in encouraging the care recipient to accept help, for example by suggesting that they have a short spell in hospital to allow staff to sort out their medication (with the additional benefit that the carer receives a break). Finally, if a doctor's attitude to the carer was supportive and sympathetic, this encouraged the carer to consider their own needs and to protect themselves from stress by having breaks from caring.

## **Review of respite services for carers for people with dementia**

Sam's wife has had Alzheimer's disease for eight years. His GP has been excellent, acting as the gateway to respite at a nursing home and from Crossroads Care, arranging regular visits from a community psychiatric nurse, and providing a long list of emergency numbers. He has also referred Sam to the Alzheimer's Society, arranged a wheelchair and directed him to the local Disability Living Centre.

Fred's wife developed symptoms six years ago but was only diagnosed with Alzheimer's disease last year. The GP insisted that her behaviour was due to 'marital problems'. When Fred finally saw a specialist, he was again told there was nothing wrong with his wife. Fred lost all confidence in his GP and became very stressed. The condition was finally diagnosed by a locum GP when his wife became quite ill; the locum immediately organised additional help.

*Appropriate management of the condition (for example, medication and equipment).* This can enable the care recipient to take best advantage of the local services on offer, and can reduce the level of problems both carer and care staff have to cope with. Carefully tailored medication can ensure that the care recipient's behaviour is well managed without them being overly sedated or vulnerable to unwelcome side effects. Innovative use of grants can also fund equipment (for instance, washing machines or mobile phones) to make the carer's life easier.

Betty's husband became so abusive, both towards her and the staff at his day centre, that he had to be admitted to a nursing home. However, he was then put on a new drug that has kept him much calmer; he is now seldom abusive and his concentration is much improved. This has meant that he has been able to return home to his wife and can also go back for day care.

*Responsive social services.* Social services are very often the only gateway to respite services, whether these are provided by the statutory, private or voluntary sectors. It is therefore very important for carers that they are able to access social services easily when they need to. If their case is closed as soon as the specific problem is dealt with, this can deter the carer from requesting respite the next time they need it, or can delay the provision of help in a crisis. On the other hand, responsive social services can serve to open up a wide range of options to the carer of which they might otherwise be unaware.

Melanie is able to access immediate respite care through her social worker on the occasions when her husband starts to become violent towards her. This means that she feels more able to cope on a daily basis and has not needed to consider residential care for him.

Ghazala has not yet used respite care for her father-in-law but now needs it in order to be able to attend an important family event. She has been trying to get a social worker for several months, but the doctor first dissuaded her and then sent her to the community centre, where she was referred to an occupational therapist. It is now only two weeks until the event, and Ghazala feels no nearer to arranging a break: 'I've been going round in circles'.

*Accessible information.* Many carers felt that lack of information had affected their access to short-term breaks. Often they had had to fight to find out what

## **Review of respite services for carers for people with dementia**

was available: 'Unless you know, you can't really choose, can you? You don't know until you have gone quite far, and you are struggling yourself.' Information was felt to be particularly hard to access for young carers as the professionals may be even less likely to include them 'in the loop'. Many carers cited voluntary-sector groups as their main source of information, but felt that statutory professionals and units such as hospitals also had a key role to play. It was suggested that services should be more widely publicised, for example in local newspapers, but it was also stressed that the best way was for information to be offered proactively by the professionals. Training and information about dementia should be offered to carers at an early stage to enable them to cope. Lack of information can also affect take up of benefits, and without adequate finance, carers can be deterred from arranging respite services.

Anju was invited to attend a nine-week carer's course run by the local hospital, which she found very helpful. There were many different speakers on a range of issues, many of which she knew nothing about, such as power of attorney. Unfortunately the course has now run out of funds.

In spite of the fact that her husband had several strokes, Julia didn't find out about the local stroke group for years. Although the hospital was very helpful in other ways, she feels staff should have given out more information: 'They don't seem to tell you anything'. The stroke group has helped to give her and her husband a regular break, with monthly bingo sessions, regular outings together, and even holidays away. They could have benefited from all these much earlier if the hospital had directed her to the stroke group. She also took a long time to find out about her husband's entitlement to Disability Living Allowance, which increased their income significantly.

*Fair and understandable benefits/charging system.* There is a strong view that carers are inhibited from using respite services because the costs are perceived as (a) prohibitive and (b) unfair. Some of those consulted feared they would not be able to continue to use short-term breaks for a long period because of the costs, whereas others had not used services for this reason. Two carers who themselves had health problems felt it was unfair that they were not able to claim Carer's Allowance as they were already on Incapacity Benefit. Most felt the actual level of Carer's Allowance was extremely low and in no way compensated them for being unable to sustain paid employment. There was also a view that it is unfair that those who have savings or pensions have to pay the full costs of care.

Audrey has seldom used local respite care services for her father-in-law, for whom she has been caring for a number of years. She now needs an urgent operation, followed by a period of recuperation, but has been told she will lose some of her Carer's Allowance if her father-in-law goes into a residential home for several weeks while she is unable to care for him (this apparently would not apply if the care he was receiving was classed as nursing care). Audrey feels this is very unfair, as she gave up her paid employment to care for him: 'It is the principle of the thing. I do feel a bit hard done by. It's been quite a psychological thing – I feel as though I have been run over by the departmental bus, just when I need more care.'

## **Review of respite services for carers for people with dementia**

*Supportive carers' networks.* Although some carers never choose to join support groups, many regard time spent in the company of other carers as a kind of break in its own right, as it leaves them feeling supported, encouraged and refreshed. Carers' networks are also seen as an invaluable source of information, both about the condition and about local services. Those who are 'further down the road' can tell newer carers what to expect and can encourage them to protect themselves by using respite services. An additional bonus is that the care recipients are made to feel welcome and encouraged to join in the games and discussions – whereas they are often stigmatised or seen as embarrassing at other community events. On the negative side, some newer carers are reluctant to join carers' networks as they do not feel ready to face the longer-term impact of the condition. Some formal services have succeeded in facilitating mutual carer support by enabling carers to meet together while looking after the care recipients (for example, the Winged Fellowship Trust).

Amanda's daughter encouraged her to join the local branch of the Alzheimer's Society as soon as she moved to a new area. She now goes to the carers' club every week and learns a lot from the carers who attend. The staff also help her fill in paperwork such as benefit claim forms. Amanda says, 'There is a feeling of belonging to a family' in the club.

*Helpful family, friends and neighbours.* Informal networks can make a significant difference to how well carers can cope between (or sometimes without) episodes of formal respite care. Families and friends can help carers keep a sense of perspective and humour, as well as providing informal respite care on a regular basis. They can also encourage the carer to address their own needs by seeking help and breaks from caring. Some families, however, have unrealistic expectations of the carer, and/or little understanding of the condition and its challenges. In one of the groups, it was stated that female carers in Asian communities often suffer from the assumption that it is their duty to take on the caring role: 'They just don't realise how much work it is.' In another situation, it had been inappropriate for the father to stay with his daughter, as he tended to target his aggression towards her.

Jyoti has good neighbours, one of whom pops in every day for a chat as soon as she is home from work. Jyoti says this helps to break up the day: 'Your life can get very narrow, it's like being in a tunnel'.

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.'

*Well-coordinated services.* A number of those consulted stressed the importance of well-coordinated services. This refers both to co-ordination *across* age and service boundaries, and linear co-ordination *along* the pathway of the disease, so that services are anticipated and planned in advance. It was suggested that respite should be managed in a centralised way by an individual who has an overview of the situation. The delivery of

respite has to be seen as one part of a much wider package of support for the care recipient and the carer. For example, carers should be offered not only practical support but also emotional support and counselling. Without this, they may feel too guilty to accept services such as short-term breaks. In summary, what is required is a more holistic, whole-systems approach, with full collaboration between providers and purchasers, agencies and disciplines.

## **5.7 What are the characteristics of an effective respite service and short-term break?**

The consultation suggests that, for short-term breaks to be effective, they not only need to be underpinned by the factors described in Section 5.6, but they also need to display six key characteristics (see the second tier of the respite pyramid, Figure 5.1). These characteristics indicate that the most effective respite services are:

- 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.

Each of these characteristics is explored in greater depth below. The material from the focus groups and interviews with carers is used to illustrate how these characteristics affected the quality of carers' experience of short-term breaks.

### **5.7.1 Recognising the importance of assessment and on-going review**

There was a strong consensus among the national contributors that thorough, sensitive assessments of both the care recipient's and the carer's needs were central to ensuring that the short-term breaks that carers received were effective. This might take the form of a formal carer's assessment, but what really mattered was that someone had taken the time to talk to the carer, and the care recipient if possible, about what outcomes they wanted and how short-term breaks might help them achieve them. The consultation part of this study was not designed to explore such outcomes in depth, and in any case, by their nature, the outcomes sought will vary with the individual carer. However, many contributors highlighted the importance of carers being able to use the time and space that respite services offered as they wished, whether this was to work, relax, catch up on sleep, do domestic tasks or keep in touch with family, friends and outside interests.

Contributors also suggested that assessment should be only the start of the process. Because dementia is a progressive condition, it was felt that it should be possible to plan a programme from diagnosis which anticipated the way in which the needs of both care recipient and carer were likely to change over

## **Review of respite services for carers for people with dementia**

time. It was important that follow-up contact was planned from diagnosis onwards as, when cases were closed after assessment, the carer often felt isolated and abandoned. On-going contact and review should be proactively offered and built into individual care plans. The combination of assessment and review, and centralised planning of services, should result in a package of co-ordinated care built around the needs, wishes and personal history of the care recipient and carer. This package might include planned breaks, care in the home and emergency arrangements. In other words, an effective respite service was one that was needs-led rather than systems- or service-led.

The carers who contributed to the consultation also emphasised the importance of assessment and on-going review. As was noted in Section 5.6 above, GPs and/or consultants were the first step in the process, as, without a diagnosis, many carers found it difficult to get their needs and those of the care recipient recognised. However, the consultation suggested that, even with a firm diagnosis, many carers do not have their needs assessed thoroughly. A straw poll of the 17 carers who took part in the focus groups showed that only three had had a carer's assessment. Two more thought they might have had one but were not sure, and most did not know what a carer's assessment was.

Contributors also noted that carers who were 'self-funding' should be able to access assessment information and help with finding services, but felt that in practice this did not always happen.

They also emphasised the need for on-going contact with social services and/or mental health services for older people, and the importance of regular reviews. A number of carers noted that, when their needs or those of the care recipient had changed, and they had contacted their local social services department to enquire about additional/different services, they found that their case had been closed. Those who had regular contact with their social worker or community psychiatric nurse appeared to have had fewer difficulties.

Laura cared for her husband who had Pick's disease. His consultant took time to ask her whether she was getting the help she needed and she had regular visits from a community psychiatric nurse who also arranged day respite and later residential respite as her husband's condition progressed.

### **5.7.2 Meeting the needs and circumstances of the carer**

The contributors to both the national interviews and local carer consultation emphasised that, if respite services are to be effective, they have to be able to take account of the differing needs and circumstances of individual carers. Whereas they recognised that there were limits to the extent to which every service could be individually tailored, they highlighted a number of factors that were particularly important in ensuring that services within an area were responsive to carers' needs.

*Access to respite in different settings.* It was clear from the consultation that carers need access to respite provided in a range of settings (for example in-home, day care and institutional/overnight care) because different settings

## ***Review of respite services for carers for people with dementia***

work better for some carers and care recipients than others. This was very much linked to the carer's personal circumstances, and the stage of illness of the care recipient. However, personal preference was also important. For example, some carers liked day services because the care recipient would not accept other people in their home, or because they felt it was impossible for them to get a real break unless the care recipient had respite away from their home. Others preferred in-home respite because it was less disruptive for the care recipient, and the carer did not have to worry about getting their relative ready to go out or arranging transport.

Many of the carers involved in the consultation were in fact using more than one respite service. This often involved a combination of one or two days at a day centre with some home care, such as a sitting service. Those caring for someone in the later stages of their illness might also be using residential respite, on either an *ad hoc* or a planned basis. These more formal respite services were sometimes supplemented with informal groups or activities (often run by voluntary-sector organisations), which involved the carer and the care recipient. The carers noted that this mix of services often worked well as it was able to address different needs, both for the carer and the care recipient. However, they also emphasised that both carers' and care recipients' needs are likely to change as an illness progresses or a carer's health and circumstances change, and so the mix of respite services being used must also be flexible.

Paul's wife goes to a day centre twice a week. He feels she benefits a lot from going there and he can really relax when she is there. Day care is the best option for him because his wife will not accept anyone coming to their home to sit with her.

*The option to have a break with or without the care recipient.* A number of contributors noted that, in the development of respite services, insufficient attention has been paid to short-term breaks where the carer and the care recipient can remain together. Clearly not all carers want this type of service, but many do. Some were already attending weekly or monthly groups, and activities run jointly for carers and care recipients. They felt that this not only gave them a break but also enabled them to meet other carers and share information and experiences. Others had used holiday schemes such as the Winged Fellowship Trust, or had made private arrangements with hotels but there was a view that this option should be more widely available. Joint holidays for the carer and care recipient were seen as particularly valuable for carers of younger people with dementia, especially where there might still be children at home.

*Access to respite at different times of the day/week.* Again the key issue here was about ensuring that services could meet carers' different needs and circumstances, and offer them a degree of choice. The carers consulted valued having access to short-term breaks at different times of the day and night, and on different days of the week. For example, weekend respite was greatly appreciated by those carers whose partners were still working or who had children, as it gave them some time to spend with their partners or family without the care recipients. Many carers also wanted, but were very rarely able to access, respite at night or in the evening. Night sitting services, which

## **Review of respite services for carers for people with dementia**

allow the carer to get a good night's sleep, were seen as particularly important in terms of maintaining the carer's well-being.

*A choice in the length of break.* Contributors explained that many carers are prepared to trade-off the 'amount' of respite they receive against the quality or appropriateness of the service offered. Professionals who assess carers and service providers needed to recognise this and allow carers some choice. A number of carers illustrated these trade-offs. For example, one carer preferred regular but limited in-home respite to residential respite once every few weeks. Another Asian carer had been offered day care for her mother, but as no one at the centre spoke her language, she preferred to go to a weekly, half-day session specially for Asian carers and care recipients.

*Flexibility over when respite is arranged.* Some flexibility over when respite services were arranged was seen as essential to meeting carers' needs. Contributors noted that, at times, carers need to plan well in advance, for example to cover a booked hospital admission or to enable them to go on holiday, whereas at other times they might want to arrange respite care at short notice, to enable them to retain some flexibility in their personal or social life. They also emphasised the need for access to respite in a crisis.

The reliability of services was regarded as particularly important and there was concern that, in some areas, residential respite places were being used for crisis admissions or being 'blocked' by those waiting to enter long-term care. By the same token, carers also recognised that creating flexibility and responding at short notice meant that services would need to operate with excess capacity, and that this could be difficult for providers working to tight budgets.

Mrs S cares for her husband who developed vascular dementia in his 50s. As well as day care, her husband goes into an NHS unit for one week in every six. Mrs S feels that the care her husband receives there is very good. The staff are very flexible and will try to accommodate family events and individual circumstances. Her grandson got married recently and the staff brought her husband to see the wedding and then took him out for a meal, so that Mrs S was free to enjoy the day without worrying about him.

*Confidence in the quality of care provided.* One of the most important factors for carers was the quality of the care provided by short-term breaks. Contributors explained that, if carers did not have confidence in the service, they found it hard to relax mentally, and so the break was less beneficial. Poor-quality residential respite services were a particular problem because they often left the care recipient disrupted or distressed, or in poorer physical health, and the carer then had to spend days or weeks getting them back into a routine and/or providing additional physical care. A number of carers in the focus groups noted that they stopped using services where the care was poor, even when they had no immediate alternative.



### **5.7.3 Ensuring services are tailored to the age, culture, condition and stage of illness of the care recipient**

In general, contributors agreed that, whereas age boundaries should be flexible, services should be appropriate to the age of the care recipient. As noted in Section 5.1, many of the contributors to the national interviews felt that there was a paucity of services for younger people with dementia, and anecdotal evidence from the focus groups supported this. Younger people with dementia (especially those in the early stages of their illness) and their carers were reluctant to use services that they perceived as being for older people, because the environment and activities offered were often inappropriate.

Martin cares for his wife who developed Alzheimer's disease in her early 50s. There are no services for younger people with dementia in his area, and so the only regular respite he was offered was a place for his wife one day a week at day centre for older people with dementia. She attended a few times but she was not happy there, so they stopped using the services. When he reached a crisis and needed a break, she was placed first on a ward for the elderly mentally ill and later on an acute ward for younger people with psychiatric conditions. The staff did not know how to cope with dementia and their excessive use of tranquillisers to control her behaviour resulted in her being 'incoherent' when he came to visit. Martin had to take his wife home after only a few days' break, and eventually found a private home which he paid for himself.

Whereas most contributors felt that services needed to be sensitive to the culture of the care recipient and their carer, there were mixed views about the extent to which specific or separate services should be developed for different groups. Some contributors favoured completely generic services and, in one of the 'good practice' areas where more than 50 per cent of the population was from black and ethnic-minority groups, this approach appeared to work well. However, others felt that, for the current generation of older people with dementia from minority ethnic communities, there was a need for some dedicated services. Practical issues such as language and diet were noted but also concerns about the extent to which people felt 'at home' in, for example, a day centre where there were only one or two people from their community.

There was also a view that services needed to reflect the differing needs of those in the early, middle or later stages of dementia. For example, those in the early stages of the illness were unlikely to feel comfortable in a setting dominated by people who were highly confused and/or requiring high levels of physical care, and might prefer one-to-one support, either at home or in the community. Conversely, carers of people in the later stages of the condition, needing higher levels of physical care, might need to make greater use of residential respite, in order to give them a break from the physical demands of caring.

Lastly, both the contributors to the national interviews and the carers noted that respite should be offered at a very early stage in the care recipient's illness. There was a perception that respite was not seen as essential for carers in this situation, particularly where respite and short-break services were in short supply. However, contributors explained that if respite was not available, there was a danger that carers would lose contact with friends or

outside interests, and might feel unable to resume these when respite was offered.

#### **5.7.4 Maintaining or improving the well-being of the care recipient**

It was clear from the consultation that whereas respite and short-term breaks were primarily seen as services for the carer, they also had an important role in maintaining or even improving the health and well-being of the care recipient. Both the carers and the national interviewees emphasised that if respite was a positive experience for the care recipient, carers were more likely to use respite services on the one hand and to derive greater benefit from them on the other.

For the care recipient, familiarity with, and continuity of, both surroundings and staff were felt to be of the greatest importance. The appointment of key workers even for those having short-term breaks, and the maintenance of high user/staff ratios, could ensure that staff recognised the care recipient's unique personality, and could therefore identify with them highly individual outcomes. It was also essential that staff were aware of new techniques, for example in enhancing communication with even the most severely disabled care recipients.

Mrs M cares for her husband who was diagnosed with dementia in his 60s. He goes to a day centre two days a week where he takes part in activities and has physiotherapy. She feels he really benefits from going to the centre. On the days he attends, he is happier and more active, and sleeps better at night, which means that she is able to sleep too. On the days he does not go to the centre, he refuses to leave the house and often stays in bed all day. His mood is more aggressive and he is very restless at night.

Rachel's husband went into a private care home for one week's respite but when she went to bring him home, he had difficulty walking. She found a deep cut on his leg that had gone septic and which took several weeks to heal. The home denied all knowledge of the cut. Rachel did not use that home again and has since found another one where she feels her husband is happy and well cared for.

#### **5.7.5 Recognising the importance of appropriately trained and caring staff**

All contributors highlighted the importance of empowered, well-trained and highly motivated staff. Whereas the carers tended to stress essential personal qualities such as empathy, friendliness and enthusiasm, the national interviewees highlighted the need for core competences in care management, recognition of symptoms and side effects, and knowledge of the range of conditions that could cause dementia. They felt that within a team it was essential to achieve a well-balanced multi-disciplinary understanding of the specific dementia-related diseases and their pathways. However, whereas some contributors felt that all services should be provided by specialist staff, others felt that, for those in the early stages of dementia, this was perhaps

## **Review of respite services for carers for people with dementia**

less important than the actual quality of the relationship and appropriateness of the activity.

Contributors stressed that much of the value of respite was in allowing the carer some emotional space from caring, as well as a break from the physical demands. This was only achievable when the carer was totally confident in the service. A trusting, supportive relationship with staff would help them to overcome guilt so that they were 'psychologically free' to have a break. Staff were also felt to have a role in helping carers to 'move on' and to accept changes in the relationship and the care they provided. This applied in particular to respite services for elderly parents of people with learning disabilities and dementia, but also to young carers who might be taking exams, moving on to further education or ready to leave home. By involving other members of the family in addition to the 'primary carer', staff could also help to develop understanding of the condition within the family and in this way help to strengthen the support networks available to the carer. They could also play a role in encouraging the informal exchange of information and support between carers.

Many contributors stressed the importance of communication between staff and carers. In an effective service, staff built up trust with families by involving and communicating with them on an on-going basis, using them as a source of expertise about routines and preferences, respecting their views and treating them as part of the team. This was as important for young carers as it was for adults. Contributors felt that staff should use respite stays to actively monitor the care recipient's condition, to receive and send back 'messages' to the carer about their health and well-being, and to offer advice on how best to support the care recipient at their particular stage of the illness. Above all, staff should recognise and understand the context of the relationship between care recipient and carer (in most cases, a relationship based on many years either as spouses or parent and child).

Mrs W's husband attends a day centre for younger people with dementia two days a week. She feels the staff are excellent – knowledgeable, friendly and caring. 'They take time to get to know the care recipient and try to design activities and trips which are linked to peoples hobbies and interests.' They also organise activities and events for carers and care recipients to do together (for instance, a barbecue or day trip to the coast).

Marion was offered daily help from a private home-care agency to help her with bathing and dressing her husband but she felt that the staff were very rough with him. They did not really understand his condition and the way it affected his behaviour, and saw his personal care as a series of tasks to be 'got through', with little attempt to get to know him.

### **5.7.6 Understanding the significance of 'affordable' services**

Contributors suggested that one of the key characteristics of a good break was affordability. By this, they meant carers' *perceptions* of affordability as opposed to what might be termed *absolute* affordability. It appears that many

## ***Review of respite services for carers for people with dementia***

carers are deterred from accessing short-term breaks because they feel they cannot afford them, and because they are very concerned about reducing a limited pool of savings when they have no idea how long the situation will last, or what their expenses may be in the future – particularly as residential care is often looming on the horizon. Although it is usually the care recipient who is being charged for the service, in reality the carer commonly has power of attorney and so is responsible for all financial decisions. Services for which care recipients were charged, albeit based on financial assessment, were more likely to be refused, as carers were very conscious of protecting the financial resources of the care recipient, and typically undervalued their own need for a break.

Vivien pays the maximum assessed charge for her husband's care; over £100 per week for two short visits a day (totalling less than one-and-a-quarter hours per day). Occasional residential respite costs her £320 per week. Vivien is very anxious about the gradual depletion of their savings: 'I don't know how long I can keep going with that'. Her worries are exacerbated by the fact that billing for these services has been very patchy, so that she is never quite sure how much she already owes and when the next invoice will arrive.

Penelope's husband receives a substantial pension from his previous employment. Although he now needs full care and toileting throughout the night, and although she has her own health problems, she does not have any help in the home as she feels she cannot afford it, and she is worried about how they will cope financially in the future. She could go out in the evening but a sitter would cost her £8 or £9 an hour, which again she feels she cannot afford. Penelope is receiving treatment for depression and feels that 'life is nothing any more'.

The next, and final, section includes an overview of key findings from the consultation and literature review, drawing attention to both similarities and differences in the evidence reported.

## Section 6 Review summary, implications for policy and recommendations for further research and improving research designs

### **6.1 Introduction**

Current policy and practice in health and social care emphasises the need to support carers in their caring role, for as long as they wish to continue to care. Respite care and short-term breaks are seen as having a key role to play in assisting carers (DH, 1999a). The present literature review has reported on the evidence found in research conducted over the past 18 years in relation to the effectiveness and cost-effectiveness of respite services specifically for carers for people with dementia. The review was complemented by a consultation with representatives from national statutory and voluntary organisations with a knowledge and interest in this area, and carers who are current or recent users of respite services in four different parts of the country.

After undertaking a painstaking and exhaustive examination of the literature, we found that the evidence from the research reports included in the review was mixed and at times contradictory. Overall, the review shows that on the basis of the outcome measures used (which are not necessarily the only measures) and on the service that was offered (which might have been inadequate), evidence of the effectiveness and cost-effectiveness of respite care and short-term breaks is limited. In contrast, there was considerable qualitative evidence from the review and also the consultation indicating that the benefits for carers who use respite services can be substantial and for some carers can make a difference to their ability to continue caring.

The absence of any firm conclusion from the review suggests that the literature may not be a good guide to the (cost-)effectiveness of respite care. The lack of one clear thread running through the literature reflects first the complexities of the topic area, in particular the diversity of services, carers' situations and the disease process, and secondly the relative weaknesses of methodological approaches to evaluation. We do not want to pre-empt a later discussion about methodological and service issues, but it is important to point out now that it would be wrong to assume that lack of evidence of effectiveness should be interpreted as evidence that respite is ineffective.

A further important point to make is that it might even be unrealistic to think that the use of respite services will lead to substantial effects for carers, especially in the case of those carers who delay the use of services until quite late in the progression of the care recipient's disease. From this point of view, respite may be 'too little..too late' (Deimling, 1991). It is probably more reasonable to hope that respite services may reduce stress and improve well-being, and lead to some improvements in the lives of carers whose relatives are in a stable condition. For patients who are declining more rapidly, the best that may be realistically hoped for is to stabilise carers' stress and well-being (Deimling, 1991).

## **Review of respite services for carers for people with dementia**

In what follows, we draw together key themes emerging from the literature review and the consultation, as well as presenting recommendations for further research and how to address research design weaknesses. Issues are discussed under the following headings.

- Overview of results (Section 6.2).
- Gaps and weaknesses in the evidence base (Section 6.3).
- Policy implications (Section 6.4).
- Recommendations for further research on respite services (Section 6.5).
- Recommendations for improving research methods (Section 6.6).
- Dissemination and implementation of research findings (Section 6.7).

### **6.2 Overview of results**

This overview draws on the evidence from the literature review and the findings from the consultation with carers and national interviewees. The overview adopts a similar structure to Section 4. It addresses benefits to carers, care recipients and the impact of respite on the use of other services. Findings from the consultation have been used at various points to aid the interpretation of the evidence from the literature review. The overview of the evidence regarding cost-effectiveness is presented at the end of the section.

#### **6.2.1 Benefits to carers**

##### ***Carers' perception of benefits***

In line with other commentators, the findings of the review indicate that where carers' views were sought, the vast majority placed a high value on respite services of all types, frequently expressing high levels of satisfaction. Generally, carers felt that respite services brought them various benefits, despite little evidence of significant or sustained reductions in levels of stress, depression and burden measured on more seemingly objective outcome measures (see below). Many studies reported carers' beliefs that respite enabled them to continue caring. Clearly, levels of satisfaction are linked to carers' perceptions of the quality of services, and the benefits these services bring to care recipients, reflecting Mason's comments on the inter-dependency of the value placed on services by carer-care-recipient dyads (Mason, 2003). Levels of service utilisation are linked to whether carers felt their relative was happy and well looked after (see, for example, Levin *et al.*, 1994; Beisecker *et al.*, 1996).

The carers and other contributors to the consultation endorsed these points. They stressed the importance of the quality of care provided by short-term breaks, explaining that if carers did not have confidence in the service, they found it hard to relax mentally and so the break was less beneficial. The skills, knowledge and attitudes of staff were particularly significant in carers' perceptions of quality of care, and yet it was notable that few studies in the review considered levels of staffing, staff training or staff attitudes towards people with dementia.

## **Review of respite services for carers for people with dementia**

The carers involved in the consultation emphasised the importance of having a degree of choice over the timing of respite, the length of respite break offered, flexibility regarding when and how the break was arranged, and the reliability of services. This suggests that the ways in which services are delivered and organised also influence carers' levels of satisfaction with services.

Evidence from the literature suggests that carers derive different benefits and disadvantages from different types of service. For example, evidence suggests that day care allows a longer break than, say, in-home respite; however, transportation and preparing the care recipient to go out can be onerous. Day-care users valued day care because it linked them with the professionals involved with the care of their relative, and was a 'safe place' for their relative. In-home respite users expressed initial caution about allowing a stranger into their home, and reported consistently that the hours of respite were not long enough. Nevertheless, they felt that in-home respite helped maintained family routines and preserved the status of the care recipient in the family, and were highly satisfied with the service (see, for example, Parahoo *et al.*, 2002). From the limited evidence available, institutional/overnight respite appears to cause most concern for carers. Carers valued this type of care because it offered a longer period of relief from caring and the particular benefit of being able to sleep without disturbance. Many carers felt it allowed them to go on caring. This type of respite could however be difficult to organise, and some carers reported feeling lonely or guilty when their relative was away from home, especially when the care recipient had been reluctant to go (for example, Pearson, 1988; Levin *et al.*, 1994; Watkins and Redfern, 1997). Carers also reported concerns about standards of care, and the deleterious effect on their relative of a change of routine (for example, sleeping patterns, continence problems, mobility) which could increase carers' workload when the care recipient returned home. Such concerns could outweigh some carers' preferences for taking more regular breaks (see, for example, Levin *et al.*, 1994).

### **Carers' preferences for different types of service**

In terms of the preferences of carers for different types of services, the evidence from the literature is limited. Different types of respite service are rarely directly compared, and those studies that do make comparisons between different types of service consider quite different outcomes (for example, Levin *et al.*, 1994; Quayhagen *et al.*, 2000; Leitsch *et al.*, 2001). Only one of the studies of respite programmes and multi-dimensional carer-support packages elicited carers' preferences for particular services. Lawton *et al.* (1991) reported that in-home respite was more popular with carers receiving a multi-dimensional package of respite services than either day care or institutional respite. Two studies attempted to compare social and medical models of day care (Leitsch *et al.*, 2001; Walker *et al.*, 2001). The evidence from these studies suggests that the social model was preferred due to a more homely environment, a greater focus on social activity and stimulation, and better relationships between staff and care recipients.

The consultation shows that, given the choice, carers would prefer to use a combination of services in order to achieve the outcomes they want for

## **Review of respite services for carers for people with dementia**

themselves and the care recipient, and that this mix of services will need to change over time, as the carer's circumstances change or the care recipient's condition progresses. This suggests that a single respite service, no matter how good, is unlikely to be effective in meeting carers' on-going needs.

The consultation also raised issues about the affordability of services, and the extent to which this affects take-up and utilisation rates. In this context, the important issue is carers' *perceptions* of affordability as opposed to what might be termed *absolute* affordability. It appears that many carers are deterred from accessing short breaks because they feel they cannot afford them, and because they are very concerned about reducing a limited pool of savings when they are unsure about how long the situation will last, or what their expenditure may be in the future.

### **A proper break?**

A consistent finding across the various studies that considered how carers used their break from caring responsibilities was that carers rarely used their time off to take part in social or recreational activities. Some studies, however, did report carers taking advantage of being relieved of their caring responsibilities by engaging in leisure pursuits and outings.

The actual amount of free time allowed by a respite service will to some extent dictate the type of activity that carers may undertake. A consistent criticism of in-home respite was that the length (and frequency) of the respite break was insufficient, and thus carers were constrained in what they could do during the few free hours they had. Evidence suggests that institutional/overnight respite allows carers the opportunity to have a good night's sleep and feel properly rested. For other types of respite, carers' time was most often spent in catching up with various chores, and sometimes resting. There is some limited evidence (Berry *et al.*, 1991) to suggest that carers using day-care service actually spend more time on caregiving activities on respite days than on non-respite days, usually in preparing the care recipient for the visit or transporting the care recipient to the day-care setting. Similarly, limited evidence from studies of in-home respite suggests that some carers use the 'respite' break to undertake caregiving tasks for which they need additional assistance, such as bathing the care recipient.

The consultation also suggests that both the total amount of respite offered and the point in the carer's caring 'career' when they first receive respite may be significant in terms of the way carers use their time. If the level of respite provided is very limited, carers often use any free time to 'do essentials'. When they have more time, they feel freer to use this in other, more pleasurable ways, such as seeing friends or pursuing hobbies and interests. Furthermore, if carers do not have access to respite at an early stage in the care recipients' illness and before the time they have to commit to caring becomes too great, they are perhaps more likely to lose their social networks, and may find them hard to re-establish when they do eventually receive respite.

There is some evidence from the literature that some carers and (care recipients) value the opportunities offered by some respite services (notably in-home respite and host-family respite) to spend their 'break' together doing



## **Review of respite services for carers for people with dementia**

something they both enjoy. The carers who contributed to the consultation also felt that such services were valuable. In particular they highlighted holiday schemes, and carer/care recipient social and activity sessions run by voluntary-sector organisations, which they felt had wider benefits in terms of providing carers with an opportunity to share information and experiences, as well as have a break.

### **Health and well-being of carers**

The evidence from the literature relating to how respite affects the health status and psychological well-being of carers is inconsistent. This is perhaps unsurprising given the range of interventions, duration of interventions, duration of follow-up, the different outcomes that were investigated, and the wide range of different outcome measurement tools utilised, including some standard measures, some measures specially adapted from standard measures and other 'one-off' measures devised for use in a single study. In addition, when studies were addressing similar outcomes, they rarely adopted the same outcome measures (see Section 2 for further discussion of outcome measurement, and Appendices 4a and 4b where the outcomes measured by each study included in the review are presented). Comparisons across various studies are therefore problematic, and combining the evidence from different studies in an attempt at meta-analysis is not possible.

None of the studies included in the review which attempted to measure carers' health status or psychological well-being were able to demonstrate that respite services of any type generated *marked* improvements in health and well-being in comparison to control groups (where these were used), or compared to carers' baseline state at point of entry to the study. There is no clear evidence from the review studies that any one type of respite has greater or lesser effect on any particular outcome, or could be seen to produce greater positive effects than other types of respite. The only notable, and perhaps unsurprising, feature is that institutional/overnight respite promotes better sleep patterns in carers during the period of respite.

Some studies indicated small statistically significant improvements on some outcome measures (for example, Gilleard *et al.*, 1987; Koslowski and Montgomery, 1993; Zarit *et al.*, 1998; Quayhagen *et al.*, 2000). However, no pattern of effect on any particular outcome emerges. Other studies showed positive but statistically insignificant effects (for example, Gilleard, 1987; Ryan *et al.*, 2002). Some studies reported improvements but these were not sustained over time (for example, Adler *et al.*, 1993; Larkin and Hopcroft, 1993; Chu *et al.*, 2000). Other studies reported few, if any, differences between carers and controls (for example, Mohide *et al.*, 1990; Wells *et al.*, 1990; Lawton *et al.*, 1991). In contrast, others demonstrated greater deterioration in control groups than in carers receiving a respite intervention (for example, Milne *et al.*, 1993; Levin *et al.*, 1994; Lorensini and Bates, 1997; Chu *et al.*, 2000), suggesting that respite interventions generally have a role in *maintaining* and *stabilising* health and well-being in the short-term.

This lack of evidence of positive effect is perhaps disappointing and sits uncomfortably against reports from carers drawn from the literature and the consultation indicating the value they place on respite and the benefits they

feel it brings. The issues highlighted in the consultation about what constitutes an effective respite service from the perspective of carers raise questions about how meaningful conclusions about effectiveness can be drawn from studies where little is reported about the extent to which the respite service being investigated actually met the needs of the carers and care recipients. The lack of evidence of effect in the review studies could be due, at least in part, to a variety of service-related factors such as the level of service offered, the way it was organised or how appropriate it was for the care recipient. Furthermore, other non-respite support services play an important part in enabling carers to access and then use respite services to maximum effect, and yet few studies in the review examined this wider context.

The consultation also suggests that carers see the benefits of respite in quite broad terms which are as much about general quality of life for both carers and care recipients as they are about specific indicators of health. The outcomes carers seek from respite are by their very nature varied and individual, reflecting the unique relationship between the carers and care recipients in question. When carers talk about the 'outcomes' or benefits of respite, they talk more about what the time and space provided by respite enables them to do (for example, work, relax, have time for themselves, catch up on sleep, do domestic tasks or keep in touch with family, friends and outside interests), than about specific health benefits. Having time for all these things is likely to have an impact on the carers' well-being and quality of life. Carers are realistic about their situation, and recognise that respite cannot fundamentally change their situation, but can alleviate some of the burden of caring.

### **6.2.2 Benefits to care recipients**

#### ***Perceptions of care recipients***

Very few studies (for example, Levin *et al.*, 1994, Pritchard and Dewing, 1999; Reid *et al.*, 2001; Walker *et al.*, 2001; Ryan *et al.*, 2002) attempted to work with care recipients themselves to elicit their views on their experiences of respite services. Where this was attempted, the number of informants was usually low. Nevertheless, the available evidence provides useful insights into the aspects of respite services that dementia sufferers value. What emerges from studies of day care, in-home respite and host-family respite is that many care recipients enjoy the different company that a respite experience offers, whether this is the company of other dementia sufferers, the support staff or the more informal social support from host-family respite. Care recipients reported that being with others who understood dementia enabled them to feel more relaxed and confident, and they felt less isolated or alone. Apart from the opportunities to socialise, care recipients valued having the chance to do the particular things they had always enjoyed whether at a day centre, in their own home, or in the homely environment offered by host-family respite. Where these opportunities were lacking (see, for example, Walker *et al.*, 2001), care recipients report feeling lonely and left out. Perhaps in-home respite, and respite within a host family, offers the greatest opportunities for tailoring activities to the individual preferences of the care recipient. In the

## **Review of respite services for carers for people with dementia**

case of host-family respite, care recipients also expressed a preference for a break in a homely environment as opposed to an institutional setting.

### **Carers' perceptions of benefits to care recipients**

Ten studies reported the views of carers regarding the beneficial (or adverse) effects that respite had on their relatives (Levin *et al.*, 1989, 1994; Lawton *et al.*, 1991; Turvey *et al.*, 1991; Larkin and Hopcroft, 1993; Beisecker *et al.*, 1996; Jarrott *et al.*, 1999; Parahoo *et al.*, 2002; Robertson, 2002; Ryan *et al.*, 2002). No evidence was retrieved regarding carers' views about respite programmes.

In terms of day care, carers described benefits to care recipients mainly in terms of social stimulation, being in different company and different environments, being assisted with personal care such as bathing and shaving, and having a meal. Some carers also reported improvements in mood and behaviour, mental functioning and sleep patterns. On returning home, care recipients had new, outside interests to talk about and were more interested in other people and events (for example, Levin *et al.*, 1989, 1994; Beisecker *et al.*, 1996; Jarrott *et al.*, 1999). Similar reports were made about in-home respite but perhaps the most notable difference was that carers felt in-home respite helped maintain the role of the person with dementia in the family (Parahoo *et al.*, 2002; Ryan *et al.*, 2002). Those services which offered an opportunity for carers and care recipients to take a break together (for example, Robertson, 2002; Ryan *et al.*, 2002) allowed couples to share 'normal' experiences which were different from the daily routine; both carers and care recipients found this refreshing. Benefits to care recipients from institutional/overnight respite were also reported, including the diagnosis and treatment of previously unrecognised illness and adjustments to medication.

Carers in the Lawton *et al.* (1991) study felt that their perceptions of how much the various respite interventions had benefited the care recipients did not match the perceptions of the care recipients themselves, who were less likely to feel the experience had been beneficial.

Despite the potential benefits that respite can bring, not all carers thought respite care was beneficial to their relatives. Some carers reported that the respite break had adversely affected the care recipient. There is limited evidence regarding the nature of these adverse effects, and this relates only to institutional/overnight respite, and is drawn from three studies (Levin *et al.*, 1989, 1994; Larkin and Hopcroft, 1993). There were suggestions from carers that the care recipient had returned home in a worse state, and the disruption to their routine had increased anxiety and confusion or promoted the onset of incontinence, or reduced their mobility because of the use of wheelchairs in the respite setting.

Differences in type of intervention, study design and reporting make comparisons difficult; however, the limited evidence from the review studies seems to suggest that only a minority of carers consider day care and institutional/overnight respite beneficial or very beneficial to their relatives (see, for example, Levin *et al.*, 1989, 1994; Larkin and Hopcroft, 1993). The earlier Levin *et al.* study (1989) reports that one in five carers thought day care was beneficial to their relative, and 25 per cent thought that institutional

## **Review of respite services for carers for people with dementia**

respite was beneficial. The later Levin *et al.* (1994) study investigated different types of respite, reporting that one in three carers thought day care was beneficial. Even fewer carers thought that institutional/overnight respite was beneficial, with 25 per cent reporting that respite had adversely affected their relative. Larkin and Hopcroft (1993) reported mixed views from a small sample of carers using institutional/overnight respite. Some of these carers felt the respite experience had been harmful to their relative. In respect of in-home respite, Levin *et al.* (1994) reported that two in three of a smaller subgroup of carers using in-home respite thought the service was beneficial to their relative. The results of a survey conducted by Turvey *et al.* (1991) indicated that two-thirds of carers using in-home respite thought the service was beneficial to their relative. A small number of survey respondents felt the service had been harmful, and almost one-third of respondents gave no response to the question about whether the service had been beneficial. The evidence is limited but does seem to indicate that, from the perspective of carers, in-home respite may be more beneficial to care recipients.

Again there is evidence that carers' perceptions of whether their relative benefits from respite is linked to utilisation (for example, Beisecker *et al.*, 1996).

Many contributors to the consultations emphasised how important it was to carers that respite services helped to maintain the health and well-being of the care recipient, or at least did not cause any deterioration. Ideally, they wanted services to provide interest and stimulation not just because this benefited the care recipient directly but also because they felt it had a positive impact on their caring relationship. However, they accepted that because of the progressive nature of dementia there were limits to what could realistically be achieved. More generally, they placed great emphasis on the service being appropriate to the age, culture and condition of the care recipient, and were reluctant to use services which they felt were inappropriate.

### **Health status, well-being and dementia-related symptoms**

A number of studies attempted to take 'objective' measurements of the effects of respite on the health status, well-being and dementia-related symptoms of care recipients (for example, Burdz and Eaton, 1988; Lawton *et al.*, 1991; Deimling, 1991; Adler *et al.*, 1993; Hirsch *et al.*, 1993; Larkin and Hopcroft, 1993; Wimo *et al.*, 1993; Curran, 1996; Watkins and Redfern, 1997; Cox, 1998; Seltzer *et al.*, 1998; Pritchard and Dewing, 1999; Dries *et al.*, 2000; Zank and Schacke, 2002). The evidence is, however, inconsistent. As noted above, variation in study design, type and duration of respite intervention, outcomes measured, and the tools used for measurement do not easily allow comparisons to be made across studies. A further complication in interpreting this evidence is the progressive nature of dementia-type illnesses. Attributing improvements or deterioration to the respite service received, or to the natural progression of the illness, is problematic.

None of the studies of in-home respite attempted to measure outcomes for the care recipient, apart from those studies noted above which reported carers' perceptions of benefit to care recipients.

## **Review of respite services for carers for people with dementia**

There is no clear evidence from the review studies that any one type of respite has greater or lesser effect on any particular outcome, or could be seen to produce greater positive effects than other types of respite. Three studies reported overall improvement on activities of daily living, dependency and behaviour for institutional/overnight respite (Burdz and Eaton, 1988) and for day care (Zank and Schacke, 2002; Pritchard and Dewing, 1999). Other studies reported mixed results with improvements for some care recipients but deterioration for others (for example, Deimling, 1991; Curran, 1996; Cox, 1998), or improvement on some outcomes but not on others (for example, Drees *et al.*, 2000). Five studies reported no significant changes for institutional/overnight respite (Adler *et al.*, 1993; Watkins and Redfern, 1997; Seltzer *et al.*, 1998), for multi-dimensional programmes (Lawton *et al.*, 1991), or for day care (Wimo *et al.*, 1993). Hirsch *et al.* (1993) found a small but significant deterioration in activities of daily living, dependency and behaviour as a consequence of institutional/overnight respite; however, most care recipients returned to previous levels of functioning after returning home. Finally, Larkin and Hopcroft (1993) found some negative physical-health consequences of institutional/overnight respite in a small sample of care recipients, including falls and episodes of pneumonia.

Perhaps the main conclusion that can be drawn from this inconsistent and rather confusing body of evidence regarding care recipients' health and well-being is that – overall – there is little evidence to suggest that respite interventions do significant harm to care recipients, indicating that any benefits to carers are not acquired at the expense of the health and well-being of the care recipient. However, it remains unclear whether respite services can bring about any significant improvements for care recipients' health, well-being and dementia-related symptoms.

### **6.2.3 Impact on use of other services**

In examining how the use of respite services impacts on other services, a number of studies explored the relationship between the use of respite and entry into long-term care, and in particular the relationship between the use of institutional/overnight respite and long-term placement (for example, Pearson, 1988; Levin *et al.*, 1989, 1994; Larkin and Hopcroft, 1993; Watkins and Redfern, 1997). Fewer studies considered the relationship between respite use and the use of other community-based services (for example, Mohide *et al.*, 1990; Lawton *et al.*, 1991; Chu *et al.*, 2000). There is no evidence regarding the impact of respite programmes or host-family respite on other services.

#### ***Impact of respite on other community services***

In terms of the use of other community-based services, there is little evidence to suggest that the use of respite services reduces or increases utilisation of other community services. The three studies of multi-dimensional carer-support packages, which investigated the use of community services, could identify no differences between respite service users and control groups (Mohide *et al.*, 1990; Lawton *et al.*, 1991; Chu *et al.*, 2000). Respondents to a survey of GPs, social workers and community nurses who referred carers to in-home respite (Milne *et al.*, 1993) felt that in-home respite reduced

## **Review of respite services for carers for people with dementia**

demands for other services, although there is no quantification of how much or what type of service might have been called on in the absence of in-home respite.

### ***Impact of respite on entry into long-term care***

In relation to the use of respite services and their impact on entry into long-term care, the evidence relating to the use of day care is contradictory. Wimo *et al.* (1993) concluded that day care had a preventative effect on institutionalisation; however, Levin *et al.* (1994) found that those using day care were just as likely to have entered long-term care as those who were not using day care over the course of their study period. Diesfeldt (1992), in a five-year follow-up study of day-care users, concluded that an increased severity of cognitive impairment was associated with an increased risk of long-term placement. In terms of in-home respite, there is very little evidence regarding its impact on long-term placement. Levin *et al.* (1994) found that care recipients using in-home respite and day care were less likely to have been admitted to long-term care than those using in-home respite, day care *and* institutional/overnight respite services.

The three studies of multi-dimensional carer-support packages indicated that, compared to those in the control groups, the entry into long-term care of patients in the study groups was postponed. The length of the delays varied, and ranged between an average of 22 days (Lawton *et al.*, 1991), a relatively short period of time, and seven weeks (Mohide *et al.*, 1990; Chu *et al.*, 2000). However, in all cases the respite care took place in the context of a comprehensive package, with no patient/carer receiving purely respite and no other service. On the contrary, this type of intervention is designed to address the multi-dimensional problems and needs that carers are likely to experience, and to provide a wide range of practical community-based services. Unfortunately, and no doubt reflecting methodological difficulties, none of the three research teams commented on the relative importance and impact of the different services making up the entire package being investigated. Putting that point to one side, it is important to mention that whereas the trend was towards delayed long-term care, receipt of a multi-dimensional support package did not necessarily lessen the degree of anxiety or make a big improvement on carers' quality of life. However, the studies give some support to the idea that assistance for the carer has favourable outcomes for the patient, as the carer is willing/able to maintain them in the community for longer. It is reasonable to suggest that any preventative effect or delay in placement in long-term care appears to be less about the provision of a single service, and more about a 'menu' of readily available forms of assistance – comprehensive help that includes practical, social and emotional support.

More studies investigated the impact of institutional/overnight respite and long-term placement (Pearson, 1988; Levin *et al.*, 1989, 1994; Larkin and Hopcroft, 1993; Watkins and Redfern, 1997). These studies suggested that the relationship between institutional/overnight respite use and entry into long-term care is complex. Placement appears to be influenced by a number of factors, including the emotional attachment between carer and care recipient, levels of carer burden, and the use and availability of other

community services. Evidence suggests that carers may only turn to institutional/overnight respite when they are becoming over-burdened, or when they are already considering the possibility of a long-term placement for their relative (Levin *et al.*, 1989, 1994; Larkin and Hopcroft, 1993; Watkins and Redfern, 1997). Most of the relevant studies supported the view that relief admissions can facilitate patient entry to long-term care rather than act as a prevention measure. Various reasons were put forward. For example, reflecting the debilitating features of dementia, affected individuals may be particularly vulnerable to complications and adverse events (for example, injury from falls, pneumonia) during respite care which may lead to further decline and necessitate long-term placement. As carers' resources are depleted, and patient needs increase, then the physical and emotional relief obtained through institutional/overnight respite, when combined with a positive perception of such care, may make the resumption of caregiving at home a less attractive option. Exceptionally, the findings of one study supported the view that relief admissions to a psychogeriatric unit did have a direct effect on reducing the numbers of patients in long-stay care (Pearson, 1988). However, these admissions took place within the context of a comprehensive psychogeriatric service, where patients received a range of other services reminiscent of the multi-dimensional carer-support packages just discussed.

### **6.2.4 Cost-effectiveness of respite services**

Five relevant economic evaluations were included in the review, four of which evaluated day-care services compared to standard care (Engedal, 1989; Wimo *et al.*, 1990, 1994; Gaugler *et al.*, 2003b) and one of which assessed multi-dimensional carer-support packages compared to standard community nursing care (Drummond *et al.*, 1991).

In terms of day care, all studies reported potential benefits available but in two studies this was associated with higher costs whereas in the other two studies this was associated with lower costs. Observed differences suggested potential advantages to be gained for the care recipient in utilising day care instead of standard care (that is at lower cost and at increased benefit) in two out of four studies (Engedal, 1989; Wimo *et al.*, 1994). Observed differences reported in the other day-care-focused studies (Wimo *et al.*, 1990; Gaugler *et al.*, 2003b) suggested that benefits to the carer were available but at increased cost. Benefits to the care recipient were also available at increased cost in the Wimo *et al.* (1990) study. Since no statistically significant differences were found in the costs and benefits across groups in any of these studies, apart from the costs in the Gaugler *et al.* (2003b) study, these results need to be viewed with caution.

For the single economic evaluation of multi-dimensional carer-support packages compared to standard care (Drummond *et al.*, 1991), observed differences suggested that the support package was associated with higher benefits for the carer and at higher cost. However, no statistically significant differences were found so, again, these results should be interpreted with caution.

## ***Review of respite services for carers for people with dementia***

In summary, it appears that day care and the multi-dimensional support care packages might provide greater benefits to carers and care recipients but associated costs might be lower or higher. Due to limitations in the methodology of all these studies, as well as the fact that none of them was UK-based, there is a great deal of uncertainty as to how cost-effective these interventions might be when applied to the UK context.

This completes our overview of evidence from the literature review and consultation. As noted at the start of the section, no one over-riding message runs through the body of research reports included in the review. Overall, evidence of the effectiveness and cost-effectiveness of respite care and short-term breaks for carers for people with dementia is limited. We would reiterate, however, that it is wrong to assume that lack of evidence of effectiveness should be interpreted as evidence that respite is ineffective.

### ***6.3 Gaps and weaknesses in the evidence base***

On the basis of the review, we have identified gaps in the topics covered in the literature as well as weaknesses in the design, analysis and reporting of studies, as discussed below.

#### **6.3.1 Gaps**

The first point to make is that the majority of literature focuses on day-care services provided in either a day centre or a hospital setting. At the other extreme, there is a dearth of literature focusing on new services set up in the wake of the Carers Special Grant. This might mean that the services do not exist, but this appears improbable in the light of comments made by contributors to the consultation. It seems more likely that the evaluation literature has not yet caught up with current or more-innovative practice. Based on the results of the review and the consultation, we have identified deficiencies in the literature about certain types of respite care and short-term break:

- UK services set up since the implementation of the Carers Special Grant,
- in-home services,
- host-family respite,
- institutional/overnight respite.

We found no UK evaluations of respite programmes or multi-dimensional carer-support packages. It is reasonable to think that this gap reflects the fact that even though service users' community care arrangements may contain a mix of different forms of service provision, trials of more-intensive experimental support programmes or packages have been concentrated in other countries. Insofar as video respite is concerned, neither the review nor the consultation has shed any light on whether this form of mini-break has ever been used and/or tested in the UK.

Little, if any, research has been undertaken looking at effectiveness and cost-effectiveness issues in relation to particular groups of carers, with the result that not a lot is known about how different types of respite care are experienced by different carers and/or care recipients. While singling out



particular carer groups runs the risk of assumptions being made that all other groups are covered, it is the case that little has been written in the literature specifically about respite services for the following groups:

- carers of younger people with dementia,
- black and ethnic-minority carers of people with dementia,
- carers of people with Down's syndrome and dementia,
- rural carers of people with dementia,
- young carers of people with dementia.

### **6.3.2 Methodological and quality issues**

A theme that has been running throughout the entire report relates to methodological and quality issues. We first commented on the challenges and complexities of undertaking evaluations, and consequent shortcomings in studies, in Section 1. As highlighted in the methods section (Section 2), some studies were excluded from the final review because of quality issues related to data collection or analysis, or poor reporting. There were shortcomings in some studies we did include, which served to reduce the strength of the evidence base. We discuss these weaknesses now in terms of design issues, outcome measures, analysis and the reporting of research.

#### ***Design issues***

The large majority of studies were not based on RCTs and, whereas this might not always be possible, the impact is that comparator groups might differ in ways other than the intervention received. These factors, rather than the intervention(s), might influence the outcomes found. The mechanism by which individuals were allocated to groups to receive interventions or not was not always blinded and again this might influence behaviour and hence outcomes observed and attributed to the intervention in question.

In some cases, there was inadequate or no use of control groups. In the latter case, this meant that studies could not assess relative differences in participants' health or well-being that could have occurred without the use of the respite service. When control groups were included, however, it was sometimes the case that carers in the control group were in receipt of services similar to those used by the study group, and hence there was control-group contamination. This could then dilute the relative impact on outcomes in the intervention group compared to the control group. However, it is appreciated that carers who feel they need a break from caring will make other arrangements, and it would be unethical for researchers to try to prevent this.

Another issue concerns time and timing. Few studies investigated medium- and long-term effects, so it was not possible to explore patterns of change over varied periods of time. This issue is related to the point about disease trajectory over time and knowing how this might influence the type of support required for the carer and the care recipient. The lack of long-term studies means that little is known about whether access to good respite has a positive effect on the long-term health of the carer – for example reduces morbidity from conditions that can be linked to stress (stroke, chronic heart disease,

## **Review of respite services for carers for people with dementia**

cancer and so on) – and therefore little is known about associated use of NHS services. Another time-related issue includes attrition rates. Sample attrition rates were high in the longitudinal studies due to participants stopping using the service, entry to long-term care or the death of the care recipient.

### **Outcome measures**

The emphasis on standard outcome measures to assess effectiveness is one of the most problematic issues. In practice, a substantial number of different instruments were employed in the studies reviewed. Interventions to support carers are likely to have a wide range of outcomes, especially given the range of intended consequences of respite care and short-term breaks. As noted at the start of the report, in some instances the purpose may be to assist carers to 'let go' and allow their relative to enter long-term care. In others, it might be to support carers to actively provide care for longer. Yet other respite services might aim to reduce the behavioural problems of care recipients, and to improve functions relating to activities of daily living. It is questionable as to how well standard instruments are able to tap into this wide range of possible outcomes.

In addition, the impact that an intervention might be expected to have on outcomes such as health and well-being, for example, might be difficult to capture due to the magnitude of the effect and the number of effects possible. Other stakeholder perspectives might be of interest too – for instance, that of the NHS – in which case other, service-orientated outcomes are likely to be important.

### **Analysis**

Respite occurs in a range of contexts and many carers use different types of respite and short-term breaks to meet different purposes and needs, possibly in combination with other community care services. However, studies did not make rigorous attempts to try to disentangle the benefits of the range of services that carers used, and yet it may be the case that other services make a difference to whether respite is effective, or relatively more effective.

Likewise, some studies did not factor in carers' other community care support, prior to using the respite service under evaluation, and it was possible that the beneficial effects of service provision might have started beforehand. Again, this meant that it was difficult to tease out the effects of the new respite care from pre-existing service support.

Limited investigation of uncertainty through statistical analysis was undertaken in many of the studies reviewed and this impacts on the robustness of the effects and costs estimated and thus the confidence that can be placed in the study findings. Few authors reported that the studies they conducted were powered to detect statistically significant differences in effectiveness between and within groups. Typically, the sample sizes required to detect any statistically significant findings in cost-effectiveness across groups require even larger sample sizes since costs, in particular, are likely to be highly skewed.

Costing informal care continues to be a particular methodological challenge in the economic evaluation literature. Among others, Koopmanschap *et al.*

## ***Review of respite services for carers for people with dementia***

(1995) have investigated how to value the production lost to society due to disease and the importance of informal, unpaid carers' productivity that has social value but which it is not straightforward to put a price on. Lack of consensus about how to analyse the data frequently meant that different studies of cost-effectiveness took different approaches and this made the synthesis of study results problematic.

### ***Reporting***

Many studies provided little or no information relating to the specific amount of respite received by carers in the study group, which then made it difficult to identify whether the volume of respite use was related to its impact. There was a lack of information about the services themselves, for example: staff/patient ratios; facilities; available activities; the way services were organised. Not describing the intervention fully meant there was a lack of study transparency, which in turn impacts on the generalisability of results.

We have already stated that the review suggests there is only limited evidence of the effectiveness of respite services and short-term breaks for carers for people with dementia, and even less evidence on the cost-effectiveness of these services. In a review of outcome evaluation studies, Intagliata (1986) likewise drew attention to the lack of evidence substantiating the beneficial impacts of respite care services for people with developmental disabilities and their families, before presenting a conceptual framework for outcome evaluation of respite care in that specific field.

By taking on board the above methodological difficulties, it is possible to argue that better studies comparing the (cost-)effectiveness of different forms of respite, or the impact of programme respite, could be conducted. We return to this issue in the final sub-section of this section where we make recommendations for addressing research design issues.

## ***6.4 Policy implications***

The SDO review of respite services and short-term breaks for carers for people with dementia is timely in the context of a number of major government initiatives. The development of the National Institute for Clinical Excellence (NICE) and the Social Care Institute of Excellence (SCIE), as well as the introduction of the NSF for Older People (DH, 2001), all highlight the government's commitment to implement evidence-based policy. Standard 7 of the NSF for Older People focuses on the provision of evidence-based mental-health services and on promoting integrated services that offer early diagnosis, treatment and support for older people and their carers.

Few would argue with the principle that services and practice should be driven by knowledge of what works best. This review, however, illustrates how difficult it may be to achieve services that are evidence-based in a context where effects of particular interventions cannot easily be separated out from other services or circumstances, 'positive' outcomes are not easily defined or measured, and where there are gaps and weaknesses in the available evidence. It is worth remembering that the majority of evidence is derived from studies that were undertaken some time ago when the desired outcomes

## ***Review of respite services for carers for people with dementia***

of services differed from those that exist today; for instance, the importance of service process outcomes are more widely recognised (Nicholas, 2003). Unfortunately, evaluation studies tended to be based on service configurations that no longer exist (respite care in NHS hospitals and to a lesser extent day hospital care).

In spite of the lack of robust (cost-)effectiveness evidence to support the use of particular types of respite care, a number of issues were highlighted which have implications for policy and practice. One of the main implications of our findings is that the planning, delivery and evaluation of short-term-break services must be set in the context of other support services (as illustrated in the effective-respite pyramid, Figure 5.1). Whatever the quality of individual short-term breaks in a locality, many other services and systems will have an impact on their take-up and effectiveness – including, for example, the medical management of dementia, access to health and social care services, and systems for assessment and review of both carers and care recipients. Counselling, benefits advice and advocacy also have an important role to play in encouraging and enabling carers to take breaks, and as such will require sufficient and secure funding.

A further implication is that services need to be sufficiently varied and diverse to meet the needs of carers and care recipients in a range of situations and from a range of backgrounds. For example, dementia does not just affect older people. Research indicates that there are around 17 000 people under 65 with dementia in the United Kingdom ([www.thecliveproject.demon.co.uk/](http://www.thecliveproject.demon.co.uk/)). The ethnic profile of Britain's older population has changed considerably in the last ten years. Asian and black Caribbean carers have different awareness of dementia than do white people but there is very little evidence on how this will affect their use of respite services and short-term breaks.

The importance of flexibility and the person-centred approach, as enshrined in Standard 2 of the NSF for Older People, imply the need for spare capacity to be built into respite services. This has particular implications for local authorities who will need to ensure that their Carers Special Grant allocation remains dedicated to developing short-term-break services now that it is no longer ring-fenced by central government.

At the same time, quality standards may need strengthening to reduce variability in the quality of, and access to, different services. They also need to have the flexibility to accommodate the wishes of carers and care recipients, which may differ for different groups reflecting the diversity just mentioned.

Anomalies in charging and benefits systems, which may deter carers from taking the breaks they need, should be addressed.

This review also has implications for the recruitment and retention of high-quality staff, and for their on-going training and development. It has highlighted the importance of training for both front-line care staff and for doctors, in the recognition, diagnosis and treatment of dementia; in techniques of care, which are associated with the best outcomes; and in understanding the needs and roles of carers. These issues will be particularly

## ***Review of respite services for carers for people with dementia***

relevant to the National Care Standards Commission, and to a range of professional training bodies.

The study has highlighted the importance of the responsiveness and accessibility of local social services departments (the gateway to most short-term breaks), and in particular of regular assessment and review (for both care recipient and carer). As local authorities now have both a duty to assess carers (even if the care recipient is not assessed), and powers to provide them with services that can help them to care (Carers and Disabled Children Act 2000), it is clear that the carer's assessment can be a key tool in identifying carers who need a break. The recent introduction of the Single Assessment Process should provide new opportunities to ensure that good assessment and review practices are in place. The need to identify carers who would benefit from a short-term break also reinforces the case for identification, and in particular for the expectation in the new General Medical Services (GMS) contract that general practices have a protocol for carer identification and a mechanism for the referral of carers for social services assessment.

Furthermore, the Carers (Equal Opportunities) Bill will, if it becomes law, give carers new rights to information and greater choices and opportunities for work, education and lifelong learning – all of which have implications for the development and promotion of respite for carers of people with dementia.

Last but by no means least, patient choice is being promoted to enhance patient access to, and involvement in, health and social care decision-making. In the case of dementia, though, it can be problematic to elicit patient preferences. In practice there is often an inter-dependence of the value placed on services by carer-care-recipient dyads. It seems appropriate, therefore, to enhance the opportunities for carers (and people with dementia) to help shape respite service provision.

### ***6.5 Recommendations for further research on respite services***

On the basis of the evidence from the literature review and the consultation, we recommend that serious consideration be given to commissioning the following further research relating to the provision of respite care and short-term breaks. The findings of such inquiries would be especially useful for service providers and commissioners.

#### ***6.5.1 New respite services and short-term breaks***

There is a case to be made for undertaking evaluation studies of services newly developed in the UK in the wake of the Carers Special Grant. The key difference between Carers Special Grant-funded schemes and more traditional models is that the former have been required to be built on consultation with local carers. One would assume that Carers Special Grant-funded schemes have been built on locally identified outcomes, and it would be interesting to see how well they are performing against these. Furthermore, it should be relatively easy to track down newly established services. Additionally, some

sort of up-to-date good-practice report might be useful on how the Carers Special Grant has been used.

### **6.5.2 Alternative forms of respite service and short-term break**

Given the predominance of studies of day-care services for carers for people with dementia, research should be undertaken into alternative forms of respite services. Evaluations should be detailed and thorough, linking the objectives that the service was meant to achieve to both quantitative and qualitative measures of outcome. Descriptive accounts are limited in their ability to inform the development of good and innovative practice

The review suggested there may be an over-reliance on the day-care model of service delivery. Studies should be conducted to explore carers', and care recipients', preferences and decision-making about the use of different forms of respite care and short-term break at different points in time (see below).

In addition, it could be enlightening to start with carers themselves rather than respite services. Taking a cohort of carers and finding out about the perceived benefits, advantages and disadvantages of using different types of short-term break (and possibly other supporting services) would shed light on the impact of using respite care on carers' health, well-being and quality of life, why carers choose to use and not use such services, and what trade-offs and choices carers make – for example, what are carers' preferences relating to quality versus quantity issues? Such research may also provide important information about how the 'whole system' can best meet the respite needs of carers and care recipients in a given community.

Carers', and care recipients', views should then be incorporated into decision-making processes about how existing services might be adapted and what new services might be implemented. In essence, it is important to find out how to add quality to people's lives through good respite breaks rather than simply separating the carer from the person with dementia by taking the latter away for a period of time.

### **6.5.3 Respite care and other community care services**

Carers do not normally use just one type of respite care in isolation from other services such as multiple forms of respite care, counselling or support groups. Consequently, research examining the effectiveness of different whole packages of care would be valuable. If research of this nature is likely to prove challenging, a more achievable alternative might be to try to find out what sustains the family overall, and from this point of view it might be useful to examine whole packages of care compared with no support at all.<sup>11</sup> This might be a way to make a distinction between different levels of service input, which are always variable. Research examining the interface between short-term breaks and entry into long-term care would also be insightful.

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<sup>11</sup>This would not be appropriate for economic evaluations where using 'use' and 'no use' as the comparison is likely to make the effectiveness in the user group much higher than in the non-user group.

#### **6.5.4 Amount of respite care**

Studies that examine the magnitude of amounts or quantities of respite care and short-term breaks that carers use would be useful, in particular to investigate the notion that there may be a threshold below which some respite services may not have significant effects.

#### **6.5.5 Respite services for specific groups of carers of people with dementia**

A discrete piece of work should be undertaken to find out more about regional availability, quality and appropriateness of respite care and short-term breaks for specific groups of carers of people with dementia, in particular: carers of younger people with dementia; black and ethnic-minority carers; and carers of people with Down's syndrome and dementia. The findings would provide information about the appropriateness of monies currently being spent in this area.

#### **6.5.6 Organisational context**

The organisational context and service configurations of respite care – for example, the impact of interagency relationships on institutional/overnight care versus day care – can make a difference to how respite is experienced. Research aimed at exploring the way in which services are organised (for example, flexibility of days/times, booking arrangements, duration and frequency), the connections between different forms of respite provision, and how support might be better integrated, could shed light in this area.

### ***6.6 Recommendations for improving research methods***

Below are our suggestions for improving the methodological quality of evaluation studies. Please note that what we are proposing is based on the view that it is important to focus research efforts on achievable areas of interest rather than trying to evaluate dimensions of effectiveness that could be much harder to prove.

#### **6.6.1 Outcome measures**

As a priority, and reflecting the difficulties of measuring outcomes related to the impact of respite care, research is needed aimed at establishing the appropriateness of different outcome measures to help gauge what is effective. If the respite service is still under development, carers and care recipients should be involved in decision-making about the key outcomes against which the service could be measured.

These days there is a much broader understanding and definition of outcomes. There is also a new body of literature being built up in this field, especially around service process outcomes relating to, for example, arranging services, service quality and person-centred care (see, for example, Qureshi, 2001), as well as outcomes specifically in relation to carers (Nicholas, 2003). Research into appropriate outcomes that can measure the

actual services (measures that have the potential to find out whether carers, and care recipients, think that the service in question is a good service) should be considered.

### **6.6.2 Pluralistic evaluations**

Recognising that respite services can often lack clearly defined goals, and may often have different objectives, pluralistic evaluations are needed that adopt a range of different methods and can take account of a broad range of potential outcomes (both intended and unintended) and reflect the different perceptions of different stakeholders. Nolan and Grant (1993), for example, identify key stakeholders as carers, care recipients, staff and the permanent residents of the care settings where respite care is provided.

### **6.6.3 Views of carers and people with dementia**

Effectiveness studies should not only use outcome measures to collect quantitative data. As indicated above, they should aim to collect in-depth information from carers and people with dementia, who use and do not use respite services. Studies should gather data on issues such as: levels of satisfaction with service provision; first-hand experiences of respite; the extent to which needs are met; when respite helps most – in the early stages? later on in the disease trajectory?; why carers continue – or stop – using services.

Very few studies included in the present review documented the voices of people with dementia, reflecting challenges when interviewing people with dementia. More recently, however, it has been shown that methodologies can be developed to engage people with dementia in research about their own experiences (Reid *et al.*, 2001; Wilkinson, 2001).

### **6.6.4 Comparative studies**

Comparative data would be valuable to show variations in different types of respite-care provision for different groups of carers and care recipients between different geographical areas. Studies should also be commissioned that examine the extent to which different types of short-term breaks best meet the needs of carers supporting younger people with dementia, black and ethnic-minority carers, carers of people with Down's syndrome and dementia, spouse carers and adult children caring for elderly parents. Work aimed at assessing the impact of rural and urban settings on access to, and provision of, respite would be useful.

### **6.6.5 Longitudinal studies**

Longitudinal studies of different types of respite care and short-term break are required to determine the medium- to long-term effects on carers and care recipients. Findings from longitudinal studies could also help explain what works best at critical milestones in the carer's caring 'career' and at different points in the disease trajectory.



### **6.6.6 Reporting of studies**

It is important for reviewers and commissioners that much greater detail about the context of the service is presented in evaluation reports. Many of the review studies say little, if anything, about the amount of respite received (frequency and duration), staffing issues, accommodation, facilities provided and available activities. For reviewers in particular, it is hard to know whether like services are being compared with like.

### **6.6.7 Primary research**

Only two out of the seven categories of respite interventions identified in the review included any cost-effectiveness analysis. In general, across the studies included in the review, it is not clear that the study sample sizes were powered to detect statistically significant differences in any effects or costs. Larger sample sizes and the inclusion of appropriate effect measures and costs would enable more robust and informative analyses to be undertaken. In order for appropriate effect measures to be included, the first step is to identify what is meant by the *effectiveness* of respite and short-term break care for carers of people with dementia. Following this, an outcome measure(s) that is(are) sensitive to be able to detect true effects could be included in a well-designed study. If the policy-makers were interested to explore the cost-effectiveness, or value for money, of one form of respite care as compared to another, the economic evaluation could be undertaken alongside the effectiveness study.

### **6.6.8 Modelling**

As well as the possibility of conducting primary research there is some scope available for conducting secondary research in the form of modelling. The quality of the model results will, in part, reflect the quality of the data input into the model. Modelling may be used to extrapolate data beyond the original study confines in order, for example, to explore longer-term costs and effects. Also it may be used to explore the uncertainty in the estimates of costs and effects using techniques such as sensitivity analysis. Recently, more use has been made of stochastic data (that is, having a mean and variance) but, based on the studies that were reviewed, no or limited statistical analysis of the data was undertaken and this limits the possibilities for modelling work.

## ***6.7 Dissemination and implementation of research findings***

Finally, we are aware that the SDO programme prioritises communicating the results of research it has commissioned, in this way supplementing the dissemination work of the researchers themselves. We recommend 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. When commissioning new research, it is important for research proposals to include a well-thought-out dissemination strategy, with an appropriate budget

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## Appendices

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### Appendix 1 Search strategy for generic and economic literature reviews

*Su Golder, Information Officer, Centre for Reviews and Dissemination*

The following search strategy was used on Ovid MEDLINE and then converted for each subsequent database.

- 1 caregiv\$.ti,ab
- 2 care giv\$.ti,ab.
- 3 carer\$.ti,ab.
- 4 informal care.ti,ab.
- 5 befriending.ti,ab.
- 6 caretak\$.ti,ab.
- 7 care taker\$.ti,ab.
- 8 care taking.ti,ab.
- 9 children caring.ti,ab.
- 10 ((parent or parents or mother or mothers or father or fathers) adj2 caring).ti,ab.
- 11 ((sons or daughters or friends) adj2 (care or caring)).ti,ab.
- 12 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives) adj2 (care or caring or support or supporting)).ti,ab.
- 13 families caring.ti,ab.
- 14 (families adj2 support).ti,ab.
- 15 or/1-14
- 16 Caregivers/
- 17 15 or 16
- 18 Respite Care/
- 19 care attendant\$.ti,ab.
- 20 (support service\$ or support program\$ or support scheme\$ or home support).ti,ab.
- 21 (short stay\$ or break or breaks).ti,ab.
- 22 day care/
- 23 (buddy scheme\$ or befriending).ti,ab.
- 24 night care.ti,ab.
- 25 (relief adj2 (support or caring or carer or caregiv\$ or care giv\$)).ti,ab.
- 26 sitting.ti,ab.
- 27 (holiday\$ or vacation\$).ti,ab.

## ***Review of respite services for carers for people with dementia***

- 28 residential home\$.ti,ab.
- 29 respite.ti,ab.
- 30 (day centre\$ or day center\$).ti,ab.
- 31 creche\$.ti,ab. or Child Day Care Centers/
- 32 (day care or daycare or day program\$ or day service\$ or day away).ti,ab.
- 33 crossroads.ti,ab.
- 34 (hotel\$ or outing\$).ti,ab.
- 35 personal assistant\$.ti,ab.
- 36 leisure.ti,ab.
- 37 time off.ti,ab.
- 38 visitor\$.ti,ab.
- 39 social club\$.ti,ab.
- 40 friendship club\$.ti,ab.
- 41 (home-based or inhome).ti,ab.
- 42 (befriending or temporary relief).ti,ab.
- 43 home care.ti,ab.
- 44 (homecare or domicillary service\$ or domicillary care or domiciliary service\$ or domiciliary care).ti,ab.
- 45 homemaker\$.ti,ab.
- 46 (home help\$ or home healthcare or home health care).ti,ab.
- 47 (home nursing or night nursing).ti,ab.
- 48 home service\$.ti,ab.
- 49 home treatment\$.ti,ab.
- 50 exp Dementia/
- 51 (dementia or demention or amentia or demented or dementing or confused or confusion).ti,ab.
- 52 prion disease\$.ti,ab.
- 53 Transmissible Spongiform Encephalopathy.ti,ab.
- 54 (senile or Wernicke\$ Encephalopathy).ti,ab.
- 55 Bovine Spongiform Encephalopathy.ti,ab.
- 56 Creutzfeldt Jakob Disease.ti,ab.
- 57 Fatal Familial Insomnia.ti,ab.
- 58 Gerstmann Straussler Scheinker Syndrome.ti,ab.
- 59 (Scrapie or kuru).ti,ab.
- 60 Down Syndrome/
- 61 down\$ syndrome\$.ti,ab.
- 62 down\$ disease\$.ti,ab.
- 63 (mongoloid\$ or mongolian or mongolism).ti,ab.
- 64 Alzheimer\$.ti,ab.
- 65 Corticobasal Degeneration.ti,ab.
- 66 Diffuse Lewy Body Disease.ti,ab.

**Review of respite services for carers for people with dementia**

- 67 Senility.ti,ab.
- 68 Huntington Chorea.ti,ab.
- 69 Kluver Bucy Syndrome.ti,ab.
- 70 Mental Deterioration.ti,ab.
- 71 (Minamata Disease or pick\$ disease).ti,ab.
- 72 Neuronal Ceroid Lipofuscinosis.ti,ab.
- 73 (Progeria or progressive aphasia).ti,ab.
- 74 (Rett Syndrome or supranuclear palsy or binwanger\$ disease).ti,ab.
- 75 Werner Syndrome.ti,ab.
- 76 Korsakoff Syndrome/  
77 korsakoff\$.ti,ab.
- 78 (vcjd or cjd or bse or mad cow disease).ti,ab.
- 79 Rett Syndrome/  
80 Supranuclear Palsy, Progressive/  
81 Werner Syndrome/  
82 neurodegenerative diseases/ or exp prion diseases/  
83 Wernicke Encephalopathy/  
84 Neuronal Ceroid-Lipofuscinosis/  
85 or/18-49  
86 or/50-84  
87 17 and 85 and 86  
88 limit 87 to yr= 1985-2003

## Appendix 2 Databases searched

- Allied and Complementary Medicine Database (AMED; Ovid)
- British Nursing Index (BNI; Ovid)
- Caredata, [www.elsc.org.uk/bases\\_floor/caredata.htm](http://www.elsc.org.uk/bases_floor/caredata.htm)
- CINAHL (Ovid)
- CENTRAL (Cochrane Library CD-ROM)
- Cochrane Database of Systematic Reviews (CDSR; Cochrane Library CD-ROM)
- Current Controlled Trials, <http://controlled-trials.com>
- Database of Abstracts of Reviews of Effects (DARE), <http://nhscrd.york.ac.uk/welcome.htm>
- Dementia Services Development Centre (DSDC) database (Dementia Services Development Centre, University of Stirling)
- EconLit (SilverPlatter)
- EMBASE (Ovid)
- Health Economics Evaluation Database (HEED; CD-ROM)
- Health Management Information Consortium (HMIC; HELMIS, DHdata and the King's Fund databases; SilverPlatter)
- Health Technology Assessment Database (HTA) <http://agatha.york.ac.uk/welcome.htm>
- International Bibliography of the Social Sciences (IBSS), [www.bids.ac.uk/](http://www.bids.ac.uk/) (BIDS)
- Internet Documents in Economics Access Service (IDEAS; working papers sections only), <http://ideas.uqam.ca>
- ISI Web of Science Proceedings (WoSP-ISTP), <http://wos.mimas.ac.uk/> (Web of Science)
- MEDLINE (Ovid)
- National Research Register (NRR; CD-ROM)
- NHS Economic Evaluation Database (NHS EED), <http://nhscrd.york.ac.uk/welcome.htm>
- Planex, [www.planex.ndirect.co.uk/validate2.asp?url=/default.asp](http://www.planex.ndirect.co.uk/validate2.asp?url=/default.asp)
- PREMEDLINE (Ovid)
- PsycINFO, [www.bids.ac.uk/](http://www.bids.ac.uk/) (BIDS)
- Social Science Citation Index (SSCI), <http://wos.mimas.ac.uk/> (Web of Science)
- Sociological Abstracts (SilverPlatter)
- System for Information on Grey Literature in Europe (SIGLE; SilverPlatter)
- The Campbell Collaboration's Social, Psychological, Educational and Criminological Trials Register (C2-SPECTR), <http://128.91.198.137/>

## Appendix 3 Data-extraction form

<b>Reference ID</b>	
<b>Bibliographic details</b>	
<b>Study aims</b>	Summarise study's aims and purpose (research question)
<b>Does the study have an economic component?</b>	
<b>Study typology code</b>	See Table 2.5
<b>INCLUSION CRITERIA</b>	
<b>Population</b>	Does study include information on carers? Yes No Uncertain Does the study include information on care-recipients? Yes No Uncertain
<b>Intervention – respite</b>	Does study include information about the effectiveness of respite services designed to allow the carer a break from caring responsibility? Yes No Uncertain Is the respite intervention reported in (a) isolation or (b) part of a package of services? Yes No Uncertain
<b>From 1985 onwards</b>	Is the study published from 1985 onwards? Yes No Uncertain
<b>Empirical research</b>	Is the study 'empirical' research? Yes No Uncertain
<b>Inclusion criteria met?</b>	Yes No Uncertain
<b>ADDITIONAL INFORMATION</b>	
<b>Country of study</b>	
<b>Applicable to UK health system?</b>	Yes No Uncertain
<b>QUALITY CRITERIA</b>	
<b>Question (E)</b>	Is the research question clear?
<b>Theoretical perspective (D)</b>	Is the theoretical or ideological perspective of the author (or funder) explicit, and has this influenced the study design, methods or research findings?
<b>Study design (E)</b>	Is the study design appropriate to answer the question?
<b>Context (D)</b>	Is the context or setting adequately described?

**Review of respite services for carers for people with dementia**

<b>Sampling (E)</b>	(Qualitative) Is the sample adequate to explore the range of subjects and settings, and has it been drawn from an appropriate population? (Quantitative) Is the sample size adequate for the analysis used and has it been drawn from an appropriate population?
<b>Data collection (E)</b>	When was fieldwork conducted?, how was data collected?, by whom?, etc. Was the data collection adequately described and rigorously conducted to ensure confidence in the findings?
<b>Data analysis (E)</b>	Was the data analysis adequately described and rigorously conducted to ensure confidence in the findings?
<b>Reflexivity (D)</b>	Are the findings substantiated by the data and has consideration been given to any limitations of the methods or data that may have affected the results?
<b>Generalisability (D)</b>	Do any claims to generalisability follow logically, theoretically and statistically from the data?
<b>Ethical standards (D)</b>	Have ethical issues been addressed and confidentiality respected?
<b>Reviewer comment on methods</b>	
<b>Quality threshold met?</b>	Yes    No    Uncertain
<b>INTERVENTION</b>	
<b>Type of intervention</b>	
<b>Type of carer</b>	Ethnic minority (EM); young (Y); rural (RU); extra resident (ER); co-resident (CR); spouse (S); other (clarify)
<b>Type of care recipient</b>	Diagnosis; stage (mild; moderate; severe)
<b>STRUCTURE OF INTERVENTION</b>	How is intervention set up?
<b>Funding</b>	How is the intervention funded?
<b>Staffing</b>	Which staff/agency is responsible?
<b>Management</b>	Setting, management, location, theoretical basis
<b>Location</b>	
<b>Care philosophy</b>	
<b>Facilities</b>	
<b>Eligibility criteria</b>	
<b>Costs</b>	How are costs of intervention met? (i.e. by carer, NHS, etc.)
<b>Experiment vs. natural</b>	
<b>Other (structure)</b>	

## **Review of respite services for carers for people with dementia**

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### **PROCESS OF INTERVENTION**

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<b>Duration</b>	How long does the intervention last?
<b>Frequency</b>	How often is the intervention given?
<b>Referral/ access</b>	How is it accessed? Which staff give care?
<b>Other (process)</b>	What, if any, other interventions are delivered as part of a care package?

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### **OUTCOME MEASURES**

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<b>Outcome measure – carers</b>	What outcome measures were adopted?
<b>Outcome measure – recipient</b>	What were the outcomes? Were there any wanted or unwanted secondary outcomes?
<b>Other (outcome measures)</b>	

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### **OTHER EFFECTIVENESS MEASURES**

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**Carer views**

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**Care recipient views**

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**Professional views**

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### **OVERALL EVALUATION RESULTS**

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**Impact on carer**

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**Impact on care recipient**

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**Impact on professional(s)**

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**Impact on organisation**

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### **DIFFERENCES BETWEEN COMPARISON GROUPS**

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#### **AUTHORS' RECOMMENDATIONS**

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**Policy and practice**

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**Research**

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**Reviewer's comments on findings**

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**Included in final review?**

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**First reviewer's initials+ date**

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**Second reviewer's initials+ date**

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*E, essential; D, desirable.*

## Appendix 4a Summary of studies/articles included in the generic review

Author(s) and country	Type of provision studied	Client group	Study aims	Study design
Adler <i>et al.</i> (1993), USA	<i>Institutional/overnight</i> In-hospital respite care at the Minneapolis Veterans Affairs Medical Center. Forty beds on a non-acute geriatric medical ward. Two week admission, repeatable every six months.	People with AD and other dementias	To examine patient and carer responses to a two-week hospital admission for respite care. Addressing the questions: (1) are performance of ADL and behavioural problems altered following a two-week hospital admission for respite care?; and (2) are carers' feelings of burden and depression affected by an institutional respite-care stay?	Quantitative, pre- and post-intervention (uncontrolled). Care recipients ( <i>n</i> =37) Outcomes: measured carers burden; depression; patients' functioning. B3
Beisecker <i>et al.</i> (1996), USA	<i>Day care</i>	People with AD	To examine carers' views on the perceived benefits of, and barriers to, the use of adult day care.	Cross-sectional. Semi-structured telephone interviews focusing on benefits and barriers to day-care use with carers who had used day-care services ( <i>n</i> =52) and carers who had not ( <i>n</i> =52). B3
Berry <i>et al.</i> (1991), USA	<i>Day care</i>  In-home respite available through home care.  On average, carers received 19 hours respite per week.	People with dementia	To examine specific mechanisms by which respite could operate in the caregiving situation and caregivers' subjective evaluations of respite.	Longitudinal. Structured interviews with 40 female carers: 20 home-care users, and 20 day-care users. Outcomes: measured burden; stress; support networks; time spent on activities; programme satisfaction. B3



## Review of respite services for carers for people with dementia

Burdz and Eaton (1988), Canada	<i>Institutional/overnight</i> In-patient respite care in one of 20 designated respite beds in various nursing homes. The length of an average respite stay was 15.3 days (SD 5.6)	People with dementia and non-dementia	To assess the impact of a respite programme on the cognitive functioning and physical functioning of dementia and non-dementia patients, and on the burden perceived by their carers.	Quantitative, pre- and post-intervention study (waiting-list controlled). Carers whose care recipient received respite care ( $n=35$ ); carers whose care recipient was on the waiting list ( $n=20$ ). Outcomes: measured carers burden; behavioural disturbances. B3
Caserta and Lund (2002), USA	<i>Video respite</i> <i>Remembering When</i> , a 20-minute video that reminisces about growing up in the 1920s and 1930s.	People with AD	To compare how well the videotape <i>Remembering When</i> captured and maintained the attention of 12 institutionalised AD patients in a group setting (three per group) vs. when solitary viewing. To identify factors related to the effectiveness of video respite in either setting.	Care recipients ( $n=12$ ) watched the film twice (as a group and individually). Verbal and non-verbal responses coded. C1
Chu <i>et al.</i> (2000), Canada	<i>Multi-dimensional carer-support package</i> <i>Early Home Care Program</i> Programme comprised case management, occupational therapy, physical therapy, social work, nursing, respiratory therapy, in-home respite and out-of-home respite, homemaking, personal care assistance, volunteer service and psychiatric consultation. Case manager made monthly contact. Frequency of contacts	People with early-stage AD	To evaluate a project that provided a comprehensive home-care programme to persons with early-stage AD and their primary caregivers over a period of 18 months.	RCT. Study group ( $n=37$ ) received Early Home Care Program for 18 months; control group ( $n=38$ ) given an information pack on community resources. Over time the study group became eligible for conventional home-care programme. Outcomes: measured carer burden; perceptions of behavioural disturbances; depression. Patients' cognitive status, depression and functional performance. B1

**Review of respite services for carers for people with dementia**

				increased as needed. Staffing involved occupational therapist, nurse and social worker, as appropriate.
Colvez <i>et al.</i> (2002), Europe-wide (Germany, Denmark, Belgium, Spain, Sweden, France)	<p><i>Day care</i> (Germany)            Provided in day centres in Germany; daily respite available, in the form of half days to full days, six days per week.</p> <p><i>Home social services</i> (Denmark)</p> <p><i>Expert centres</i> (Belgium and Spain)</p> <p><i>Group living</i> (Sweden and France)</p> <p><i>Respite hospitalisation program</i> (France)</p>	People with AD	To explore the work burden and health of carers of people with dementia using five different existing programmes in Europe.	<p>Cross-sectional. Questionnaire survey of carers (<math>n=322</math>), including day-care users (<math>n=50</math>) and respite hospitalisation programme users (<math>n=37</math>)</p> <p>Outcomes: measured ADL, carer's perceived health and burden</p> <p>B3</p>
Cox (1998), USA	<p><i>Respite programme Maryland Alzheimer's Demonstration Grant</i></p> <p>Provided financial reimbursement to enable eligible families to purchase up to 164 hours per year of respite care at a maximum rate of \$6.40 per hour. Funds available for in-home respite, short stays in a nursing home or day care. Short-stay respite in nursing homes usually 4–5 days. In-home respite workers had to complete a 20-hour training course offered by the program which dealt specifically with the care of Alzheimer's patients.</p>	People with AD or related disorder	To compare the utilisation of respite by African-American and white carers.	<p>Longitudinal (six months). Interviews with 228 African-American and white carers. Follow-up interviews with respite users: African-American carers (<math>n=61</math>) and white carers (<math>n=62</math>).</p> <p>Outcomes: measured caregiver conflict with family; expressive support; burden; anxiety; depression; coping ability; patient's cognitive and behavioural functioning.</p> <p>B3</p>

**Review of respite services for carers for people with dementia**

Curran (1996), UK (Scotland)	<p><i>Day care</i></p> <p>Provided in a dementia-specific day centre operated by local voluntary organisation. Staffing comprised a day care co-ordinator, three care assistants and up to three volunteers</p>	People with dementia	To determine the effects of day-care attendance on people with dementia	<p>Longitudinal (follow-up at nine months). Semi-structured interviews with carers (<math>n=19</math>).</p> <p>Outcomes: measured psychological health; depression; patients' mental state, dependence and behavioural disturbance.</p> <p>B3</p>
Deimling (1991), USA	<p><i>Respite programme</i></p> <p><i>TOPS (Time Off Promotes Strength)</i></p> <p>Forms of respite care available: in-home from a Home Health Aide; day care; short-stay institutional care in a 178-bed nursing home. Programme targeted low-income and minority families. In the programme's first two years it delivered an average of 18 hours in-home respite per month to each of 124 families; an average of 22 hours of day care per month to 41 families; and 40 hours of institutional respite care to 20 families. Home Health Aides trained to provide comprehensive in-home care, including personal care services.</p>	People with AD	To examine the impact of respite on family caregivers helping stable and declining patients over a four to six month period.	<p>Longitudinal (four to six months). Uncontrolled. Collected pre- and post-test quantitative data from 78 families.</p> <p>Outcomes: measured depression; symptoms of health problems; relationship strain; activity restrictions due to caregiving.</p> <p>B3</p>
Diesfeldt, H. (1992), Europe (The Netherlands)	<p><i>Day care</i></p> <p>Provided in a psychogeriatric day-care centre located in and associated with a skilled nursing facility. Staff included recreational therapists and registered nurse. Most patients</p>	People with dementia	To examine (a) to what extent day care can provide an effective alternative to institutional placement of demented psychogeriatric patients; and (b) the determinants that reduce or	<p>Five-year longitudinal follow-up of cohort of 224 patients.</p> <p>Outcomes: measured patient's status (living in community; institutionalised; dead).</p> <p>B3</p>

**Review of respite services for carers for people with dementia**

	attended two days a week; a minority attended three or more days a week.		enhance the risk of institutionalisation.	
Droes <i>et al.</i> (2000), Europe (The Netherlands)	<i>Multi-dimensional carer-support package Amsterdam Meeting Centres</i> An integrated family-support programme. Provided day care in four day-care centres, together with practical, emotional and social support, and information, for patients and carers, including discussion groups and informative meetings. Day care organised three days per week, 10.00 a.m. to 4.00 p.m. Small, professional staff (psychologist; activity therapist; nurse assistant).	People with dementia	To test the hypothesis that integrated family support is more effective in influencing behaviour problems and mood of the dementia patient than non-integrated support, such as psychogeriatric day care only.	Quasi-experimental pre-test/post-test control group design with matched groups. Follow up after three months, and seven months, of support. Study group ( <i>n</i> =33) received integrated family support; control group ( <i>n</i> =23) received psychiatric day care only. Outcomes: measured patients' functioning, depression, behaviour problems, mood. B2
Gaugler <i>et al.</i> (2003a), USA	<i>Day care Adult Day Care Collaborative Study</i> Patients day care used at least two days per week for three months or longer during the study period.	People with dementia	To determine whether adult day service use interacts with decreases in primary caregiving hours to alleviate caregiver stress and negative mental health over time.	Quasi-experimental. Analysis drew on short-term (three month) data from study group ( <i>n</i> =169) and control group ( <i>n</i> =231). Outcomes: measured primary stressors (role captivity, overload, worry and strain, depression, anger, positive affect); hours per day spent assisting/managing ADLs, IADLs, behaviour problems and memory problems; time estimates of help received from formal and informal support; programme satisfaction. B2
Gibson, F. (1996), UK (Northern	<i>Day care Rural Action on Dementia</i>	People with dementia	To explore service innovation and evaluate the Rural Action	Longitudinal (follow-up at 12–18 months), multi-method study including: interviews with carers

**Review of respite services for carers for people with dementia**

Ireland)	<i>Project</i> Project comprised four small day centres. Managed by Age Concern Northern Ireland. Initial intention that patients attended for one day per week. Core staffing comprised Belfast-based middle manager (70–80 miles distant); 'local' co-ordinator, care worker and driver/carer supplemented by varying numbers of volunteers,		on Dementia Project	( <i>n</i> =25), volunteers ( <i>n</i> =16), managers and practitioners ( <i>n</i> =16) and Age Concern staff ( <i>n</i> =7); document examination; participant observation; and daily diaries. B3
Gilleard (1987), UK (Scotland)	<i>Day care</i> Provided in psychogeriatric day hospitals.	People with dementia	To assess the impact on the families of patients referred for psychogeriatric day care in the Lothians.	Longitudinal study (follow-up at six or seven months), collecting qualitative and quantitative data from carers ( <i>n</i> =129). Outcomes: measured behavioural problems; carers' psychological health; strain. B3
Grant <i>et al.</i> (2003), USA	<i>In-home respite</i> Experimental programme, up to six hours per week limited to the two-week study period.	People with AD	To determine whether in-home respite was associated with a reduction in psychological and physiological indicators of stress in spouse carers of patients with AD.	Quasi-experimental intervention study. Fifty-five carers assigned to either intervention or waiting-list control group. Outcomes: measured depression/anxiety, catecholamines, blood pressure and heart rate. B2
Hirsch <i>et al.</i> (1993), USA	<i>Institutional/overnight</i> In-patient respite programme at the Palo Alto Veterans Affairs Medical Center. Between two and five beds on a secured, 50-bed long-term care dementia unit available	People with a range of dementias	To evaluate the effects of an in-patient dementia respite programme on ADL and behaviour in clients.	Quantitative, pre- and post-intervention (uncontrolled) study. Care recipients ( <i>n</i> =39) Outcomes: measured functional and behavioural problems B3

**Review of respite services for carers for people with dementia**

				depending on demand. Up to two weeks of respite every three months.
Jansson <i>et al.</i> (1998), Europe (Sweden)	<i>In-home respite Circle Model</i> Unpaid volunteers providing in-home respite following joint training with carers, co-ordinated by local church groups in six areas. Up to five hours per week in-home care, over four-month period.	People with dementia sufferers	To develop, test and evaluate the Circle Model to meet the needs of family carers; to assess the experiences of participants.	Qualitative evaluation of experimental intervention. Carers ( $n=25$ ); volunteers ( $n=27$ ) B3
Jarrott <i>et al.</i> (1999), USA	<i>Day care Adult Day Care Collaborative Study</i> Patients used day care at least two days per week for three months or longer during the study period.	People with dementia	To examine family caregivers' experiences and satisfaction with adult day service programmes for an elderly relative with dementia.	Quasi-experimental. Analysis based on carers in study group at initial interview ( $n=261$ ), three-month interview ( $n=175$ ) and 12-month interview ( $n=90$ ). Outcomes: measured primary stressors (role captivity, overload, worry and strain, depression, anger, positive affect); hours per day spent assisting/managing ADLs, IADLs, behaviour problems and memory problems; time estimates of help received from formal and informal support; programme satisfaction. B2
Jarrott <i>et al.</i> (2000), USA	<i>Day care Adult Day Care Collaborative Study</i> Patients used day care at least two days per week for three months or longer during the study period.	People with dementia	To examine whether caregivers get relief from some caregiving activities (i.e. spend less time on them) by using adult day care and if these gains are similar or different for employed and non-employed caregivers.	Quasi-experimental. Analysis based on sub-sample of carers in study group who had completed the initial and three-month interviews. Final sample comprised 40 employed carers and 82 non-employed carers. Outcomes: measured primary stressors (role captivity, overload, worry and strain, depression, anger,

**Review of respite services for carers for people with dementia**

				positive affect); hours per day spent assisting/managing ADLs, IADLs, behaviour problems and memory problems; time estimates of help received from formal and informal support; programme satisfaction. B2
Kosloski and Montgomery (1993), USA	<i>Respite programme Michigan Model Respite Programs</i> Six model programmes provided at seven sites in both urban and rural locations throughout the state of Michigan. At two sites, respite comprised day care provided between 8.00 a.m. and 5.00 p.m. on weekdays. At another two sites, respite was in-home care provided through the day and evening on weekdays. Three sites provided in-home and adult day care. Services were free for all families with an income of less than \$9000; minimal fees based on a sliding scale for those on higher incomes. No limit to the amount of services that could be used during the periods of availability. Over six month study period, use of respite ranged from four to 1137 hours, with a mean of 120 hours and a median of 130 hours – so about five hours a week on average, but quite variable. All respite workers	People with AD	To evaluate the impact of respite care on informal caregivers participating in the Michigan Model Respite Program.	Quasi-experimental. Non-equivalent control group. Pre-tests and post-tests at six months. Forty-seven families in study group; 25 in comparison group. Outcomes: measured caregiver subjective burden and objective burden; morale; ADLs. B2

**Review of respite services for carers for people with dementia**

	had been provided with specialised training by programme directors at each site.			
Larkin and Hopcroft (1993), USA	<i>Institutional/overnight</i> Veterans hospital on a Dementia Study Unit. During respite patients receive varied hospital services. Respite usually obtainable once every three months. Two-week in-patient stay.	People with AD	To examine the influence of a hospital respite program in moderating carer stress.	Quantitative, longitudinal study. Carer recipients ( $n=21$ ); carers ( $n=22$ ). Outcomes: measured stress; psychological distress; patients' functional impairment. B3
Lawton <i>et al.</i> (1991), USA	<i>Multi-dimensional carer-support package</i> <i>Philadelphia Geriatric Center's Multi-Service Respite Service Demonstration Project</i> Respite services provided: institutional respite beds for both emergency and planned respite; day care; in-home respite care. Additional core services provided: assessment; carer education; service management (information and referral; service co-ordination and monitoring), and counselling and transportation. Many carers paid completely for respite care; others made a contribution. Day care: one to five days weekly. Institutional respite limited to a stay of no more than 21 days. Staffing included trained social workers.	People with AD and related disorders	To examine the effects of respite service on family carers; to identify the forms of respite they chose and preferred; to estimate the nature and number of different types of respite services required by a population of a given size; to determine the effectiveness of respite on utilisation of other services and on rates of nursing home placement.	RCT. Study group ( $n=315$ ) received respite and other services for 12 months; control group ( $n=317$ ) given a list of local agencies and resources. Outcomes: measured caregiving attitudes relating to burdens and satisfactions; physical health; mental health (depression; positive and negative affect). Patients' severity of illness; days alive. B1
Leitsch <i>et al.</i>	<i>Day care</i>	People with	To systematically compare	Quasi-experimental. Analysis based



**Review of respite services for carers for people with dementia**

(2001), USA	<i>Adult Day Care Collaborative Study</i>	dementia	medical and social adult day service models within New Jersey that service patients with dementia and their families in order to identify the differences in service provision and the impact of the different models on caregiving.	on sub-sample of carers in study group who had completed the initial and three-month interviews. Final sample comprised 106 carers using a medical day-care model and 154 carers using a social day-care model. Outcomes: measured primary stressors (role captivity, overload, worry and strain, depression, anger, positive affect); hours per day spent assisting/managing ADLs, IADLs, behaviour problems and memory problems; time estimates of help received from formal and informal support; programme satisfaction. B2
Levin <i>et al.</i> (1989), UK (England)	<i>Day care</i> Day care in (psychiatric) day hospital, day centres, special day clubs and residential homes. Some joint ventures between statutory agencies and volunteers. Provision more intensive in one area, where day hospital patients might have attended four or five days per week. Staffing included community psychiatric nurses, social workers and volunteers. Short-term 'relief' breaks in residential care.	People with dementia	To examine respite services for the carers of confused elderly people.	Longitudinal (follow-up at 12 months). Initial survey of older people known to services; two sets of structured interviews with carers 12 months apart. T.1 ( <i>n</i> =150); T.2 ( <i>n</i> =137). Day-care sample ( <i>n</i> ~60); institutional 'relief' care sample ( <i>n</i> ~37). Outcomes: measured carers' psychological health; distress; 'patient relatedness'; care recipients' mental state. B3
Levin <i>et al.</i> (1994), UK (England)	<i>Day care</i> Provided by health, social services and the voluntary sector in a day centre, day hospital and residential home, day club or hospital ward. On	People with dementia	To identify the specific problems faced by carers; to assess which were more and which were less stressful; and to explore the effectiveness of services in alleviating them.	Longitudinal (follow-up at 12 months). Initial survey of older people known to services; two sets of structured interviews with carers 12 months apart. T.1 ( <i>n</i> =287); T.2 ( <i>n</i> =243). Day care sample ( <i>n</i> =193);

**Review of respite services for carers for people with dementia**

	average, patients attended one day per week in one research site, and two days per week in other two sites. <i>In-home sitting services</i> Residential 'relief' care			institutional 'relief' care sample ( $n=167$ ); in-home 'sitting services' sample ( $n=85$ ). Outcomes: measured carers' psychological health; care recipients' behaviour and depression. B3
Lorensini and Bates (1997), Australia	<i>Day care</i>	People with dementia	To examine the health, psychological and social consequences that impact on information caregivers, including physical health, depression, stress, arousal, life satisfaction, well-being, social resources and social interaction.	Cross-sectional. Questionnaire survey of three groups: carers using day care ( $n=45$ ); carers not using day care ( $n=40$ ); non-carers ( $n=47$ ). Outcomes: measured symptom and life satisfaction (depression; stress-arousal; life satisfaction; satisfaction of friendships); social interaction; physical health; functional independence. B3
Lund <i>et al.</i> (1995), USA	<i>Video respite</i> Generic videotapes, mainly one called <i>Favorite Things</i> (35 minutes long) whose main character was a friendly visitor who talked and asked about familiar things like parents, growing up, babies, pets, colours, animal sounds, holidays and gardens.	People with AD	To report on the development of video respite, and to present early findings from a two-year study of the <i>Favorite Things</i> generic videotape in comparison with an existing television programme (Lawrence Welk).	Observations recorded of care recipients ( $n=31$ ) verbal and non-verbal responses to study tape and a comparison television programme. Pre- and post-intervention data collected from carers ( $n=31$ ) over a one-month study period. C1
Melzer, D. (1990), UK (England)	<i>Day care</i> <i>Institutional/overnight respite</i> Provided in a respite care unit for elderly people with dementia: seven day places and seven beds.	People with dementia	To offer a comprehensive framework for service evaluation relevant to a new respite care unit, and report some results of its evaluation.	Cross-sectional evaluation, using multiple methods of data collection including document analysis, questionnaire survey of patients ( $n=100$ ), interviews with carers ( $n=19$ ) and literature review. B3

**Review of respite services for carers for people with dementia**

Milne <i>et al.</i> (1993), UK (England)	<i>In-home respite Age Concern Carer Support Scheme (CSS)</i> Care provided for 'agreed periods of a few hours'.	People with dementia and stroke patients	Evaluation of carers' stress, coping and strain.	Cohort study. Seventy-eight carers of elderly persons referred in one year to CSS. Outcomes: measured stress, coping, general health, carer satisfaction. B3
Mohide <i>et al.</i> (1990), Canada	<i>Multi-dimensional carer-support package Caregiver Support Program</i> Programme comprised: caregiver-focused health care, education about dementia and caregiving, assistance with problem-solving, in-home respite, self-help family caregiver support group. 'On-demand' respite was also available. Participants not charged for services. Respite element comprised a four-hour block of scheduled weekly in-home respite. 'On-demand' respite available, but no further details given. Community nursing services provided by Hamilton-Wentworth and Halton Branches of the VON Visiting Nursing Program (a non-profit organisation). CSN nurses underwent an 80-hour training program. Respite workers recruited from the Hamilton-Wentworth Visiting Homemakers Association; they received 18 hours of training over a six-week period.	People with dementia	To determine the effectiveness of the Caregiver Support Program in reducing burden on carers managing moderately to severely demented elderly at home.	RCT. Study group ( <i>n</i> =30) received the Carer Support Package for six months. Control group ( <i>n</i> =30) received conventional community nursing care for same period. Outcomes: measured depression; anxiety; quality of life; health; life satisfaction; impact of caring; patient's functional status. B1
Parahoo <i>et al.</i>	<i>In-home respite</i>	People with	To evaluate the domiciliary	Qualitative evaluation.

**Review of respite services for carers for people with dementia**

(2002), UK (Northern Ireland)	Domiciliary assistance provided between three and 11 hours per weeks, sessions defined by carer. Service available day/night and weekends.	dementia aged under 65	respite by assessing: satisfaction to carers' and dementia suffers; carers' perceptions of benefits, problems.	Carers ( $n=8$ ); care recipient ( $n=1$ ). B3
Pearson (1988), UK (England)	<i>Institutional/overnight</i> In-hospital relief admissions to psychogeriatric unit.	People with dementia	To measure the degree of disability in the patient population, and to establish benefits and disadvantages perceived by carers in a relief admission programme.	Cross sectional study using quantitative and qualitative methods collecting data on sleep, social activities, views on caring and patients' degree of disability. Carers ( $n=25$ ); care recipients ( $n=25$ ). B3
Perry and Bontinen (2001), Canada	<i>Institutional/overnight</i> Adult Day Program extended to include weekend care as a pilot project operating an eight-bed overnight respite service.	People with AD and related dementias	To explore carers' experience with a pilot respite program of weekend care for persons with AD or a related dementia.	Cross-sectional qualitative study, using staff focus groups, client interviews and participant observation. Carers ( $n=19$ ). B3
Pritchard, E. and Dewing, J. (1999), UK (England)	<i>Day care</i> <i>Specialized Early Care for Alzheimer's (SPECAL) Project</i> Provided day care at the weekly Friday Club. The Friday Club was the starting point for the development of 24 hours of care for each patient and carer. SPECAL managed by Alzheimer's Society and Oxfordshire Community Health NHS Trust. Staffing includes SPECAL Co-ordinator; care assistants; trained counsellor; camera person (voluntary); volunteers; research psychologist employed on an	People with AD	To evaluate the SPECAL Project	Cross-sectional evaluation. Multiple methods of data collection including interviews with people with dementia ( $n=5$ ), carers ( $n=5$ ), other stakeholders ( $n=23$ ); focus group; questionnaire survey ( $n=22$ ); documentation analysis; dementia care mapping. Outcomes: measured carer burden; organisational culture (stakeholders). B3

**Review of respite services for carers for people with dementia**

hourly basis.				
Quayhagen <i>et al.</i> (2000), USA	<i>Day care (early stage)</i> Four hours per week provided over an eight-week period Other interventions studied were: cognitive stimulation; dyadic counselling; and dual supportive seminar.	People with early stage dementia	To evaluate the efficacy of four non-pharmacological interventions on outcomes for spouses coping with dementia	RCT (three months) evaluating four different treatment programmes and wait-list control group. Early day care study carers ( $n=16$ ). Outcomes measured for carers: marital satisfaction; emotional status; morale; physical health status; stress; coping; social support; programme evaluation. Outcomes measures for patients: immediate memory; delayed memory verbal fluency; problem solving; behaviour functioning. B1
Reid <i>et al.</i> (2001), UK (England)	<i>Day care</i> Provided by the voluntary sector in two settings, and joint voluntary/statutory sector provision in the third.	People with dementia	To consider unmet needs among caregivers and day-care attenders in Sheffield and to look at some of the contextual debates associated with conducting social research with people with dementia.	Cross-sectional. Qualitative data collected on experiences of care and satisfaction with care setting in 19 interviews and group discussions with people with dementia. B3
Robertson (2002), UK (Scotland)	<i>Host-family respite</i> Breaks for carers and their partners staying together with a host family in family home. Host families recruited by social services, service jointly provided by health and social care agencies.	People with dementia	To assess the impact of short breaks for couples.	Qualitative cohort study. Carers ( $n=6$ ); care recipients ( $n=4$ ). B3
Ryan <i>et al.</i> (2002), UK (England)	<i>In-home respite</i> <i>Community Dementia Support Service (CDSS)</i> Sessions lasting three–four hours, available between two and 15 hours per week, seven	People with dementia	To evaluate the CDDS by taking a pluralistic evaluative approach, involving people with dementia, their carers and CDDS staff.	Non-experimental multi-method. Carers ( $n=23$ ); care recipients ( $n=6$ ); CDDS staff. Semi-structured interviews/discussion groups. Service data. Outcomes: measured carers'

**Review of respite services for carers for people with dementia**

	days between 7.00 a.m. and 9.00 p.m. (exceptionally to 11.00 p.m.). Team of 10 support workers matched to carer-care-recipient dyads.			psychological health. B3
Seltzer <i>et al.</i> (1988), USA	<i>Institutional/overnight In-hospital respite programme</i> Respite admissions were for a period of two weeks and a repeat admission could be scheduled after an interval of three or more months.	People with AD	To assess the short-term effects of respite admission on the cognitive and functional status of patients with AD.	Quantitative, pre- and post-intervention study (uncontrolled). Care recipients ( $n=37$ ). Outcomes: measured patients' cognitive and functional status. B3
Turvey <i>et al.</i> (1991), UK (Scotland)	<i>In-home respite</i> (no service details)	People with dementia	To examine client satisfaction with in-home respite.	Survey of satisfaction as part of regular client assessment. Conducted six months from first referral to service (169 responses 73% of service users). B3
Walker <i>et al.</i> (2001), UK (Scotland)	<i>Day care</i> Provided in two settings: day centre in the voluntary sector, and day hospital, managed by a Primary Health Care Trust and located within a hospital specialising in the care of older people. Day centre available five days per week. Objective to give each patient at least two days. Day hospital provided a seven-day service. Following referral, patients began a six-week assessment period, attending twice a week. Recommendations then made about future care. Day-centre staffing: registered general	People with dementia	To evaluate day-care services for people with dementia from the perspective of major stakeholders (those who provide the service and those who use it).	Cross-sectional evaluation using multiple methods of data collection. Interviews with people with dementia: day centre ( $n=5$ ); day hospital ( $n=5$ ). Interviews with carers explored perceptions and experiences of day-care services: day centre ( $n=7$ ); day hospital ( $n=7$ ). Dementia care mapping: day centre ( $n=11$ ); day hospital ( $n=10$ ). Focus group discussion with staff: day centre ( $n=12$ ); day hospital ( $n=9$ ). Observation; a short questionnaire. Outcomes: measured quality of life; perceived problems; strain. B3

## Review of respite services for carers for people with dementia

	nurses, and a qualified social worker. Some staff taking a Scottish Vocational Qualification in dementia care. Day hospital staffing: two teams comprising nurses and health care assistants operating with one of two consultant psychiatrists.			
Watkins and Redfern (1997), UK (England)	<i>Institutional/overnight</i> An overnight NHS in-patient respite service using qualified nursing staff. The service catered for up to 15 patients per night. Length of stay varied from one to four nights per week.	People with AD, non-specific dementia and Parkinson's disease	To collect data about information concerning the relationships between the way in which CREST was structured, nursing actions and patients' and carers' outcomes.	Quantitative, cross-sectional study. Care recipients ( $n=34$ ); carers ( $n=27$ ). Outcomes: measured coping; patients' ability with ADL and behavioural problems. B3
Wells <i>et al.</i> (1990), Australia	<i>Day care</i> Provided in special dementia day centres, operatives in ordinary houses, halls or purpose-built buildings. Average attendance 11.9 hours per week. Most centres had one or more paid staff on duty at any one time, but one centre had no paid staff and one had five. Most used volunteers.	People with dementia	To examine the effects on carers' psychological symptoms of special day-care programmes for dementia sufferers.	Pre- and post-intervention study (three months). 219 carers interviewed: 155 currently using special day care; 64 about to start. In latter group, 52 re-interviewed three months later (37 still using day care). Outcomes: measured behavioural problems; psychological problems; anxiety and depression; quality of life; guilt; grief. B3
Wimo <i>et al.</i> (1993), Europe (Sweden)	<i>Day care</i> Provided in day-care units located in apartments in blocks of flats. Mean attendance was 1.9 visits per week. Three members of staff.	People with dementia	To examine the effects of day care on symptoms and behaviour of demented patients and on institutionalisation.	One-year quasi-experimental study. Day-care group ( $n=55$ ); control group ( $n=44$ ). Outcomes: measured cognition; ADL functions; behavioural disturbances, institutionalisation. B2

**Review of respite services for carers for people with dementia**

Zank S and Schacke C. 2002., Europe (Germany)	<p><i>Day care</i></p> <p>Provided in geriatric day-care units. Patients in study group planned to attend for at least two days per week. Patients and carer apart for approx. eight hours per day. Staff included trained nurses, geriatric nurses, and untrained young men doing community work instead of military service.</p>	People with dementia	To evaluate the effects of geriatric day care on patients and caregivers.	<p>Quasi-experimental, longitudinal (nine months) control group design. Study group at T.1 (<math>n=83</math>); control group (<math>n=65</math>). Study group at T.2 (<math>n=51</math>); control group (<math>n=44</math>). Study group at T.3 (<math>n=43</math>); control group (<math>n=40</math>).</p> <p>Outcomes: measured life satisfaction, perceived social support, depression, self-esteem, cognitive impairment, non-cognitive dementia symptoms, ADLs.</p> <p>B2</p>
Zarit <i>et al.</i> (1998), USA	<p><i>Day care</i></p> <p><i>Adult Day Care Collaborative Study</i></p> <p>Patients used day care at least two days per week for three months or longer during the study period.</p>	People with dementia	To evaluate the effectiveness of adult day-care services in alleviating caregiving stress and improving psychological well-being for primary caregivers to relatives with dementia.	<p>Quasi-experimental. For the short-term (three month) analysis, data available from study group (<math>n=121</math>) and control group (<math>n=203</math>). For the long-term (12 months) analysis, data available from study group (<math>n=73</math>) and control group (<math>n=120</math>).</p> <p>Outcomes: measured primary stressors (role captivity, overload, worry and strain, depression, anger, positive affect); hours per day spent assisting/managing ADLs, IADLs, behaviour problems and memory problems; time estimates of help received from formal and informal support; programme satisfaction.</p> <p>B2</p>

*Under Study design, categorisation (B1, etc.) is according to the typology of study designs (see Table 2.5).*

*AD, Alzheimer's disease; IADL, instrumental activities of daily living.*



## Appendix 4b Economic evaluations of support services for carers for people with dementia

Author(s)	Interventions*	View-point	Research methods and follow up	Economic evaluation study design	Costs identified and measured	Consequences identified and measured	Allowance for uncertainty	Main results	Country, funder and provider
Drummond <i>et al.</i> (1991) (relates to Mohide <i>et al.</i> 1990)	I, Caregiver Support Package (CSP) ( <i>n</i> =30); C, standard care ( <i>n</i> =30) (loss to follow up: I, 27%; c, 33%)	Health care and social care	RCT (B1) 6 months	CUA	Nursing, respite worker, homemaker, day programme, physician, overnight institutional respite	Center for Epidemiological Studies Depression Scale, state anxiety portion of the State-Trait Anxiety Inventory, Caregiver Quality of Life Instrument, QALYs; carer-focused.	No statistically significant differences in costs were found. No statistically significant differences in consequences were found.	Whereas observed differences suggest that costs were higher & benefits were greater in the intervention group, neither finding was statistically significant. The intervention resulted in an incremental cost per QALY gained of Canadian \$20 000.	Canada, public funding, Government
Engedal (1989)	I, Day care ( <i>n</i> =38), C, standard care ( <i>n</i> =39) (intention-to-treat approach)	Health care and social care	RCT (B1) 12 months	CCA	Day care, hospital beds, nursing home beds, home nurses and home	Mini Mental Status examination, Geriatric Mental Status examination,	Cost differences across groups were not tested. No statistically	No statistically significant differences were found in terms of costs or effects across	Norway, public funding, Government

**Review of respite services for carers for people with dementia**

					helps	Kendrick's Objective Learning Test, activities of daily living from the Barthel index; patient-focused.	significant differences in consequences across groups were found.	groups. The prime reason suggested for lower costs for the intervention group compared to the control group was that patients in the intervention group spent less time in acute care. Mental capacity deteriorated at the same rate across groups.	
Gaugler <i>et al.</i> (2003b) (relates to Gaugler <i>et al.</i> 2003a)	I, Day care ( <i>n</i> =154); C, standard care ( <i>n</i> =231) (loss to follow up: I, 48%; C, 34%)	Social care and carer	Quasi-experimental (B2) 12 months	CEA	Day care, formal care, informal care, carer loss of earnings	Seven-item Role Overload Scale providing a negative appraisal of primary stress 20-item Center for Epidemiological Studies for Depression Scale to assess depression; carer-focused.	Costs were found to be statistically significantly higher in the intervention group at 12 months. Role overload and depression was alleviated (better) in the intervention and these findings were statistically significant.	Costs were higher and benefits were greater in the intervention group compared to the control group over the long-term. To alleviate depression and role overload by one unit, the cost was \$2.20 and \$4.51 respectively.	USA, public funding, not known

**Review of respite services for carers for people with dementia**

Wimo <i>et al.</i> 1990	I, Day care ( <i>n</i> =47); C, standard care ( <i>n</i> =47)† (intention-to-treat approach)	Health care and social care and carer	Pre- and post-intervention (C1) 6 months	CEA	Day care, social care, home nursing care, remuneration to families, institutional care	Caring professionals judged the well-being of the patients; patient-focused. Relatives/carers were asked to assess the effects of day care on their own situation (carer-focused). Both assessments were converted to well-being (utility scores).	Cost differences were tested (test type was not stated). No statistical tests were applied to consequences.	The cost per well year was SEK 48 076 based on the staff opinions. The cost per well year was SEK 43 931 based on the carer well-being scores	Sweden, not stated, Government
Wimo <i>et al.</i> (1994) (relates to Wimo <i>et al.</i> 1993)	I, Day care ( <i>n</i> =55); C, standard care (on the waiting list for day care; <i>n</i> =45) (intention-to-treat approach)	Health care and social care, and carer	Quasi-experimental (B2) 12 months	CUA	Day care, social care, home nursing care, remuneration to families, institutional care	Index of Well-being and the Rosser Index, Mini Mental Status Examination, Multi Dimensional Dementia Assessment Scale and the RASIB Scale, activities of daily living from the Barthel index (patient-focused but based on observation).	Non-parametric tests were used to compare differences in costs across groups. This is inconsistent with current practice. No statistically significant differences in consequences (utilities) across groups were found.	There were no statistically significant differences in costs or consequences found. However, observed differences revealed that deterioration in the utility indices were lower (better) in the intervention group and the costs lower.	Sweden, not stated, Government

CCA, cost-consequences analysis; CUA, cost-utility analysis; CEA, cost-effectiveness analysis.

\*In the Intervention column, I means intervention and C means control group (including sample sizes at baseline).

†45 participants had dementia and two were diagnosed with psychogeriatric disorders.

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## Appendix 5 Representatives of national organisations consulted

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<b>Organisation</b>	<b>Representative</b>	<b>Role</b>
Mencap	Brian Macginnis	Special Advisor
Joint Review Team (Social Services Inspectorate /Audit Commission)	Derek Sleigh	Joint Reviewer
Carers UK	Emily Holzhausen	Public Affairs Manager
National Care Standards Commission	Heather Wing	Director for Adult Services
Department of Health	Helen Tomkys	Carers Policy Manager
For Dementia	Jane Capus	Admiral Nurse
Alzheimer Scotland	Jan Kileen	Public Policy Director
The Children's Society	Jenny Franks	Young Carers Co-ordinator
Help the Aged	Jonathan Ellis	Head, Health and Social Care Team
The Stroke Association	Kate Hodson	Information Officer
Alzheimer's Concern Ealing (ACE)	Kulbir Gill	Director
Alzheimer's Society	Mike Ellison	Information Officer for Younger People with Dementia
Winged Fellowship Trust	Patrick Wallace	Chief Executive
The Royal College of Nursing	Pauline Ford	Advisor for Older People
Princess Royal Trust for Carers	Peter Tihanyi	Head of Policy
Crossroads – Caring for Carers	Sandy Caley	National Service Development Manager
MIND	Sophie Corlett	Policy Director

***Review of respite services for carers for people with dementia***

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National Institute for Mental Health	Susan Benbow	Consultant Psychiatrist and Older Peoples' Lead
Tizard Centre, University of Kent/Mental Health Foundation	Alisoun Milne	Senior Lecturer in Social Gerontology; also on secondment to Mental Health Foundation
Becton Centre, West Hants Trust /Department of Health	Andy Barker	Consultant in Old Age Psychiatry; one-and-a-half days a week works for Department of Health on elderly mental health issues in policy branch.

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## Appendix 6 Telephone interview schedule: consultation with national bodies

- 1 Could you start by briefly describing your role, including any particular experience of/remit for respite services?
- 2 In general, how would you describe the current state of respite care/short breaks for carers of people with dementia?
- 3 Where services appear to be working effectively, what are the characteristics that make a difference?
- 4 In what ways do (or should) respite services address the specific needs of the cared-for person, for example at different stages of their illness?
- 5 How do (or should) services accommodate the needs of carers at different stages of their 'caring careers'?
- 6 Have you any comments about how services meet (or should meet) the needs of the specific groups of carers and cared-for people mentioned in 'the scope of the study'?
- 7 With your responses to the previous questions in mind, can you summarise what you think effectiveness and cost-effectiveness mean in relation to these services?
- 8 How do you think the effectiveness of respite services should be evaluated, i.e. what should be measured and how?
- 9 Can you describe what, in your view, would be an ideal pattern of respite services for people with dementia?
- 10 What barriers and difficulties do you think providers encounter in trying to deliver effective services?
- 11 From your observations, to what extent have recent policy developments helped providers to offer more innovative services? (for example, carers' assessments; continuing care; Carers Special Grant; NSFs; Health Act flexibilities)
- 12 Are you aware of any particular examples of good practice in this field – or of areas that have taken significant steps to improve respite services? (If so, we would like more details, including the key contact.)
- 13 Are you aware of any relevant 'grey' (unpublished) literature that may not be picked up in our literature review?
- 14 Finally, what evidence or information do you think would be most useful to people working in this field?

## Appendix 7 Topic guide for carers' groups

- 1 Ask the group to introduce themselves and say a little about their situation.
- 2 What services have you used to give you a break?
- 3 How well have these services met your needs as a carer?  
  
(Explore any specific needs of the carer, e.g. with respect to age/ethnic group/health/other responsibilities/personal preferences)
- 4 How well have these services met the needs of the person you care for?  
  
(Explore any specific needs of the user, e.g. with respect to age/ethnic group/condition/stage of illness/personal preferences, etc.)
- 5 What, if anything, did you particularly value about these services? Why?
- 6 What, if anything, could in your view be improved in these services? Why?
- 7 If you haven't used services (or have stopped using them), why was this so?
- 8 So what would you see as the key elements of an effective respite service?
- 9 Do you feel that respite services provide 'value for money'? Please give reasons.

## Appendix 8 Telephone interview schedule: consultation with carers

1 Please could you start by telling me a little about your situation?

(Note for interviewer: e.g. relationship to person they care for, how long they have been caring, any other important factors which they feel comfortable about disclosing.)

2 What services, if any, are you currently using to give you a break?

3 What services, if any, have you used in the past to give you a break?

(Note for interviewer: if the carer has never used any services, go straight to question 10.)

4 How well have these services met your needs as a carer?

(Note for interviewer: explore any specific needs of the carer, e.g. with respect to age/ethnic group/health/other responsibilities/personal preferences.)

5 In your view, how well have these services met the needs of the person you care for?

(Note for interviewer: explore any specific needs of the user, e.g. with respect to age/ethnic group/condition/stage of illness/personal preferences)

6 What, if anything, do/did you particularly value about these services?

(Note for interviewer: explore with the interviewee why he or she values these characteristics.)

7 What, if anything, in your view could be improved in these services?

8 If you have stopped using any services, or changed the way you use services, what were your reasons?

9 Are there other services in your area that you know about, but haven't used? If yes, what are the reasons for this?

10 If you haven't used *any* services, what are your reasons for this?

11 Finally, if you were to design the ideal pattern of respite services in your area, what else would it include and how would it be different from the way things are now?



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