

Centre for Reviews and Dissemination

Psychosocial Interventions for  
Non-Professional Carers of  
People with Parkinson's Disease:  
A Scoping Review



Promoting the use of research based knowledge

CRD THE UNIVERSITY of York

REPORT 37



# **Psychosocial interventions for non-professional carers of people with Parkinson's disease: A scoping review**

**Susanne Hempel  
Gill Norman  
Su Golder  
Raquel Aguiar-Ibáñez  
Alison Eastwood**

**Centre for Reviews and Dissemination  
University of York  
York YO10 5DD  
UK**

**December 2007**

© 2007 Centre for Reviews and Dissemination, University of York

ISBN 978-1-900640-45-9

This report can be ordered from: The Publications Office, Centre for Reviews and Dissemination, University of York, York YO10 5DD. Telephone 01904 321458; Facsimile: 01904 321035:  
email: [crd-pub@york.ac.uk](mailto:crd-pub@york.ac.uk)

**Price £12.50**

The Centre for Reviews and Dissemination is funded by the NHS Executive and the Health Departments of Wales and Northern Ireland. The views expressed in this publication are those of the authors and not necessarily those of the NHS Executive or the Health Departments of Wales or Northern Ireland.

Printed by York Publishing Services Ltd.

# CENTRE FOR REVIEWS AND DISSEMINATION

The Centre for Reviews and Dissemination (CRD) is a facility commissioned by the NHS Research and Development Division. Its aim is to identify and review the results of good quality health research and to disseminate actively the findings to key decision makers in the NHS and to consumers of health care services. In this way health care professionals and managers can ensure their practice reflects the best available research evidence. The reviews will cover: the effectiveness of care for particular conditions; the effectiveness of health technologies; and evidence on efficient methods of organising and delivering particular types of health care.

## Further Information

General Enquiries:	01904 321040
Information Service:	01904 321078
Publications:	01904 321458
Fax:	01904 321041
Email:	<a href="mailto:crd@york.ac.uk">crd@york.ac.uk</a>

## CRD Reports

1.	Which way forward for the care of critically ill children? (1995)	£7.50
2.	Relationship between volume & quality of health care (1995)	£5.00
4.	Undertaking systematic reviews of research on effectiveness. 2nd edition (2001)	£12.50
5.	Ethnicity and health (1996)	£12.50
6.	Improving access to cost-effectiveness information for health care decision making: the NHS Economic Evaluation Database. (2nd Edition 2001)	£9.50
7.	A pilot study of 'Informed Choice' leaflets on positions in labour (1996)	£7.50
8.	Concentration and choice in the provision of hospital services (1997)	
	<b>Summary Report</b>	£6.00
	<b>Part I</b> - Hospital volume and quality of health outcomes	£12.50
	<b>Part II</b> - Volume and the scope of activity and hospital costs	£9.50
	<b>Part III</b> - Concentration, patient accessibility and utilisation of service	£7.50
	<b>Complete set of reports</b>	£30.00
9.	Preschool vision screening: results of a systematic review (1997)	£9.50
10.	Systematic review of interventions in the treatment and prevention of obesity (1997)	£12.50
11.	A systematic review of the effectiveness of interventions for managing childhood nocturnal enuresis (1997)	£12.50
13.	Screening for ovarian cancer: a systematic review (1998)	£12.50
14.	Women and secure psychiatric services: a literature review (1999)	£12.50
15.	Systematic review of the international literature on the epidemiology of mentally disordered offenders (1999)	£12.50
16.	Scoping review of literature on the health and care of mentally disordered offenders (1999)	£12.50
17.	Therapeutic community effectiveness: community treatment for people with personality disorders and mentally disordered offenders (1999)	£12.50
18.	A systematic review of water fluoridation (2000)	£20.00
19.	The longevity of dental restorations: a systematic review (2001)	£20.00
20.	Informed choice in maternity care: an evaluation of evidence based leaflets (2001)	£20.00
21.	Scoping review of the effectiveness of mental health services (2001)	£12.50
22.	The effectiveness of interventions used in the treatment/management of chronic fatigue syndrome and/or myalgic encephalomyelitis in adults and children (2002)	£12.50
23.	Access to the online evidence base. A survey of the Northern and Yorkshire Region (2003)	£7.50
24.	Outcomes measurement in psychiatry (2003)	£12.50
25.	Scoping review of sabotage and/or tampering in the NHS (2004)	£12.50
26.	Predictors of delay in seeking medical help in patients with suspected heart attack, and interventions to reduce delay: A systematic review (2004)	£12.50
27.	A systematic review of cancer waiting time audits (2005)	£12.50
28.	Systematic review of the clinical and cost effectiveness of ultrasound in screening for developmental dysplasia of the hip in newborns (2005)	£12.50
29.	Diagnostic value of systematic prostate biopsy methods in the investigation for prostate cancer: a systematic review (2005)	£12.50
30.	The effects of psychosocial interventions in cancer and heart disease: a review of systematic reviews (2005)	£12.50
31.	Systematic review of barriers, modifiers and benefits involved in participation in cancer clinical trials (2006)	£12.50
32.	Systematic review of interventions to increase participation of cancer patients in RCTs	£12.50
33.	Parenteral oestrogens for prostate cancer: a systematic review of clinical effectiveness and dose response (2006)	£12.50
34.	Systematic review of the clinical effectiveness of self care support networks in health and social care (2006)	£12.50
35.	The treatment and management of CFS/ME in adults and children (2007)	£12.50
36.	Diagnostic accuracy and cost-effectiveness of faecal occult blood tests used in screening for colorectal cancer: a systematic review (2007)	£12.50

---

## **ACKNOWLEDGEMENTS**

We would like to thank Dr Hilary Arksey, Dr Aimee Aubeeluck and Elspeth Maguire for reviewing the protocol for this scoping review and express our gratitude for their useful comments and suggestions. Many thanks also to James Coates and John Galloway for advice on the database and Paul Wilson for comments on the report.

The project was funded by the Parkinson's Disease Society UK (Grant ref K-0603).

### **Authors' contributions**

SH, GN, SG and AE wrote the proposal and the protocol. SG performed the searches and managed the citation library, SH and GN screened the studies, GN extracted the data, SH checked the data, AE managed the project and acted as third reviewer where necessary and RAI reviewed the economic evaluations. SH drafted the report and all authors contributed to the report.

---

## INDEX OF CONTENTS

EXECUTIVE SUMMARY .....	vi
1. INTRODUCTION .....	1
1.1 Research question .....	1
1.2 Background .....	1
1.3 Objective .....	1
1.4 Preliminary work .....	1
1.5 Scope .....	2
2. METHODS .....	4
2.1 Study inclusion criteria .....	4
2.2 Literature search .....	4
2.3 Study selection .....	4
2.4 Categorisation and data extraction .....	5
2.5 Unclassifiable potential includes and near misses .....	6
2.6 Analysis and output .....	6
3. RESULTS .....	7
3.1 Search results .....	7
3.2 Included studies .....	7
3.2.1 Published studies .....	9
3.2.1.1 Study design summary .....	14
3.2.1.2 Intervention, orientation and providers .....	15
3.2.1.3 Setting and method of delivery .....	17
3.2.1.4 Carer and patient populations .....	18
3.2.1.5 Outcomes .....	19
3.2.1.6 Economic evaluations .....	21
3.2.2 Ongoing studies .....	21
3.3 Near misses .....	21
3.4 Unavailable publications .....	21
4. DISCUSSION .....	23
4.1 Currently available evidence and research issues .....	23
4.2 Identified research gaps .....	25
5. CONCLUSIONS .....	28
6. REFERENCES .....	28
APPENDIX 1: SEARCH STRATEGIES .....	32
APPENDIX 2: CATEGORISATION OF RESEARCH PROJECTS .....	45
APPENDIX 3: NEAR MISSES .....	50
APPENDIX 4: UNAVAILABLE PUBLICATIONS .....	51
APPENDIX 5: DETAILS OF INCLUDED STUDIES AND ONGOING PROJECTS .....	52

---

## EXECUTIVE SUMMARY

### Background

Parkinson's disease imposes a unique constellation of physical and mental symptoms which present particular challenges to the patient and their carer. The role of a carer is often critical to a person with Parkinson's disease maintaining independent living and a reasonable quality of life.

Psychosocial interventions can potentially support carers in their role. Although overviews of the impact of carer interventions exist for other carer groups, there is no available summary of potential interventions for those caring for people with Parkinson's disease and their unique support needs.

### Objective

The Centre for Reviews and Dissemination (CRD), based at the University of York was commissioned by the Parkinson's Disease Society to undertake a scoping review to map the available evidence on interventions for carers.

The aim is to provide an overview of existing research on the effectiveness and cost-effectiveness of psychosocial interventions for non-professional carers of people with Parkinson's disease.

The results of this scoping review can be used to inform decisions about research priorities. The map of the existing literature aims to enable the Parkinson's Disease Society to focus resources on areas that currently do not have a strong evidence base and would benefit from further research.

### Methods

We systematically searched for, identified and categorised the available research evaluating the effects of psychosocial interventions to support non-professional carers of people with Parkinson's disease. In order to produce a thorough and systematic overview, internationally recognised guidelines produced by CRD were adopted and tailored for the requirements of a scoping review. Our experience coupled with the use of established methods ensured that this scoping review is transparent, thorough, unbiased and accurate.

We employed thorough literature searches of 30 electronic databases, supplemented by internet searches and scanning of bibliographies of relevant publications which aimed to identify relevant published, unpublished and ongoing research. Only studies meeting predefined inclusion criteria were eligible for inclusion in the review ensuring transparency of the review process. Measures were taken throughout the review process to avoid errors and bias in the selection and coding of studies to ensure accurate results.

A structured report and a searchable database of the identified research were provided which together allow a comprehensive overview of the available research. As part of this process, the robustness and reliability of the existing evidence was evaluated. Additionally, gaps in the evidence base were identified and implications for future research were highlighted. Using our assessment of the available evidence, recommendations were formulated about the types of studies required to answer questions about the effects of psychosocial interventions aimed at non-professional carers of people with Parkinson's disease.

### Results

The scoping review identified 35 research records, of which 30 were published, either as a full paper publication or as a conference abstract, and 5 were registered ongoing projects. Only three published randomised controlled trials of scientifically sound research design were identified, of which only one investigated a psychosocial intervention exclusively aimed at carers of people with Parkinson's disease and reported carer outcomes. Only two studies were controlled trials, two compared different cohorts and eight studies collected data from the participants before and after the intervention. All other published studies presented simple evaluations (post-test only studies), followed case series or



were surveys and interviews that asked about services that respondents may have used. Two publications lacked detail so that the evaluation format remained unclear; it is unlikely that these were RCTs or controlled trials.

None of the published studies formally assessed cost effectiveness in a full economic evaluation. Three studies reported on costs of the intervention and one identified ongoing project has the potential to report on a full economic evaluation once it is published.

Most investigated interventions were relatively unique and involved multiple elements such as information and education and informal exchange with other carers in a support group. As a specific psychotherapeutic intervention, only a cognitive behavioural therapy (CBT) approach has been explicitly utilised more than once. Communication was the research focus in a number of studies and several studies either incorporated a support group element in their intervention package or evaluated it as sole intervention. An information or education element was part of most investigated interventions, although what information exactly was presented in the intervention was usually not reported. Respite care was mentioned in most surveys and several studies stressed the fact that their intervention package was delivered by a multidisciplinary team.

In the majority of the identified studies the investigated intervention was not primarily and exclusively aimed at carers but was embedded as part of a treatment programme for people with Parkinson's disease. Most studies were conducted in general samples of carer and/or patient populations, rather than focussing on defined subgroups of carers or patients.

Many of the identified research studies appear to have been pilot studies involving very small numbers of participants. Several studies did not assess the effectiveness of the intervention in terms of coping or health and any changes that the intervention may have caused but assessed the satisfaction with the intervention. Not all identified studies were designed to evaluate the effectiveness of the intervention for the carer; the data collection (or the reporting) was restricted to the recipients of care alone.

## **Research gaps**

From this scoping review it is clear that there is considerable scope for future research on psychosocial interventions for non-professional carers of people with Parkinson's disease.

Although some research was identified, the available evidence suggests a full systematic review would not be useful to guide decision making at the moment. This scoping review demonstrates a need for more primary research.

In particular, there is a need for high quality research studies. Future studies should employ rigorous research designs such as RCTs or quasi-randomised studies to allow a clear indication of the interventions' effectiveness or should at least consider the use of a control group given the progressive nature of Parkinson's disease. These future studies should employ appropriately sized participant samples. Furthermore, the complexity of psychosocial interventions should be incorporated into the research design. Psychosocial interventions are likely to consist of several elements and the analysis should be guided accordingly.

This review highlights several interventions and areas that may merit further investigation. These include CBT, a specific cognitive behavioural education programme (EduParc), multidisciplinary approaches or the means of delivery and models of respite care. In addition, the available evidence on interventions for carers of other patient groups should be consulted for indicators of potentially successful interventions.

More studies are needed that assess the effectiveness of an intervention with appropriate outcomes that are clinically meaningful indications of change, for example in terms of coping or health, rather than simply asking about the satisfaction with a programme. Care should be taken to select outcomes that at least fulfil basic psychometric standards. Additionally, data should be collected on health care resource consumption required for each of the alternative psychosocial interventions to allow the assessment of the cost-effectiveness of the interventions.

Research is needed that puts the focus of attention on the carer. Notwithstanding more complex issues such as the care stages and predictions regarding which interventions may work for which carer, there is a basic need to collect carer data. Where interventions are available for carers these should be evaluated in their effects on the carer, rather than limiting research reports to patient outcomes. Only this will provide more information on which interventions will effectively support carers in their role of caring for a person with Parkinson's disease.

## **Conclusions**

This scoping review indicates that some research has recently been dedicated to the evaluation of psychosocial interventions for non-professional carers of people with Parkinson's disease. However, researchers appear to have only just begun to think about the clinical and the cost-effectiveness of interventions for carers. There is currently very little information available to show which interventions will effectively support carers in their role of caring for a person with Parkinson's disease.

There is considerable scope for future research on the effectiveness of psychosocial interventions for carers of people with Parkinson's disease. Few interventions have been studied and these have mainly been examined with research methods that do not provide conclusive evidence on the effectiveness or cost-effectiveness of the interventions. High quality research, employing appropriate and rigorous research designs and involving carer samples large enough to detect effects is warranted. This overview of the available evidence, along with other existing research relating to comparable carer groups, can inform future decisions about research funding priorities.

---

# 1. INTRODUCTION

## 1.1 Research question

What is the available evidence for the effects of psychosocial interventions to support non-professional carers of people with Parkinson's disease?

## 1.2 Background

Parkinson's disease imposes a unique constellation of physical and cognitive symptoms which presents particular challenges to people with the disease and their carers. The role of a carer is often critical to the affected person maintaining a reasonable quality of life and independent living.

As in many chronic conditions the burden of caring falls primarily on the spouse and family members of the affected person. While medication can allow individuals with early stage disease to achieve functional independence, disease progression almost invariably results in increased dependency on carers. Research suggests that the number of care-related activities performed daily (ranging from help with tasks such as bathing to management of financial resources) increases three-fold as patients progress from early to late stage disease (Carter et al., 1998). Apart from physical symptoms, the cognitive symptoms which many people experience can require high levels of emotional support from the carer and may account for a significant amount of the stress experienced by the carer (Aarsland et al., 1999). The burden which caring for a person with a chronic condition imposes is severe and can adversely affect the physical or psychiatric health of the carer; e.g. levels of psychiatric morbidity can be up to five times higher in carers for spouses with Parkinson's disease compared to other spouses (O'Reill et al., 1996). The stress experienced by a carer can impact adversely on the person with Parkinson's disease, affecting both the quality of care provided and the relationship between an individual and their carer (Davies et al, 1999). Severe stress in their carer may eventually result in an individual entering residential care earlier than otherwise necessary.

Although there has been substantial research on the impact of health-related interventions for carers of elderly people (Stoltz et al, 2004), there is no available summary of potential interventions for those caring for people with Parkinson's disease and their unique support needs. Furthermore, while the effectiveness of psychosocial interventions for people with Parkinson's disease has been reviewed (Deane et al., 2002), there is no systematic assessment of the research available on support strategies for carers.

## 1.3 Objective

The objective was to undertake a scoping review of the literature on the effects, including the effectiveness and cost-effectiveness, of psychosocial interventions for carers of people with Parkinson's disease. The overall aim of the review was to provide a map of the available evidence.

This scoping review aimed to provide the Parkinson's Disease Society with a thorough overview of the evidence base, identifying the focus, quantity and the level of evidence of the existing research and highlighting any gaps in the literature. It also aimed to provide insights into methodological issues by highlighting the strengths and weaknesses of the research designs which have been employed, and where there is a need for further studies in order for interventions to be appropriately evaluated. It is hoped that the results of the review will be useful in informing the Society's decisions about research funding priorities.

## 1.4 Preliminary work

Prior to undertaking this project, we have carried out a search for guidelines, completed and ongoing scoping reviews and systematic reviews on the topic of Parkinson's disease. For this, 11 electronic databases and internet resources were searched. This search identified 1463 records. Of these, 18 addressed carers of patients with Parkinson's Diseases. None of the 18 items were scoping reviews or systematic reviews. As we did not identify a systematic research overview which could inform decisions into research priorities in this area, the current research was undertaken. From a further exploratory search of the literature, using the MEDLINE database as our sample, we estimated that a

literature search of a full range of databases was likely to identify 1200 potentially relevant records of published and ongoing research on support for carers of patients with Parkinson's disease.

A protocol outlining the planned review was prepared and sent out for comments to a group of independent experts. The expert panel consisted of a practicing health visitor, a psychologist with expertise in carer needs and a health care researcher with experience in literature reviews on carer research. A review protocol documenting the precise details of the review process ensures transparency and makes the process as objective and systematic as possible (NHS Centre for Reviews and Dissemination, 2001). Full discussion took place before the protocol was finalised and input from the Parkinson's Disease Society was invited.

## **1.5 Scope**

The focus of this scoping review is on empirical studies that can establish the effectiveness and the cost-effectiveness of psychosocial interventions to support carers of people with Parkinson's disease.

Our search aimed to identify any psychosocial intervention to support carers with Parkinson's disease, such as counselling, support groups, cognitive behavioural therapy (CBT), coping strategies, relaxation training, occupational therapy, provision of respite care, health and safety or accident prevention training, or any combination of these approaches. The review aimed to evaluate the evidence base for psychosocial interventions. Psychosocial interventions involve aspects of psychological and social behaviour that could be used to improve the situation of the carer. Pharmacological interventions for carers, such as antidepressant drugs, were outside the scope of the review.

This scoping review addresses carer interventions. Therefore, identified interventions had to be aimed at the carer or jointly aimed at the carer and the patient to be eligible for inclusion in the review. Psychosocial interventions that clearly focussed on the carer while therapeutically targeting the patient only (e.g. provision of respite care) were also considered. Therapeutic approaches primarily focussed on the patient were outside the scope of the review.

The review focuses on identifying interventions aimed at non-professional carers. The search aimed to identify an exhaustive range of carer-patient relationships, e.g. by explicitly searching for family members such as spouse, children and parents but could also identify other carers such as friends and neighbours. Excluded were interventions aimed at professional carers (such as health care professionals) as their situations and needs differ considerably from those of non-professional carers.

This review targets carers for people with Parkinson's disease. Carers for people with Parkinsonian symptoms associated with other diagnoses were excluded from the review as Parkinson's disease imposes unique demands on patients and carers. Additionally, carers for people with other diagnoses will have other needs that might be primarily associated with the specific condition rather than with, for example, temporary Parkinsonian symptoms. Studies with mixed carer populations but clearly including carers of people with Parkinson's disease were included in the review.

The review aims to provide an overview of existing and ongoing research studies. Research studies were defined as those that provide empirical data on the evaluation of an intervention. Eligible for inclusion in the review were effectiveness studies such as randomised controlled trials (RCTs), controlled clinical trials, before-after studies or surveys. Any identified systematic review (as defined by the Database of Abstracts of Reviews of Effects (DARE) criteria, maintained by CRD, <http://www.york.ac.uk/inst/crd/>) would be documented. Opinion pieces and non-systematic literature overviews were excluded from the review and were only used to identify further research. Pure descriptions of a service without any kind of user evaluation were not eligible for inclusion in the review. Also eligible for inclusion were economic evaluations (as defined by the NHS Economic Evaluation Database (NHS EED) criteria, maintained by CRD, <http://www.york.ac.uk/inst/crd/>) such as cost-effectiveness analyses, cost-utility analyses and cost-benefit analyses. The review did not aim to identify other studies such as cost studies or studies assessing health care resource utilisation. This is because economic evaluations provide comparative analyses of the health consequences and costs of the identified interventions, while other types of studies, such as cost studies would provide more limited information that would not be enough to decide if the interventions under assessment would represent 'good value for money'. However, when a cost study was identified, it was classified as

'other' under the 'economic evaluation' heading (see below) to provide a more comprehensive view of the available evidence.

This review considered all reported outcomes and no inclusion criteria for eligible outcomes were specified. Outcomes were defined as the documented effect of the intervention. This could be any evaluation of the effect, the effectiveness or the cost-effectiveness of the intervention. Studies had to report at least one outcome to be eligible for inclusion in this scoping review.

### 2.1 Study inclusion criteria

Only studies meeting the following criteria were eligible for inclusion in the review:

*Participants:* Any non-professional carer for people with Parkinson's disease.

*Intervention:* Any psychosocial intervention to support carers.

*Outcome:* Any outcome was considered.

*Study design:* Any research study which evaluated an intervention.

### 2.2 Literature search

An extensive number and variety of potentially relevant databases were searched to provide a comprehensive mapping of the existing literature. In addition to published journal articles, the search aimed to identify research that has been presented in other forms, such as conference presentations, and also ongoing research. This aimed to prevent publication bias - the study selection for reviews can be biased towards those reporting positive results which are more likely to be published in full papers and in MEDLINE-indexed or other high profile journals (Kahn et al., 2003). Sensitive search strategies (combination of search terms) were devised to identify as many studies as possible relating to Parkinson's disease and carers. These were not restricted to any specific interventions or outcomes and were tailored for each individual database.

A full list of the 30 searched databases and search strategies used are documented in Appendix 1. The selection of databases took the interdisciplinary nature of the evidence base into account and covered several research disciplines such as psychological or medical research. No language restriction was applied to the searches, allowing the inclusion of studies published in languages other than English. This helps to prevent language bias which refers to the fact that studies with statistically significant results are more likely to be published in English language publications (Moher et al., 1996) and may therefore produce a biased selection of research. All databases were searched from inception with no date restrictions applied to the searches.

In addition, published reviews and reference lists of ordered papers were screened in order to identify further relevant research. Searches of relevant internet sites were carried out to identify further research studies. The list of the internet sites searched is also documented in the Appendix 1.

### 2.3 Study selection

The initial results of the searches (records providing titles and abstracts of studies) were screened independently by two reviewers. The screening was undertaken in a reference manager software program (Endnote Version 9; Thomson ResearchSoft, 2006). Initially, based on the titles and abstracts, records were classified depending on whether they met or were likely to meet the inclusion criteria, or could provide information on relevant research. The review protocol specified a priority hierarchy for ordering records. However, available resources allowed ordering full paper copies of all studies that met the inclusion criteria according to the abstract of the study, all studies potentially meeting the inclusion criteria, and all reviews that could possibly contain information on further relevant research.

The full publications were then screened by one reviewer and the decision checked by a second reviewer. Any discrepancies in the screening decisions were resolved through discussion, with reference to a third opinion where necessary. The duplicate screening and the independent selection of studies is an important step to avoid errors and bias in the review process.

Further potential studies identified in published reviews and reference lists of ordered papers were followed up and the same screening procedure was applied. All research projects meeting inclusion criteria were added to a database of included studies and ongoing projects for further coding.

## 2.4 Categorisation and data extraction

The included studies were categorised to describe the existing evidence on psychosocial interventions for non-professional carers of people with Parkinson's disease. The categorisation provided a concise overview of the studies that have met the specified inclusion criteria. It outlined the nature of the study, coded and extracted key data on study characteristics, and thus described the existing research evidence in detail. The procedure combined broad categorisation, permitting a clear overview of the studies with the extraction of key study parameters where available. The coding was undertaken using the software program Endnote Version 9 (Thomson Scientific, 2006). We used clear and predefined categories to ensure a standardised coding procedure to minimise errors and support transparency. These categories were tailored to allow easy searching of the Excel database that was created as part of the project output (see Analysis and output section). The categorisation was performed by one reviewer and checked by a second reviewer. Any discrepancies were resolved through discussion and reference to the review manager for a third opinion. The categorisation was piloted on a subsample to evaluate the suitability of the categories and to eliminate ambiguity.

The studies were categorised according to the following criteria:

**Study design:** Studies were categorised as: randomised controlled trial; controlled trial/quasi-experimental study; cohort study; before-after study; case-series/post-test only study; case study; survey and economic evaluation. The number of participants and the country the study was carried out in were also extracted.

**Intervention:** Interventions were categorised as psychotherapy; self-help/support group; behavioural; practical caring advice; telephone helpline; education and information; respite care; rehabilitation; other; and unclear. A description of the intervention as provided by the authors was also extracted from the papers. Furthermore, the orientation of the intervention, i.e. carer, patient, or carer and patient orientated, was documented. Additionally, the provider for the intervention was extracted.

**Setting and method of delivery:** Studies were categorised according to where the service took place, for example to identify home-based interventions. The method of delivery categorised how much direct involvement the interventions required.

**Carer population:** The information on the carer population was coded to identify studies that focussed on a particular subgroup of carers (e.g. spouses of the patient or children caring for their parents).

**Patient population:** The information on the patient population was coded to identify studies that focussed on a particular subgroup of patients (e.g. patients with a specific disease stage or exclusively carers of people with Parkinson's disease).

**Carer outcomes:** The carer outcomes were broadly categorised and the specific outcomes and assessment methods were extracted.

**Patient outcomes:** The patient outcomes were broadly categorised and the specific outcomes and assessment methods were extracted.

**Economic evaluation:** The type of economic evaluation (cost-effectiveness, cost-minimisation analysis, cost-consequences analysis, cost-utility analysis or cost benefit analysis) was recorded. If the studies only assessed cost data they were recorded as 'other'.

Additionally, authors, publication year, the citation details of the included paper and related publications, the coding source (full paper or abstract only), and the authors' conclusions were extracted. Methodological comments on the study design were documented in a separate field. As this is a scoping review, the studies were not critically appraised to assess for potential biases and errors. Therefore, we cannot comment on the validity of the authors' conclusions. The review aimed to document studies rather than publications; multiple publications of the same study were cross-referenced and documented in the same study record. The specified categories are outlined in detail in Appendix 2.

The studies were categorised with the focus on evaluated carer interventions. This was particularly important in the case of surveys, which typically assessed other aspects of caring in addition to the effect of an intervention. As this review aims to bring together the evidence on psychosocial interventions for carers, only relevant information was extracted rather than summarising the entire published article. Many studies also contained detailed information on patient treatments. Again, the carer intervention was considered central and this was extracted, rather than the complete description of all possible intervention elements.

Ongoing studies were clearly marked but also classified as above using the information available from the search record. Identified systematic reviews would have been documented in a suitably adapted format where applicable. Wherever categories could not be accurately completed they were marked as 'unclear'.

## **2.5 Unclassifiable potential includes and near misses**

Publications which did not meet all specified inclusion criteria to be eligible for inclusion in the current review but which were records of potentially interesting projects in relation to this scoping review topic were listed when it was considered possible that future publication may describe these projects in sufficient detail that could establish their relevance to the current review (see Appendix 3). The references of publications that were ordered but could not be obtained were also collected and provided additionally (see Appendix 4). Foreign language studies which could not be translated by the review team (we read many European languages) and without an English abstract would also have been listed where necessary to quantify the volume of potentially relevant additional research.

## **2.6 Analysis and output**

This report summarises the nature of the existing studies, tabulating by study design, interventions, participants and outcomes. We provide an overview of study designs employed together with their potential for accurate unbiased assessment of the effectiveness and cost-effectiveness of an intervention. Study designs vary considerably in vulnerability to bias and their ability to give reliable answers to questions about the effects of interventions. Categorisation of the study design characteristics of the existing research studies therefore contribute to a more complete understanding of the evidence base and an indication of whether the research may provide robust evidence. However, the design alone cannot be taken as the basis for a decision on the validity of study results, for which an appraisal of the study quality using an appropriate assessment tool would be required. A critical appraisal of the identified studies was outside the scope of this project and would have required a full systematic review.

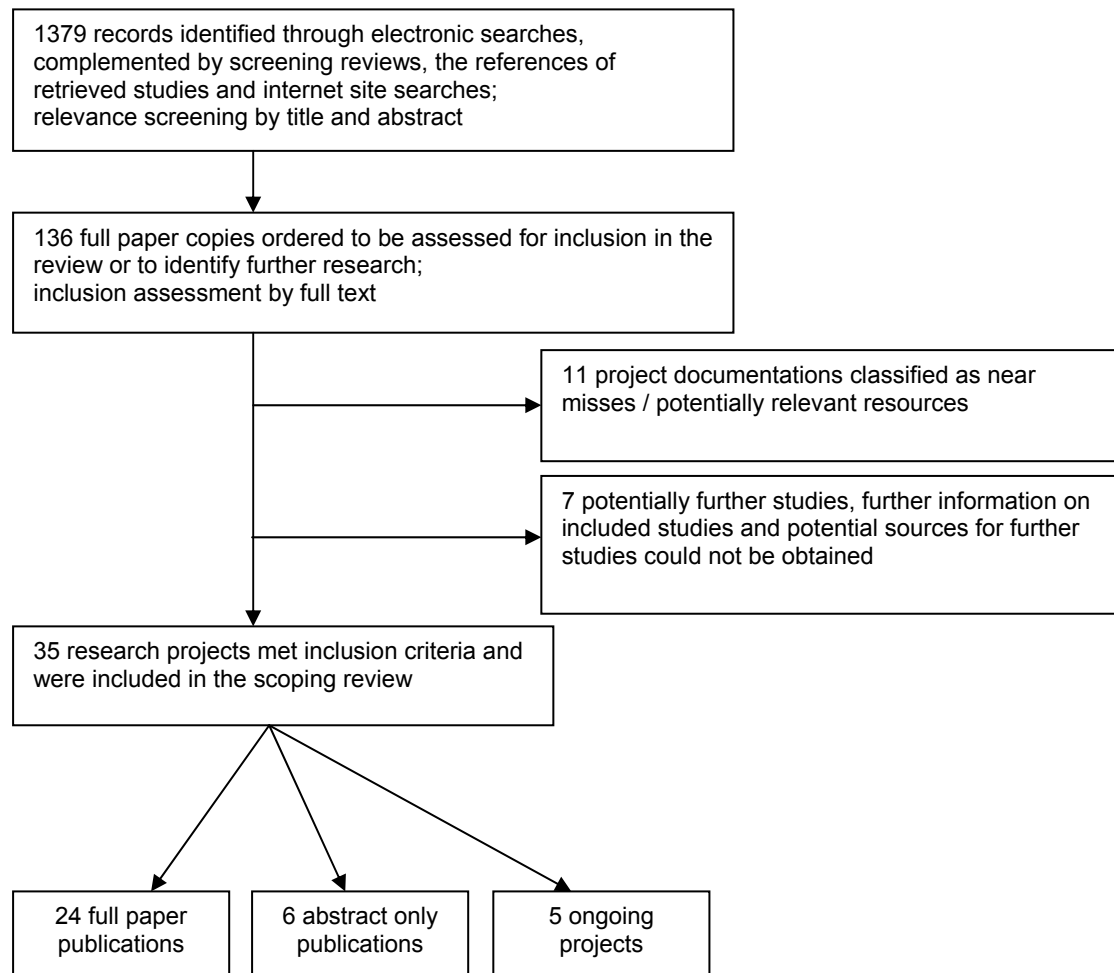
As well as this report as an additional tool, a database of the existing evidence on psychosocial interventions for carers of people with Parkinson's disease has been produced. This database of included studies contains our full categorisation, is easily electronically searchable and provides a concise mapping of the available evidence. The database was created using the Excel software program (Microsoft Corporation, 2003) that it is accessible and useful for the Parkinson's Disease Society; suitable options were discussed with our database developer to meet the funder's needs. The database contains all evaluations that met the inclusion criteria for the review, a documentation of the categorisation used and data extraction strategy. It also outlines strategies to facilitate the use and convenient searching of the database.

This scoping review also aims to highlight gaps in existing research. The existing evidence based is discussed and research issues specific to the research on psychosocial interventions for carers of people with Parkinson's disease presented.



### 3.1 Search results

The study flow for the scoping review is documented in figure 1. The search of the electronic databases retrieved 1379 records. The search was complemented by screening reviews, the references of retrieved studies and internet site searches.



**Figure 1: Study selection process**

One hundred and thirty six full paper copies of publication records were ordered, assessed for inclusion in the review and screened to identify further relevant research. Full details of the search results are reported in Appendix 1.

### 3.2 Included studies

Thirty-five records met the inclusion criteria (see Table 1). Of these, 30 were published studies that have presented research results (Aoun et al., 2006; Bayés et al., 2005; Birgersson & Edberg, 2004 ; Boddy et al., 1992; Brandow et al., 1997; Chibuk et al., 2006; Davies et al., 1999; DeFronzo et al., 2006; Feinberg & Whitlatch, 1998; Gardner et al., 2006; Haw et al., 1999; Holloway, 2006; Klein & Rivers, 2006; Lieberman et al., 2005; Lloyd, 1999; Lovett & Gallagher, 1988; Marziali et al., 2005; Moore, 2006; Mott et al., 2005; Nasar & Bankar, 2006; Oxtoby, 1999; Secker & Brown, 2005; Sheriff & Chenoweth, 2003; Szekely et al., 1982; Taba et al., 2005; Thomas & Sweetnam, 2002; Trend et al., 2002; Watts et al., 1999; Whitehouse, 1994; Yarrow, 1999). Five were descriptions of research

projects that were registered in research databases but for which no publication could be found yet (Forsyth, ongoing; Furmston, ongoing; Laidlaw, ongoing; Leroi, ongoing; Thompson, ongoing).

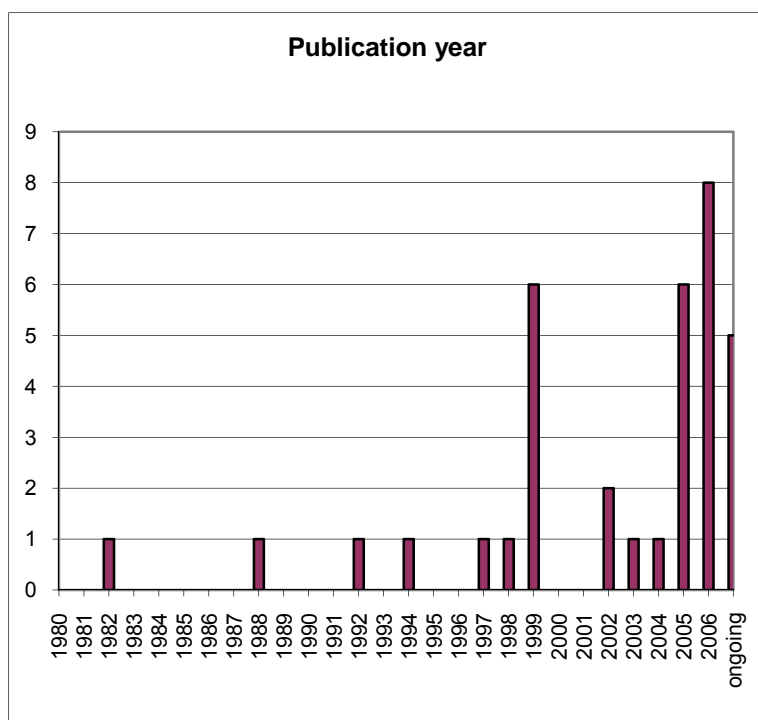
Of the 30 published studies, 24 were published as full papers (Aoun et al., 2006; Birgersson & Edberg, 2004; Boddy et al., 1992; Davies et al., 1999; DeFronzo Dobkin et al., 2006; Feinberg & Whitlatch, 1998; Haw et al., 1999; Holloway, 2006; Klein & Rivers, 2006; Lieberman et al., 2005; Lloyd, 1999; Lovett & Gallagher, 1988; Marziali et al., 2005; Mott et al., 2005; Nasar & Bankar, 2006; Oxtoby, 1999; Secker & Brown, 2005; Sheriff & Chenoweth, 2003; Szekely et al., 1982; Thomas & Sweetnam, 2002; Trend et al., 2002; Watts et al., 1999; Whitehouse, 1994; Yarrow, 1999). For six research studies only a conference abstract reporting results was identified (Bayés et al., 2005; Brandow et al., 1997; Chibuk et al., 2006; Gardner et al., 2006; Moore, 2006; Taba et al., 2005).

**Table 1: Identified research**

Project identifier	Country	Design	Intervention type
<b>Completed research, full paper</b>			
Aoun, 2006	Australia	survey	respite care; education/information; self-help/support group; unclear
Birgersson, 2004	Sweden	other (interview)	education/information; other; respite care; self-help/support group
Boddy, 1992	UK	b-a study	behavioural; self-help/support group
Davies, 1999	UK	survey	respite care
DeFronzo Dobkin, 2006	USA	CS	education/information; psychotherapy
Feinberg, 1998	USA	cohort study; cost	respite care
Haw, 1999	UK	CT	self-help/support group; education/information; other
Holloway, 2006	UK	b-a study	education/information
Klein, 2006	USA	b-a study	behavioural
Lieberman, 2005	USA	survey	self-help/support group
Lloyd, 1999	UK	survey	respite care; other
Lovett, 1988	USA	RCT	education/information; psychotherapy
Marziali, 2005	Canada	CS	self-help/support group
Mott, 2005	Australia	survey	self-help/support group; psychotherapy; helpline; education/information; other
Nasar, 2006	UK	CS	other (PD club)
Oxtoby, 1999	UK	cohort study; cost	education/information; psychotherapy; other
Secker, 2005	UK	RCT	psychotherapy
Sheriff, 2003	Australia	b-a study	psychotherapy; education/information
Szekely, 1982	USA	b-a study	self-help/support group; practical advice; other
Thomas, 2002	UK	unclear	self-help/support group; education/information
Trend, 2002	UK	b-a study; cost	psychotherapy; behavioural; practical advice; education/information; rehabilitation; practical advice
Watts, 1999	UK	CT	practical advice; psychotherapy; self-help/support group
Whitehouse, 1994	UK	RCT	Other (PD nurse)
Yarrow, 1999	UK	survey	respite care; education / information; helpline; self-help/support group
<b>Completed research, conference abstract only</b>			
Bayés, 2005	Spain	CS	education/information; psychotherapy
Brandow, 1997	USA	b-a study	psychotherapy; education/information
Chibuk, 2006	Canada	survey	education/information; helpline; practical advice; respite care; self-help/support group; behavioural; other
Gardner, 2006	USA	CS	education/information; practical advice
Moore, 2006	Israel	unclear	other (caregiver clinic)
Taba, 2005	Spain, Finland, Italy, The Netherlands, UK, Estonia, Germany	b-a study	education/information; psychotherapy
<b>Ongoing research, database entry</b>			
Forsyth	UK	RCT	other (lavender pillow)
Furmston	UK	RCT; econ.	unclear
Laidlaw	UK	CT	psychotherapy
Leroi	UK	RCT	behavioural
Thompson	UK	unclear	education/information

Notes: b-a study: before-after study; cost: costs provided; econ: economic evaluation; CS: case series / post-test only study; CT: controlled trial; PD: Parkinson's disease; RCT: Randomised controlled trial

Of the published studies, 13 were conducted in the UK, 8 in the USA, 3 in Australia, 2 in Canada, 1 in Israel, 1 in Spain, 1 in Sweden and 1 contained data from several European countries. All identified registered ongoing research projects were based in the UK (the search was not restricted to UK databases). Although the searches were not restricted to any publication date (and the earliest date of inception for any of the databases was 1951), all identified research was published in the last 25 years, the majority in the late 1990s or more recently as figure 2 shows. Several included studies were published in a book on carers for people with Parkinson's disease edited by Percival and Hobson (1999).



**Figure 2: Publication year distribution**

Three of the completed studies assessed the costs of the intervention in addition to the clinical effectiveness, but did not undertake an economic evaluation (Feinberg & Whitlatch, 1998; Oxtoby, 1999; Trend et al., 2002). Only one ongoing study appears to plan to undertake an economic evaluation (Furmston, ongoing).

Complete categorisation details for all included studies are given in Appendix 5, with studies listed in alphabetical order within the categories full publications, abstract only, and ongoing research.

### 3.2.1 Published studies

Included studies, published in full or abstract only, are briefly presented in this section according to the type of study design.

#### ***Randomised controlled trials***

Three identified published projects (Lovett & Gallagher, 1988; Secker & Brown, 2005; Whitehouse, 1994) employed a randomised controlled trial (RCT) design. Key characteristics of the studies are presented in table 2.

Lovett and Gallagher (1988) randomly assigned carers of whom some cared for frail elders with Parkinson's disease (exact number unclear) to classes on increasing life satisfaction, classes on increasing problem-solving skills or a waiting list. Secker and Brown (2005; see also Brown & Secker, 2004; Brown, 2006) studied the effects of Cognitive Behavioural Therapy (CBT) for carers in a small randomised controlled trial. Whitehouse (1994) randomised patients, of which some had Parkinson's disease, to receive either support from a Parkinson's disease nurse practitioner or not; the support was also available for the carer and carer data were obtained but not reported in the publication.

Of all 3 identified published RCTs only 1 evaluated a psychosocial intervention and reported the effectiveness for the carers in a sample of exclusively carers of people with Parkinson's disease.

**Table 2: Published RCTs – key characteristics**

Project	Intervention type	Sample	Comments	Carer outcomes
Lovett, 1988	education/information; psychotherapy	111 carers (40% carers for memory impaired patients with Alzheimer s disease, PD, stroke or other dementing illness)	Two parallel groups compared to waiting list; unclear how many participants were carers for PD patients; all patients were frail elders	coping; health; other
Secker, 2005	psychotherapy	30 carers	Compared to waiting list; carers scored 5 or more ('case level problems') on the GHQ-28; good quality small RCT, though unblinded; 3 month follow-up	coping health
Whitehouse, 1994	other (nurse support)	64 patients (40 with PD) and their carers	Compared to no contact; Carer Strain Index was used but no carer outcome results were reported; the unit of randomisation was the patient and not the carer	none

Notes: PD: Parkinson's disease

### **Controlled trials**

Two identified publications described controlled trials (Haw et al., 1999; Watts et al., 1999). The key characteristics are presented in table 3.

**Table 3: Controlled trials – key characteristics**

Project	Intervention type	Sample	Comments	Carer outcomes
Haw, 1999	self-help/support group; education/information; other	22 carers, 22 patients	3 parallel groups; communication skills results not presented separately for the 3 groups	other
Watts, 1999	practical advice; psychotherapy; self-help/support group	24 carers, 36 patients	2 parallel groups, patients were aged at least 55, diagnosed for more than 6 months and with MMSE score over 20; 3 month follow-up	coping; health; other

Haw et al. (1999) studied the results of three communication therapy group formats for patients and carers. Watts et al. (1999) compared group sessions that incorporated psychological treatment or practical approaches to managing Parkinson's disease.

### **Cohort studies**

Two identified publications compared cohorts with access to different treatments (Feinberg & Whitlatch, 1998; Oxtoby, 1999). The key characteristics are presented in table 4.

**Table 4: Cohort studies – key characteristics**

Project	Intervention type	Sample	Comments	Carer outcomes
Feinberg, 1998	respite care	168 carers (12.6% for PD patients)	Compares 2 carer cohorts experiencing different care models; carers were authorised to receive in-home respite assistance by a Caregiver resource center, eligible were low-moderate income; this study was not a full economic evaluation	health, other
Oxtoby, 1999	education/information; psychotherapy; other	36 patients and their carers	Compared to patients from other consultant (prospective data collection); a cost study of the project appeared to have been performed	none

Feinberg and Whitlatch (1998) examined the preferences of cohorts of carers experiencing consumer-directed or professionally-managed respite care models; a small percentage of participants cared for a person with Parkinson's disease and costs were also reported. Oxtoby (1999; see also Oxtoby, 1988) described a controlled trial on an integrative management model for people with Parkinson's disease and their carers, however, the data collection appeared to have been primarily patient orientated with no specific information on the carer effectiveness.

### **Before-after studies**

Eight published before-after studies were identified (Boddy et al., 1992; Brandow et al., 1997; Holloway, 2006; Klein & Rivers, 2006; Sheriff & Chenoweth, 2003; Szekely et al., 1982; Taba et al., 2005; Trend et al., 2002). Of these, two were only published as a conference abstract rather than a full publication. The details are presented in table 5.

**Table 5: Before-after studies – key characteristics**

<b>Project</b>	<b>Intervention type</b>	<b>Sample</b>	<b>Comments</b>	<b>Carer outcomes</b>
<b>Full paper publications</b>				
Boddy, 1992	behavioural; self-help/support group	4 carers, 4 patients	Patients on the adult community speech therapy caseload were eligible to be included in the study; study might be the pilot for Haw, Trewhitt, Boddy & Evans (1999)	other
Holloway, 2006	education/information	21 carers, 22 patients	Data on measures of illness patterns or other outcomes showed little change over a 12-month period and were apparently therefore not presented; some publications by same author under Lloyd (e.g. Lloyd 1999 under surveys)	other
Klein, 2006	behavioural	7 carers, 8 patients	Only 4 patients (no carer) participated in post-programme evaluation for outcomes other than programme satisfaction, only the health questionnaire was used for the post evaluation	other
Sheriff, 2003	psychotherapy; education/information	25 carers, 25 patients	Patients included were those with mid-stage Parkinson's disease; no statistical results were provided	health; coping; other
Szekely, 1982	self-help/support group; practical advice; other	7 patients and their carers (family members)	Intervention was available to carers but no carer outcomes were reported; patients were mildly or moderately impaired (Hoehn stage II or III)	none
Trend, 2002	psychotherapy; behavioural; practical advice; education/information; rehabilitation; practical advice	69 carers, 118 patients	Patients with cognitive impairment were excluded; study examined patients who were enrolled in an RCT comparing treatment with delayed treatment, in which no carer intervention was reported; a cost study was also reported but this was not a full economic evaluation; 6 months follow-up (showed a trend towards greater strain)	coping health
<b>Abstract only publications</b>				
Brandow, 1997	psychotherapy; education/information	10 carers, 10 patients	Patients with significant dementia were excluded	other
Taba, 2005	education/information; psychotherapy	151 carers, 137 patients	Appears to be the same programme as evaluated by Bayés et al. (2005) under case series	coping; health; other

Boddy et al. (1992) evaluated the participants' satisfaction with group communication sessions in a very small study which appeared to have been the pilot study for the described controlled trial on communication therapy groups (Haw et al. (1999). Holloway (2006; also Holloway, 2006b and Lloyd & Chatzifotou, 2001) described a user-led care pathway approach to the management of Parkinson's

disease which included an information pack on community services and problem/needs forms for patients and carers. Klein and Rivers (2006, also Klein & Adams, 2006) asked patients and carers to evaluate a Taiji programme; pre- and post-intervention data were only obtained for a few patients. Sheriff and Chenoweth (2003) evaluated an intervention that included counselling support for carers and patient tailored targeted education and training. Szekely et al. (1982) evaluated an intervention that included practical caring advice, exercise and a support group. Trend et al. (2002) described a multidisciplinary rehabilitation intervention that included meetings for carers; the authors have also published an RCT on the patient intervention which reported carer outcomes, however, this did not mention a concrete carer intervention (Wade et al., 2003). Brandow et al. (1997) presented in a conference abstract results of a communication and problem-solving skill intervention aimed at couples. Taba et al. (2005) described in a conference abstract a cognitive behavioural education programme (EduPark) applied in several European countries which also seemed to have been evaluated by Bayés et al. (2005).

### **Case series/post-test only studies**

Five case series or post-test only studies documenting the experiences of individuals or groups with a treatment were identified (table 6).

**Table 6: Case series/post-test only studies – key characteristics**

Project	Intervention type	Sample	Comments	Carer outcomes
Full paper publications				
DeFronzo Dobkin, 2006	education/information; psychotherapy	3 carers, 3 patients	Participants were carers of patients with recurrent major depressive disorder	other
Marziali, 2005	self-help/support group	34 carers (appr. 1/3 for PD patients)	Carers of people with Alzheimer's, Stroke, or Parkinson's disease	copings; health; other
Nasar, 2006	other (PD club)	29 patients (out of 32)	Intervention was available to carers but no carer effectiveness assessment took place	none
Abstract only publications				
Bayés, 2005	education/information; psychotherapy	38 carers	Participating carers had significant depression symptoms and cared for people with early to moderate stage PD; appears to be the same programme as evaluated by Taba et al. (2005) under before-after studies	other
Gardner, 2006	education/information, practical advice	171 carers (education), 94 (further intervention)	Pre- (retrospective) and post-intervention knowledge assessed	other

Note: PD: Parkinson's disease

DeFronzo Dobkin et al. (2006) described the effects of psycho-educational sessions on three patient-carer dyads. Marziali et al. (2005) explored the benefits of an internet videoconferencing environment for carers of persons with neurodegenerative diseases including Parkinson's disease. Nasar and Bankar (2006) evaluated a Parkinson's disease club for patients and carers involving support from a multidisciplinary team but the data collection involved only patients. Bayés et al. (2005) published a conference abstract on the satisfaction with the before mentioned EduPark programme (see Taba et al., 2005). Gardner et al. (2006) evaluated an education session, skill building classes and the distribution of care-giving aids.

### **Surveys and interviews**

Several of the identified publications were written surveys and interviews with patients and carers that evaluated existing services for users rather than being a direct evaluation of an intervention implemented by the researcher. Most evaluated a number of services and provided very little information beyond that the carers have used the services and that some of the respondents liked the intervention while others did not. For consistency we have extracted the authors' conclusions for every study (see Appendix 5) but with regard to the surveys, these seldom referred to any specific psychosocial intervention for carers. Table 7 allows an overview over all 8 identified surveys and interviews.

**Table 7: Surveys and interviews – key characteristics**

Project	Intervention type	Sample	Comments	Carer outcomes
Full paper publications				
Aoun, 2006	respite care; education/information; self-help/support group; unclear	373 carers (of 1962 contacted), 38% for PD patients; 503 patients (of 1962 contacted), 34% with PD	Nationwide survey on service provision, patients included had Parkinson's disease, motor neuron disease, multiple sclerosis or Huntingtons disease	other
Birgersson, 2004	education/information; other; respite care; self-help/support group	6 carers, 6 patients	Transcribed and content analysed interviews	other
Davies, 1999	respite care	83 carers, 83 patients	Detailed responses from individual carers as free interview response	copng; other
Lieberman, 2005	self-help/support group	132 patients	Groups were also attended by carers but no results for carer were reported; publication described a further evaluation of different internet based support groups but carer were not mentioned	none
Lloyd, 1999	respite care; other	140 carers, 202 patients	A case series evaluating a care pathway is also presented which is linked to Holloway 2006	copng; other
Mott, 2005	Self-help/support group, psychotherapy, helpline, other	303 carers	A number of interventions surveyed	other
Yarrow, 1999	respite care; education/information; helpline; self-help/support group	1693 (of 2500 surveyed) 12% current carers, 10% former carers	PDS membership survey, many services covered	other
Abstract only publications				
Chibuk, 2006	education/information; helpline; practical advice; respite care; self-help/support group; behavioural; other	Over 300 carers	Several interventions surveyed	other

Notes: PD: Parkinson's disease

Aoun et al. (2006) published a nationwide survey on existing service provision; this was not restricted to carers of people with Parkinson's disease. Birgersson and Edberg (2004) interviewed six couples about their varying experiences of support. Davies et al. (1999) interviews referred to respite care and the mixed feelings it evoked. Lieberman et al. (2005) surveyed support groups attended by people with Parkinson's disease and their carers; the data collection was restricted to patients and the effects on the carer were not investigated and a further effectiveness study did not mention carers. Lloyd's survey (1999) reported how many people used and appreciated particular respite care services. Mott et al. (2005) survey asked about several support services. A large Parkinson Disease Society membership survey published by Yarrow (1999) contained also some information from carers and their satisfaction with the society. The carer survey by Chibuk et al. (2006), published as a conference abstract only, referred also to many interventions and assessed which services were most valued.

### **Unclear designs**

Two study descriptions were lacking in detail and it was unclear what research design had been applied (table 8).

**Table 8: Unclear designs– key characteristics**

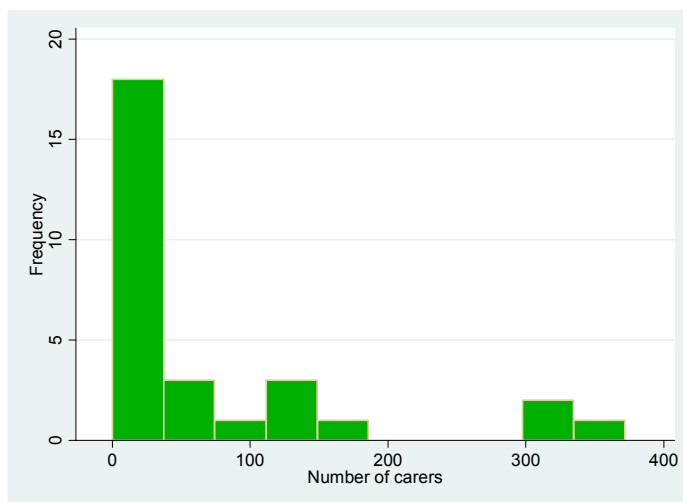
Project	Intervention type	Sample	Comments	Carer outcome
Full paper publications				
Thomas, 2002	self-help/support group, education/information	25 carers	Unclear whether a formal carer effectiveness assessment has taken place and how many carers took part in the evaluation (25 carer took part in the intervention, no further details); no statistical results were provided	coping, other
Abstract only publications				
Moore, 2006	other (care giver clinic)	49 carers	No details of outcomes provided	other

Thomas and Sweetnam (2002, see also Thomas, 2002) described an initiative involving a booklet on healthcare for carers and meetings providing information on available resources but it was unclear what format the effectiveness evaluation took. Moore (2006; 2004) reported experiences with a clinic for family caregivers in two research abstracts that gave very little information about the research methods.

*3.2.1.1 Study design summary*

The above has shown that 3 RCT evaluations of a carer intervention have been published (Lovett & Gallagher, 1988; Secker & Brown, 2005; Whitehouse, 1994), 2 studies used a controlled trial design (Haw et al., 1999; Watts et al., 1999), 2 identified studies compared different cohorts (Feinberg & Whitlatch, 1998; Oxtoby, 1999) and 8 studies used a before-after design for either carers, patients or both (Boddy et al., 1992; Brandow et al., 1997; Holloway, 2006; Klein & Rivers, 2006; Sheriff & Chenoweth, 2003; Szekely et al., 1982; Taba et al., 2005; Trend et al., 2002). All other studies presented simple evaluations (post-test only studies), followed case series or cohorts or were surveys and interviews that asked about services that respondents may have used. Two publications lacked detail so that the evaluation format remained unclear, it is however unlikely that these were RCTs or controlled trials.

The number of participants in the individual studies ranged from 3 carers and 3 patients (DeFronzo Dobkin, 2006) to a survey with 1693 respondents (of which only 12% were current carers, Yarrow, 1999). Most studies that analysed the effects of an intervention implemented by the researcher, rather than surveying existing service use, were characterised by very small numbers of participants only. Figure 3 shows a histogram of the number of participating carers for a person with Parkinson's disease for whom data were presented in the publication.



**Figure 3: Number of participating carers for person with Parkinson's disease for whom data were available**

As the figure shows, the studies represented only a small number of carers. Ten studies had ten or less participating carers for whom data were available. Excluding the survey data, the number of



participating carers in the identified publications that presented carer outcomes ranged from 3 to 137. The respective numbers in full paper publications only ranged from 3 to 69 where reported. None of the included studies reported a power calculation.

### 3.2.1.2 Interventions, orientation and providers

A variety of interventions was evaluated in the identified research. Table 9 provides a detailed overview on the investigated interventions for each included published study.

**Table 9: Intervention details**

Project identifier	Design	Intervention details
Full paper publications		
Aoun, 2006	survey	when asked what was helpful survey respondents mentioned availability of respite care, home assistance, and home care, support groups and support and information from health professionals, discussion with social worker
Birgersson, 2004	interview	a number of interventions were rated including a Parkinson out-patient service and meals on wheels
Boddy, 1992	b-a	6 weekly 2-hour group communication sessions covering speech-related topics with relevant exercises; a separate carers group ran for last quarter of the session; transport provided
Davies, 1999	interview	Respite care at home, intervention varied in duration between patients
DeFronzo Dobkin, 2006	CS	3-4 CBT-based psycho-educational sessions on PD and depression, advice on feedback to patient; patients were given concurrent CBT (12-14 sessions)
Feinberg, 1998	cohort, cost	in-home respite care either agency-based versus direct pay
Haw, 1999	CT	communication group (patient and carer together, working on communication) versus support group (patient and carer apart, patient working on communication, carers on communication and support activities) versus mixed group (1st hour together on communication issues, 2nd hour separate, patient working on communication, carers in support group)
Holloway, 2006	b-a	user-led care-pathway; information pack including details of local information and advisory services, carers centre; problems-needs form for clinic appointments; clinic summary, planned service record
Klein, 2006	b-a	twelve 45 minute Taiji classes, video and recommended home practice for patient and carer
Lieberman, 2005	survey	support groups for PD; 10-12 participants attend, half patients, half caregivers
Lloyd, 1999	survey	day care, respite care, holidays, night sitting service, community care assessment, meals service
Lovett, 1988	RCT	class on increasing life satisfaction, versus class on increasing problem-solving skills versus waiting list; weekly 2-hour sessions for 10 weeks
Marziali, 2005	CS	Web-based weekly video-conference support groups over 3 month period, computer training given
Mott, 2005	survey	A number of interventions were surveyed including: support groups, counselling, telephone helplines, websites, libraries
Nasar, 2006	CS	Parkinson's disease club co-ordinated by PD nurse; meetings every 2 months, visits from multidisciplinary team; caregivers provided with help and support to reduce emotional stress and maintain good health; carer intervention was part of a larger programme with interventions for patients
Oxtoby, 1999	cohort, cost	multidisciplinary model for the management of PD; special attention to social and emotional aspects of illness in patients and carers, involvement in monitoring and decision making (versus usual care); carer intervention was part of a larger programme with interventions for patients
Secker, 2005	RCT	11-19 weekly sessions of CBT versus no treatment/waiting list (group sessions offered to control group after study completion); respite care to enable attendance of carer
Sheriff, 2003	b-a	counselling support provided by social worker as required; education and training group sessions targeted to patients functional issues; carer intervention was part of a larger programme with interventions for patients
Szekely, 1982	b-a	13 week, 2 hour interdisciplinary group therapy; patients given exercise tapes (American Parkinson Disease Association approved exercises), encouraged to practise; patients and carers exercise together, then separate or joint discussion groups with nurse coordinator, nurse psychologist and physical therapist
Thomas, 2002	unclear	Booklet on healthcare for carers; meeting to provide information on available resources

Trend, 2002	b-a, cost	multidisciplinary rehabilitation 1 day/week for 6 weeks including elements of relaxation, information, group therapy, advice
Watts, 1999	CT	eight fortnightly group sessions (1.5hrs) of either psychological treatment group or practical approaches to managing PD; both groups included support group element
Whitehouse, 1994	RCT	non-specific support from Parkinson's disease nurse practitioner; carer intervention provided within context of 2 home visits and 5 telephone contacts to patient from Parkinson's disease nurse practitioner versus no contact
Yarrow, 1999	survey	both interventions provided by the PDS and interventions generally were surveyed
Abstract only publications		
Bayés, 2005	CS	psycho-education in Parkinson's disease program (EduPark), multiple group sessions covering the following components: self-monitoring, health empowerment, stress management, anxiety and depression, assertiveness, social support
Brandow, 1997	b-a	5 2-hour sessions teaching communication and problem-solving skills (Prevention and Relationship Enhancement Program (PREP))
Chibuk, 2006	survey	multiple services were surveyed
Gardner, 2006	CS	initial education session followed by five 2 hour sessions of skills building classes and distribution of care-giving aids; follow-up available in community; respite care available to enable participation
Moore, 2006	unclear	caregiver clinic providing information, support, advice, teaching coping skills, and encouragement to seek further help
Taba, 2005	b-a	(cognitive behavioural education) EduPark programme: 8 educational sessions on self-monitoring, health promotion, management of stress, depression and anxiety, social competence, social support

Notes: b.a.: before-after study; CBT: Cognitive behavioural therapy; CS: Case series / post-test only study; CT: controlled trial; PD: Parkinson's disease; RCT: Randomised controlled trial; CS: case series

Many of the investigated interventions appeared unique in their exact treatment approach. Most studies evaluated interventions that combined multiple elements, for example, education and information classes on Parkinson's disease, practical advice and a support group element where carers could exchange experiences.

As a specific psychotherapeutic intervention, only a CBT approach has been explicitly utilised more than once (DeFronzo Dobkin et al., 2006; Secker & Brown, 2005; compare also EduPark (Bayés et al., 2005; Taba et al. 2005). Communication was the focus of Haw et al. (1999) and the preceding study (Boddy et al., 1992) and was also integrated in Brandow et al. (1997). Many of the surveys and also six of the other evaluation studies either incorporated a support group element in their intervention package (e.g. Boddy 1992; Haw et al., 1999; Szekely et al., 1982; Thomas & Sweetnam, 2002; Watts et al., 1999) or evaluated it as a sole intervention (Marziali et al., 2005). An information or education element was part of most investigated interventions, although what information exactly was presented in the intervention was usually not reported and the information could be Parkinson's disease specific or address personal growth (psycho-education) of the carer. Respite care was mentioned in several surveys and Feinberg and Whitlatch (1998) compared different models of respite care provision. Several studies stressed the fact that their intervention package was delivered by a multidisciplinary team (Nasar & Bankar, 2006; Oxtoby, 1999; Sheriff & Chenoweth, 2003; Szekely et al., 1982; Trend et al., 2002).

Most identified studies described treatment programmes that were aimed at both, the carer and the patient. Usually this meant that there was a carer intervention embedded in a more extensive treatment programme for the patient with Parkinson's disease. In most cases, the carer element ran parallel to the patient intervention, for example in the form of carer meetings while the patients attended other therapy (e.g. Trend et al., 2002). Only in a few interventions did the patient and the carer visit the treatment programme together (e.g. Klein & Rivers, 2006; Brandow et al., 1997) or received support in joint meetings (e.g. Lieberman et al., 2005; Whitehouse, 1994). Some interventions appeared to have been mainly treatments for the patient (DeFronzo Dobkin et al., 2006; Klein & Rivers, 2006) where the carer undertook a therapist or exercise partner role, although with a clear benefit for the carer in mind (e.g. to ease frustration with Parkinson's disease symptoms). Other interventions also involved the carer in the therapy for the patient (e.g. Boddy et al., 1992 and later Haw et al., 1999) but offered additionally elements only for carers (e.g. a carer support group). Several interventions seemed to have been inspired by specific Parkinson's disease symptoms such as speech (communication), movement (Taiji) or depression (CBT). Only 9 interventions focussed entirely on the carer, judging from the identified publications. For a breakdown of the intervention orientation see Table 10.

**Table 10: Intervention orientation**

Intervention orientation	Project identifier
carer	Davies, 1999; Feinberg, 1998; Lovett, 1988; Marziali, 2005; Secker, 2005; Thomas, 2002; Bayés, 2005; Gardner, 2006; Moore, 2006
carer and patient	Boddy, 1992; Haw, 1999; Holloway, 2006; Lieberman, 2005; Nasar, 2006; Oxtoby, 1999; Sheriff, 2003; Szekely, 1982; Trend, 2002; Watts, 1999; Whitehouse, 1994; Brandow, 1997; Taba, 2005
patient	DeFronzo Dobkin, 2006; Klein 2006
unclear	Aoun, 2006 [survey]; Birgersson, 2004 [interview]; Chibuk, 2006 [survey]; Lloyd, 1999 [survey]; Mott, 2005 [survey]; Yarrow, 1999 [survey]

In the survey publications it was usually not stated what the intervention orientation was or different interventions were evaluated ranging from carer orientated to patient orientated or aiming at the carer and the patient.

For each study, we have also extracted the provider of the intervention where the information was available from the papers (see Appendix 5), so that these agencies could potentially be contacted for collaboration or further information. In most cases though, the information on the provider of the service was not available. The named organisations in the included studies were: Australian disease-specific societies including the Parkinson's Association (Aoun et al., 2006), Swedish patient organisations, county council and city council (Birgersson & Edberg, 2004); Californian care giver resource centres (Feinberg & Whitlatch, 1998); Bridlington (UK) day hospital (Nasar & Bankar, 2006); NHS (Oxtoby, 1999; Secker & Brown, 2005; Trend et al., 2002; Thomas & Sweetnam, 2002); Sidney War Memorial Hospital (Sheriff & Chenoweth, 2003); an American Parkinson's Disease Clinic (Szekely et al., 1982); Parkinson's Disease Society UK (Boddy et al., 1992), Parkinson's Disease Society branches (Watts et al., 1999); Institute of Neurology, London (Whitehouse, 1994); UK Parkinson's Disease Society and other (Yarrow, 1999); Struthers Parkinson Centre, USA (Gardner et al., 2006) and Tel Aviv Parkinson Centre (Moore, 2006).

### 3.2.1.3 Setting and method of delivery

We extracted the setting in which the evaluated intervention took place and the type of delivery method employed. The interventions varied in how much direct contact with a (usually) healthcare professional the evaluated interventions required. Table 11 gives a breakdown of the different delivery methods that were employed. We differentiated interventions where the interaction was based on a one-to-one basis with the carer (individual direct), group interventions with direct contact (group direct) and indirect interventions where for example a web page was provided (indirect).

**Table 11: Delivery method**

Delivery method	Project identifier
individual direct	Davies, 1999; DeFronzo Dobkin, 2006; Feinberg, 1998; Lloyd, 1999; Oxtoby, 1999; Secker, 2005; Whitehouse, 1994; Moore, 2006;
group direct	Boddy, 1992; Haw, 1999; Klein, 2006; Lieberman, 2005; Lovett, 1988; Nasar, 2006; Szekely, 1982; Thomas, 2002; Watts, 1999; Bayés, 2005; Brandow, 1997; Gardner, 2006; Taba, 2005
indirect	Marziali, 2005
mixture or unclear	Aoun, 2006 [survey]; Birgersson, 2004 [interview]; Holloway, 2006; Mott, 2005 [survey]; Sheriff, 2003; Trend, 2002; Yarrow, 1999 [survey]; Chibuk, 2006 [survey]

Most identified research investigated the effects of direct contact provision, either for individuals or in a group setting. No study was identified that assessed the effect of the provision of information material without an additional direct interaction element. The only indirect intervention (Marziali et al., 2005) set up a virtual support group where carers could exchange experiences. In some cases the intervention consisted of different modules that required different delivery methods or, as was principally the case for the surveys, different interventions were assessed (mixture or unclear).

Interventions were also characterised by the effort it took for the carer to attend the service. For example, home-based interventions have the advantage that no travelling is involved and usually no provision need be made for the person that is cared for. Table 12 shows where the described interventions took place.

**Table 12: Setting**

Setting	Project identifier
home-based	Davies, 1999; Feinberg, 1998; Lloyd, 1999; Marziali, 2005; Whitehouse, 1994
not home-based	Boddy, 1992; Haw, 1999; Lieberman, 2005; Lovett, 1988; Nasar, 2006; Oxtoby, 1999; Secker, 2005; Sheriff, 2003; Szekely, 1982; Thomas, 2002; Trend, 2002; Watts, 1999; Bayés, 2005; Brandow, 1997; Gardner, 2006; Moore, 2006; Taba, 2005
mixture or unclear	Aoun, 2006 [survey]; Birgersson, 2004 [interview]; DeFronzo Dobkin, 2006; Holloway, 2006; Klein, 2006; Mott, 2005 [survey]; Yarrow, 1999 [survey]; Chibuk, 2006 [survey]

Most studies evaluated an intervention that took place outside the home of the carer. Some of these interventions included respite care to enable participation (Secker & Brown, 2005; Gardner et al., 2006) or provided transport for the participants (Boddy et al., 1992). The home-based interventions took the form of respite care (Davies et al., 1999; Feinberg & Whitlatch, 1998; Lloyd, 1999), visits from a specialist nurse (Whitehouse, 1994) or an internet based support group (Marziali et al., 2005). A number of interventions involved a home and an external element (e.g. Klein & Rivers, 2006) and for all surveys it was unclear what the setting was or if it varied according to the numerous assessed services.

### 3.2.1.4 Carer and patient populations

We also wanted to establish whether any research on subgroups of carers or patients had been conducted. Table 13 summarises this aspect.

**Table 13: Carer populations**

Carer population	Project identifier
general	Davies, 1999; DeFronzo Dobkin, 2006; Haw, 1999; Holloway, 2006; Klein, 2006; Lieberman, 2005; Lloyd, 1999; Mott, 2005; Nasar, 2006; Oxtoby, 1999; Sheriff, 2003; Szekely, 1982; Thomas, 2002; Trend, 2002; Watts, 1999; Yarrow, 1999; Chibuk, 2006; Gardner, 2006; Moore, 2006; Taba, 2005
spouse	Birgersson, 2004; Boddy, 1992; Brandow, 1997
other	Aoun, 2006; Feinberg, 1998; Lovett, 1988; Marziali, 2005; Secker, 2005; Whitehouse, 1994; Bayés, 2005

Most studies appeared to have been conducted using a general, unselected set of carers rather than having studied a defined subgroup of carers. Three research projects evaluated interventions for the spouse of the person with Parkinson's disease (Boddy et al., 1992; Brandow et al., 1997) or followed the experiences with interventions of spouses (Birgersson & Edberg, 2004).

Five of the included studies (Aoun et al., 2006; Feinberg & Whitlatch, 1998; Lovett & Gallagher, 1988; Marziali et al., 2005; Whitehouse, 1994) were not restricted to carers of people with Parkinson's disease but rather included participants caring for other patient groups and were therefore not a typical sample of carers for people with Parkinson's disease. The carers in Secker and Brown (2005) had to show at least 'case level problems' on a General Health Questionnaire to be eligible for inclusion; Bayés et al. (2005) noted that the studied carers had significant depression symptoms according to a self rating scale.

We further distinguished studies that had investigated the effects of interventions for carers that cared for specific subgroups of people with Parkinson's disease. Table 14 shows that most research concerned the general population of people with Parkinson's disease.

**Table 14: Patient populations**

Patient population	Project identifier
General	Birgersson, 2004; Davies, 1999; Feinberg, 1998; Haw, 1999; Holloway, 2006; Klein, 2006; Lieberman, 2005; Lloyd, 1999; Mott, 2005; Nasar, 2006; Oxtoby, 1999; Secker, 2005; Szekely, 1982; Thomas, 2002; Yarrow, 1999; Chibuk, 2006; Gardner, 2006; Moore, 2006; Taba, 2005
Other	Aoun, 2006; Boddy, 1992; DeFronzo Dobkin, 2006; Lovett, 1988; Marziali, 2005; Sheriff, 2003; Trend, 2002; Watts, 1999; Whitehouse, 1994; Bayés, 2005; Brandow, 1997

Boddy et al. (1992) selected an all male patient sample eligible for speech therapy, Sheriff and Chenoweth (2003) included only patients with mid-stage Parkinson's disease, Trend et al. (2002) restricted their intervention to patients without cognitive impairment, Brandow et al. (1997) excluded patients with significant dementia and Watts et al. (1999) studied only patients over 55 years of age.

The other studies in this category used participant samples that consisted not entirely of people with Parkinson's disease or samples of carers that did not entirely consists of carers of people with Parkinson's disease but who cared for patients with other conditions.

Most samples in the identified studies appeared to have been convenience samples. Only few made attempts to draw a representative sample of carers of patients with Parkinson's disease (e.g. Aoun et al., 2006; Lieberman et al., 2005) or tried to enrol consecutive patients in the study (e.g. Birgersson & Edberg, 2004).

### 3.2.1.5 Outcomes

Several identified studies assessed satisfaction with the intervention; some studies based their intervention assessment entirely on this outcome. Fewer studies assessed the effectiveness of the intervention in terms of health and coping. This comes closer to the question of whether the intervention is effective, i.e. bringing about actual changes. Very few studies provided a formal indication of change, for example in comparison to the status before the intervention (before-after studies), or in comparison to an untreated control group (controlled trial, RCT). The carer outcomes employed in the included studies are presented in table 15.

**Table 15: Carer outcome details**

Project identifier	Design	Carer outcome details
Full paper publications		
Aoun, 2006	survey	helpfulness of services received
Birgersson, 2004	interview	experience of support received
Boddy, 1992	b-a	perceptions of communication problem, relevance of group, attitudes to group
Davies, 1999	interview	range of outcomes related to carer s self-perception of coping, health and impact on daily life including other responsibilities
DeFronzo Dobkin, 2006	CS	desirability, practicality and helpfulness of programme
Feinberg, 1998	cohort, cost	caregiver satisfaction with several aspects of care, Center for Epidemiological Studies Depression Scale (CES-D), respite service use and cost
Haw, 1999	CT	questionnaire on approval of intervention, whether intervention was beneficial, rating of couple s communication before and after intervention
Holloway, 2006	b-a	usefulness of information pack; benefits of problems-needs form, over-all evaluation of situation
Klein, 2006	b-a	value of programme (thematic analysis in physical, psychological and social domains), home practice
Lieberman, 2005	survey	n.a.
Lloyd, 1999	survey	service use, satisfaction with services received, free-response comments on coping
Lovett, 1988	RCT	Beck Depression Inventory (BDI), Philadelphia Geriatric Center Morale Scale, Perceived Stress Scale, Schedule for Affective Disorders and Schizophrenia, caregiver-specific unpleasant events and activities, restrictions in social activities resulting from caregiving interview, support interview, self-efficacy interview
Marziali, 2005	CS	Carer views on intervention, changes in physical and mental health; distress associated with caring, stress associated with caregiving
Mott, 2005	survey	service use and usefulness of services
Nasar, 2006	CS	carers suggested the PD club should meet every month
Oxtoby, 1999	cohort, cost	n.a.
Secker, 2005	RCT	General Health Questionnaire-28 (GHQ-28), Geriatric Depression Scale (GDS-15), Caregiver Strain Index, Caregiver Burden Inventory
Sheriff, 2003	b-a	carer health questionnaire
Szekely, 1982	b-a	n.a.
Thomas, 2002	unclear	experiences such as more time for family, coping better with caring, time for self

Trend, 2002	b-a, cost	Hospital Anxiety and Depression, Euroquol-5d, Carer Strain Index
Watts, 1999	CT	CAPE Behaviour Rating Scale, General Health Questionnaire (GHQ-28), Beck Depression Inventory (BDI), Symptom Rating Test (SRT), Machin Strain Scale, Ways of Coping with Caring checklist, helpfulness, interest, comprehensibility and opportunity to talk of intervention
Whitehouse, 1994	RCT	n.a.
Yarrow, 1999	survey	use of services; importance of services; experience of service use
Abstract only publications		
Bayés, 2005	CS	usefulness of and satisfaction with programme, willingness to participate in similar programme, would recommend programme to others
Brandow, 1997	b-a	Center for Epidemiological Studies Depression Scale (CES-D), Social Provisions Scale, global measures of health and life satisfaction, Marital Adjustment Test, Communication Patterns Questionnaire, Marital Satisfaction Inventory, State-Trait Anxiety Inventory (State)
Chibuk, 2006	survey	services needed and valued most
Gardner, 2006	CS	knowledge gain in care-giver skills
Moore, 2006	unclear	number of visits to clinic required
Taba, 2005	b-a	coping with disease-related problems, mood elevation, disease-related psychosocial problems, quality of life, depression, comprehensibility and feasibility of programme

Notes: b.a.: before-after study; CBT: Cognitive behavioural therapy; CS: Case series/post-test only study; CT: controlled trial; n.a.: not applicable as no carer outcome was reported; PD: Parkinson's disease; RCT: Randomised controlled trial; CS: case series

Many studies, and especially the surveys, asked about the satisfaction with services rather than investigating changes in terms of health or coping triggered by the intervention. Several studies that assessed the areas of health and coping employed a high number of outcome measures. Among these studies, most of the measures were of the same kind, i.e. the same assessment method such as self reports, was used rather than a mixture of assessment methods. Several of the multiple measures seemed to indicate conceptual overlap. Four studies did not report any results the intervention had on the carer (noted as 'n.a.' in the table) and collected only outcome data for the cared for person with Parkinson's disease (Lieberman et al., 2005; Oxtoby, 1999; Szekely et al., 1982; Whitehouse, 1994).

Twenty studies included patient outcomes in their data collection, either in addition to carer outcomes or as sole effect measurement. Table 16 breaks down the information on the patient outcomes. We distinguished the type of patient outcome as direct outcomes (direct), such as a health measure, as indirect effectiveness measures, such as service use (service), and as other measures such as the satisfaction with a service (other).

**Table 16: Patient outcomes**

Patient outcomes	Project identifier
None	Davies, 1999; Feinberg, 1998; Lovett, 1988; Mott, 2005 [survey]; Secker, 2005; Thomas, 2002; Bayés, 2005; Chibuk, 2006; Gardner, 2006; Moore, 2006
Direct	Boddy, 1992; DeFronzo Dobkin, 2006; Haw, 1999; Klein, 2006; Lieberman, 2005 [survey]; Lloyd, 1999; Nasar, 2006; Oxtoby, 1999; Sheriff, 2003; Szekely, 1982; Trend, 2002; Watts, 1999; Whitehouse, 1994; Brandow, 1997; Taba, 2005
Service	Marziali, 2005; Sheriff, 2003
Other	Aoun, 2006 [survey]; Birgersson, 2004 [interview]; Boddy, 1992; DeFronzo Dobkin, 2006; Haw, 1999; Holloway, 2006; Klein, 2006; Lieberman, 2005 [survey]; Oxtoby, 1999; Watts, 1999; Yarrow, 1999; Brandow, 1997; Taba, 2005

The details of the patient outcomes were also extracted for each research project and can be seen in Appendix 5.

Overall, only 2 studies went beyond self assessed health, coping or satisfaction with the programme by presenting health service use information or physician assessments of the participants, if in a rather anecdotal way. Marziali et al. (2005) reported on the delay in admission to institutional care the intervention may have enabled. Sheriff and Chenoweth (2003) reported the reduction in the number of

unplanned admissions to inpatient services as assessed by the staff. These additional assessments were restricted to patient outcomes, not carer outcomes.

### *3.2.1.6 Economic evaluations*

Three of the included published studies provided cost information regarding the intervention (Feinberg & Whitlatch, 1998; Oxtoby, 1999; Trend et al., 2002). None of these could be classified as a full economic evaluation according to the CRD guidelines for classification of economic papers in the NHS EED database (NHS Centre for Reviews and Dissemination, 2001b).

Feinberg and Whitlatch (1998) compared direct pay respite care and agency-based respite care and reported the hourly wages paid for each type of care, the number of hours of care with each type of intervention/group and the monthly bill amounts paid in each group. However, there was no estimation of the overall costs incurred by each type of care provided, nor an estimation of the obtained clinical effectiveness.

A further study appeared to report the cost estimation of the Romford Project (Oxtoby, 1999). However, a full economic evaluation did not seem to have been carried out (or at least it was not stated so in the publication), given that no comparison of the cost-effectiveness of the Romford Project with an alternative intervention was conducted.

Gage, Kaye, Owen, Trend & Wade (2006) conducted a cost estimation of the multidisciplinary rehabilitation program (Trend et al., 2002) although they did not compare these costs with those of any other alternative programmes or interventions. A description of the methods used for the cost analysis was given (i.e. data sources were reported, the price year was stated, and the costs estimated were those incurred by the health service and the travelling costs incurred by patients).

### **3.2.2 Ongoing studies**

The literature searches also identified five registered ongoing projects for which no publication was found yet. Three planned an RCT (Forsyth, ongoing; Furnston, ongoing; Leroi, ongoing), 1 a controlled trial (Laidlaw, ongoing) and for 1 (Thompson, ongoing) it was not clear which research design will be employed. The studied interventions were the use of a Lavender pillow, occupational therapy, CBT, a sleep hygiene programme and the effects of an education programme. One of the ongoing projects (Furnston, ongoing) showed the potential to be a full economic evaluation once it is finished and an appropriate economic analysis is performed. The authors mentioned that, apart from the clinical outcomes to assess the effectiveness of the interventions compared at analysis, the costs will be estimated as well. It appeared that a 'health economic form' will be used to collect the cost data across the trial. The available details of the projects are given in Appendix 5.

### **3.3 Near misses**

A number of publications were identified which did not meet all specified inclusion criteria to be eligible for inclusion in the current review but which are records of potentially interesting projects. A list of these references is presented in the Appendix 3. The references refer either to projects that may contain a carer intervention but the intervention was not evaluated, or to projects that may contain a carer element but this was not clearly stated in the publication. It is possible (though not certain) that future publications may describe these projects in sufficient detail that could establish their relevance to the current review. This resource list can be used to contact the study authors or project representatives directly if the approach appears interesting to the Parkinson's Disease Society.

### **3.4 Unavailable publications**

Appendix 4 provides a list of all citations that were identified in our searches as studies potentially meeting inclusion criteria or possibly containing references to eligible studies but a full paper of the record was not available. Thus, we were not able to verify whether the studies would meet the specified inclusion criteria and were indeed evaluations of a psychosocial intervention for non-professional carers of peoples with Parkinson's disease.

The resource list could be used to contact the author directly if the study appears to be important to the Parkinson's Disease Society. It should be noted though that several of these publications appeared to describe studies already included in the current review, usually because the study was additionally described in an accessible peer-reviewed journal. There is only a low probability that the unobtainable reviews contain references to potentially relevant studies that have not been identified already within our searches.



---

## 4 DISCUSSION

The number of identified studies suggested that some research has been dedicated to the evaluation of psychosocial interventions for non-professional carers of people with Parkinson's disease. All the available evidence was relatively new, suggesting that carers are only recently receiving more attention. On closer inspection with regard to the publication status, evidence level and characteristics of the identified studies, it becomes apparent that more high quality research is needed regarding the clinical effectiveness of interventions for carers. In addition, no existing evidence on cost-effectiveness of interventions for carers was identified and more research is needed.

### 4.1 Currently available evidence and research issues

#### *Level of evidence*

Only three identified published projects (Lovett & Gallagher, 1988; Secker & Brown, 2005; Whitehouse, 1994) employed a randomised controlled trial (RCT) design - a strong research design in which participants are randomised to either a treatment group or a control group. This is a powerful research method for evaluating effects of an intervention. It avoids confounding factors to be mistaken for a treatment effect, a common problem of weaker designs, and is therefore a scientifically sound research method. Of the three identified RCTs, only one small study investigated a dedicated Parkinson's disease carer intervention: exclusively aimed at carers and exclusively aimed at carers of people with Parkinson's disease and reported carer outcomes (Secker & Brown, 2005). This highlights the need for additional good quality well designed RCTs.

The need for a control group was obvious in several existing studies. Psychological research does traditionally reject scientifically superior randomised controlled trials as favoured in medicine. However, a number of quasi-experimental designs exists and should be applied by authors of research studies (Cook & Campbell, 1979). At least a before-after design should be in place to have an indication of change. Surveys asking participants how they currently rate services they receive provide valuable information and can direct research but are not an ideal research design to evaluate the effectiveness of interventions. Surveys only provide information from respondents, not from all people that have received an intervention. The survey data could furthermore be as much a description of the participant who has used the service as these are a description of the service (e.g. users of web information might differ from other carers). In addition, several surveys on carers have been published; as resources are limited, new research projects should rather focus on more direct evaluations of interventions, using robust research designs, and building on the information existing surveys and other studies provide.

For all evaluations of interventions for carers of people with Parkinson's disease a further research aspect has to be taken into account. The effects of the intervention have to be measured against the effects of a progressively worsening condition which can increase the carer's burden and strain considerably. Without the comparison to a control group, the positive effects of an intervention may not be detectable.

Finally, so far, no full economic evaluation of a psychosocial intervention for non-professional carers of people with Parkinson's disease has been published. All identified evaluations were essentially cost studies or part of an ongoing project. Research should evaluate apart from the clinical effectiveness also the cost effectiveness of interventions. Cost-effectiveness is an important aspect that can differentiate the usefulness of alternative interventions. The current scoping review has documented a substantial range of elaboration of interventions which intuitively suggests great differences in involved costs. Analysed programmes should take the cost of the intervention into account to establish the relationship between involved costs and benefits for carers in order to identify those interventions that provide good 'value for money'.

#### *Interventions*

This review focussed on the existing psychosocial interventions for the carers of people with Parkinson's disease. This does not allow a systematic comparison to the literature on carers of people with other conditions. However, it is obvious that currently only very little evidence exists for different therapeutic approaches applied to carers for people with Parkinson's disease. A comparison to published reviews on psychosocial interventions for the elderly (e.g. Yin, Zhou & Bashford, 2002)

indicates that rather more interventions have been evaluated for other carer groups. Given the care circumstances it is also surprising that no evaluations of systemic approaches and family therapy interventions were identified, although these have been established to support other patient-carer constellations (e.g. Sellwood et al., 2001). However, several identified research projects incorporated elements into their intervention or in the case of surveys asked about the satisfaction with therapeutic approaches that have been studied in other fields, such as cognitive behavioural therapy, support groups, respite care or multidisciplinary care approaches.

The missing research might be a reflection of missing available support for carers that could be scrutinised in research projects. If the research study also has to cover the costs of establishing a service and evaluating it, it is clear that research is restricted to research programmes with substantial funding (e.g. enabling carers to be seen by a cognitive behavioural therapist does involve substantial costs). However, it is not obvious why research is also missing on interventions that do not involve such high input, e.g. investigations of different formats of information material or investigations on what information is appropriate at which care stage; or research topics that concern the optimisation of existing services, e.g. respite care provision.

Many of the evaluated interventions that were described in the Parkinson's disease carer literature appeared unique in their approach. Although it is important that interventions are tailored to the specific needs of carers for people with Parkinson's disease, it is unclear whether the interventions in existing evaluations were derived from specific experiences or other areas that gave clear indications of promising results. Future research in such an empty research field as the literature on carers for people with Parkinson's disease should take existing evidence from related fields and indications from published studies into account when planning new research studies.

### ***Outcomes and data collection***

Another issue that needs to be considered are the outcomes employed to measure the effects of an intervention. Not all changes that can be measured are also clinically meaningful improvements. The combination of relying on statistical significance tests and a high number of outcome measures as demonstrated in several identified studies means also that the chances of statistically significant results increase above the nominal level. This said, the statistical description of results should be presented for the reader to follow the authors' conclusion. Some existing publications in the field provided only general statements, rather than numeric results that have been obtained (e.g. Sheriff & Chenoweth, 2003; Thomas & Sweetnam, 2002).

The existing literature has used a huge variety of outcome measures. While some studies asked directly about the satisfaction with the intervention, others assessed changes in carer strain. While the satisfaction is a very important factor, it might not assess the clinical effectiveness of the intervention as such, e.g. is the carer strain actually lightened. For further research, care should be taken in choosing outcomes that fulfil basic psychometric standards. For many outcomes used in the identified research studies, it is unclear how reliable the measurements are and whether they indeed succeed in assessing what they set out to assess; the former concerning the reliability and the latter concerning the validity of the measure.

Several existing studies employed a large number of measures but all measures were of the same kind, e.g. the assessment method was identical, such as entirely based on self reports. The measures indicated also a fair amount of conceptual overlap, so that the informational value was not equal to the number of employed measures. A useful addition to direct outcomes would be the assessment of objective measures such as the use of health services. In general, future research should dedicate more consideration to the quality of employed measures.

A study by Wade et al. (2003) related to the included study by Trend et al. (2002) demonstrated the importance of follow up points for the data collection but also the difficulty this imposes for research that involves progressive diseases (see also Playford, 2003). The carers appeared to be worse off six months after a patient intervention. This could indicate that it is more difficult to go back to the caring routine after an intensive intervention is withdrawn and that interventions need to be maintained rather than being offered in short spells. However, when evaluating interventions, a potential negative effect of the interventions needs to be separated from negative effects the natural course of the disease imposes, i.e. by worsening of symptoms over time; hence the need for controlled studies.

### **Participants**

In several identified studies there was no information on the effectiveness of the intervention for carers reported. Although interventions were directed at both, patients and carers, and carers took part in the intervention, the research study emphasis was on patients, not carers. In order to evaluate a carer intervention, carers need to become more the focus of research.

Apart from the identified surveys, the employed sample sizes in the existing literature on interventions for carers were very small and rarely were any attempts made to find representative samples of carer populations (or at least to distinguish defined subgroups of carers). Many of the existing studies had a pilot study character, in which an approach has been tested in a very small sample, possibly because there was no indication of effectiveness before. Future research should utilise larger samples to evaluate interventions, consulting the existing literature for indications of potential effectiveness. In order to find a sufficient number of participants that on the one hand is large enough to potentially demonstrate an effect of a clinically meaningful size and on the other hand does not waste research resources and participants' time, power analyses should be undertaken while planning a new research study. None of the identified existing research studies reported a power calculation.

Furthermore, it is important for research papers to distinguish the different stages patients and carers go through in the course of the disease. There is almost no evidence currently available that breaks down carer and patients groups in any way. Parkinson's disease can occur in relatively young people that are at different stages in their life with different demands and life styles compared to patients with a later onset. This presents very different challenges for patients as well as carers. Furthermore, Parkinson's disease as a progressive disease will elicit different support from a carer over the course of the disease. Where possible, interventions tailored for different disease stages should be evaluated. In any case, research should evaluate differential effects of interventions provided for different stages of the condition within the provided samples. A carer of a newly diagnosed person with Parkinson's disease may have different needs and issues than a carer of a person in the final stages of the disease. For example, interventions such as providing information and support may not be welcome and may be rather overwhelming for carers of newly diagnosed patients (see also Oxtoby, 1988 for a similar discussion regarding patients).

Generally, experiences with interventions can vary among individuals. For example, the existing surveys seemed to indicate that respite care triggers positive and negative responses from patients and carers. With regard to this, future research should focus on the patient and carer variables that can predict when a particular intervention is likely to be a success.

## **4.2 Identified research gaps**

From this scoping review it is clear that there is considerable scope for future research on psychosocial interventions for non-professional carers of people with Parkinson's disease.

This scoping review enables an overview of the available evidence and can be used to assess whether a synthesis of the existing literature in a systematic review would be indicated currently. Although a number of research projects have been identified, the available evidence does not suggest that a full systematic review would be useful to guide clinical decisions at the moment. It is apparent that the identified research is rather heterogeneous with few high evidence level studies and the field is characterised by a general lack of research that is aimed exclusively at carers of people with Parkinson's disease and studies that indeed assess the effectiveness of the intervention for the carers in an appropriately sized sample. This scoping review demonstrates rather a need for more primary research.

In particular, there is a need for high quality research studies. Where appropriate future studies should employ rigorous research designs such as RCTs or quasi-randomised studies to allow a clear indication of the interventions' effectiveness. As a minimum studies should consider the use of a control group given the progressive nature of the disease as discussed above. Future studies should employ larger participant samples than used in most existing research studies. Despite difficulties in recruiting participants, power calculations should be undertaken to assess beforehand how many participants are needed to demonstrate the effectiveness of the intervention. Furthermore, given the nature of the research field, the complexity of a psychosocial intervention should be acknowledged and incorporated in the research. Psychosocial interventions are likely to consist of several elements

and it is not necessarily clear what the active ingredient in such a complex system is, e.g. providing CBT for carers consists of the actual therapeutic input, but may depend also on the therapist, the frequency or method of delivery or on concomitant features such as the attention or acknowledgement of strain the carer gains, to name only a few possibilities. Appropriate steps should be undertaken for the research process and the Medical Research Council for example provides clear research guidance for the investigation of complex interventions (MRC, 2000).

Regarding the type of intervention that should be investigated further, the available evidence on psychosocial interventions for non-professional carers of people with Parkinson's disease and related carer literature on interventions for carer of other patient groups should be consulted as indicators of potentially successful interventions. From the results of this scoping review, there appear to be several approaches that could be taken further.

One example is a CBT approach, as although this has already been investigated in a randomised controlled trial (Secker & Brown, 2005), the number of participants was small and it remains to be seen whether the results hold in a larger sample of carers and can be shown as cost-effective. Two identified research abstracts (Bayés et al., 2005; Taba et al., 2005) suggested that a specific cognitive behavioural education programme (EduParc) has been piloted in several European countries; however, its effectiveness remains to be shown conclusively. A multidisciplinary rehabilitation approach has been highlighted by several authors in the existing literature, what is however missing, is the use of a rigorous research design to investigate its effectiveness. Trend et al. (2002) have also published a randomised controlled trial on a multidisciplinary approach (Wade et al., 2003); however the carer intervention appeared not to be included in this more rigorous research design. The provision of respite care is, judging from the identified surveys, widely applied as a carer intervention and has been investigated in a couple of research studies. However, very little is still known about the means of delivery and what kind of models of provision of respite care may be most effective. By no means an exhaustive list of promising approaches, these examples show that the existing literature can give concrete indications for future research.

Regarding the outcomes and data collection, more studies are needed that assess the effectiveness of an intervention with appropriate outcomes that are clinically meaningful indications of change, for example in terms of coping or health rather than simply asking about the satisfaction with the programme in question. Care should be taken to select outcomes that at least fulfil basic psychometric standards. Additionally, data should be collected on health care resource consumption required for each of the alternative psychosocial interventions to allow the assessment of the cost-effectiveness of the interventions.

In general, more research is needed that puts the carer in the focus of the research attention. Even independent of more complex issues such as the stages and predictions regarding which interventions may work for which carer, there is a basic need to collect carer data. Although this scoping review has identified several research studies that evaluated interventions available for carers, several studies reported no carer outcomes. Where interventions are available these should be evaluated in terms of their effects on the carer, rather than limiting research reports to patient outcomes. Only this will provide information about which interventions will effectively support carers in their role of caring for a person with Parkinson's disease.

---

## 5. CONCLUSIONS

This scoping review identified a small body of existing literature evaluating the effectiveness of psychosocial interventions for non-professional carers of people with Parkinson's disease. Thirty-five research projects were identified, 5 of which are ongoing. A number of different study designs were employed, in the majority these were less robust designs. Only 3 published RCTs were identified of which only 1 investigated an intervention exclusively aimed at carers of people with Parkinson's disease and reported results for carers. Two published studies were controlled trials, 2 compared different cohorts and 8 studies collected data before and after an intervention. All other published studies presented simple evaluations (post-test only) or were surveys and interviews that asked about services that respondents may have used and for 2 publications the format remained unclear. No completed economic evaluations were found.

There is considerable scope for informative future research on the effectiveness of psychosocial interventions for non-professional carers of people with Parkinson's disease. Researchers appear to have only just begun to think about the clinical and the cost effectiveness of such interventions. Not many interventions have been studied and these have mainly been evaluated with research methods that do not provide conclusive evidence on the effectiveness of the interventions. High quality research, using robust research designs, employing appropriate carer samples and incorporating the complex nature of psychosocial interventions is warranted. Future research should build on the existing evidence; this scoping review has identified several approaches that may merit further investigation. Studies should put the carer in the focus of the research attention and evaluate the effects of interventions on carers.

This overview of the available evidence, along with other existing research relating to comparable carer groups, can inform future decisions about research funding priorities.

---

## 6. REFERENCES

- Aarsland D, Larsen JP, Karlsen K, Lim NG, Tandberg E. (1999) Mental symptoms in Parkinson's disease are important contributors to caregiver distress. *International Journal of Geriatric Psychiatry* 14(10): 866-874.
- Aoun S, Kristjanson L, Oldham L. (2006) The challenges and unmet needs of people with neurodegenerative conditions and their carers. *ACCNS Journal for Community Nurses* 11(1):17-20.
- Bayés A, Crespo MC, Prats A, Villa V. (2005) Psycho-education in Parkinson's disease directed at relatives and caregivers. *Journal of the Neurological Sciences* 238:S352.
- Birgersson A, Edberg A. (2004) Being in the light or in the shade: persons with Parkinson's disease and their partners' experience of support. *International Journal of Nursing Studies* 41(6):621-630.
- Boddy M, Evans J, Lloyd C. (1992) Group communication - meeting the needs of clients and carers. *College of Speech and Language Therapy Bulletin* Sep:6-7.
- Brandow RK, McRae CA, O'Brien CF. (1997) Improving quality of life: Results of a relationship enhancement program for couples. *Movement Disorders* 12(1):134.
- Brown R. (2006) *Research Grant Summary: Code RG1: A randomised controlled trial of cognitive-behaviour therapy for carers of patients with Parkinson's disease*. London:Parkinson's Disease Society.
- Brown RG, Secker DL. (2004) A randomized controlled trial of cognitive behavioral therapy (CBT) for carers of patients with Parkinson's disease. *Movement Disorders* 19 (suppl 9):734.
- Carter JH, Stewart BJ, Archbold PG, Inoue I, Jaglin J, Lannon M, Rost Ruffner E, Tennis M, McDermott MP, Amyot D, Barter R, Cornelius L, Demong C, Dobson J, Duff J, Erickson J, Gardiner N, Gauger L, Gray P, Kanigan B, Kiryluk B, Lewis P, Mistura K, Malapira T, Zoog K. (1998) Living with a person who has Parkinson's disease: the spouse's perspective by stage of disease. Parkinson's Study Group. *Movement Disorders* 13(1):20-28.
- Chibuk ME, Kovacs-Burns KA, Yang T. (2006) Survey of caregivers of persons with Parkinson's disease in Alberta: Services needed, used and valued. *Movement Disorders* 21:S134.
- Cook TD, Campbell DT. (1979) *Quasi-experimentation: Design and analysis issues for field settings*. Boston:Houghton-Mifflin.
- Davies A, Cousins R, Turnbull CJ, Playfer JR, Bromley DB. (1999) The experience of caregiving for people with Parkinson's disease. In Percival R, Hobson P (Eds). *Parkinson's disease: studies in psychological and social care* (pp. 154-198). Leicester/London: British Psychological Society/Parkinson's Disease Society.
- Deane K, Ellis-Hill C, Jones D, Whurr R, Ben-Shlomo Y, Playford ED, Clarke CE. (2002) Systematic review of paramedical therapies for Parkinson's disease. *Movement Disorders* 17:984-991.
- DeFronzo Dobkin R, Allen LA, Menza M. (2006) A cognitive-behavioral treatment package for depression in Parkinson's disease. *Psychosomatics: Journal of Consultation Liaison Psychiatry* 47(3):259-263.
- Feinberg LF, Whitlatch CJ. (1998) Family caregivers and in-home respite options: The consumer-directed versus agency-based experience. *Journal of Gerontological Social Work* 30:9-28.
- Forsyth DR (ongoing). The effects of lavender aroma on sleep disturbance, mood and daytime function in Parkinson's patients and their carers.
- Furmsten A (ongoing). A pilot randomised controlled trial of occupational therapy to optimise independence in Parkinson's disease.

- Gage H, Kaye J, Owen C, Trend P, Wade D. (2006) Evaluating rehabilitation using cost-consequences analysis: an example in Parkinson's disease. *Clinical Rehabilitation* 20:232-238.
- Gardner JM, Johnson ML, Varpness SC, Wichmann RL, Woods MS. (2006) Creating Parkinson's disease awareness and skills for family caregivers. *Movement Disorder* 21:S136.
- Haw C, Trewhitt T, Boddy M, Evans J. (1999) Involving carers in communication groups for people with Parkinson's disease. In R. Percival & P. Hobson (Eds.), *Parkinson's disease: studies in psychological and social care*. Leicester: BPS Books.
- Holloway M, (2006) Traversing the network: a user-led care pathway approach to the management of Parkinson's disease in the community. *Health & Social Care in the Community* 14(1):63-73.
- Holloway M, (2006b) Pathways through care: a patient/care giver approach to the management of Parkinson's disease in the community. *Movement Disorders* 21:S44-S45.
- Kahn KS, Kunz R, Kleijnen J, Antes G. (2003) *Systematic reviews to support evidence-based medicine: how to review and apply findings of healthcare research*. London: Royal Society of Medicine Press Ltd.
- Klein PJ, Adams WJ. (2006) Taiji buddies: An instructional video for individuals with Parkinson's and their support partners. *Movement Disorders* 21: S142.
- Klein PJ, Rivers L. (2006) Taiji for individuals with Parkinson disease and their support partners: program evaluation. *Journal of Neurologic Physical Therapy* 30(1):22-27.
- Laidlaw KM (ongoing). Single case analysis of the benefits to patients and carers of cognitive behaviour therapy for depression in Parkinson's disease.
- Leroi ID. (ongoing). A pilot study of a sleep hygiene education program vs. placebo in Parkinson's Disease sufferers: effect on carer well-being.
- Lieberman MA, Winzelberg A, Golant M, Wakahiro M, DiMinno M, Aminoff M, Christine C. (2005) Online support groups for Parkinson's patients: a pilot study of effectiveness. *Social Work in Health Care* 42(2):23-38.
- Lloyd M. (1999) The new community care for people with Parkinson's disease and their carers. In R. Percival & P. Hobson (Eds.), *Parkinson's disease: studies in psychological and social care*. Leicester: BPS Books.
- Lloyd M, Chatzifotiou S. (2001) Using the resources of the service user in the management of the care pathway. (An intervention to improve the care pathways for Parkinson's disease patients and their carers) *Practice*, 13:55-66.
- Lovett S, Gallagher D. (1988) Psychoeducational interventions for family caregivers: preliminary efficacy data. *Behavior Therapy* 19(3):321-330.
- Marziali E, Donahue P, Crossin G. (2005) Caring for others: internet health care support intervention for family caregivers of persons with Alzheimer's, stroke, or Parkinson's disease. *Families in Society* 86(3):375-383.
- Microsoft Corporation. Excel [computer program]. Redmond, WA. 2003.
- Moher D, Fortin P, Jadad AR, Juni P, Klassen T, Le Lorier J, Liberati A, Lindeet K, Penna A. (1996) Completeness of reporting of trials published in languages other than English: Implications for conduct and reporting of systematic reviews. *Lancet* 347: 363-366.
- Moore O. (2004) Family caregivers of Parkinson's disease patients deserve professionals attention and support: A report from one year of experience with caregivers' clinic. *Movement Disorder* 19: S232.

- Moore O. (2006) Clinic for family caregivers of Parkinson's disease patients. *Movement Disorders* 21: S48.
- Mott S, Kenrick M, Dixon M, Bird G. (2005) Living with Parkinson's disease: the carer's perspective. *International Journal of Therapy and Rehabilitation* 2(4):159-164.
- MRC. (2000) *A framework for development and evaluation of RCTs for complex interventions to improve health*. London: Medical Research Council.
- Nasar M, Bankar R. (2006) Improving outcome in Parkinson's disease. *British Journal of Hospital Medicine* 67(1):6-7.
- NHS Centre for Reviews and Dissemination. (2001) *Undertaking systematic reviews of research on effectiveness. CRD's guidance for those carrying out or commissioning reviews*. 2<sup>nd</sup> ed. CRD Report No. 4. York: NHS Centre for Reviews and Dissemination.
- NHS Centre for Reviews and Dissemination (2001b). *Improving access to cost-effectiveness information for health care decision-making: The NHS Economic Evaluation Database*. 2<sup>nd</sup> ed. CRD Report No. 6. York: NHS Centre for Reviews and Dissemination.
- O'Reilly F, Finnan F, Allwright S, Smith GD, Ben-Shlomo Y. (1996) The effects of caring for a spouse with Parkinson's disease on social, psychological and physical well-being. *British Journal of General Practice* 46(410):507-512.
- Oxtoby M. (1999) The Romford Project: action research in a time of rapid change. In Percival & R & Hobson & P (Eds.), *Parkinson's Disease: studies in psychological and social care*. Leicester: British Psychological Society.
- Oxtoby M, Findley L, Kelson N, Pearce P, Porteous A, Thurgood S, Wood A. (1988) *A strategy for the management of Parkinson's disease and for the long-term support of patients and their carers*. London: Parkinson's Disease Society.
- Percival R, Hobson P. (1999) *Parkinson's Disease: studies in psychological and social care*. Leicester: British Psychological Society.
- Playford ED. (2003) Multidisciplinary rehabilitation for people with Parkinson's disease. *J Neurol Neurosurg Psychiatry* 74:148-149.
- Secker DL, Brown RG. (2005) Cognitive behavioural therapy (CBT) for carers of patients with Parkinson's disease: A preliminary randomised controlled trial. *Journal of Neurology, Neurosurgery & Psychiatry* 76(4):491-497.
- Sellwood W, Barrowclough C, TARRIER N, Quinn J, Mainwaring J, Lewis S. (2001). Needs-based cognitive-behavioural family intervention for carers of patients suffering from schizophrenia: 12-month follow-up. *Acta Psychiatr Scand*;104(5):346-55.
- Sheriff JN, Chenoweth L. (2003) Challenges in conducting research to improve the health of people with Parkinson's disease and the well-being of their family carers. *International Journal of Rehabilitation Research* 26(3):201-205.
- Stoltz P, Uden G, Willman A. (2004) Support for family carers who care for an elderly person at home – a systematic literature review. *Scand J Caring Sc* 18:111-119.
- Szekely B, Neiberg Kosanovich N, Sheppard W. (1982) Adjunctive treatment in Parkinson's disease: physical therapy and comprehensive group therapy. *Rehabil Lit* 43:72-76.
- Taba P, Kanarik E, Krikmann U, Macht M, Simons G, Spliethoff-Kamminga NGA, Ricci Bitti PE, Lankinen A, Bayés Rusinol A. (2005) Cognitive behavioural education programme for Parkinsonian patients and carers. *Journal of the Neurological Sciences* 238:S371-S372.



- Thomas S. (2002) First steps to carer health. *Primary Health Care* 11:16-17.
- Thomas S, Sweetnam C. (2002) Clinical update. Parkinson's disease: caring for the carers. *Primary Health Care* 12(4):27-31.
- Thompson SBN. (ongoing). Evaluation of an education programme for people with Parkinson's disease (PD) and their carers.
- Thomson Scientific. Endnote [computer program] version 9. Carlsbad, CA, 2006. Available from: <http://www.endnote.com/>
- Trend P, Kaye J, Gage H, Owen C, Wade D. (2002) Short-term effectiveness of intensive multidisciplinary rehabilitation for people with Parkinson's disease and their carers. *Clinical Rehabilitation* 16: 717-725.
- Wade DT, Gage H, Owen C, Trend P, Grossmith C, Kaye J. (2003) Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study. *Journal of Neurology, Neurosurgery & Psychiatry* 74(2):158-162.
- Watts S, Kaiser P, Porter J, Cockton N, Morley M. (1999) *A psychological group approach to meeting the needs of people with Parkinson's disease and their carers*. In: R Percival and P Hobson (Eds.), *Parkinson's disease: Studies in psychological and social care*. Leicester: BPS Books: 199-216.
- Whitehouse C. (1994). A new source of support: the nurse practitioner role in Parkinson's disease and dystonia. *Professional Nurse* 9(7):448, 450-441.
- Yarrow S. (1999). Members' 1998 survey of the Parkinson's Disease Society of the United Kingdom. In Percival R, Hobson P (Eds.), *Parkinson's disease: studies in psychological and social care*. Leicester: BPS Books: 79-82.
- Yin T, Zhou Q, Bashford C. (2002) Burden on family members: Caring for the frail elderly: A meta-analysis of interventions. *Nursing Research* 51(3):199-208.

---

## APPENDIX 1: SEARCH STRATEGIES

### Databases Searched

The following databases were searched in order to retrieve references to studies relating to interventions for carers of people with Parkinson's disease (PD):

### Databases of Systematic Reviews

Cochrane Database of Systematic Reviews (CDSR) (Cochrane Library: <http://www.library.nhs.uk/>)  
Database of Abstracts of Reviews of Effects (DARE) (CRD Internal Database)

### Health/Medical Related Databases

Allied and Complementary Medicine Database (AMED) (OvidWeb: <http://gateway.ovid.com/athens>)  
British Nursing Index (BNI) (OvidWeb: <http://gateway.ovid.com/athens>)  
CENTRAL (Cochrane Central Register of Controlled Trials) (Cochrane Library: <http://www.library.nhs.uk/>)  
Cumulative Index to Nursing and Allied Health Literature (CINAHL) (OvidWeb: <http://gateway.ovid.com/athens>)  
EMBASE (OvidWeb: <http://gateway.ovid.com/athens>)  
Health Management Information Consortium (HMIC) (HELMIS, DHdata and the King's Fund databases) (OvidWeb: <http://gateway.ovid.com/athens>)  
Health Technology Assessment Database (HTA) (CRD Internal Database)  
MEDLINE (OvidWeb: <http://gateway.ovid.com/athens>)  
MEDLINE In Process and other non-indexed citations (OvidWeb: <http://gateway.ovid.com/athens>)  
PsycINFO (OvidWeb: <http://gateway.ovid.com/athens>)

### Social Care Databases

Applied Social Sciences Index and Abstracts (ASSIA) (CSA Illumina: <http://uk1.csa.com/>)  
International Bibliography of the Social Sciences (IBSS) (OvidWeb: <http://gateway.ovid.com/athens>)  
Register of Interventions and Policy Evaluation (C2 – RIPE) (Campbell Collaboration: <http://www.campbellcollaboration.org/frontend.asp>)  
Social Care Online (SCIE <http://www.scie-socialcareonline.org.uk/>)  
Social Science Citation Index (SSCI) (Web of Science: <http://wos.mimas.ac.uk/>)  
Social Services Abstracts (CSA Illumina: <http://uk1.csa.com/>)  
Social, Psychological, Educational and Criminological Trials Register (C2-SPECTR) (Campbell Collaboration: <http://128.91.199.101/>)  
Sociological Abstracts (CSA Illumina: <http://uk1.csa.com/>)

### Databases of Conference Proceedings

ISI Proceedings: science and technology (Web of Knowledge: <http://wos.mimas.ac.uk/>)  
ISI Proceedings: social sciences and humanities (Web of Knowledge: <http://wos.mimas.ac.uk/>)

### Economic Databases

EconLit (WebSPIRS: <http://arc.uk.ovid.com/>)  
Health Economics Evaluation Database (HEED) (CD-ROM)  
NHS Economic Evaluation Database (NHS EED) (CRD Internal Database)

### Databases for Ongoing and Recently Completed Research

ClinicalTrials.gov  
ESRC SocietyToday Database (<http://www.esrc.ac.uk/ESRCInfoCentre/index.aspx>)  
MetaRegister of Controlled Trials (<http://www.controlled-trials.com/>)  
National Research Register (NRR) (<http://www.update-software.com/national/>)  
Research Findings Electronic Register (ReFeR)  
([http://www.info.doh.gov.uk/doh/refr\\_web.nsf/Home?OpenForm](http://www.info.doh.gov.uk/doh/refr_web.nsf/Home?OpenForm))

## Search strategies

The search terms were chosen to achieve a balance between recall and precision. The searches did not discriminate between services for the carers and the cared for. Search terms for the interventions were not used as not to miss interventions that were not known beforehand or new to the field. A variety of keywords and search terms were used to indicate the study population (carers) and the condition (Parkinson's disease).

The 'soft' nature of this topic makes producing a search strategy with high precision difficult. Many of the keywords relevant to the topic have multiple meanings and/or are commonly used words in other contexts. Social science databases often lack abstracts or have little or no indexing. This can restrict sophisticated searching. The search strategies are therefore as comprehensive as possible within the restrictions of the interfaces. No language or date restrictions were applied to the search strategies.

## Databases of systematic reviews

### Cochrane Database of Systematic Reviews (CDSR)

Searched via: The Cochrane Library: <http://www.library.nhs.uk/>

Issue 2: 2006

Date Searched: 05/07/06 .

This search strategy retrieved 146 reviews (121 completed and 25 protocols);

#1 Caregiv\* or care giv\* or carer\* or informal care or befriending or caretak\* or care taker\* or care taking

#2 Caregivers/

#3 child\* next (care or cares or caring or support or supports or supporting)

#4 (son or sons or daughter\* or friend\* or partner\* or spous\*) next (care or cares or caring or support or supports or supporting)

#5 (husband\* or wives or wife or spouse\* or grandparent\* or grandchild\* or neighbour\* or neighbor\* or relatives or relations or families or family or familial) next (care or cares or caring or support or supports or supporting)

#6 (parent\* or mother\* or father\* or maternal or paternal or filial) next (care or cares or caring or support or supports or supporting)

#7 (peer or peers) next (care or cares or caring or support or supports or supporting)

#8 parkinson\*

#9 exp parkinsonian disorders/

#10 ramsay hunt paralysis syndrome\* or Paralysis Agitans or Hemiparkinsonism or shaking palsy or basal ganglia disease

#11 #1 or #2 or #3 or #4 or #5 or #6 or #7

#12 #8 or #9 or #10

#13 #11 and #12

### Database of Abstracts of Reviews of Effects (DARE)

Searched via: CRD internal database

Version: July 2006

Date Searched: 05/07/06

This search strategy produced 10 records;

S caregiv\$ or care(w)giv\$ or carer\$ or informal(w)care or befriending or caretak\$ or care(w)taker\$ or care(w)taking

S child\$(w)(care or cares or caring or support or supports or supporting)

S (son or sons or daughter\$ or friend\$ or partner\$ or spous\$(w))(care or cares or caring or support or supports or supporting)

S (husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial)(w)(care or cares or caring or support or supports or supporting)

S (parent\$ or mother\$ or father\$ or maternal or paternal or filial)(w)(care or cares or caring or support or supports or supporting)

S (peer or peers)(w)(care or cares or caring or support or supports or supporting)

S parkinson\$

S ramsay(w)hunt(w)paralysis(w)syndrome\$ or Paralysis(w)Agitans or Hemiparkinsonism or shaking(w)palsy or basal(w)ganglia(w)disease

S s1 or s2 or s3 or s4 or s5 or s6

S s7 or s8  
S s9 and s10

## Health/Medical Related Databases

### Allied and Complementary Medicine Database (AMED)

- 1 caregiv\$.ti,ab. (1523)
- 2 care giv\$.ti,ab. (69)
- 3 carer\$.ti,ab. (818)
- 4 informal care.ti,ab. (48)
- 5 befriending.ti,ab. (5)
- 6 caretak\$.ti,ab. (55)
- 7 care taker\$.ti,ab. (2)
- 8 care taking.ti,ab. (4)
- 9 caregivers/ (1278)
- 10 (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (488)
- 11 ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (187)
- 12 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (1015)
- 13 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (258)
- 14 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (77)
- 15 parkinson\$.ti,ab. (752)
- 16 basal ganglia disease/ or parkinson disease/ (634)
- 17 ramsay hunt paralysis syndrome\$.ti,ab. (0)
- 18 Paralysis Agitans.ti,ab. (5)
- 19 Hemiparkinsonism.ti,ab. (2)
- 20 shaking palsy.ti,ab. (0)
- 21 basal ganglia disease.ti,ab. (1)
- 22 or/1-14 (4092)
- 23 or/15-21 (797)
- 24 22 and 23 (30)

### British Nursing Index (BNI)

Searched via: OvidWeb: <http://gateway.ovid.com/athens>

Date Range: 1985 to June 2006

Date Searched: 05/07/06

This search strategy retrieved 21 records;

- 1 caregiv\$.ti,ab. (981)
- 2 care giv\$.ti,ab. (55)
- 3 carer\$.ti,ab. (1943)
- 4 informal care.ti,ab. (40)
- 5 befriending.ti,ab. (13)
- 6 caretak\$.ti,ab. (14)
- 7 care taker\$.ti,ab. (1)
- 8 care taking.ti,ab. (8)
- 9 carers/ or respite care/ (1912)
- 10 (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (1343)
- 11 ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (273)
- 12 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (1199)
- 13 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (778)
- 14 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (77)
- 15 parkinson\$.ti,ab. (353)
- 16 parkinson disease/ (203)

- 17 ramsay hunt paralysis syndrome\$.ti,ab. (0)
- 18 Paralysis Agitans.ti,ab. (0)
- 19 Hemiparkinsonism.ti,ab. (0)
- 20 shaking palsy.ti,ab. (0)
- 21 basal ganglia disease.ti,ab. (0)
- 22 or/1-14 (6150)
- 23 or/15-21 (354)
- 24 22 and 23 (21)

### **CENTRAL (Cochrane Central Register of Controlled Trials)**

Searched via: The Cochrane Library: <http://www.library.nhs.uk/>

Version: Issue 2: 2006

Date Searched: 05/07/06

The same search strategy was used as for the Cochrane Database of Systematic Reviews (CDSR).  
This resulted in 35 records.

### **Cumulative Index to Nursing and Allied Health Literature (CINAHL)**

Searched via: OvidWeb: <http://gateway.ovid.com/athens>

Date Range: 1982 to June Week 5 2006

Date Searched: 05/07/06

This search strategy retrieved 132 records;

- 1 caregiv\$.ti,ab. (9856)
- 2 care giv\$.ti,ab. (1154)
- 3 carer\$.ti,ab. (3017)
- 4 informal care.ti,ab. (181)
- 5 befriending.ti,ab. (15)
- 6 caretak\$.ti,ab. (459)
- 7 care taker\$.ti,ab. (15)
- 8 care taking.ti,ab. (61)
- 9 Caregivers/ (6191)
- 10 (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (3949)
- 11 ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (978)
- 12 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (4061)
- 13 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (2101)
- 14 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (501)
- 15 parkinson\$.ti,ab. (2225)
- 16 basal ganglia diseases/ or parkinson disease/ (2384)
- 17 ramsay hunt paralysis syndrome\$.ti,ab. (0)
- 18 Paralysis Agitans.ti,ab. (1)
- 19 Hemiparkinsonism.ti,ab. (2)
- 20 shaking palsy.ti,ab. (2)
- 21 basal ganglia disease.ti,ab. (3)
- 22 or/1-14 (25061)
- 23 or/15-21 (2755)
- 24 22 and 23 (132)

### **EMBASE**

Searched via: OvidWeb: <http://gateway.ovid.com/athens>

Search Range: 1980 to 2006 Week 26

Date Searched: 05/07/06

This search strategy resulted in 312 records.

- 1 caregiv\$.ti,ab. (9445)
- 2 care giv\$.ti,ab. (797)
- 3 carer\$.ti,ab. (2665)
- 4 informal care.ti,ab. (303)
- 5 befriending.ti,ab. (20)

- 6 caretak\$.ti,ab. (1392)
- 7 care taker\$.ti,ab. (32)
- 8 care taking.ti,ab. (113)
- 9 caregiver/ (10231)
- 10 (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (10025)
- 11 ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (1807)
- 12 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (8046)
- 13 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (5658)
- 14 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (618)
- 15 parkinson\$.ti,ab. (33191)
- 16 parkinson disease/ or parkinsonism/ (36267)
- 17 ramsay hunt paralysis syndrome\$.ti,ab. (0)
- 18 Paralysis Agitans.ti,ab. (30)
- 19 Hemiparkinsonism.ti,ab. (154)
- 20 shaking palsy.ti,ab. (18)
- 21 basal ganglia disease.ti,ab. (53)
- 22 or/1-14 (38048)
- 23 or/15-21 (42139)
- 24 22 and 23 (312)

#### **Health Management Information Consortium (HMIC)**

Searched via: OvidWeb: <http://gateway.ovid.com/athens>

Date Ranges: HELMIS 1984 - 98, DHdata 1983 – 2006/05 and the King's Fund database 1979 – 2006/05

Date Searched: 05/07/06

This search resulted in 19 records;

- 1 caregiv\$.ti,ab. (399)
- 2 care giv\$.ti,ab. (137)
- 3 carer\$.ti,ab. (4553)
- 4 informal care.ti,ab. (259)
- 5 befriending.ti,ab. (54)
- 6 caretak\$.ti,ab. (43)
- 7 care taker\$.ti,ab. (1)
- 8 care taking.ti,ab. (29)
- 9 carers/ or family care/ or home care/ or "home care of patient"/ or personal care/ (4200)
- 10 (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (3543)
- 11 ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (616)
- 12 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (1859)
- 13 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (882)
- 14 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (116)
- 15 parkinson\$.ti,ab. (96)
- 16 parkinsons disease/ (74)
- 17 ramsay hunt paralysis syndrome\$.ti,ab. (0)
- 18 Paralysis Agitans.ti,ab. (0)
- 19 Hemiparkinsonism.ti,ab. (0)
- 20 shaking palsy.ti,ab. (0)
- 21 basal ganglia disease.ti,ab. (0)
- 22 or/1-14 (12488)
- 23 or/15-21 (108)
- 24 22 and 23 (19)

## Health Technology Assessment Database (HTA)

Searched via: CRD internal database

Version: July 2006

Date Searched: 20/07/06.

The same search strategy was used as for the DARE database. This search produced no records.

## MEDLINE

Searched via: OvidWeb: <http://gateway.ovid.com/athens>

Date Range: 1966 to June Week 3 2006

Date Searched: 05/07/06

This search strategy retrieved 256 records;

- 1 caregiv\$.ti,ab. (13641)
- 2 care giv\$.ti,ab. (2348)
- 3 carer\$.ti,ab. (3469)
- 4 informal care.ti,ab. (353)
- 5 befriending.ti,ab. (35)
- 6 caretak\$.ti,ab. (1864)
- 7 care taker\$.ti,ab. (62)
- 8 care taking.ti,ab. (114)
- 9 Caregivers/ (9620)
- 10 (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (10464)
- 11 ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (1386)
- 12 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (7111)
- 13 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (5120)
- 14 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (671)
- 15 parkinson\$.ti,ab. (38029)
- 16 exp parkinsonian disorders/ (33151)
- 17 ramsay hunt paralysis syndrome\$.ti,ab. (0)
- 18 Paralysis Agitans.ti,ab. (66)
- 19 Hemiparkinsonism.ti,ab. (160)
- 20 shaking palsy.ti,ab. (19)
- 21 basal ganglia disease.ti,ab. (52)
- 22 or/1-14 (44983)
- 23 or/15-21 (44711)
- 24 22 and 23 (256)

## MEDLINE In-Process, Other Non-Indexed Citations

Searched via: OvidWeb: <http://gateway.ovid.com/athens>

Date Range: July 03, 2006

Date Searched: 05/07/06

This search strategy retrieved 13 records;

- 1 caregiv\$.ti,ab. (583)
- 2 care giv\$.ti,ab. (67)
- 3 carer\$.ti,ab. (120)
- 4 informal care.ti,ab. (19)
- 5 befriending.ti,ab. (2)
- 6 caretak\$.ti,ab. (47)
- 7 care taker\$.ti,ab. (1)
- 8 care taking.ti,ab. (4)
- 9 (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (233)
- 10 ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (54)
- 11 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (215)

- 12 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (168)
- 13 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (40)
- 14 parkinson\$.ti,ab. (993)
- 15 ramsay hunt paralysis syndrome\$.ti,ab. (0)
- 16 Paralysis Agitans.ti,ab. (0)
- 17 Hemiparkinsonism.ti,ab. (4)
- 18 shaking palsy.ti,ab. (0)
- 19 basal ganglia disease.ti,ab. (1)
- 20 or/1-13 (1391)
- 21 or/14-19 (995)
- 22 20 and 21 (13)

### PsycINFO

Searched via: OvidWeb: <http://gateway.ovid.com/athens>

Date Range: 1967 to June Week 4 2006

Date Searched: 05/07/06

This search yielded 144 records;

- 1 caregiv\$.ti,ab. (15551)
- 2 care giv\$.ti,ab. (394)
- 3 carer\$.ti,ab. (2390)
- 4 informal care.ti,ab. (239)
- 5 befriending.ti,ab. (65)
- 6 caretak\$.ti,ab. (2624)
- 7 care taker\$.ti,ab. (17)
- 8 care taking.ti,ab. (74)
- 9 caregivers/ or caregiver burden/ (9572)
- 10 (child\$ adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (12744)
- 11 ((son or sons or daughter\$ or friend\$ or partner\$ or spouse\$) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (3535)
- 12 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (12205)
- 13 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (9546)
- 14 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).ti,ab. (1749)
- 15 parkinson\$.ti,ab. (7874)
- 16 parkinsons disease/ or parkinsonism/ (5824)
- 17 ramsay hunt paralysis syndrome\$.ti,ab. (0)
- 18 Paralysis Agitans.ti,ab. (13)
- 19 Hemiparkinsonism.ti,ab. (22)
- 20 shaking palsy.ti,ab. (4)
- 21 basal ganglia disease.ti,ab. (16)
- 22 or/1-14 (50450)
- 23 or/15-21 (8063)
- 24 22 and 23 (144)

### Social Care Databases

#### Applied Social Sciences Index and Abstracts (ASSIA)

Searched via: CSA Illumina: <http://uk1.csa.com/>

Date Range: 1987 – Current

Date Searched: 14/07/06

This search strategy retrieved 85 records;

(KW=(ramsay hunt paralysis syndrome\* or Paralysis Agitans or Hemiparkinsonism or shaking palsy or basal ganglia disease or parkinson\*) or DE= (ramsay hunt paralysis syndrome\* or Paralysis Agitans or Hemiparkinsonism or shaking palsy or basal ganglia disease or parkinson\*) or TI=(ramsay hunt paralysis syndrome\* or Paralysis Agitans or Hemiparkinsonism or shaking palsy or basal ganglia disease or parkinson\*) or AB=(ramsay hunt paralysis syndrome\* or Paralysis Agitans or Hemiparkinsonism or shaking palsy or basal ganglia disease or parkinson\*)) and (KW=(Caregiv\* or



carer\* or befriending or caretak\* or care or cares or caring or support or supports or supporting) or DE=(Caregiv\* or carer\* or befriending or caretak\* or care or cares or caring or support or supports or supporting) or TI=(Caregiv\* or carer\* or befriending or caretak\* or care or cares or caring or support or supports or supporting) or AB=(Caregiv\* or carer\* or befriending or caretak\* or care or cares or caring or support or supports or supporting))

### **International Bibliography of the Social Sciences (IBSS)**

Searched via: OvidWeb: <http://gateway.ovid.com/athens>

Date Range: 1951 to July Week 01 2006

Date Searched: 05/07/06

The following search strategies retrieved 1 record;

- 1 caregiv\$.mp. (537)
- 2 care giv\$.mp. (38)
- 3 carer\$.mp. (351)
- 4 informal care.mp. (102)
- 5 befriending.mp. (6)
- 6 caretak\$.mp. (93)
- 7 care taker\$.mp. (2)
- 8 care taking.mp. (6)
- 9 (child\$ adj2 (care or cares or caring or support or supports or supporting)).mp. (2157)
- 10 ((son or sons or daughter\$ or friend\$ or partner\$ or spous\$) adj2 (care or cares or caring or support or supports or supporting)).mp. (255)
- 11 ((husband\$ or wives or wife or spouse\$ or grandparent\$ or grandchild\$ or neighbour\$ or neighbor\$ or relatives or relations or families or family or familial) adj2 (care or cares or caring or support or supports or supporting)).mp. (1182)
- 12 ((parent\$ or mother\$ or father\$ or maternal or paternal or filial) adj2 (care or cares or caring or support or supports or supporting)).mp. (654)
- 13 ((peer or peers) adj2 (care or cares or caring or support or supports or supporting)).mp. (56)
- 14 parkinson\$.mp. (28)
- 15 ramsay hunt paralysis syndrome\$.mp. (0)
- 16 Paralysis Agitans.mp. (0)
- 17 Hemiparkinsonism.mp. (0)
- 18 shaking palsy.mp. (0)
- 19 basal ganglia disease.mp. (0)
- 20 or/1-13 (4419)
- 21 or/14-19 (28)
- 22 20 and 21 (1)

### **Register of Interventions and Policy Evaluation (C2 – RIPE)**

Searched via: The Campbell Collaboration: <http://www.campbellcollaboration.org/frontend.asp>.

Date Searched: 17/07/06

This website was browsed for relevant studies. No relevant studies were identified.

### **Social Care Online**

Searched via: <http://www.scie-socialcareonline.org.uk/>

Date Searched: 17/07/06

The following search strategy retrieved 81 records (26 records contained an author named Parkinson but were not about Parkinson's disease and were therefore not entered into the Endnote Library).

@p=("parkinson\*" or "ramsay hunt paralysis syndrome\*" or "Paralysis Agitans" or "Hemiparkinsonism" or "shaking palsy" or "basal ganglia disease") or @k=("parkinsons")

### **Social Science Citation Index (SSCI)**

Searched via: Web of Science: <http://wos.mimas.ac.uk/>

Date Range: 1956- Present

Date Searched: 17/07/06

This interface does not accept terms such as 'taking' in 'care taking', so this term was excluded from the search strategy. This search retrieved 231 records;

#1 Caregiv\* or care giv\* or carer\* or informal care or befriending or caretak\* or care taker\*

#2 child\* and (care or cares or caring or support or supports or supporting)

#3 (son or sons or daughter\* or friend\* or partner\* or spous\*) and (care or cares or caring or support or supports or supporting)  
#4 (husband\* or wives or wife or spouse\* or grandparent\* or grandchild\* or neighbour\* or neighbor\* or relatives or relations or families or family or familial) and (care or cares or caring or support or supports or supporting)  
#5 (parent\* or mother\* or father\* or maternal or paternal or filial) and (care or cares or caring or support or supports or supporting)  
#6 (peer or peers) and (care or cares or caring or support or supports or supporting)  
#7 #1 or #2 or #3 or #4 or #5 or #6  
#8 parkinson\* or ramsay hunt paralysis syndrome\* or Paralysis Agitans or Hemiparkinsonism or shaking palsy or basal ganglia disease  
#9 #7 and #8

### **Social Services Abstracts**

Searched via: CSA Illumina: <http://uk1.csa.com/>

Date Range: 1979- Current

Date Searched: 14/07/06

This database was searched with the same search strategy as ASSIA and retrieved 13 records.

### **Social, Psychological, Educational and Criminological Trials Register (C2-SPECTR)**

Searched via: The Campbell Collaboration: <http://128.91.199.101/>

Date Searched: 17/07/06

Because this database is small and has a simple search interface only the 'parkinsons' terms were searched for in indexed and non-indexed fields and automatic truncation was selected. This search retrieved 1 record;

Terms searched in Indexed fields: parkinsons

OR

Terms searched in non-indexed fields: ramsay hunt paralysis syndrome or Paralysis Agitans or Hemiparkinsonism or shaking palsy or basal ganglia disease

### **Sociological Abstracts**

Searched via: CSA Illumina: <http://uk1.csa.com/>

Date Range: 1952- Current

Date Searched: 14/07/06

This database was searched with the same search strategy as ASSIA and retrieved 10 records.

### **Databases of Conference Proceedings**

#### **ISI Proceedings: science & technology**

Searched via: Web of Knowledge: <http://wos.mimas.ac.uk/>

Date Range: 1990 – Present

Date Searched: 17/07/06

This database was searched with the same search strategy as SSCI and retrieved 95 records.

#### **ISI Proceedings: social sciences and humanities**

Searched via: Web of Knowledge: <http://wos.mimas.ac.uk/>

1990 - Present

Date Searched: 17/07/06

This database was searched with the same search strategy as SSCI and retrieved 7 records.

### **Economic databases**

#### **EconLit**

Searched via: WebSPIRS: <http://arc.uk.ovid.com/>

Date Range: 1969 – 2006/05

Date Searched: 05/07/06

This search retrieved 2 records.

#1 Caregiv\* or care giv\* or carer\* or informal care or befriending or caretak\* or care taker\* or care taking

#2 child\* adj (care or cares or caring or support or supports or supporting)

#3 (son or sons or daughter\* or friend\* or partner\* or spous\*) adj (care or cares or caring or support or supports or supporting)  
#4 (husband\* or wives or wife or spouse\* or grandparent\* or grandchild\* or neighbour\* or neighbor\* or relatives or relations or families or family or familial) adj (care or cares or caring or support or supports or supporting)  
#5 (parent\* or mother\* or father\* or maternal or paternal or filial) adj (care or cares or caring or support or supports or supporting)  
#6 (peer or peers) adj (care or cares or caring or support or supports or supporting)  
#7 parkinson\*  
#8 ramsay hunt paralysis syndrome\* or Paralysis Agitans or Hemiparkinsonism or shaking palsy or basal ganglia disease  
#9 #1 or #2 or #3 or #4 or #5 or #6  
#10 #7 or #8  
#11 #9 and #10

#### **Health Economics Evaluation Database (HEED)**

Searched via: CD-ROM

Version: Issue: July 2006

Date Searched: 18/07/06

This search strategy retrieved 51 records.

(parkinson\* or 'ramsay hunt paralysis' or 'Paralysis Agitans' or 'Hemiparkinsonism' or 'shaking palsy' or 'basal ganglia disease') And (Caregiver OR carer OR befriending OR caretaker OR care OR cares OR caring OR support OR supports OR supporting)

#### **NHS Economic Evaluation Database (NHS EED)**

Searched via: CRD Internal Database

Version: July 2006

Date Searched: 05/07/06

The same search strategy was used as for DARE. This search produced 11 records.

#### **Databases for Ongoing and Recently Completed Research**

##### **ClinicalTrials.gov**

Searched via: <http://www.clinicaltrials.gov/>

Searched: 21/07/06

This search retrieved 17 records of which 2 were deemed potentially relevant and entered into the Endnote Library.

(parkinson OR parkinsons OR ramsay hunt paralysis syndrome or Paralysis Agitans OR Hemiparkinsonism OR shaking palsy OR basal ganglia disease) AND (Caregiver OR caregivers OR carer OR carers OR befriending OR caretaker OR caretakers OR care OR cares OR caring OR support OR supports OR supporting) [ALL-FIELDS]

##### **ESRC SocietyToday Database**

Searched via: <http://www.esrc.ac.uk/ESRCInfoCentre/index.aspx>

Searched: 17/07/06

This search strategy retrieved 7 records (all of which were not relevant and none of which were imported into the Endnote library).

Any of these words;

parkinson ramsay hunt paralysis agitans hemiparkinsonism shaking ganglia

##### **MetaRegister of Controlled Trials**

Searched via: <http://www.controlled-trials.com/>

Searched: 20/07/06

All registers (except clinicaltrials.gov) were searched using a series of searches. This search strategy retrieved 41 records (one study was deemed potentially relevant and imported into the Endnote library).

Any of these words

parkinson parkinsons ramsay hunt paralysis agitans hemiparkinsonism shaking ganglia

### National Research Register (NRR)

Searched via: <http://www.update-software.com/national/>

Version: Issue 2: 2005.

Date Searched: 20/07/05.

This search retrieved 230, many of which were duplicates within the database. 34 were deemed potentially relevant and entered into the Endnote Library.

#1 (parkinson\* or (ramsay next hunt next paralysis next syndrome\*) or (paralysis next agitans) or hemiparkinsonism or (shaking next palsy) or (basal next ganglia next disease))

#2 (carer\* or caregiv\* or (care next giv\*) or (informal next care) or befriending or caretaker\* or (care next taker\*) or care)

#1 and #2

### Research Findings Electronic Register (ReFeR)

Searched via: [http://www.info.doh.gov.uk/doh/refr\\_web.nsf/Home?OpenForm](http://www.info.doh.gov.uk/doh/refr_web.nsf/Home?OpenForm)

Date Searched: 20/07/06

This search strategy retrieved 10 records (all of which were not relevant and none was imported into the Endnote library).

parkinson\* OR "ramsay hunt paralysis syndrome" or "Paralysis Agitans" or Hemiparkinsonism or "shaking palsy" or "basal ganglia disease"

### Tables of Records Retrieved

#### Databases of Systematic Reviews

Database	Host	Dates covered	Date searched	Records Retrieved
CDSR	Internet	2006 Issue 2	05/07/06	146
DARE	CRD Internal Database	July 2006	05/07/06	10

#### Health/Medical Related Databases

Database	Host	Dates covered	Date searched	Records Retrieved
AMED	OvidWeb	1985 – June 2006	05/07/06	30
BNI	OvidWeb	1985 – June 2006	05/07/06	21
CENTRAL	Internet	Issue 2 2006	05/07/06	35
CINAHL	OvidWeb	1982 – June Week 5 2006	05/07/06	132
EMBASE	OvidWeb	1980 – 2006 Week 26	05/07/06	312
HMIC – King's Fund Database, Dhdata and HELMIS	OvidWeb	HELMIS 1984 - 98, DHdata 1983 – 2006/05 and King's Fund Database 1979 – 2006/05	05/07/06	19
HTA	CRD Internal Database	July 2006	20/07/06	0
MEDLINE	OvidWeb	1966 – June Week 3 2006	05/07/06	256
MEDLINE in process	OvidWeb	3 <sup>rd</sup> July 2006	05/07/06	13
PsycINFO	OvidWeb	1967 – June Week 4 2006	05/06/07	144

### Social Care Databases

Database	Host	Dates covered	Date searched	Records Retrieved
ASSIA	CSA illumine	1987 – Current	14/07/06	85
IBSS	OvidWeb	1951 – July Week 01 2006	05/07/06	1
C2 - RIPE	Internet	July 2006	17/07/06	0
Social Care Online	Internet	July 2006	17/07/06	81
SSCI	Web of Science	1956 – Present	17/07/06	231
Social Services Abstracts	CSA illumine	1979 – Current	14/07/06	13
C2-SPECTR	Internet	July 2006	17/07/06	1
Sociological Abstracts	CSA illumine	1952 - Current	14/07/06	10

### Databases of Conference Proceedings

Database	Host	Dates covered	Date searched	Records Retrieved
ISI Proceedings: Science and Technology	Web of Science	1990 - Present	17/07/06	95
ISI Proceedings: Social Sciences and Humanities	Web of Science	1990 – Present	17/07/06	7

### Economic Databases

Database	Host	Dates covered	Date searched	Records Retrieved
EconLit	WebSPIRS	1969 – 2006/05	05/07/06	2
HEED	CD – ROM	July 2006	18/07/06	51
NHS EED	Internet	July 2006	05/07/06	11

### Databases for Ongoing and Recently Completed Research

Database	Host	Date searched	Records Retrieved
ClinicalTrials.gov	Internet	21/07/06	17
ESRC	Internet	17/07/06	7
MetaRegister of Controlled Trials	Internet	20/07/06	41
NRR	Internet	20/07/06	230
ReFeR	Internet	20/07/06	10

### Bibliographic Records Retrieved

Total Records Retrieved: 2011

Records Retrieved after deduplication: 1379

Records entered into the Endnote Library after deduplication

### Internet searches

The following internet sites were also searched in September 2006 to identify further research:

Northwest PADRECC/ Portland/Seattle (Northwest) PADRECC

<http://www.va.gov/portland/PADRECC/index.htm>

Center for Parkinson's Disease and Movement Disorders/ San Francisco PADRECC

<http://www.sf.med.va.gov/general.asp?durki=427>

Los Angeles (Southwest) PADRECC

<http://www.parkinsons.va.gov/PARKINSONS/SouthWest/index.asp>

Philadelphia PADRECC  
<http://www.parkinsons.va.gov/PARKINSONS/Philadelphia/index.asp>

Houston PADRECC <http://www.parkinsons.va.gov/PARKINSONS/Houston/index.asp>

Richmond (Southeast) PADRECC  
<http://www1.va.gov/netsix-padrecc/>

American Parkinson Disease Association  
<http://www.apdaparkinson.org/user/index.asp>

European Parkinson's Disease Association (EPDA) <http://www.epda.eu.com/>

National Parkinson Foundation  
[www.parkinson.org](http://www.parkinson.org)

Parkinsonpoly  
<http://www.parkinsonpoly.org.uk>

Family Caregiver Alliance  
[www.caregiver.org](http://www.caregiver.org)

Duplicate report

Carers UK : Carers Online  
<http://www.carersonline.org.uk>

### **Screening of bibliographies**

The references of all obtained full paper copies of publications were screened for further potential studies meeting inclusion criteria or further publications which may contain references to further potential studies meeting inclusion criteria.

---

## APPENDIX 2: CATEGORISATION OF RESEARCH PROJECTS

Below are the categories used to code the research projects that met the inclusion criteria. Each field in the database used to code and extract the data is described in terms of content, data type, which categories were used and further information on the definition of the categories.

**Author:** First author

Field type: free text

- Name of first author of study

**Year:** Publication year

Field type: free text

- Publication year, empty field for ongoing projects

**Identifier:** Unique Endnote number

Field type: free text

- Endnote number including hash key, multiple Endnote numbers for duplicate publications of the same study

**Reference:** Bibliographic details

Field type: free text

- Full reference of main publication and further identified publications of the same project

**Data Source:** Source coding was based on

Field type: mutually exclusive

Categories

- full paper
- abstract
  - Only published as conference abstract
- database
  - Entry from ongoing research database

**Research status:** Published studies versus research record

Field type: mutually exclusive

Categories

- Completed
- Ongoing
  - Used for trial registry entries only, not for promises of further research / extensions of project

**Country:** Research location

Field type: free text

- Country study was conducted in

**Study design:** Type of study/formal design

Field type: multiple options

Categories

- RCT
  - Randomised Controlled Trial: participants are randomly assigned to different treatment groups
- controlled trial
  - quasi-experimental, study with control group, group allocation is controlled by experimenter / investigator
- cohort study
  - Compares different cohorts of whom only one has experienced a particular intervention
- before-after study
  - Pre and post intervention data is available

- case series
  - Case series / post-test only studies: simple evaluation, data collection after intervention only
- case study
  - Progress of one person is studied
- survey
  - Survey on existing service rather than intervention implementation
- economic evaluation
  - Cost-effectiveness, cost-minimisation analysis, cost-consequences analysis, cost-utility analysis or cost benefit analysis
- cost
  - Cost data provided but no full economic evaluation
- other
- unclear

**Sample size:** Sample size

Field type: free text

- Available information on number of participating carers, or carers and patients or patients alone where applicable; for surveys the number of surveyed participants is also stated together with number of respondents where available

**Intervention type:** Intervention classification

Field type: multiple options

Categories

- psychotherapy
  - CBT, coping strategies, family therapy, counselling
- self-help / support group
  - support comes primarily from non-professionals
- behavioural
  - carer behaviour, incl. relaxation, behaviour therapy
- practical advice
  - practical care improvement advice, incl. Health & Safety, accident prevention training, lifting techniques
- telephone helpline
  - (specific but common intervention)
- education/information
  - leaflet, web page, information / explanation
- respite care
  - Patient or carer and patient intervention
- rehabilitation
  - Specific interventions unclear
- other
- unclear

**Intervention details:** Detailed intervention description

Field type: free text

- Specified exact method where stated (name or short explanation) and provides brief description with regard to the intensity and the duration of the intervention (e.g. 5 sessions a 1h)

**Provider:** Provider of intervention

Field type: free text

- Specified intervention provider where stated (e.g. NHS)

**Orientation:** Intervention orientation

Field type: mutually exclusive

Categories

- carer
  - Carer orientated



- patient
  - Patient orientated
- both
  - Carer and patient orientated
- neither
  - (rare exception)
- unclear

**Delivery method:** Method of delivery for intervention

Field type: multiple options

Categories

- individual direct
  - Direct contact on individual basis (e.g. therapist, outreach worker, email contact)
- group direct
  - direct contact with group (e.g. group therapy)
- indirect
  - e.g. written material, web page
- other
- unclear

**Setting:** Setting intervention took place

Field type: multiple options

Categories

- home-based
  - 'intervention comes to carer', including web page access, email contact, help line, written leaflet to take home, even applies to respite care as carer does not need to go anywhere
- not home based
  - carer needs to go somewhere for interventions, patient and carer live at home
- Other
- Unclear

**Carer population:** Carer sample description

Field type: mutually exclusive

Categories

- general
  - sample of carers for people with Parkinson's disease
- other
  - mixed carer samples (not exclusively caring for person with Parkinson's disease); indication that specific subgroup was studied
- spouse
- younger carers
  - children and adolescents
- older carers
  - over 65
- ethnic minority
- other subgroup
  - defined subgroups other than the above mentioned
- unclear

**Patient population:** Cared for person sample description

Field type: multiple options

Categories

- general
  - sample of people with Parkinson's disease
- other
  - mixed patient samples (not exclusively Parkinson's disease); indication that specific subgroup was studied

- younger patients
  - exclusively under 65
- older patients
  - exclusively over 65
- female only
- male only
- other subgroups
  - defined subgroups other than the above mentioned
- unclear

**Carer outcome:** Carer outcome type

Field type: multiple options

Categories

- coping
  - ratings of psychological coping with carer situation such as Caregiver Strain, Caregiver Burden, Caregiver Hassles, Quality of Life, Life satisfaction
- health
  - medical data, physical / health consequences of caring such as General Health, Symptom Checklist, Accessing of healthcare resources
- other
  - e.g. satisfaction with service
- unclear
- none

**Carer outcome details:** Specific carer outcomes

Field type: free text

- Outcomes used for the assessment including the type of assessment method were available and not obvious from the name (e.g. 'Questionnaire')

**Patient outcome:** Outcome type for person with Parkinson's disease (PD)

Field type: multiple options

Categories

- direct
  - Disease progression, Dependency / independence of living, Cognitive function, Physical function, Depression, Anxiety, Dementia, Quality of Life, Life satisfaction, Barthel index
- service
  - Accessing of healthcare resources
- other
  - e.g. satisfaction with service
- unclear
- none

**Patient outcome details:** Specific outcomes for person with (PD)

Field type: free text

- Outcomes used for the assessment including the type of assessment method were available and not obvious from the name (e.g. 'Questionnaire')

**Economic evaluation:** Economic evaluation study type

Field type: multiple options

Categories

- cost-effectiveness analysis
- cost-minimisation analysis
- cost-consequences analysis
- cost-utility analysis
- cost-benefit analysis
- other
  - e.g. cost of intervention reported by no comparison
- unclear
- none

**Authors conclusions:** Authors' conclusions

Field type: multiple options

- The authors' conclusions were stated. Without critical appraisal, the study results and authors' conclusions must be read with caution rather than an unbiased assessment of the evidence

**Comments:** Methodological comments

Field type: free text

- Comments, primarily regarding the methodology, such as RCTs in which patients, not carers were randomised to treatment groups

**DB Record:** Consecutive number

Field type: automatically generated

- Consecutive number of included research study for database cross-references

---

## APPENDIX 3: NEAR MISSES

Full paper copies of these potentially relevant descriptions of projects were ordered and obtained. The identified publication did not meet all specified inclusion criteria for the current review. However, a future publication may describe an evaluation of a psychosocial intervention for non-professional carers of people with Parkinson's disease. Several service descriptions appear promising and the Parkinson Disease Society might decide to establish contact with the authors of the descriptions:

Jones, C, Bowron, A, Wood, B, Walker, R. (2005) Developing a Parkinson's Disease service. *Professional Nurse*.20(7):22-24.

[service appears to be aimed at carer as well, but no specific carer intervention was reported]

Hurwitz, A. (1986) Home visiting by nursing students to patients with Parkinson's disease. *Journal of Neuroscience Nursing*.18(6):344-348.

Hurwitz, B, Bajekal, et al. (1999) Evaluating community-based Parkinson's disease nurse specialists: rationale, methodology, and representativeness of patient sample in a large randomized controlled trial. *Adv Neurol*. 80:431-438.

Jarman, B, Hurwitz, et al. (2002) Effects of community based nurses specialising in Parkinson's disease on health outcome and costs: randomised controlled trial. *BMJ*.324:1072-1075.

Hurwitz, B, Jarman, et al. (2005) Scientific evaluation of community-based Parkinson's disease nurse specialists on patient outcomes and health care costs. *Journal of Evaluation in Clinical Practice*. 11(2):97-110.

[the programme could contain a carer intervention, but none of the existing publications meets all inclusion criteria]

Ellgring, J, H. (1999) Depression, psychosis, and dementia: Impact on the family. *Neurology*. 52(7 SUPPL.):S17-S20.

Ellgring, H, Seiler, et al. (1993) Psychosocial aspects of Parkinson's disease. *Neurology*. Dec; 43 (suppl 6):S41-S44.

[probably a psychosocial intervention for carers with Parkinson's disease, but these available publications are not evaluations of such]

Van Tilburg, L. (1989) California's Regional Resource Centers: A program serving families and caregivers of brain-impaired adults. *Pride Institute Journal of Long Term Home Health Care* 8:12-21.

[publication does not meet inclusion criteria but the Centre has (unpublished) evaluations of their services and can be contacted directly]

Diaz, N, Bronstein, J, M. (2005) Parkinson's Disease Research Education and Clinical Centers (PADRECC): Background and overview. *Neurorehabilitation*. 20(3):153-160.

Bluestone, A. (2005) Out beyond the waves. *Families, Systems, & Health*. 23(1):115-120.

Pinkston, M E, Linsk, L N. (1984) Behavioral family intervention with the impaired elderly. *Gerontologist*.24(6):576-583.

Mapp, S. (1995) Holiday home. (Parkinson disease respite care). *Community Care*. 31 Aug - 6 Sept(1083):19.

Moore, K, A, Seeney, F. Parkinson's disease: How sufferers and carers cope. *International Journal of Psychology*. 1996;31(3-4):5663-5663.

Suddes, M. Managed Care: Evaluating the Impact of a Multidisciplinary Care Pathway and the Care Programme Approach in Parkinson's Disease . Ongoing project.

Hall, M. Reducing Caregiver Stress and Sleep Disturbances in Patients With Progressive Dementia. Ongoing project.

---

## APPENDIX 4: UNAVAILABLE PUBLICATIONS

The following records were identified in our searches as potential includes, further information on included projects or publications that potentially refer to further relevant studies but a full paper of the record was not available.

### **Potential further studies**

A full publication would be necessary to verify whether the study meets the specified inclusion criteria and the study is indeed an evaluation of a psychosocial intervention for non-professional carers of people with Parkinson's disease:

Ellgring H, Nagel K, Rosner J, Oertel W. Die Angehörigen-Seminare in München. dPV Nachrichten 1987; 11: 15-19. [author contacted, no reply]

White, Leroy. Whole Systems for Improving Continuing Care for People with Parkinson's Disease and Their Carers. In: Javor, Andras, Eimeren v, Wilhelm, Duru, Gerard, editors. Publications I: The 7th International Conference on System Science in Health Care, 29 May 2 June 2000, Budapest, Hungary. Villeurbanne, France: International Society for System Science in Health Care; 2000. p. 177-82. [Leroy White, University of Bristol contacted, no reply]

### **Further information on included studies**

Boddy, Margaret, Evans, Jane, Lloyd, Caroline. Group communication - meeting the needs of clients and carers. College of Speech and Language Therapy Bulletin 1992;Sep vol:no 485 p6-7. [further information on included project, see Haw, 1999]

Oxtoby, M. Starting from the beginning: a new approach to the management of PD. The Parkinsonian 1989. 3. Project RN. Final Report. London: Parkinson's Disease Society, 1993. [further information on included project, see Oxtoby, 1999]

Lloyd, M. Assessment and Service Provision under the New Community Care arrangements for People with Parkinson's Disease and their Carers. Manchester: University of Manchester; 1998. Report No.: 13. [further information on included project, see Holloway, 2005]

### **Reviews, potential (if unlikely) source for further new studies meeting inclusion criteria**

Cutler, Loraine. Counseling caregivers. Generations: Journal of the American Society on Aging 1985;10:53-57. [not Parkinson's disease specific]

Greenberg, E V. A Daily Break: Respite and Personal Care for the Caregiver. In: Radin, Lisa, Radin, Gary, editors. What if it's not Alzheimer's? A caregiver's guide to dementia. Amherst, NY: Prometheus Books; 2003. p. 305-10. [probably review article, not Parkinson's disease specific]

---

## APPENDIX 5: DETAILS OF INCLUDED STUDIES AND ONGOING PROJECTS

The research descriptions that met inclusion criteria are presented here. They appear in alphabetical order within the categories published full paper studies, studies published as conference abstract only, and ongoing projects.

### Full papers

**Author:** Aoun

**Year:** 2006

**References**

Aoun S. Kristjanson L, Oldham L. The challenges and unmet needs of people with neurodegenerative conditions and their carers. Journal for Community Nurses, 2006, 11: 17-20.

**Identifier:** #584

**Coding source:** full paper

**Research status:** completed

**Country:** Australia

**Study design:** survey

**Sample size**

373 carers (of 1962 contacted), 38% for PD patients, 503 patients (of 1962 contacted), 34% with PD

**Intervention type**

respite care; education/information; self-help/support group; unclear

**Intervention description**

when asked what was helpful survey respondents mentioned availability of respite care, home assistance, and home care, support groups and support and information from health professionals, discussion with social worker.

**Provider**

Disease-specific societies including the Parkinson's association and others

**Orientation:**

unclear

**Delivery method**

individual direct; group direct; unclear

**Setting:** unclear

**Carer population**

other

**Patient population**

other

**Carer outcome**

other

**Carer outcome details**

helpfulness of services received

**Patient outcome:**

other

**Patient outcome details**

helpfulness of services received

**Economic evaluation:**

none

**Authors conclusions**

The results highlighted the need for novel, tailored and flexible models of care for patients in each diagnostic group, as each had a unique care requirements.

**Comments**

Nationwide survey on service provision, patients included had Parkinson's disease, motor neuron disease, multiple sclerosis or Huntington s disease

**DB Record Number:** 34

## Full papers (Contd)

**Author:** Birgersson

**Year:** 2004

### **References**

Birgersson AMB, Edberg A-K. Being in the light or in the shade: persons with Parkinson's disease and their partners' experience of support. International Journal of Nursing Studies 2004; 41: 621-630.

**Identifier:** #708

**Coding source:** full paper

**Research status:** completed

**Country:** Sweden

**Study design:** other

### **Sample size**

6 carers, 6 patients

### **Intervention type**

education/information; other; respite care; self-help/support group

### **Intervention description**

a number of interventions were rated including a Parkinson out-patient service and meals on wheels

### **Provider**

sources including patient organisations, county council and city council

### **Orientation**

unclear

### **Delivery method**

unclear

### **Setting**

unclear

### **Carer population**

spouse

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

experience of support received

### **Patient outcome**

other

### **Patient outcome details**

experience of support received

### **Economic evaluation**

none

### **Authors conclusions**

There is a need for more specialised and individually adjusted support.

### **Comments**

Transcribed and content analysed interviews

**DB Record Number:** 17

## Full papers (Contd)

**Author:** Boddy

**Year:** 1992

### **References**

Boddy M, Evans J, Lloyd C. Group communication - meeting the needs of clients and carers. College of Speech and Language Therapy Bulletin 1992, September: 6-7.

**Identifier:** #805

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** before-after study

### **Sample size**

4 patients, 4 carers

### **Intervention type**

Behavioural; self-help/support group

### **Intervention description**

6 weekly 2-hour group communication sessions covering speech-related topics with relevant exercises; a separate carers group ran for last quarter of the session; transport provided

### **Provider**

Parkinson's Disease Society; unclear

### **Orientation**

both

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

spouse

### **Patient population**

male only; other

### **Carer outcome**

other

### **Carer outcome details**

perceptions of communication problem, relevance of group, attitudes to group

### **Patient outcome**

other

### **Patient outcome details**

perceptions of communication problem, realism about communication, improvement in communication, attitudes to group

### **Economic evaluation**

none

### **Authors conclusions**

This approach provided a sympathetic and positive communicative environment which enabled people to demonstrate their potential.

### **Comments**

Patients on the adult community speech therapy caseload were eligible to be included in the study; study might be the pilot for Haw, Trewhitt, Boddy & Evans (1999)

**DB Record Number:** 35



## Full papers (Contd)

**Author:** Davies

**Year:** 1999

### **References**

Davies ADM, Cousins R, Turnbull CJ, Playfer JR, Bromley DR. The experience of caring for people with Parkinson's Disease. In: Parkinson's disease: studies in psychological and social care. Percival R, Hobson P (Eds) London : BPS Books , 1999. Chap 7: p155-196

**Identifier:** #1674

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** other (interview)

### **Sample size**

83 carers, 83 patients

### **Intervention type**

respite care

### **Intervention description**

respite care at home, Intervention varied in duration between patients

### **Provider**

unclear

### **Orientation**

carer

### **Delivery method**

individual direct

### **Setting**

home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

coping; other

### **Carer outcome details**

range of outcomes related to carer's self-perception of coping, health and impact on daily life including other responsibilities

### **Patient outcome**

none

### **Patient outcome details**

n.a.

### **Economic evaluation**

none

### **Authors conclusions**

There are very few sources of professional emotional support for PD carers, respite care can improve a carer's ability to cope.

### **Comments**

Detailed responses from individual carers from interview

**DB Record Number:** 10

## Full papers (Contd)

**Author:** DeFronzo Dobkin

**Year:** 2006

### **References**

DeFronzo Dobkin R, Allen LA, Menza M. A cognitive-behavioural treatment package for depression in Parkinson's Disease. Psychosomatics 2006; 47: 259-263.

**Identifier:** #686

**Coding source:** full paper

**Research status:** completed

**Country:** USA

**Study design:** case series

### **Sample size**

3 patients, 3 carers

### **Intervention type**

education/information; psychotherapy

### **Intervention description**

3-4 CBT-based psychoeducational sessions on PD and depression, advice on feedback to patient; patients were given concurrent CBT (12-14 sessions)

### **Provider**

unclear

### **Orientation**

patient

### **Delivery method**

individual direct

### **Setting**

unclear

### **Carer population**

general

### **Patient population**

other subgroup

### **Carer outcome**

other

### **Carer outcome details**

desirability, practicality and helpfulness of programme

### **Patient outcome**

Direct; other

### **Patient outcome details**

Hamilton Rating Scale for Depression, Beck Depression Inventory, Inference Questionnaire, State-Trait Anxiety Inventory, Adaptive Inferential Feedback Questionnaire, desirability, practicality and helpfulness of programme

### **Economic evaluation**

none

### **Authors conclusions**

Providing carers with a specific set of skills can potentially ameliorate the impact of caregiver burden on PD patients' psychosocial adjustment.

### **Comments**

Participants were carers of patients with recurrent major depressive disorder.

**DB Record Number:** 32

## Full papers (Contd)

**Author:** Feinberg

**Year:** 1998

### **References**

Feinberg LF, Whittlatch CJ. Family caregivers and in-home respite options: the consumer-directed versus agency-based experience. Journal of Gerontological Social Work 1998; 30: 9-28

**Identifier:** #764

**Coding source:** full paper

**Research status:** completed

**Country:** USA

**Study design:** cohort study; cost study

### **Sample size**

168 carers (12.6% for PD patient)

### **Intervention type**

respite care

### **Intervention description**

in-home respite care either agency-based versus direct pay

### **Provider**

Caregiver resource centers

### **Orientation**

carer

### **Delivery method**

individual direct

### **Setting**

home-based

### **Carer population**

other

### **Patient population**

general

### **Carer outcome**

health; other

### **Carer outcome details**

caregiver satisfaction with several aspects of care, Center for Epidemiological Studies Depression Scale (CES-D), respite service use and cost

### **Patient outcome**

none

### **Patient outcome details**

n.a.

### **Economic evaluation**

Other

### **Authors conclusions**

There is a clear preference for consumer direction in respite care in the home.

### **Comments**

Compares 2 carer cohorts experiencing different care models; carers were authorised to receive in-home respite assistance by a Caregiver resource center, eligible were low-moderate income; this study was not a full economic evaluation

**DB Record Number:** 13

## Full papers (Contd)

**Author:** Haw

**Year:** 1999

### **References**

Haw C, Trehwitt P, Boddy M, Evans J. Involving carers in communication groups for people with Parkinson's disease. In: Parkinson's disease: studies in psychological and social care. Percival R, Hobson P (Eds) London : BPS Books , 1999. Chap10: 229-235

**Identifier:** #1686

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** controlled trial

### **Sample size**

22 carers, 22 patients

### **Intervention type**

self-help/support group; education/information; other

### **Intervention description**

communication therapy groups: communication group (patient and carer together for whole period working on communication) versus support group (patient and carer apart for whole period, patient working on communication and carers on communication and support activities) versus mixed group (1st hour together on communication issues, 2nd hour separate, patient working on communication, carers in support group)

**Provider:** unclear

### **Orientation**

both

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

questionnaire on approval of intervention, whether intervention was beneficial, rating of couple's communication before and after intervention

### **Patient outcome**

Direct; other

### **Patient outcome details**

communication skills, questionnaire on approval of intervention, activity ratings, home observation rating by carer, rating of couple's communication before and after intervention

### **Economic evaluation**

none

### **Authors conclusions**

Speech and language therapy needs to develop a partnership with patients and their carers; carers should have greater access to support.

### **Comments**

3 parallel groups; communication skills results not presented separately for the three groups

**DB Record Number:** 14

## Full papers (Contd)

**Author:** Holloway

**Year:** 2005

### **References**

Holloway M. Traversing the network: a user-led Care Pathway approach to the management of Parkinson's disease in the community. Health and Social Care in the Community 2005; 14: 63-73.

Holloway M. Pathways through care: A patient/care giver approach to the management of Parkinson's disease in the community. Movement Disorders 2006; 21: S13: O155.

Lloyd M, Chatzifotiou S. Using the resources of the service user in the management of the care pathway. Practice 2001; 13: 55-66.

**Identifier:** #1109, #114; #1408;

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** before-after study

### **Sample size**

22 patients, 21 carers

### **Intervention type**

education/information

### **Intervention description**

user-led care-pathway; information pack including details of local information and advisory services, carers' centre; problems-needs form for clinic appointments; clinic summary, planned service record

**Provider:** unclear

**Orientation:** both

### **Delivery method**

Indirect; direct

### **Setting**

home-based; not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

usefulness of information pack; benefits of problems-needs form, over-all evaluation of situation

### **Patient outcome**

other

### **Patient outcome details**

usefulness of information pack; benefits of problems-needs form, over-all evaluation of situation

### **Economic evaluation**

none

### **Authors conclusions**

The Care pathway framework is feasible within normal clinic procedures and improves patients' care.

### **Comments**

Data on measures of illness patterns or other outcomes showed little change over a 12-month period and were apparently therefore not presented; some publications by same author under Lloyd (e.g. Lloyd 1999 under surveys)

**DB Record Number:** 9

## Full papers (Contd)

**Author:** Klein

**Year:** 2006

### **References**

Klein PJ, Rivers L. Taiji for individuals with Parkinson's disease and their support partners: Program Evaluation. Journal of Neurological Physical Therapy 2006; 30: 22-27.

Klein PJ, Adams WJ. Taiji buddies: An instructional video for individuals with Parkinson's and their support partners. Movement Disorders 2006; 21: S142

**Identifier:** #103, #1416

**Coding source:** full paper

**Research status:** completed

**Country:** USA

**Study design:** before-after study

### **Sample size**

7 carers, 8 patients

### **Intervention type**

behavioural

### **Intervention description**

twelve 45 minute Taiji classes, video and recommended home practice for patient and carer

### **Provider**

unclear

### **Orientation**

patient

### **Delivery method**

group direct

### **Setting**

not home-based; home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

value of programme (thematic analysis in physical, psychological and social domains), home practice

### **Patient outcome**

Other; direct

### **Patient outcome details**

value of programme (thematic analysis in physical, psychological and social domains), Berg Balance scale, Timed Up and Go test, SF12, home practice

### **Economic evaluation**

none

### **Authors conclusions**

This preliminary study provides support for further examination and application of the Taiji Buddy programme.

### **Comments**

Only 4 patients (no carer) participated in post-programme evaluation for outcomes other than programme satisfaction, only the health questionnaire was used for the post evaluation

**DB Record Number:** 33

## Full papers (Contd)

**Author:** Lieberman

**Year:** 2005

### **References**

Lieberman MA, Winzelberg A, Golant M, Wakahiro M, DiMinno M, Aminoff M et al. Online support groups for Parkinson's patients: a pilot study of effectiveness. *Social Work in Health Care* 2005; 42: 23-28.

**Identifier:** #1148

**Coding source:** full paper

**Research status:** completed

**Country:** USA

**Study design:** case series; survey

### **Sample size**

132 patients

### **Intervention type**

self-help/support group

### **Intervention description**

support groups for PD; 10-12 participants attend, half patients, half caregivers; groups were either homogenous for patient age and time since diagnosis or heterogeneous

### **Provider**

unclear

### **Orientation**

both

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

none

### **Carer outcome details**

n.a.

### **Patient outcome**

Direct; other

### **Patient outcome details**

satisfaction with support group, participation, Centre for Epidemiological Study Depression Scale (CES-D), Parkinson's Disease Questionnaire (PDQ39), Functional Status Questionnaire (FSQ), demographic data, PD history, medication use,

### **Economic evaluation**

none

### **Authors conclusions**

Parkinson's disease patients are willing to participate in professionally directed online support groups, dropouts are high, patients show improved quality of life, participants in homogenous groups show a decrease in depression. r

### **Comments**

Groups were also attended by carers but no results for carer were reported; publication described a further evaluation of different internet based support groups but carer were not mentioned

**DB Record Number:** 3

## Full papers (Contd)

**Author:** Lloyd

**Year:** 1999

### **References**

Lloyd M. The new community care for people with Parkinson's disease and their carers. In: Parkinson's disease: studies in psychological and social care. Percival R, Hobson P (Eds) London : BPS Books , 1999. Chap 2: 13-59

Lloyd M. Where has all the care management gone? The challenge of Parkinson's disease to the health and social care interface. British Journal of Social Work 2000; 30: 737-754.

**Identifier:** #746, #1678

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** survey

### **Sample size**

140 carers, 202 patients

### **Intervention type**

respite care; other

### **Intervention description**

day care, respite care, holidays, night sitting service, community care assessment, meals service

### **Provider**

unclear

### **Orientation**

unclear

### **Delivery method**

individual direct

### **Setting**

home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

coping; other

### **Carer outcome details**

self-reported service use, satisfaction with services received, free-response comments on coping

### **Patient outcome**

direct

### **Patient outcome details**

service use, satisfaction with services received, free-response comments on coping

### **Economic evaluation**

none

### **Authors conclusions**

"Community care" is not really operating as such for people with PD, but health and medical care is as good or better than prior to 1993.r

### **Comments**

A case series evaluating a care pathway is also presented which is linked to Holloway 2005.

**DB Record Number:** 19



## Full papers (Contd)

**Author:** Lovett

**Year:** 1988

### **References**

Lovett S, Gallagher D. Psychoeducational interventions for family caregivers: preliminary efficacy data. Behavior Therapy 1988; 19: 321-330

**Identifier:** #577

**Coding source:** full paper

**Research status:** completed

**Country:** USA

**Study design:** RCT

### **Sample size**

111 carers (40% carers for memory impaired patients with Alzheimer's disease, Parkinson's disease, stroke or other dementing illness)

### **Intervention type**

education/information; psychotherapy

### **Intervention description**

class on increasing life satisfaction for caregivers versus class on increasing problem-solving skills for caregivers versus waiting list; classes were weekly 2-hour sessions for 10 weeks

### **Provider**

unclear

### **Orientation**

carer

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

other

### **Patient population**

other

### **Carer outcome**

health; coping; other

### **Carer outcome details**

Beck Depression Inventory (BDI), Philadelphia Geriatric Center Morale Scale, Perceived Stress Scale, Schedule for Affective Disorders and Schizophrenia, caregiver-specific unpleasant events and activities, restrictions in social activities resulting from caregiving interview, support interview, self-efficacy interview

### **Patient outcome**

none

### **Patient outcome details**

n.a.

### **Economic evaluation**

none

### **Authors conclusions**

Family caregivers benefit substantially from structured programmes designed to teach skills for better coping.

### **Comments**

Two parallel groups compared to waiting list; unclear how many participants were carers for PD patients; all patients were frail elders

**DB Record Number:** 28

## Full papers (Contd)

**Author:** Marziali

**Year:** 2005

### **References**

Marziali, E, Donahue P, Crossin G. Caring for others: Internet health care support intervention for family caregivers of persons with Alzheimer's, stroke, or Parkinson's disease. Families in Society 2005; 86: 375-383.

Marziali E. Virtual support groups for family caregivers of persons with dementia. Geriatrics and Aging 2005; 8: 73-74.

**Identifier:** #693, #317

**Coding source:** full paper

**Research status:** completed

**Country:** Canada

**Study design:** case series

### **Sample size**

34 (approximately 1/3 carers for Parkinson's patients)

### **Intervention type**

self-help/support group

### **Intervention description**

Web-based weekly video-conference support groups over 3 month period, computer training given

### **Provider**

unclear

### **Orientation**

carer

### **Delivery method**

indirect

### **Setting**

home-based

### **Carer population**

other

### **Patient population**

other

### **Carer outcome**

coping; health; other

### **Carer outcome details**

Carer views on intervention, changes in physical and mental health; distress associated with caring, stress associated with caregiving.

### **Patient outcome**

service

### **Patient outcome details**

delay in admission to institutional care

### **Economic evaluation**

none

### **Authors conclusions**

The project supports the use of technology for delivering evidence-based models of intervention with caregivers of people with long-term debilitating diseases.

### **Comments**

Carers of people with Alzheimer's, Stroke, or Parkinson's disease

**DB Record Number:** 30

## Full papers (Contd)

**Author:** Mott

**Year:** 2005

### **References**

Mott S, Kenrick M, Dixon M, Bird G. Living with Parkinson's disease: the carer's perspective. International Journal of Therapy and Rehabilitation 2005; 12: 159-164

**Identifier:** #603

**Coding source:** full paper

**Research status:** completed

**Country:** Australia

**Study design:** survey

**Sample size**

303 carers

**Intervention type**

self-help/support group; psychotherapy; helpline; education/information; other

**Intervention description**

a number of interventions were surveyed including: support groups, counselling, telephone helplines, websites, libraries

**Provider**

unclear

**Orientation**

unclear

**Delivery method**

group direct; individual direct; indirect; unclear;

**Setting**

unclear

**Carer population**

general

**Patient population**

general

**Carer outcome**

other

**Carer outcome details**

service use and usefulness of services

**Patient outcome**

none

**Patient outcome details**

n.a.

**Economic evaluation**

none

**Authors conclusions**

The needs of the PD carer must not be underestimated or ignored.

**Comments**

A number of interventions were surveyed

**DB Record Number:** 12

## Full papers (Contd)

**Author:** Nasar

**Year:** 2006

### **References**

Nasar MA, Bankar RN. Improving outcome in Parkinson's Disease. British Journal of Hospital Medicine 2006; 67: 6-7

Nasar MA, Dyer P, Short C, Wilmott C. What is the role of Parkinson's disease club in PD care? Parkinsonism and Related Disorders 1999, 5: S1-S122; P-TU-016

**Identifier:** #838, #1721

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** post-test only

### **Sample size**

29 (out of 32)

### **Intervention type**

other

### **Intervention description**

Parkinson's disease club co-ordinated by PD nurse; meetings every 2 months, visits from multidisciplinary team; caregivers provided with help and support to reduce emotional stress and maintain good health; carer intervention was part of a larger programme with interventions for patients

### **Provider**

Bridlington day hospital

### **Orientation**

both

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

carers suggested the PD club should meet every month

### **Patient outcome**

direct

### **Patient outcome details**

management of medication, coping, planning diet, knowing when to obtain support, ability to discuss problems, general helpfulness of club discussion, attendance at club

### **Economic evaluation**

none

### **Authors conclusions**

The PD club is fulfilling the needs of patients and their caregivers.

### **Comments**

Intervention was available to carers but no carer effectiveness assessment took place

**DB Record Number:** 11

## Full papers (Contd)

**Author:** Oxtoby

**Year:** 1999

### **References**

Oxtoby M. The Romford Project: action research in a time of active change. In: Parkinson's disease: studies in psychological and social care. Percival R, Hobson P (Eds) London : BPS Books , 1999. Chap 16 285-292

Oxtoby, M, Findley, L, Kelson, N, Pearce, P, Porteous, A, Thurgood, S et al. A strategy for the management of Parkinson's disease and for the long-term support of patients and their carers. 1988; Parkinson's Disease Society, London.

**Identifier:** #1681, #1684;

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** cohort study, cost study

### **Sample size**

36 patients and their carers

### **Intervention type**

education/information; psychotherapy; other

### **Intervention description**

multidisciplinary model for the management of PD; special attention to social and emotional aspects of illness in patients and carers, involvement in monitoring and decision making (versus usual care); carer intervention was part of a larger programme with interventions for patients

### **Provider**

NHS neurology department

### **Orientation**

both

### **Delivery method**

individual direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

none

### **Carer outcome details**

n.a.

### **Patient outcome**

other

### **Patient outcome details**

views on diagnosis delivery and subsequent management; knowledge of existence of PDS

### **Economic evaluation**

other

### **Authors conclusions**

The feasibility and acceptability of the Romford project are proven.

### **Comments**

Compared to patients from other consultant (prospective data collection); a cost study of the project appeared to have been performed

**DB Record Number:** 8

## Full papers (Contd)

**Author:** Secker

**Year:** 2005

### **References**

Secker DL, Brown RG. Cognitive behavioural therapy (CBT) for carers of patients with Parkinson's disease: a preliminary randomised controlled trial. J Neurol Neurosurg Psychiatry 2005; 76: 491-497.

Brown RG, Secker DL. A randomized controlled trial of Cognitive Behavioral Therapy (CBT) for carers of patients with Parkinson's disease. Movement Disorders 2004; 19: S9: P734

Brown RG. Research Grant Summary: Code RG1: A randomised controlled trial of cognitive-behaviour therapy for carers of patients with Parkinson's disease. 2006; Parkinson's Disease Society: London

Charlesworth G. Cognitive behavioural therapy reduces psychological distress in carers of people with Parkinson's disease. Evidence Based Mental Health 2005; 8: 103.

**Identifier:** #16, #1658, #1442, #1688, #267

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** RCT

**Sample size**

30

**Intervention type**

psychotherapy

**Intervention description**

11-19 weekly sessions of CBT versus no treatment/waiting list (group sessions offered to control group after study completion); respite care to enable attendance of carer

**Provider:** NHS

**Orientation**

carer

**Delivery method**

individual direct

**Setting**

not home-based

**Carer population**

other

**Patient population**

general

**Carer outcome**

coping; health

**Carer outcome details**

General Health Questionnaire-28 (GHQ-28), Geriatric Depression Scale (GDS-15), Caregiver Strain Index, Caregiver Burden Inventory

**Patient outcome**

none

**Patient outcome details**

n.a.

**Economic evaluation**

none

**Authors conclusions**

The results offer preliminary support to the value of CBT in the management of psychological morbidity in Parkinson's disease carers.

**Comments**

Compared to waiting list; carers scored 5 or more ('case level problems') on the GHQ-28; good quality small RCT, though unblinded; 3 month follow-up

**DB Record Number:** 2

## Full papers (Contd)

**Author:** Sheriff

**Year:** 2003

### **References**

Sheriff JN, Chenoweth L. Challenges in conducting research to improve the health of people with Parkinson's disease and the well-being of their family carers. International Journal of Rehabilitation Research 2003; 26: 201-205

**Identifier:** #62

**Coding source:** full paper

**Research status:** completed

**Country:** Australia

**Study design:** before-after study

### **Sample size**

25 carers, 25 patients

### **Intervention type**

Psychotherapy; education/information

### **Intervention description**

counselling support provided by social worker as required; education and training group sessions targeted to patients' functional issues; carer intervention was part of a larger programme with interventions for patients

### **Provider**

War Memorial Hospital, Sydney

### **Orientation**

both

### **Delivery method**

individual direct; group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

other subgroup

### **Carer outcome**

health; coping; other

### **Carer outcome details**

carer health questionnaire

### **Patient outcome**

Direct; service

### **Patient outcome details**

Unified Parkinson's Disease Rating Scale (UPDRS), targeted rehabilitation assessment tools, health-related questionnaires; number of unplanned admissions to inpatient services reduced (recorded by staff)

### **Economic evaluation**

none

### **Authors conclusions**

The multidisciplinary rehabilitation program achieved its aims of enhancing the health and well-being of people with PD and their carers in effective ways.

### **Comments**

Patients included were those with mid-stage Parkinson's disease; no statistical results were provided

**DB Record Number:** 5

## Full papers (Contd)

**Author:** Szekely

**Year:** 1982

### **References**

Szekely BC, Kosanovich NN, Sheppard W. Adjunctive treatment in Parkinson's disease: physical therapy and comprehensive group therapy. Rehabilitation Literature 1982; 43: 72-76

**Identifier:** #1676

**Coding source:** full paper

**Research status:** completed

**Country:** USA

**Study design:** before-after study

### **Sample size**

7 patients and their carers (family members)

### **Intervention type**

self-help/support group; practical advice; other

### **Intervention description**

13 week, 2 hour interdisciplinary group therapy; patients given exercise tapes (American Parkinson Disease Association approved exercises), encouraged to practise; patients and carers exercise together, then separate or joint discussion groups with nurse coordinator, nurse psychologist and physical therapist

### **Provider**

Parkinson's Disease Clinic

### **Orientation**

both

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

other subgroup

### **Carer outcome**

none

### **Carer outcome details**

n.a.

### **Patient outcome**

direct

### **Patient outcome details**

measures of mobility, Beck Depression Inventory, Bradburn Affect Balance Scale, activity ratings, home observation rating by carer

### **Economic evaluation**

none

### **Authors conclusions**

Adjunctive therapy (physical therapy with family extended group discussion) is useful in maximising functioning in PD patients.

### **Comments**

Although intervention was available to carers, no carer outcomes were reported here; patients were mildly or moderately impaired (Hoehn stage II or III)

**DB Record Number:** 15



## Full papers (Contd)

**Author:** Thomas

**Year:** 2002

### **References**

Thomas S, Sweetnam C. Parkinson's disease. Caring for the carers. Primary Health Care 2002; 12: 27: -31.

Thomas S. First steps to carer health. Primary Health Care 2002; 11: 16-17

**Identifier:** #639, #643

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** unclear

**Sample size**

25

### **Intervention type**

self-help/support group; education/information

### **Intervention description**

booklet on healthcare for carers; meeting to provide information on available resources

### **Provider**

NHS

### **Orientation**

carer

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

coping; other

### **Carer outcome details**

experiences such as more time for family, coping better with caring, time for self

### **Patient outcome**

none

### **Patient outcome details**

n.a.

### **Economic evaluation**

none

### **Authors conclusions**

The Cornwall Carers project is in its early stages, but demonstrates that much more work can be done for carers.

### **Comments**

Unclear whether a formal carer effectiveness assessment has taken place and how many carers took part in the evaluation (25 carer took part in the intervention, no further details); no statistical results were provided

**DB Record Number:** 29

## Full papers (Contd)

**Author:** Trend

**Year:** 2002

### **References**

Trend P, Kaye J, Gage H, Owen C, Wade D. Short-term effectiveness of intensive multidisciplinary rehabilitation for people with Parkinson's disease and their carers. *Clinical Rehabilitation* 2002; 16: 717-725

Gage H, Kaye J, Owen C, Trend P, Wade D. Evaluating rehabilitation using cost-consequences analysis: an example in Parkinson's disease. *Clinical Rehabilitation* 2006; 20: 232-238.

Playford E. Multidisciplinary rehabilitation for people with Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry* 2003; 74: 148-149.

Wade D, gage H, owen C, trend P, Grossmith C, Kaye J. Multidisciplinary rehabilitation for people with Parkinson's disease: a randomised controlled study. *Journal of Neurology, Neurosurgery and Psychiatry* 2003; 74: 158-162.

**Identifier:** #84, #75, #264, #1680

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** before-after study; cost study

**Sample size:** 69 carers, 118 patients

### **Intervention type**

Psychotherapy; behavioural; practical advice; education/information; rehabilitation; practical advice

### **Intervention description**

multidisciplinary rehabilitation 1 day/week for 6 weeks including elements of relaxation, information, group therapy, advice

**Provider:** NHS

**Orientation:** both

**Delivery method:** group direct; individual direct

**Setting:** not home-based

**Carer population:** general

### **Patient population**

other

### **Carer outcome**

coping; health

### **Carer outcome details**

Hospital Anxiety and Depression, Euroquol-5d, Carer Strain Index

### **Patient outcome**

direct

### **Patient outcome details**

Mobility, Speech, Hospital Anxiety and Depression, Euroquol-5d, SF36, PDQ-39, Stand-walk-sit, nine-hole peg, PD disability questionnaire

### **Economic evaluation**

other

### **Authors conclusions**

This intensive co-ordinated programme provided immediate benefit to people with Parkinson's disease and their carers; follow-up treatments may be needed to maintain any benefit.

### **Comments**

Patients with cognitive impairment were excluded; this before and after study examined patients who were enrolled in an RCT comparing treatment with delayed treatment, in which no carer intervention was reported; a cost study was also reported but this was not a full economic evaluation; 6 months follow-up (showed a trend towards greater strain)

**DB Record Number:** 4

## Full papers (Contd)

**Author:** Watts

**Year:** 1999

### **References**

Watts S, Kaiser P, Porter J, Cockton N, Morley M. A psychological group approach to meeting the needs of people with Parkinson's disease and their carers. In: Parkinson's disease: studies in psychological and social care. Percival R, Hobson P (Eds) London : BPS Books , 1999. Chap 8: 199-216

**Identifier:** #1675

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** controlled trial

### **Sample size**

24 carers, 36 patients

### **Intervention type**

practical advice; psychotherapy; self-help/support group

### **Intervention description**

eight fortnightly group sessions (1.5hrs) of either psychological treatment group or practical approaches to managing PD; both groups included support group element

### **Provider**

PDS branches

### **Orientation**

both

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

older patients

### **Carer outcome**

coping; health; other

### **Carer outcome details**

CAPE Behaviour Rating Scale, General Health Questionnaire (GHQ-28), Beck Depression Inventory (BDI), Symptom Rating Test (SRT), Machin Strain Scale, Ways of Coping with Caring checklist, helpfulness, interest, comprehensibility and opportunity to talk of intervention

### **Patient outcome**

Direct; other

### **Patient outcome details**

Hoehn and Yahr scale, General Health Questionnaire (GHQ-28), Beck Depression Inventory (BDI), Symptom Rating Test (SRT), Ways of Coping checklist, helpfulness, interest, comprehensibility and opportunity to talk of intervention

### **Economic evaluation**

none

### **Authors conclusions**

The results support psychological approaches as potentially useful strategies to add to the services offered to people with PD and their families.

### **Comments**

2 parallel groups, patients were aged at least 55, diagnosed for more than 6 months and with MMSE score over 20; 3 month follow-up

**DB Record Number:** 21

## Full papers (Contd)

**Author:** Whitehouse

**Year:** 1994

### **References**

Whitehouse C. A new source of support. The nurse practitioner in Parkinson's disease and dystonia. Professional nurse 1994; 9: 448-451

**Identifier:** #680

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** RCT

### **Sample size**

64 patients (40 with Parkinson's disease) and their carers

### **Intervention type**

other

### **Intervention description**

non-specific support from Parkinson's disease nurse practitioner; carer intervention provided within context of 2 home visits and 5 telephone contacts to patient from Parkinson's disease nurse practitioner versus no contact

### **Provider**

Institute of Neurology, London

### **Orientation**

both

### **Delivery method**

individual direct

### **Setting**

home-based

### **Carer population**

other

### **Patient population**

other

### **Carer outcome**

none

### **Carer outcome details**

n.a.

### **Patient outcome**

direct

### **Patient outcome details**

usefulness of intervention, nature of most useful aspects of intervention

### **Economic evaluation**

none

### **Authors conclusions**

A nurse practitioner acting as a link between patient, hospital and community services meets many of the needs of both patient and carer.

### **Comments**

Compared to no contact; Carer Strain Index was used to elicit information but no carer outcomes were reported; the unit of randomisation was the patient and not the carer

**DB Record Number:** 27

## Full papers (Contd)

**Author:** Yarrow

**Year:** 1999

### **References**

Yarrow S. Members' 1998 survey of the Parkinson's Disease Society of the United Kingdom. In: Parkinson's disease: studies in psychological and social care. Percival R, Hobson P (Eds) London : BPS Books , 1999. Chap 4: p79-91

**Identifier:** #1685

**Coding source:** full paper

**Research status:** completed

**Country:** UK

**Study design:** survey

### **Sample size**

1693 (of 2500 surveyed), 12% current carers, 10% former carers

### **Intervention type**

respite care; education/information; helpline; self-help/support group

### **Intervention description**

both interventions provided by the PDS and interventions generally were surveyed

### **Provider**

PDS and other

### **Orientation**

unclear

### **Delivery method**

unclear

### **Setting**

unclear

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

use of services; importance of services; experience of service use

### **Patient outcome**

other

### **Patient outcome details**

use of services; importance of services

### **Economic evaluation**

none

### **Authors conclusions**

The methods of getting information found most helpful were The Parkinson and leaflets or books; talks from professionals such as doctors, therapists and social workers were the aspect of PDS branch activity most appreciated.

### **Comments**

PDS membership survey, many services covered

**DB Record Number:** 6

## Abstracts

**Author:** Bayés

**Year:** 2005

### **References**

Bayes A, Crespo MC, Prats A, Villa V, EduPark Consortium. Psycho-education in Parkinson's disease directed at relatives and caregivers. Journal of the Neurological Sciences 2005; 238: S352: 0992

**Identifier:** #1180

**Coding source:** abstract

**Research status:** completed

**Country:** Spain

**Study design:** case series

**Sample size**

38

### **Intervention type**

education/information; psychotherapy

### **Intervention description**

psycho-education in Parkinson's disease program (EduPark), multiple group sessions covering the following components: self-monitoring, health empowerment, stress management, anxiety and depression, assertiveness, social support

### **Provider**

unclear

### **Orientation**

carer

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

other

### **Patient population**

other subgroup

### **Carer outcome**

other

### **Carer outcome details**

usefulness of and satisfaction with programme, willingness to participate in similar programme, would recommend programme to others

### **Patient outcome**

none

### **Patient outcome details**

n.a.

### **Economic evaluation**

none

### **Authors conclusions**

EduPark achieves satisfaction among carers.

### **Comments**

Participants were carers with significant depression symptoms caring for people with early to moderate stage PD; appears to be the same programme as evaluated by Taba et al. (2005) under before-after studies

**DB Record Number:** 18

## **Abstracts (Contd)**

**Author:** Brandow

**Year:** 1997

### **References**

Brandow RK, McRae CA, O'Brien CF. Improving quality of life: results of a relationship enhancement program for couples. Movement Disorders 1997; 12: S1: P508

**Identifier:** #1718

**Coding source:** abstract

**Research status:** completed

**Country:** USA

**Study design:** before-after study

### **Sample size**

10 carers, 10 patients

### **Intervention type**

Psychotherapy; education/information

### **Intervention description**

5 2-hour sessions teaching communication and problem-solving skills (Prevention and Relationship Enhancement Program (PREP))

### **Provider**

unclear

### **Orientation**

both

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

spouse

### **Patient population**

other subgroup

### **Carer outcome**

coping; health; other

### **Carer outcome details**

Center for Epidemiological Studies Depression Scale (CES-D), Social Provisions Scale, global measures of health and life satisfaction, Marital Adjustment Test, Communication Patterns Questionnaire, Marital Satisfaction Inventory, State-Trait Anxiety Inventory (State)

### **Patient outcome**

Direct; other

### **Patient outcome details**

Center for Epidemiological Studies Depression Scale (CES-D), Social Provisions Scale, global measures of health and life satisfaction, Marital Adjustment Test, Communication Patterns Questionnaire, Marital Satisfaction Inventory, State-Trait Anxiety Inventory (State), physician assessed Hoehn and Yahr stage, Schwab and England scale, ADL score from the UPDRS

### **Economic evaluation**

none

### **Authors conclusions**

The authors concluded that data from longer term follow-up were required to assess the intervention.

### **Comments**

Patients with significant dementia were excluded from the study.

**DB Record Number:** 31

## Abstracts (Contd)

**Author:** Chibuk

**Year:** 2006

### **References**

Chibuk ME, Kovacs-Burns KA, Yang T. Survey of caregivers of persons with Parkinson's disease in Alberta: Services needed, used and valued. *Movement Disorders* 2006; 21: S1: P265.

**Identifier:** #1410

**Coding source:** abstract

**Research status:** completed

**Country:** Canada

**Study design:** survey

**Sample size**

over 300

### **Intervention type**

education/information; helpline; practical advice; respite care; self-help/support group; other; behavioural

### **Intervention description**

multiple services were surveyed

### **Provider**

unclear

### **Orientation**

unclear

### **Delivery method**

unclear

### **Setting**

unclear

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

services needed and valued most

### **Patient outcome**

none

### **Patient outcome details**

n.a.

### **Economic evaluation**

none

### **Authors conclusions**

Providing more information about available services and targeting those most needed and valued will improve overall quality of life for everyone affected by Parkinson's.

### **Comments**

Several interventions surveyed; service needed and valued most was access to a Parkinson clinic

**DB Record Number:** 7



## **Abstracts (Contd)**

**Author:** Gardner

**Year:** 2006

### **References**

Gardner JM, Johnson ML, Varpness SC, Wichmann RL, Woods MS. Creating Parkinson's disease awareness and skills for family caregivers. *Movement Disorders* 2006; 21: S1: P271.

**Identifier:** #1413

**Coding source:** abstract

**Research status:** completed

**Country:** USA

**Study design:** case series

### **Sample size**

171 (education); 94 (skills-building)

### **Intervention type**

education/information; practical advice

### **Intervention description**

initial education session followed by five 2 hour sessions of skills building classes and distribution of care-giving aids; follow-up available in community; respite care available to enable participation.

### **Provider**

Struthers Parkinson Center, community partner organisations

### **Orientation**

carer

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

knowledge gain in care-giver skills

### **Patient outcome**

none

### **Patient outcome details**

n.a.

### **Economic evaluation**

none

### **Authors conclusions**

Combining education about Parkinson's disease with classes emphasising hands-on skills make carers better equipped to handle their complex situation.

### **Comments**

Retrospective assessments of knowledge before and after the intervention were conducted

**DB Record Number:** 20

## **Abstracts (Contd)**

**Author:** Moore

**Year:** 2006

### **References**

Moore O. Clinic for family caregivers of Parkinson's disease patients. Movement Disorders 2006; 21: S48; O167

Moore O, Giladi N. Family caregivers of Parkinson's disease patients deserve professionals attention and support: A report from one year of experience with caregivers' clinic. Movement Disorders 2004; 19: S9: P658

**Identifier:** #1409, #1441

**Coding source:** abstract

**Research status:** completed

**Country:** Israel

**Study design:** unclear

### **Sample size**

49

### **Intervention type**

other

### **Intervention description**

caregiver clinic providing information, support, advice, teaching coping skills, and encouragement to seek further help

### **Provider**

Tel Aviv Parkinson Centre

### **Orientation**

carer

### **Delivery method**

individual direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

other

### **Carer outcome details**

number of visits to clinic required

### **Patient outcome**

none

### **Patient outcome details**

n.a.

### **Economic evaluation**

none

### **Authors conclusions**

The clinic for family caregivers is an effective intervention for the benefit of the whole family of a patient with Parkinson's disease.

### **Comments**

No details of outcomes provided to substantiate the authors' conclusions

**DB Record Number:** 1

## Abstracts (Contd)

**Author:** Taba

**Year:** 2005

### **References**

Taba P, Kanarik E, Krikmann Ü, Macht M, Simons G, Splethoff-Kamminga NGA, Ricci Bitti, Lankinen & Bayés Rusinol. Cognitive behavioural education programme for Parkinsonian patients and carers. Journal of the Neurological Sciences 2005; 238: S371-S372: 1071

**Identifier:** #1407

**Coding source:** abstract

**Research status:** completed

**Country:** Spain, Finland, Italy, The Netherlands, UK, Estonia, Germany

**Study design:** before-after study

### **Sample size**

137 patients, 151 carers

### **Intervention type**

education/information; psychotherapy

### **Intervention description**

EduPark (cognitive behavioural education) programme: 8 educational sessions on self-monitoring, health promotion, management of stress, depression and anxiety, social competence, social support

### **Provider**

unclear

### **Orientation**

both

### **Delivery method**

group direct

### **Setting**

not home-based

### **Carer population**

general

### **Patient population**

general

### **Carer outcome**

coping; health; other

### **Carer outcome details**

coping with disease-related problems, mood elevation, disease-related psychosocial problems, quality of life, depression, comprehensibility and feasibility of program

### **Patient outcome**

Direct; other

### **Patient outcome details**

coping with disease-related problems, mood elevation, disease-related psychosocial problems, quality of life, depression, comprehensibility and feasibility of program

### **Economic evaluation**

none

### **Authors conclusions**

The programme can be recommended as a feasible complement to medical treatment for people with Parkinson's disease and their carers.

### **Comments**

Appears to be the same programme as evaluated by Bayés et al. (2005)

**DB Record Number:** 16

## Ongoing studies

**Author:** Forsyth

**Year:**

### **References**

Forsyth DR. The effects of lavender aroma on sleep disturbance, mood and daytime function in Parkinson's patients and their carers. Cambridge City Primary Care Trust

**Identifier:** #1655

**Coding source:** database entry

**Research status:** ongoing

**Country:** UK

**Study design:** RCT

### **Sample size**

60 patients

### **Intervention type**

other

### **Intervention description**

lavender pillow versus lavender fragrance given for one month, it is not absolutely clear that therapy will also be given to carers; the nature of the intervention means it is very likely the case for carers who are the patient's spouse

### **Provider**

unclear

### **Orientation**

unclear

### **Delivery method**

indirect

### **Setting**

home-based

### **Carer population**

unclear

### **Patient population**

unclear

### **Carer outcome**

coping; health

### **Carer outcome details**

sleep disturbance, mood, daytime function

### **Patient outcome**

direct

### **Patient outcome details**

sleep disturbance, mood, daytime function

### **Economic evaluation**

unclear

### **Authors conclusions**

n.a.

### **Comments**

The design of the trial is cross-over with single-blinding; it is probable that patients rather than carers were the unit of randomisation; project end date: June 2003

**DB Record Number:** 25

## Ongoing studies (Contd)

**Author:** Furmston

**Year**

### **References**

Furmston, A. A pilot randomised trial of occupational therapy to optimise independence in Parkinson's disease (The PD OT Trial). R&D for Birmingham and Solihull Consortium

**Identifier:** #1661

**Coding source:** database entry

**Research status:** ongoing

**Country:** UK

**Study design:** RCT; economic evaluation

### **Sample size**

50 patients

### **Intervention type**

unclear

### **Intervention description**

standard community-based occupational therapy, caregiver training versus waiting list (deferred therapy), carer intervention is part of a broader occupational therapy program for patients

### **Provider**

unclear

### **Orientation**

patient

### **Delivery method**

individual direct

### **Setting**

home-based

### **Carer population**

general

### **Patient population**

other subgroup

### **Carer outcome**

none

### **Carer outcome details**

n.a.

### **Patient outcome**

direct

### **Patient outcome details**

Instrumental activity of daily living, Rivermead mobility index, Unified Parkinson's Disease Rating scale ADL scale, Parkinson's Disease Questionnaire (PDQ39), EuroQuol-5D, Hospital Anxiety and Depression Scale (HADS)

### **Economic evaluation**

economic evaluation, details unclear

### **Authors conclusions**

n.a.

### **Comments**

Patients included were those with later PD (Hoehn and Yahr score III to IV; it is probable that patients rather than carers are the unit of randomisation; this study has the potential to be a full economic evaluation; project end date: March 2007

**DB Record Number:** 26

## Ongoing studies (Contd)

**Author:** Laidlaw

**Year:**

### **References**

Laidlaw K, Single case analysis if the benefits to patients and carers of cognitive behaviour therapy for depression in Parkinson's disease. Lothian Primary Care Trust

**Identifier:** #1654

**Coding source:** database entry

**Research status:** ongoing

**Country:** UK

**Study design:** controlled trial

### **Sample size**

12 carers, 12 patients

### **Intervention type**

psychotherapy

### **Intervention description**

cognitive behaviour therapy (CBT)

### **Provider**

unclear

### **Orientation**

unclear

### **Delivery method**

unclear

### **Setting**

unclear

### **Carer population**

unclear

### **Patient population**

unclear

### **Carer outcome**

unclear

### **Carer outcome details**

unclear

### **Patient outcome**

unclear

### **Patient outcome details**

unclear

### **Economic evaluation**

unclear

### **Authors conclusions**

n.a.

### **Comments**

It is not absolutely clear that therapy will be given to carers as well as patients; project end date: October 2003

**DB Record Number:** 22

## Ongoing studies (Contd)

**Author:** Leroi

**Year:**

### **References**

Leroi I. A pilot study of a sleep hygiene education program vs placebo in Parkinson's disease sufferers: effect on carer well-being. South Manchester University Hospitals NHS trust.

**Identifier:** #1556

**Coding source:** database entry

**Research status:** ongoing

**Country:** UK

**Study design:** RCT

### **Sample size**

16 carers, 16 patients

### **Intervention type**

behavioural

### **Intervention description**

sleep hygiene program compared to placebo

### **Provider**

unclear

### **Orientation**

both

### **Delivery method**

unclear

### **Setting**

unclear

### **Carer population**

spouse

### **Patient population**

other subgroup

### **Carer outcome**

coping; health; other

### **Carer outcome details**

PD carer quality of life scale (PD-QOL), General Health Questionnaire (GHQ), Burden Interview, Epworth Sleepiness Scale, NPI carer distress scale

### **Patient outcome**

Direct; other

### **Patient outcome details**

Epworth Sleepiness Scale, Geriatric Neuropsychiatric Inventory, UPDRS-motor scale, Hoehn-Yahr scale

### **Economic evaluation**

none

### **Authors conclusions**

n.a.

### **Comments**

Patients included were those with mid-stage Parkinson's disease and a sleep disturbance as determined by screening questionnaire; it is probable that patients rather than carers are the unit of randomisation; project end date: January 2006

**DB Record Number:** 23

## Ongoing studies (Contd)

**Author:** Thompson

**Year**

**References**

Thompson SBN. Evaluation of an education programme for people with Parkinson's disease (PD) and their carers

**Identifier:** #1645

**Coding source:** database entry

**Research status:** ongoing

**Country:** UK

**Study design:** unclear

**Sample size**

40

**Intervention type**

Education/information

**Intervention description**

education programme addressing knowledge about disease and its effects; skills to deal with specific problems resulting from PD, integration of knowledge and skills for self-management of disease

**Provider**

unclear

**Orientation**

both

**Delivery method**

unclear

**Setting**

unclear

**Carer population**

unclear

**Patient population**

unclear

**Carer outcome**

unclear

**Carer outcome details**

unclear

**Patient outcome**

unclear

**Patient outcome details**

unclear

**Economic evaluation**

unclear

**Authors conclusions**

n.a.

**Comments**

The focus of this intervention is unclear. It's also not clear if the sample size of 40 refers to the total of the patients and their carers or to the number of each; project end date: April 2005

**DB Record Number:** 24