

**'Experiences of providing care to people with long term conditions'  
Report Appendices**

DH 1968 JH 07.03

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## APPENDIX 1 PROFORMAS

<b>Author/s</b>	Motor Neurone Disease			<b>Ref No</b>	<b>CA0001</b>
<b>Title (first 4 words)</b>	Report on the Results...		<b>Year of publication</b>		2002
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low	
<b>Reviewer's initials</b>	AMC		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a report on the results of a questionnaire directed at previous carers of individuals who have MND. The authors point out that is it NOT a scientific document but a record of quantitative and qualitative data derived via questionnaire.

The survey presents its initial findings in numerical form. These cover demographic issues, clinical information and details of contact with professionals and services. The appendices, which present data in narrative form, are extensive and detail individual responses to particular situations. In summary..... previous carers felt that

- Delivery of the diagnosis was a major concern. The sufferer MUST be accompanied by a sympathetic friend/relative.
- Over half of the respondents (n=97) were not given information on the Motor Neurone Disease Association.
- Services had to be 'fought for' with the result that many individuals felt they received too little too late. Carers felt angry at the delays. Some were physically unable to handle the equipment themselves when it eventually arrived.
- The issue of paying for equipment was very prominent.
- Some individuals loaned or donated equipment to other carers/sufferers.
- Professionals need to be educated about identifying symptoms early so that appropriate referral can be made.

- Support strategies must be in place to help those who care for people with MND.
- Carers need more information on the disease process, especially relating to its prognosis. Some people were told to look in the Yellow Pages for information.
- Carers need more information on financial benefits and how to get them.
- Carers report very uneven care and support at end of life.
- Carers need to be aware of the range of professional services available to them and to the person they are caring for.

<b>Author/s</b>	Motor Neurone Disease Association			<b>Ref No</b>	<b>CA0002</b>
<b>Title (first 4 words)</b>	Report on the results.....			<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low	
<b>Reviewer's initials</b>	AMC			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a report on the results of a questionnaire directed at present carers of individuals who have MND. The authors point out that is it NOT a scientific document but a record of quantitative and qualitative data derived via questionnaire.

The survey, as with its companion piece on previous carers, covers demographics, clinical aspects of care and contact with professionals and services. Findings are presented in numerical form. The recommendations and appendices deliver data in narrative form. From these it is apparent that present carers and previous carers have much in common.

from the recommendations, present carers....

- .....often need care themselves, mostly due to their age.
- .... were 100% white (defined as an ethnic grouping).
- .....did not respond in large numbers to the survey.

from the appendices, present carers...

- have big issues to resolve around diagnosis and how it is handled by professionals
- need much more information on what exactly MND is and how they can cope with it.
- need much more guidance on benefits and professional help
- need much more input on the provision of services and equipment

- need to be involved in the decision making processes that accompany treatment.
- Need proactive involvement from specialist organisations.
- Need respite.
- Want to know more about treatment on offer.
- Need regular contact from professionals, not just in emergencies.

<b>Author/s</b>	Graham Nickson			<b>Ref No</b>	<b>CA0003</b>
<b>Title (first 4 words)</b>	Services for People with TBI			<b>Year of publication</b>	2003
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Traumatic brain injury (tbi)</b>				
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low	
<b>Reviewer's initials</b>	AMC			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a report of findings of a survey of Social Services Departments in the UK. The author recognises that many individuals who suffer TBI now survive although the nature of the disability has serious implications for their immediate family. Hence, the focus is on service provision for individuals with traumatic brain injuries and their carers. The general thrust of the argument is that services for individuals are patchy and services for carers are patchier still.

Given that the results were obtained from a self-completed survey of departments the **views of carers are not obviously present**. For example, although all departments surveyed claimed to have respite facilities available for carers only a quarter could provide a contact name. This leads to the conclusion that such services are aspirational rather than actual.

The report suggests that on the evidence provided services for individuals with TBI and their families are not seen as a priority area. To address this it recommends that departments use an additional classification to accommodate the needs of TBI sufferers and their families.

<b>Author/s</b>	Chesson, R., Maehle, V., Wardell, F.			<b>Ref No</b>	<b>CA0004</b>
<b>Title (first 4 words)</b>	Helping to Manage Parkinson's Disease		<b>Year of publication</b>		2000
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low	
<b>Reviewer's initials</b>	AMC		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The report recognises the valuable contribution made by informal carers. They want here to investigate the particular contribution made by carers to treatment. Aims were to

- i. Establish the carer's role
- ii. Determine how far carers might wish to be involved in disease management
- iii. Obtain professionals' views on carer involvement
- iv. How can professional contribute to carer involvement

Data were compiled via questionnaire and semi-structured interview involving carers.

Professionals were interviewed in focus groups and were further asked to comment on

vignettes drawn from carer experience of being involved in therapy.

- The carer's role involves many physical tasks related to activities of daily living (shopping, shaving &etc).
- Carers also report many examples of participating in activities more closely related to a professional/therapeutic role (medication, exercises &etc.).
- Some carers reported that for practical or emotional reasons (their own poor health or the nature of their relationship to the sufferer) they did not want to be involved in these aspects of caring
- Some sufferers did not want carer involvement.

From the professional perspective the role of the carer is recognised and valued.

- Carers can continue with therapy between appointments/visits
- Carers can feedback to professionals on how successful interventions have been.
- The relationship between the carer, the sufferer and the professional can be altered as the levels of intervention are adjusted.

The study recommends that

- I. careful monitoring of carer involvement goes on to ensure carers are not overtaxed.
- II. Professionals remain sensitive to changing relationships between carer and sufferer.
- III. Professionals may require training to achieve this.

<b>Author/s</b>	Politynska, B.E., Miller, E., Berrios, G.E.			<b>Ref No</b>	<b>CA0005</b>
<b>Title (first 4 words)</b>	The Impact of the Physical....			<b>Year of publication</b>	?
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	<u><b>UK</b></u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The work reported was funded by a grant from the PD Society, UK. It represents preliminary data from a larger study designed to examine the impact of looking after someone with PD. In this case it is always a spouse. There is no date attached to the study and the most recent reference is 1990.

- Three separate scales were used to determine carer strain/distress. General Health Questionnaire (GHQ), Geriatric Depression Scale (GDSC), Gilliard Strain Scale(GSS).
- The carers social network was mapped out using interview and network density was derived by linking members of the network known to each other.
- Results indicate that carer well-being is influenced more by depression in the sufferer than by any physical symptoms.
- The three scales also indicate that carers suffer stress as a result of their caring.
- The authors are cautious about making claims related to social networks due to the lack of data but suggest that networks are reduced thereby increasing carer stress. Whether this is as a consequence or a cause is open to debate.

<b>Author/s</b>	Politynska et al (PDS funded)			<b>Ref No</b>	<b>CA0006</b>
<b>Title (first 4 words)</b>	Factors affecting Psychological well-being			<b>Year of publication</b>	2003
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. Review</u></b>	Other
<b>Typology</b>	<b><u>T1</u></b>	T2	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Parkinson's Disease and other chronic conditions</b>				
<b>Confidence Rating</b>	High		Medium		Low
<b>Reviewer's initials</b>	SS			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Attributes influencing strain on carers:

- Sex of carer – women more likely to be stressed than males as less likely to accept formal help than males
- Quality of past and present relationship with patient
- Degree of dementia (carer strain more likely caused by mental illness than physical)
- Levels of carer strain not correlated with level of care giving..
- Experienced strain does not necessarily equate to carers handing over caring to alternative supports.

<b>Author/s</b>	Bridgett McCall (PDS)			<b>Ref No</b>	<b>CA0007</b>
<b>Title (first 4 words)</b>	Coping with Parkinson's Disease			<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	<b><u>T1</u></b>	T2	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>			Other (USA)	
<b>User's Long Term Condition</b>	<b>PARKINSONS DISEASE</b>				
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low	
<b>Reviewer's initials</b>	Ss			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Parkinson's Disease Society ensure carers as well as patients should be involved in management of treatment

Carers' needs are as important as patients'

Carers can feel isolated and depressed – need support from others, maybe other carers. Carers National Association is useful contact

<b>Author/s</b>	Johnson, Phillips, Thomas		<b>Ref No</b>	<b>CA0008</b>
<b>Title (first 4 words)</b>	Experiences & concerns of families		<b>Year of publication</b>	1997
<b>Research methods</b>	Quantative	<u><b>Qualitative</b></u>	Mixed	Lit. review      Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4
<b>Location of study</b>	<u><b>UK</b></u>		Other (USA)	
<b>User's Long Term Condition</b>	<b>Epilepsy</b>			
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Experiences of parents of children with epilepsy – 3 phases:

1. awareness; 2. Way diagnoses is dealt with; 3. Family responses to diagnoses  
GP crucial to parents perceptions of epilepsy and implications for children and family.

Type of hospital referred is important – children's hospital with specialist epilepsy unit better than adult psychiatric hospital

If parents have good information about epilepsy and are competent to deal with it they can develop partnerships with teachers which facilitates the inclusion of children with epilepsy into schools.

<b>Author/s</b>	Cockerill & Warren			<b>Ref No</b>	<b>CA0009</b>
<b>Title (first 4 words)</b>	Care for care-givers			<b>Year of publication</b>	1990
<b>Research methods</b>	Quantative	<b><u>Qualitative</u></b>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (Canada)</u></b>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low	
<b>Reviewer's initials</b>	SS			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

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Conclusions of study support those of other studies (e.g. Alzheimer's): care-givers are often related to patient, and under-utilize formal care services. This may be due to:

1. Lack of information
2. The feeling of failure or guilt to ask for help
3. Feeling that respite services are unsatisfactory
  - Need to provide community support for care-givers
  - Need to discover why respite care is not being utilized

<b>Author/s</b>	Fyffe, C & McCubbery, J			<b>Ref No</b>	<b>CA0010</b>
<b>Title (first 4 words)</b>	If only we had somewhere			<b>Year of publication</b>	1996
<b>Research methods</b>	Quantitative	<b>Qualitative</b>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b>Other (Australia )</b>		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	<b>High</b>		Medium	Low	
<b>Reviewer's initials</b>	SS			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Aim: explore and identify needs of people with acquired brain injury and their carers.

Key themes identified from respondents' comments (patients and carers)

1. Inappropriate communication and poor information from professionals
2. Varied service quality and co-ordination
3. Community re-integration and isolation – absence of services/ support in patients' home locality.
4. Lack of support for family and carers – need someone to talk to.
5. Specific rural issues – distance from services/ professionals, cost/ time/ availability of transportation to visit hospitals or specialist clinic

Need for local GPs to bridge gap between patients and carers and community support services.

Medical practitioners can be used to provide specialist knowledge to community agencies and link to specialist metropolitan services

<b>Author/s</b>	Teijlingen et al			<b>Ref No</b>	<b>CA0011</b>
<b>Title (first 4 words)</b>	Service use and needs		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	<b>UK</b>	Other (USA) _____			
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	<b>High</b>	Medium		Low	
<b>Reviewer's initials</b>	SS		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Carers of MND patients experience sleep disturbance
- Carers may experience physical and emotional stress
- Carers of people with MND are most likely family but non-statutory organisations offer support not easily available from statutory organisations

<b>Author/s</b>	Gronwall D., Wrightson P. and Waddell P			<b>Ref No</b>	<b>CA0012</b>
<b>Title (first 4 words)</b>	Head Injury the Facts			<b>Year of publication</b>	1998
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK			<b><u>Other (New Zealand)</u></b>	
<b>User's Long Term Condition</b>	<b>Head injury</b>				
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low	
	Confident it is based on prof experience and research which is generalisable				
<b>Reviewer's initials</b>	HQ			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Not research but a guide to what happens and what to expect based on views/experiences of professional work and research with people with head injuries and their families. Maybe the sort of info that carers in other studies e.g. Hupert 1995 have said they would like. Re carers emphasises the often long term nature of recovery and the need for support. Also both parties needs for some control over the situation and for some privacy.

<b>Author/s</b>	Mowat L.	<b>Ref No</b>	<b>CA0013</b>
<b>Title (first 4 words)</b>	As Long as Possible	<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative Not research.	Qualitative An individual account by a carer written as a "love story"	Mixed Lit. review <b>Other</b>
<b>Typology</b>	T1	<b>T2</b>	T3 T4
<b>Location of study</b>	<b>UK</b>	Other (USA)	
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>		
<b>Confidence Rating</b>	High Not confident about generalisability tho' no doubt its an authentic individual account	Medium	<b>Low</b>
<b>Reviewer's initials</b>	HQ	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

An individual account

Pace of change means need for constant adjustments, as previous solutions no longer work. Services not particularly good at coping with this. Hard to avoid temptations to take over and/or being patronising and to cope with frustrations of person with MND. Also recognition of some feelings of (unjustified) hostility towards other carers. Individual carers and care packages variable, some good some not so. Tech equipment useful but prone to breakdown. Communication a key issue in this case. Hospice needed at the end, and death dealt with well. Supportive GP. However really I could only tell what might be generalisable by reading other research. The value of this kind of work might be in conveying the nature of the individual experience and illustrating some of the ways in which this is tied to the individual characteristics of those involved and their relationships with each other. The person with MND remains a definable and respected individual to the end but the temptation to infantilise is acknowledged, and the practical and emotional difficulties of coping are acknowledged and explored.

<b>Author/s</b>	Hubert J.			<b>Ref No</b>	<b>CA0014</b>
<b>Title (first 4 words)</b>	Life after Head Injury			<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>			Other (USA)	
<b>User's Long Term Condition</b>	Head Injury				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	HQ			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

The hospital experience: Praise for A&E and intensive care though some would have liked more information about what was happening, and what to expect. Specialist social worker or psychologist, if allocated, found helpful by parents as consistent information point. Some reports of conflict between parents and partners about who had "rights" to the patient...

Transition from intensive care to general wards where person got less attention and treatment experienced by carers as "abandonment" or being put "on the back burner". Moves to inappropriate wards with staff inexperienced in head injuries caused anxieties particularly. when staff reacted negatively (i.e.blaming) to violent struggles or outbursts.

Parents would have appreciated counselling, or other parents who had been through the same experience to talk to – both for emotional support and information.

Positive experiences of specialist rehab wards in terms of restoration of functioning, though one or two felt this should be possible in a more homely environment rather than an institutional setting.

At home with family

Personality changes, and cognitive disability harder to deal with than physical impairments. Grief for "lost" child. These are the least "visible" effects of BI but the

hardest to deal with and the ones which local services tended to offer least help with (in the view of families).

Areas of conflict: disagreements about levels of autonomy; problems of trying not to upset person “walking on eggshells”; abuse and ill temper, anger, frustration of person with BI. Difficulties in accessing support to deal with this, and in knowing what “should” be done. (e.g. should the person drink (alcohol), and might arguments and emotional stress cause fits)

Professionals (e.g. care manager, consultants) with experience/knowledge of head injury and after-effects most valuable. Those who did not know much about it, less so. This point much mentioned in several chapters. Headway – also valued.

Disruptions of household, renegotiations of relationships, affect siblings

The author suggests some of the above difficulties might be eased through provision of more information about what to expect and “training” for families on how to deal with changes. Also much more on-going support for longer periods.

Variable levels of on-going support depending on where family lived. Many feel “forgotten” as time goes on.

JH makes a number of recommendations. P 107/8

#### *Hospital*

Named member of staff to provide families with on-going information about the person, and general info about the nature of head injury (including some in writing for reference later).

Professional counselling to be available: to help initially and to help later with re-negotiating relationships

Should be trained staff on general wards to assist with continuity after transfer from intensive care or specialist units

Head injured person should have access to own counselling from knowledgeable person.

#### *Home*

Access to counselling to continue

Rehabilitation should continue as long as needed in the individual case .

Importance of daytime occupation

Regular professional contact should continue to provide family “advocate” role and re-assess needs of person with BI and family.

As soon as possible should be access to assistance to take up paid employment, and to leave home if desired.

<b>Author/s</b>	Grundy, D. and Swain, A. (eds)			<b>Ref No</b>	<b>CA0015</b>
<b>Title (first 4 words)</b>	ABC of Spinal Cord Injury			<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Spinal cord injury</b>				
<b>Confidence Rating</b>	High	Medium	Low		
<b>Reviewer's initials</b>	HA			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is described as a 'standard introductory text on the subject of (spinal cord injury) for all health care staff working with patients'. It presents advice, suggestions and good practice. However, it does not appear to draw on any empirical studies and does not seem to me to include any information that would be relevant to the review.

<b>Author/s</b>	Williams et al (eds)			<b>Ref No</b>	<b>CA0016</b>
<b>Title (first 4 words)</b>	Mental Health Services			<b>Year of publication</b>	1996
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	T2	T3	T4	
<b>Location of study</b>	<u>UK</u>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Brain Injury (+ Huntington's Disease + early onset dementia)</b>				
<b>Confidence Rating</b>	High	Medium	<u>Low</u>		
<b>Reviewer's initials</b>	HA			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

HAS Team visited six districts in England and Wales and talked to service users and carers, as part of a HAS review to evaluate the state of mental health services for people with (see above). The report gives very minimal info re methods for collecting qualitative data (Annex A). I have little confidence in evidence collected from users and carers, as no methods details given re numbers, representativeness, - everything that makes a 'sound' study, really. Having said that, comments included

- Lack of appropriate rehabilitation facilities and respite care (p.44)
- Problems finding specialist help (p.44)
- Poor communication (p.44)
- Inadequate support for carers of people with ABI – a need for early counselling, information and recognition that relatives affected by the injury may need help in their own right.

See pages 45-51 for if you do include the work and want more detailed info broken down according to the three conditions groups. But I'd be wary of using this, personally.

<b>Author/s</b>	Coene, E.H. and Griffiths, R.K. (eds)			<b>Ref No</b>	<b>CA0017</b>
<b>Title (first 4 words)</b>	Parkinson's Disease: a self-care manual		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	Medium	Low		
<b>Reviewer's initials</b>	HA		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a self-help/self-care manual with advice, suggestions and good practice. However, it does not appear to draw on any empirical studies and does not seem to me to include any information that would be relevant to the review.

Chapter 16, 'Outline of Professional Help', reviews help that is available from (1) the NHS and (2) social services departments. It is very factual, concentrating on information about the roles of different professionals and how they might help sufferers and their carers. It also includes telephone numbers for organisations to contact for advice on professional help. I do not think this is the sort of information that the review is looking for.

Chapter 26, Patients' and Carers' Rights, contains information about sufferers' basic NHS rights to health and social services, mentioning relevant pieces of legislation e.g. the Chronically Sick and Disabled Person's Act 1970 and the Disabled Person's (Services, Consultation & Representation) Act 1986. As far as carers are concerned, it mentions the Carers (Recognition and Services) Act 1995 and their rights to assessment, and gives contact details of the Carers National Association (now Carers UK). There is just one page given over to carers. Again, I do not think this is what you are wanting to report in the literature review.

<b>Author/s</b>	Defriez, M. et al		<b>Ref No</b>	<b>CA0018</b>
<b>Title (first 4 words)</b>	The perception of the current...		<b>Year of publication</b>	2003
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	<u>UK</u>		Other (USA)	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a 'multi-stakeholder study' on the provision of care for patients with MS primarily seeking the perspectives of the patient and the healthcare professional, using semi-structured interviews, focus groups, patient and doctor questionnaires. However, carers were present at six of the interviews 'and were keen to share their experience of being a carer'.

#### Carer views expressed

- There was a general consensus that there was a lack of continued and co-ordinated care or no-one to overlook the whole process.
- Many carers were unaware of all their benefit and social service entitlements.
- The impact on carers of having a partner or relative with MS varied enormously.
- The majority of carers found caring for someone with MS time consuming and tiring.
- Many carers had to change their lifestyle.
- Several carers had retired early to care for their partners.
- Several carers had moved house to accommodate their partners needs.

<b>Author/s</b>	Hoad A., Oliver M. & Silver J.		<b>Ref No</b>	<b>CA0019</b>
<b>Title (first 4 words)</b>	The Experience of Spinal...		<b>Year of publication</b>	1990
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review Other
	All collected in one interview per respondent			
<b>Typology</b>	T1	<b>T2</b>	T3	T4
	Although at least one author is a user of services			
<b>Location of study</b>	<b>UK</b>		Other (USA)	
<b>User's Long Term Condition</b>	<b>Spinal Cord Injury</b>			
<b>Confidence Rating</b>	High	<b>Medium</b>	Low	
	31 primary carers of a sample of those who had been admitted to Stoke Mandeville in 1971-84. (fieldwork 15 years ago?)			
<b>Reviewer's initials</b>	HQ		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

250+ pages

Focus on meaning of SCI for family members (who were primary carers) 16 wives

15 parents

60% response rate

*Experience in hospital:* lack of privacy for husband and wife to sort issues out together.

Lack of knowledge about spinal injury among professionals outside specialist facilities eg those in receiving hospitals (A&E). Views of Stoke Mandeville generally v. positive. Availability of some accommodation for relatives valued. However some reservations about: blunt delivery of negative prognosis; visiting times precluded contact with medical staff which carers would have valued; limited interactions with social workers (though some were experienced as supportive); Some kind of keyworker approach advocated – (I don't know if they do this now, they may do.)

Also would have liked a system of case conferences – don't know if they do this now either.

However someone with whom relatives could have a continuous relationship while person in hospital would be valued.

Unquestioning assumption by professionals that carers would assume responsibility for care, not liked. Teaching sessions re physical care were, if they happened at all, generally too little too late. Sensitive negotiation of caring activities

needed. Bowel evacuations a problem which should be openly but sensitively discussed, and taught to those who were going to do it.

2/3 rated info provision inadequate. Lack of information on benefits, services, physical/emotional impacts of injury. Ditto sexuality and fertility. Some would have liked access to counselling – or someone to talk to. (subsequently the hospital has introduced relatives days which were valued by those who had been to them, but seen as not enough - trying to do too much and not enough recognition of differences between patients and thus caring responsibilities.)

### *Post discharge*

Having to change their role. Extent and meaning of role change influences how people perceive (feel about) their lives. Important to understand experience of individual in context of their social environment. Conceptual framework helps to suggest explanations for some of the reported variability in responses.

Number of physical caring tasks performed tended to decrease over time (compared with immediate post discharge) except aid with bowel management and “organisational” management.

Also decreases in % reporting disturbed sleep (1 in 4 at most).

Decline in leisure and social activities outside the home (majority). Inaccessible buildings one reason, along with lack of toilets suitable for disabled people.

Holidays problematic.

Many felt initially unprepared for extent of care which would be required. However just over half said the amount had decreased since discharge.

Uncertainty over how much the person should be expected to do for themselves a problem for carers.

Malaise Inventory Scores indicative of nos. of symptoms outside the normal range.

“A number” expressed desire for counselling. A few had paid privately for it.

Some worries about the future and own ageing. Concern about keeping up care among those who were older.

Most felt there had not been negative effects on children or siblings. Generally not an expectation that they would help with care, though they did some tasks they might otherwise not have done. Sometimes benefits from e.g. father being around more.

On the whole people reported the quality of the relationship with their injured spouse to be unchanged, though there were a few reports of deterioration, and a few of improvement.

Carers get the brunt of any emotional outbursts/frustration etc.

Parents caring support each other (mostly)

Role change: this study included wives only, no husbands. Half took on more house maintenance, car maintenance etc. A few of the husbands (with SCI) did more childcare than they had before. How much this mattered depended on how rigid gender divisions had been before and what kind of expectations prevailed in the social environment. Carers commented on need to be aware of the possibility of taking over too much.

Parents felt less role change but some had anticipated changes in retirement like greater freedom and more breaks which they now did not get.

Informal networks generally important sources of help/support. Public ignorance of spinal injury a problem. Relatives usually have no real idea what is involved.

*Community services* (generally felt to lack recognition of carers needs)

GPs. Variable but in general lacked specialist knowledge as well as detailed understanding of what routine care entailed. "Willingness to learn" on part of GP valued.

District nurses. (62% getting) Variable. Some regarded as excellent. Timing to fit with carers needs often problematic. Too happy to leave things to carers. Might not lift or change catheters because of "risks" which carers were expected to bear.

Social workers. Contact fleeting. Most (80%) currently not receiving.

Few getting domiciliary care. Some resentment about strict demarcation e.g. no help with the family ironing or cleaning of communal areas like the living room. Also about restrictions on the tasks they would do.

People believed more physiotherapy might be helpful, but none got any (once out of hospital).

Difficulties in accessing suitable respite/breaks.

SIA helpful to those who belonged. None belonged to carers organisations, but this was the late 80's.

Housing: half had moved since the accident. 7% not happy with current accommodation. Adaptations: variation in quality of service and OTs. "Armies of people" to deal with re adaptations or moves. Long waits for work to be done when needed quickly. Difficulties in getting poor or inappropriate work rectified. [lots of more recent work on this]. Having some financial resources helped in being able to have some control. Another recommendation for keyworkers.

Long waits while compensation claims were pursued: 39% had pursued a claim, a few more thought they should have). Most found this a struggle, especially when outside their previous roles. Problem when LA refused to provide adaptations because case in progress

Equipment: 64% felt they had what they needed. [Again there is more up to date work on this so doubt if this source is useful for this info.]

Employment & income: had been effects on carers career for some (% in work dropped from 78 to 45). Lost promotion prospects, or own business. Others (few) took up work. Loss of income usually greater than eventual compensation, but of course financial hardship greater for those who don't get compensation.

Benefits 78% AA (52% higher rate AA). ICA 32%. Some felt they needed benefits advice. Accounts of doing without entitlements for years before finding out about them.

<b>Author/s</b>	Weinert, C., Long, K.A.			<b>Ref No</b>	<b>CA0020</b>
<b>Title (first 4 words)</b>	Support systems for the spouses...		<b>Year of publication</b>	1993	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Multiple sclerosis</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This paper looks at the support systems in place for spouses of individuals with MS who live in rural areas. The authors claim from the literature that inhabitants of rural areas have more long-term illness than their urban counterparts. They also have fewer services and where these exist they are more likely to be refused in preference to informal arrangements.

This clearly places more burden of care on family members.

The study aimed to describe the overall levels of social support available, to describe the sources of this support and to examine any apparent gender differences.

Data was derived from a secondary study and 303 individuals (the well partner) responded to a mailed questionnaire. Findings were tabulated and compared with findings from other samples.

From this it becomes apparent that:-

- Rural care-givers report the lowest levels of perceived support
- Rural care-givers have very similar resources in terms of numbers of people they could turn to as were reported elsewhere
- Rural care-givers are more likely to use friends and neighbours as sources of support.

When considering the impact of gender on the sample it was found that:-

- Women with ill spouses reported higher levels of social support than vice-versa

- Men with ill spouses reported that they preferred to rely on their own devices
- Neighbours were used as resources more by women with ill spouses than vice-versa
- Religion was reported as a source of strength more by women than by men

The authors conclude that professional support services ought to be aware of the reliance on friends and neighbours by those in rural environments when targeting their interventions.

<b>Author/s</b>	Brown, J.B.			<b>Ref No</b>	<b>CA0021</b>
<b>Title (first 4 words)</b>	User, carer and professional experience.....		<b>Year of publication</b>	2003	
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Motor neurone disease</b>				
<b>Confidence Rating</b>	<u>High</u>		Medium	Low	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This highly qualitative study tries to answer the question, 'What are the lay and professional values of care in the context of MND and is there a difference between them which affects care delivery and receipt?'

Principal findings are:-

- The professional carers' main role is in reducing suffering
- The lay carers' main role is simply (sic) to provide 'care'.
- The patient perspective is balanced between a recognition of the need for functional intervention and the need to be treated as a human being.
- The MND trajectory defies categorisation as either **terminal** or **chronic** and this affects both professional and lay carers as they try to intervene.

Carers experiences are summarised as:-

- A feeling of shock as they began to appreciate the impact of the diagnosis.
- A search for meaning, usually through information sources.
- The stress of caring coupled with the loss of their previous life
- Accepting the inevitable death of their partner
- Struggling to keep career/job going

References:

Oliver, D. (1995) *Motor Neurone Disease: a family affair*. London: Sheldon Press

<b>Author/s</b>	Grice et al			<b>Ref No</b>	<b>CA0026</b>
<b>Title (first 4 words)</b>	maintaining quality of life			<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SS		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Palliative care is the mainstay of treatment currently available. This clinical assessment of disease progression was required every four weeks. Other issues arose therefore there was a need for a separate care facility which was established with support of George Barton Motor Neurone Disease Trust, which serves 1.8 million residents in Lancashire and South Cumbria.
- One aspect of the service = measure muscle power using the Medical Research Council Scale and Myometer.
- Second aspect = co-ordination of a multidisciplinary team. Referrals are made to the appropriate team member depending on the patient's specific needs. Referrals are made to nurses for teaching care to relatives - hospices and respite homes. OT's - assess for patient difficulties with daily living activities and the provision of equipment to help with this.

<b>Author/s</b>	Young, C			<b>Ref No</b>	<b>CA0024</b>
<b>Title (first 4 words)</b>	Truth and Myths			<b>Year of publication</b>	1994
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SP			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Interviews with carers as part of a larger study investigating many aspects of MS. Majority of carers (mainly spouses) were under great stress but had no plans to leave their partner.

There was a strong sense of commitment to caring, but little sense of fulfilment in doing so.

Only 7 out of 12 carers in the largest group interviewed reported positive experiences as a result of caring.

Carers appreciated contact with the medical research team.

Carers often pay a high price in terms of their own health.

<b>Author/s</b>	Firth			<b>Ref No</b>	<b>CA0027</b>
<b>Title (first 4 words)</b>	Brainchild of the north			<b>Year of publication</b>	1996
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High	Medium	Low	<b>N/A</b>	
<b>Reviewer's initials</b>	HR			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article discusses a service set up in Northumberland to address the health and social needs of people with head injuries after they leave hospital. They have found that they need to attend to carers needs as well as those of the people with head injury.

<b>Author/s</b>	Rankin, G.			<b>Ref No</b>	<b>CA0030</b>
<b>Title (first 4 words)</b>	Lots of help at....			<b>Year of publication</b>	1997
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SP			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Nothing relevant to this project.

<b>Author/s</b>	Kerstan,P. McLellan,DL. Gross-Paju,K. Grigoriadis,N. et al		<b>Ref No</b>	<b>CA0038</b>
<b>Title (first 4 words)</b>	A questionnaire assessment of unmet		<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative	<u><b>Qualitative</b></u>	Mixed	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK	<u><b>Other (K Belgium Estonia Greece Italy)</b></u>		
<b>User's Long Term Condition</b>				
<b>Confidence Rating</b>	High	Medium	<u><b>Low</b></u>	
<b>Reviewer's initials</b>	HR	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article was evaluating an unmet needs questionnaire as an international assessment tool. There was limited information on carers experiences in the UK but it did highlight the most pressing unmet needs for carers were for increased finances, services and information and respite care.

<b>Author/s</b>	Smith			<b>Ref No</b>	<b>CA0040</b>
<b>Title (first 4 words)</b>	Banging heads together			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	Low	<b><u>N/A</u></b>	
<b>Reviewer's initials</b>	HR			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a discussion article which quotes a carer as saying that her husband spent four months on a non-specialist ward which led to acute emotional vulnerability and she sees it as a major failing in the system. She felt that head injury was not given the right level of priority in the acute hospital.

<b>Author/s</b>	Mir, G., Tovey, P.			<b>Ref No</b>	<b>CA0046</b>
<b>Title (first 4 words)</b>	Cultural competency: professional action...		<b>Year of publication</b>	2002	
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Cerebral palsy</b>				
<b>Confidence Rating</b>	High	Medium	<u>Low</u>		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Carers' views in this instance are heavily mediated to the point of exclusion by the central aim of the study which is to investigate whether or not cultural competency exists in professional services as they are directed at South Asian carers of individuals with cerebral palsy (CP). Given the design of the study any carer views elicited must be treated with caution as they are not necessarily representative of the caring experience *per se* but more of the experience of an ethnic minority receiving potentially inequitable treatment within an institutionally racist environment. In this case, the condition (CP) may be incidental to the broader agenda.

To generate data interviews were carried out with variety of health professional as well as with 20 South Asian carers. However, it should be noted that, 'this paper draws heavily, though not exclusively on the data from service professionals'. In this detail the impact of carer views is further diluted.

To justify their investigation the authors point to a higher incidence of CP in South Asian communities and a lack of knowledge about the needs of carers. The higher incidence is never fully explained although concluding remarks refer to a medical focus on genetic causes of CP which seems to conflict with carers views who see poor medical care as significant in the condition. This is a major point that needs much fuller consideration.

Ultimately the political and policy oriented nature of the piece obscures the voice of carers.

<b>Author/s</b>	Mapp			<b>Ref No</b>	<b>CA0056</b>
<b>Title (first 4 words)</b>	A world apart			<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	Low	<u>N/A</u>	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a discussion article which quotes a director of Headway who reports that relatives of people with head injury report the ten most difficult problems after head injury are: personality changes, slowness, poor memory, irritability, bad temper, tiredness, depression, rapid mood changes, tension and anxiety, threats of violence.

<b>Author/s</b>	Cheeson, R.		<b>Ref No</b>	<b>CA0058</b>
<b>Title (first 4 words)</b>	Psychosocial aspects of caring		<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	<u>UK</u>		Other (USA)	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	HA		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

Author conducted semi-structured interviews with 60 (36 men; 24 women) caring for relatives with MS. Efforts were made to recruit carers below retirement age. Sample was somewhat skewed, in sense that many carers recruited through the MS Society. Also interviewees were a selective group in that they volunteered so might not be typical of carers of people with MS. Research undertaken in Scotland: Aberdeen, Argyle and Clyde, Edinburgh and Orkney (nb: different legislation in Scotland, e.g. Community Care and Health (Scotland) Bill).

Key findings relating to use of health and social care services were:

- In most cases, services provided only where the person with MS was highly dependent, and in several cases services had only been recently provided.
- Some carers reported paying for help with housework; this applied to households where levels of disability were lower.
- Few carers indicated that comprehensive packages of care, including health and social care, were in place.
- Main issues related to delays in services being provided, the need for information and difficulties in accessing services and allowances.
- Carers would have welcomed a more proactive approach on the part of service providers, as they or the person they cared for had been reluctant to seek help.

- Carers described feeling ‘abandoned’ at the time of diagnosis, even though they felt that their lives were affected too. Over two-thirds reported a lack of information at this critical point. Information was required on: benefits, housing adaptations, equipment, relevant services, the disease itself, coping strategies.
- Some carers reported a need for emotional support and counselling. Several carers suggested that health professionals lacked knowledge of MS. Needs relating to housework and personal care were more likely to be met than those of a psychological nature. It appeared from the interviews that carers were more likely to feel ‘on top of the situation’ and less likely to highlight their own unmet psychological needs where services were in place.
- Several carers rated services very highly. Occupational therapists were often identified as particularly helpful. Even where regular help was obtained, carers often provided considerable assistance themselves and/or paid for additional services (e.g. cleaning) or items of equipment (e.g. one carer/patient contributed £3,500 to a special shower; council paid another £2,000; other items included an ‘electric’ bed and transport/paying for taxis).
- Carers in Orkney were unusual in expressing high levels of satisfaction with services, especially in relation to the integration of health and social care services
- About two-thirds of interviewees had specially adapted bathrooms and modifications (grab rails or ramps).
- Carers expressed dissatisfaction with respite care. It was seen as unsuitable for care recipients, who were then unhappy (and so were carers), one got an infection whilst using hospital respite facilities and came out ‘worse than he went in’. Other criticisms included that respite was boring, with little stimulation or activities.

Author was surprised to find that carers had low levels of contact with the voluntary sector, even though many recruited through the MS Society. The only other organisation commonly referred to was Crossroads. Crossroads was seen to be fulfilling an important role in service provision, but not perceived as providing emotional support for the carer or as fulfilling advocacy or lobbying functions. Organisations such as Carers Scotland, the Coalition of Carers or the Princess Royal Trust for Carers were little mentioned. Neither did carers tend to visit/use carers’ centres and speak with staff there.

<b>Author/s</b>	Robinson, I. and Hunter, M.			<b>Ref No</b>	<b>CA0062</b>
<b>Title (first 4 words)</b>				<b>Year of publication</b>	1998
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	HA			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This was a final draft report for the MS Society, intended to complement an earlier report (Dispatch from the Front Line), which I have not seen. The concluding section (Section 5) of this second report is a rewritten version on one section from the first report, and the reader is told that it needs to be read in conjunction with both reports. Section 5 of the present report refers to tables and figures which do not seem to be included in the document. Data gathering for the present report involved a range of methods: focus groups, critical incident analysis; and the Delphi technique. Information was collected in six different areas of the country from people with MS, their carers and professionals. The following issues are discussed in the report.

- Male carers have particular difficulty in convincing professional staff (social services and nurses, for example) of their competence in relation to domestic and personal care. Carers face a more general problem in convincing professional staff of that they have their own particular expertise based on experience.
- The impression of many carers is that, in most of their contacts with service providers, the main aim appears to be to prevent them from getting the services, aids and adaptations needed, even though they also appear to be eligible for them. There is too much 'battling with bureaucracy'. There are major co-ordination problems within and between health and social services. Services often appear to lack the 'common sense' needed to be able to adapt rules and procedures to the everyday needs of carers
- There is concern about the increasing discrepancy between the rhetoric of 'patient care' delivered through 'patient's or client's charters'

and what many carers experience in practical terms as a worse service on the ground, e.g. services, and access to those services, has not changed at all, and in resource terms might even have become worse.

- 'Out of hours' services can be very poor, yet MS and its problems are experienced 24 hours a day and have to be managed on that basis.
- Finding an advocate is often seen as the only way through the system, but it is not always possible to find one who supports carers' views rather than their own.
- Respite care is often welcomed in principle, but is a double edged sword in practice as concerns are expressed about the nature and quality of care in these settings.
- Carers might wish to join the person with MS in respite care and share the 'break', but this often proves difficult or impossible, which can put an additional strain on an already stressed relationship.
- Day care may be undertaken as a 'warehousing' process for people with MS. Staff qualifications, experience and commitment may be very low, especially in some local authority day care centres. Medical and health problems may not be recognised or managed effectively in day centres.
- There can be major problems when younger people with MS are mixed with older elderly people in respite care facilities.
- Carers can feel forced into seeking long-term residential care because of the lack of (modest) additional services in the community, resulting in a significant breakdown in the relationship and much extra public cost.
- Information needs are one of the most substantial and long term needs of carers. The communication process at the time of diagnosis is particularly important, and it is not helpful if doctors are over-protective and reluctant to give the diagnosis at an early stage, or communicate it in such euphemistic terms that the carers (and patient) do not know what has been communicated. A fast track to relevant information is important at this early critical stage, as it can impact on the whole process of dealing with MS in the first few months, and possibly the first few years.
- Carers wanted accessible and relevant guidance and support independently of government agencies, health trusts and authorities.
- Greater attention needs to be paid to establishing a standard and supportive information system at the time of diagnosis. Community

based systems of information are very patchy and subject to change through changing policies and resource allocations.

- Male carers often felt that support groups and similar activities were not for them. They wanted immediate and practical help and a break from MS, rather than to keep talking about the disease and associated problems and issues.
- The value of counselling was questionable. For the most part, carers' immediate concerns were very practical. Many carers managed dealing with the problems and issues of MS through informal channels and processes, rather than through the more formal structure of counselling that many professionals see as a key first requirement.

<b>Author/s</b>	MS Society (Foley F. the author)			<b>Ref No</b>	<b>CA0067</b>
<b>Title (first 4 words)</b>	Relationships and intimacy: the..		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
	Booklet produced by MS society to advise members on living with MS				
<b>Typology</b>	<b><u>T1</u></b>	T2	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	Medium	Low	<b><u>N/A</u></b>	
	It is not research though I'm confident its useful advice..				
<b>Reviewer's initials</b>	HQ		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Reports some of the impacts of MS on relationships, intimacy and sexuality. Not explicitly based on research but includes quotes – some from partners. Re carers: indicates can be difficulties in switching between roles of lover and carer, but otherwise the emphasis is on the physical and emotional impacts of MS, how this can affect sexual feelings/responses and some solutions to common problems. I am sure it would be regarded as useful information by many carers of people with MS.

Carers experiences might include: fatigue of cared for person (and own), reduced physical sensations caused by MS, other symptoms e.g. incontinence, all impacting on sexual relationships and intimacy.

<b>Author/s</b>	Cunningham C., Wilson M. and Whiteley S.	<b>Ref No</b>	<b>CA0070</b>
<b>Title (first 4 words)</b>	Living on Equal Terms	<b>Year of publication</b>	1998
<b>Research methods</b>	Quantitative    Qualitative <b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1 <b><u>T2</u></b>	T3	T4
<b>Location of study</b>	<b><u>UK</u></b>	Other (USA)	
<b>User's Long Term Condition</b>	<b>Brain Injury</b>		
<b>Confidence Rating</b>	High <b><u>Medium</u></b>	Low	
	Evaluation of a service for 43 people with BI. Not focused on carers		
<b>Reviewer's initials</b>	HQ	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Evaluation of a service called Connections designed to support people with acquired BI to live in ordinary housing. Not about carer views, indeed occasional tensions with family members reported by staff over conflicting definitions of person's needs. Still families valued the quality of the service to their injured member, because such support had previously been lacking. Very limited coverage of family issues.

**Much more reports of users views. Definitely one for the user study**

<b>Author/s</b>	Reynolds et al			<b>Ref No</b>	<b>CA0071</b>
<b>Title (first 4 words)</b>	Evaluation of the role of the PDNS		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other		
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low		
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

No real significant difference between follow-up care provided by PDNS or consultant.

Need PDNS and consultant for best patient treatment/ care

PDNS only clinic provide unsatisfactory service

PDNS only not very cost effective

Study bias and no control centre

<b>Author/s</b>	McPherson et al			<b>Ref No</b>	<b>CA0074</b>
<b>Title (first 4 words)</b>	Information needs of families			<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK	<b><u>Other (Scotland &amp; New Zealand)</u></b>			
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SS			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Patients and carers need information about a range of things after discharge
- More prompting required

<b>Author/s</b>	Margaret Lloyd			<b>Ref No</b>	<b>CA0076</b>
<b>Title (first 4 words)</b>	Where has all the care management gone		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	<u>Mixed</u>	Lit. review	Other
<b>Typology</b>	T1	T2	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<b>Medium</b>	Low		
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Reported stress and mental illness from carers heavily involved in giving personal, physical and night care → need community care management arrangements
- Majority of PD patients were cared for by relative with no outside support
- Level of outside care provided was not influenced by health of carer.
- Lack of information about services
- Possible solution to difficulties of multi-agency working is for service user and carer to be care manager - they have contact with different systems

<b>Author/s</b>	Magill-Evens et al			<b>Ref No</b>	<b>CA0082</b>
<b>Title (first 4 words)</b>	Are families with adolescents		<b>Year of publication</b>	2001	
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (Canada)</u></b>		
<b>User's Long Term Condition</b>	<b>Cerebral Palsy</b>				
<b>Confidence Rating</b>	High		<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Uses Bronfenbrenner's (1977) ecological framework as theoretical guide.  
 Aim to determine if young people with CP and their families have different experiences to families with no disabled adolescent  
 Used 4 quantitative measurements and 3 categories: non-disabled;  
 adolescent with mild CP; adolescent with CP influencing cognition

Overall no significant difference between experiences of families with or without disabled young person  
 Parents' expectations of adolescents with severe CP were significantly lower than those of adolescents with less severe CP (cp1). Although parents of CP1 had lower expectations to those of non-disabled adolescents (control)

Fathers and siblings may be most affected by having a disabled adolescent in the family – may have decreasing contact with friends

<b>Author/s</b>	Frosse et al			<b>Ref No</b>	<b>CA0083</b>
<b>Title (first 4 words)</b>	Comparing opinions of people		<b>Year of publication</b>		1999
<b>Research methods</b>	Quantitative	<u><b>Qualitative</b></u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Epilepsy, Cerebral Palsy</b>				
<b>Confidence Rating</b>	<b>High</b>		Medium	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Use ISIS as instrument to capture data from people with disabilities about their experiences.

People with disabilities reported great need for social relationships, also for significant people (parents in most cases)

Reported need for more respite services

This study is important to give disabled people a voice and enable them to influence policy and decisions

Limitations of study:

Participants have mild disabilities, not severe

Small and geographically limited sample

<b>Author/s</b>	Lee, M.M.K et al. (6 authors)		<b>Ref No</b>	<b>CA0087</b>
<b>Title (first 4 words)</b>	Psychosocial Well-Being (of) Carers		<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK	<b>Other Hong Kong</b>		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>			
<b>Confidence Rating</b>	High	<b>Medium</b>	Low	
<b>Reviewer's initials</b>	SB	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

An exploratory study to explore factors associated with quality of life and emotional states of the carers of people with epilepsy in Hong Kong. Well designed and executed, but findings can not be generalised to the general population of carers of people in H.K. because of:

No control group of non carers;

Sample drawn from a support group and questionnaires completed by people supporting members to a hospital/support facility;

Homogeneity among carer group – all committed to caring for the person with epilepsy hence no less well adjusted individuals in the sample;

Small sample size (65)

The study used rating scales of mood, quality of life and intensity of epileptic and psychosocial variables. About half of participant carers reported experiencing less satisfactory psychosocial adjustment than the general population. 22% had severe levels of anxiety and 14% severe levels of depression; 75% had below average scores on the quality of life measure.

Contrary to findings of previous studies, care-givers of people with additional illnesses or learning disabilities were not more distressed than care-givers of people with epilepsy only.

About 50% of carers reported receiving adequate levels of support – mainly from families but also from agencies. The latter contradicts the common belief that Asian families are reluctant to accept support due to the association between dependency and shame.

Factors positively associated with carers' well-being and quality of life were: perceived level of support; and participation in social and leisure activities in the absence of the patient. Older age was a possible negative factor for psychosocial adjustment.

In terms of medical variables, achieving better control of seizures was reported as the key to achieving better quality of life for both carers and the person with epilepsy.

The researchers signal the importance of using measures of subjective experiences in studies of social and psychological aspects of epilepsy.

<b>Author/s</b>	Taylor et al			<b>Ref No</b>	<b>CA0090</b>
<b>Title (first 4 words)</b>	Patients' aims for epilepsy surgery		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other(USA)		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	<u>High</u>	Medium		Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Most frequently cited aims [of surgery] by patients and carers:  
 To be working  
 To drive a car  
 Independence/ freedom/ Socialisation  
 Relief from medication  
 Change in behaviour [desired by carers on behalf of patients]  
 Improvements in personal safety

<b>Author/s</b>	Krawetz,Fleisher, Pillay,Staley,Arnett,Maher		<b>Ref No</b>	<b>CA0092</b>
<b>Title (first 4 words)</b>	Family Functioning in subjects		<b>Year of publication</b>	2001
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review    Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>	
<b>User's Long Term Condition</b>	<b>Epilepsy</b>			
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article has no relevant information on carer experiences

<b>Author/s</b>	Espie et al			<b>Ref No</b>	<b>CA0097</b>
<b>Title (first 4 words)</b>	The epilepsy outcome scale		<b>Year of publication</b>	1998	
<b>Research methods</b>	Quantitative	Qualitative	<u>Mixed</u>	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	<u>High</u>		Medium	Low	
<b>Reviewer's initials</b>	SS		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Based on a study concerned with the principal concerns carers have about people with epilepsy, and the development of a useful outcome measure for use in clinical practice.
- Epilepsy Outcome Scale developed as a measuring tool for profiling and quantifying concerns about epilepsy among people with learning difficulties.

<b>Author/s</b>	McGrath, P.J., Rosmus, C. <i>et al</i>			<b>Ref No</b>	<b>CA0099</b>
<b>Title (first 4 words)</b>	Behaviours care-givers use to .....			<b>Year of publication</b>	1998
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	T2	T3	<b><u>T4</u></b>	
<b>Location of study</b>	UK			<b><u>Other (Canada)</u></b>	
<b>User's Long Term Condition</b>	<b>Mental retardation</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This brief report outlines an attempt to create a checklist that care-givers could use to determine pain in non-verbal individuals with mental retardation. As such it does not meet the criteria for this project.

<b>Author/s</b>	Lane, A.B. et al			<b>Ref No</b>	<b>CA0102</b>
<b>Title (first 4 words)</b>	Seizure-Free may not be...		<b>Year of publication</b>	1997	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		Other (USA)		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Abstract only. This study suggests that care-givers of patients who have undergone surgery for intractable epilepsy risk increased care-giver burden regardless of surgery outcome. Nothing else pertinent.

<b>Author/s</b>	Kleinman et al		<b>Ref No</b>	<b>CA0105</b>
<b>Title (first 4 words)</b>	The social course of epilepsy		<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review      Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other (CHINA)</u>	
<b>User's Long Term Condition</b>	<b>Epilepsy</b>			
<b>Confidence Rating</b>	<u>High</u>		Medium	Low
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Consultation with TCM practitioners
- Burden of patient is family burden – Family members give up work, are blamed for causing epilepsy
- In Chinese society care of patient is responsibility of family until marriage when it becomes responsibility of spouse
- Stigma in school, work, society. Thus patients are confined to home out of fear of disgrace.
- Addressing Epilepsy means having interdisciplinary systems between health policy and social policy and social theory.

<b>Author/s</b>	Oddy and Herbert			<b>Ref No</b>	<b>CA0110</b>
<b>Title (first 4 words)</b>	Intervention with families following		<b>Year of publication</b>	2003	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Observations from the literature review:

- Families report lack of information
- Families feel the outside world do not understand their problems and difficulties
- Cognitive and personality changes are the most difficult to cope with
- Denial is a factor in family responses
- Not all families are distressed after brain injury
- Families feel excluded by professionals
- In support groups carers preferred a semi-structured format with guest speakers 25-50% of the time

Implications for service providers:

Admission procedures in rehab units need to keep relatives involved and informed with regular contacts and inclusion in reviews

<b>Author/s</b>	Laroi			<b>Ref No</b>	<b>CA0112</b>
<b>Title (first 4 words)</b>	The family systems approach			<b>Year of publication</b>	2003
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other(Belgium)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	Low <b><u>N/a</u></b>		
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article does not have any reference to carers experiences of caring for someone with brain injury but does argue for family therapy for families of people with brain injury to re-establish or redistribute roles.

<b>Author/s</b>	Sneeuw K. et al.			<b>Ref No</b>	<b>CA0113</b>
<b>Title (first 4 words)</b>	The role of health...			<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	T2	T3	<b><u>T4</u></b>	
	<b>(one study epilepsy, the others outside TGs e.g. cancer patients)</b>				
<b>Location of study</b>	UK	<b><u>Other Netherlands</u></b>			
	Review of 23 studies (which met inclusion criteria). International (English) literature search.				
<b>User's Long Term Condition</b>	<b>General</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
	Low relevance of groups.			The findings may well hold for the target groups also.	
<b>Reviewer's initials</b>	HQ			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Judgements made by significant others (care-givers, family members) and health care providers about health related quality of life are reasonably accurate (that is they correlate well with the person's own judgements). Health provider results not as close as care-giver results but this could be an artefact of small sample sizes in the relevant studies. Of course there is still a minority of instances in which there is significant disagreement.

<b>Author/s</b>	Kreutzer, Kolakowsky-Hayner, Demm, Meade			<b>Ref No</b>	<b>CA0120</b>
<b>Title (first 4 words)</b>	A structured approach to family		<b>Year of publication</b>		2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article discusses the Brain Injury Family Intervention, which is a tool designed to address common issues, concerns and challenges for families accommodating brain injury.

It addresses families' experiences of changes in work to care for the person with TBI, financial difficulties, increased responsibility, healthcare issues, communication and role changes.

It is based on 8 assumptions:

- Brain injury causes drastic life changes for all the family
- Most people want their own life back
- Well informed people do better
- Every family member deserves respect
- Each family member is important
- Every adult family member has to right to make choices; good or bad
- The family end up with most responsibility for helping the person with TBI
- Family members must take care of themselves effectively to help others

The treatment is based on steps that address carer experiences:

1. **Recognising and coping with changes:** addresses carer's anxiety and confusion, understanding of the emotional and behavioural changes,

taking on new responsibilities, the tendency of carers to forget about themselves, guilt

2. **Understanding and promoting long term recovery:** addresses carers striving for the perfect treatment, keeping motivation after the initial 6 months, ensuring family members are all consistent and dealing with emotional Vs physical recovery
3. **Managing stress and other problems:** address coping with overwhelming stress, perceiving progress, avoiding taking on too many responsibilities, developing support networks beyond healthcare professionals
4. **Working with rehabilitation professionals:** addresses frustration with finding rehabilitation services, helping them ask questions and disagreeing with professionals and inconsistencies with advice.

The programme is based on a literature review, clinical experience and carer views and needs validation

<b>Author/s</b>	Machamer, J., Temkin, N., Sureyya, D.		<b>Ref No</b>	<b>CA0121</b>
<b>Title (first 4 words)</b>	Significant other burden and factors.....	<b>Year of publication</b>		2002
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review    Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK	<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic brain injury</b>			
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>	
<b>Reviewer's initials</b>	AMC	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study examined the caring experiences of 180 family members of people with moderate to severe TBI at 6 months post-injury.

Burden and depression of the significant other (SO) was measured using standard psychometric tools. The TBI patient was assessed on severity, neuropsychological status and function. Data were then subject to statistical manipulation. From this the following results are available:-

- The majority of the relatives endorse positive experiences
- Most frequently reported concerns were around fear of the future, stress associated with caring and financial worries.

#### Cautions

Less stress was identified in this study. The authors believe that this may be due to the severity of the TBI in the study or a lack of sensitivity in the instruments measuring stress.

The sampling may also have influenced the overall reporting of positive experiences. The relatively early timeframe also suggests that a longitudinal study could reveal different results.

The lifestyle of the TBI individual pre-injury also seems to affect the outcome for the SO who report more negative experiences where the TBI patient had a troubled history.

The authors further concede that the results 'may appear obvious'.

## References

Gillen, R. *et al* (1998) Distress, depressive symptoms and depressive disorder among care-givers of patients with brain injury *Journal of Head Trauma Rehabilitation* 13, 31-43

Marsh, N.V. *et al* (1998) Care-giver burden at six months following traumatic brain injury  
*Brain Injury* 12, 225-238

(and same authors, same volume, same study at one year follow-up appears on pp. 1045-1059)

Sander, A.M. *et al* (1997) Predictors of psychological health in care-givers of patients with closed head injury *Brain Injury* 11, 235-249

<b>Author/s</b>	Boyle, G.J., Haines, S.			<b>Ref No</b>	<b>CA0123</b>
<b>Title (first 4 words)</b>	Severe traumatic brain injury....		<b>Year of publication</b>	2002	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other(Australia)</b></u>		
<b>User's Long Term Condition</b>	<b>Traumatic brain injury (TBI)</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This paper begins from the premise that family function can affect outcome for brain injured persons. To generate data 25 carers completed two psychometric tests. Results were then compared with 32 individuals who had no brain-injured family members.

Two hypotheses were advanced. H1, that families with a brain-injured member will exhibit increased levels of conflict, control and communication problems. H2, that these difficulties will result in families participating less in recreational, cultural and intellectual activities resulting in lower cohesion and independence than control groups.

After statistical manipulation the findings suggests that:-

- The most common problems reported were loss of relationships with family and friends and reduced participation in former activities
- When compared with the control group the carers reported consistently lower scores across all domains save for 'control' which suggests that carers rely heavily on established procedures and patterns to cope with their situation
- Results suggest that carers have particular problems in the areas of expressiveness, recreation, control and depression/dejection

One reference might be worth following up:-

Acorn, S., Offer, P. (eds) (1998) *Living with brain injury: a guide for families and care-givers* Toronto: University of Toronto Press

<b>Author/s</b>	Carnevale, Anselmi, Busichio, Millis			<b>Ref No</b>	<b>CA0125</b>
<b>Title (first 4 words)</b>	Changes in Ratings of care-giver			<b>Year of publication</b>	2002
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK			<u><b>Other (USA)</b></u>	
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	HR			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article reviewed the benefit of a behaviour management program for persons with TBI and their Carers and the effect on reducing carer burden. It found that there were no significant changes in the measures associated with treatment.

Articles:

Kreutzer, Serio, Bergquist Family needs after brain injury: A quantitative analysis J. Head Trauma Rehabilitation 1994:9: 104-115

Kolakowsky- Hayner, Miner Kreutzer Long term life quality and family needs after traumatic brain injury J. Head Trauma Rehabilitation 2001; 16 374-385

<b>Author/s</b>	Hibbard, Cantor, Charatz, Rosenthal, Ashman, Gunderson, Ireland-Knight, Gordon, Avner, Gartner			<b>Ref No</b>	<b>CA0126</b>
<b>Title (first 4 words)</b>	Peer Support in the		<b>Year of publication</b>	2002	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High		<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study evaluates the impact of a community based peer support program for individuals and their families after TBI. Relevant findings:

- All family members reported some impact on their ability to cope from the peer support program
- Half the families reported enhanced quality of life
- The partners had increased knowledge about TBI after the program
- The greatest benefit reported was shared experience and the role of the wounded healer
- Partners praised the mentors ability to prepare them for the personal 'overload' as services began to withdraw
- The program enhanced partners abilities to communicate with professionals

Implications:

- Need for more information about community resources early in the rehab phase

<b>Author/s</b>	Struchen M. et al.		<b>Ref No</b>	<b>CA0127</b>
<b>Title (first 4 words)</b>	A multidimensional measure of..		<b>Year of publication</b>	2002
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
	241 care-givers 83% Female 78% Caucasian. Self completion of various scales. Varied time since injury occurred, not all co-resident.			
<b>Typology</b>	T1	<u>T2</u>	T3	T4
	The focus of this paper is psychometric testing of a Care-giver Appraisal Scale (CAS)			
<b>Location of study</b>	UK		<u>Other (USA)</u>	
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>			
<b>Confidence Rating</b>	High	Medium	<u>Low</u>	
	Not meant to uncover carer views or experiences. Some important factors, like finances, probably operate differently in US context			
<b>Reviewer's initials</b>	HQ		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Investigates factor structure and concurrent validity of 47 item scale. Consequently reduces it to 35 items. Four underlying factors are named:

Perceived burden

Care-giver relationship satisfaction

Care-giving ideology

Care-giving mastery (weakest factor)

Checks factor scores against other scales intended to measure those concepts.

The content of the scale could be of interest since it allegedly reflects research on carers, although this particular study did not check out with people whether they thought anything important had been left out. An interview based study was running concurrently but results of it did not feed into this.

<b>Author/s</b>	Ergh et al			<b>Ref No</b>	<b>CA0128</b>
<b>Title (first 4 words)</b>	Predictors of care-giver and family		<b>Year of publication</b>		2002
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>BRAIN INJURY</b>				
<b>Confidence Rating</b>	High		<u>Medium</u>	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Neurobehavioural and affective problems of patient more likely to influence care-giver distress and family functioning
- More support received by care-giver, less distressed they are
- Family dysfunctioning inversely related to perceived social support
- Other factors such as alcoholic tendencies or socioeconomic position of patient were not related to care-giver stress.
- Care-givers with lowest social support experienced highest distress, but also were caring for patients with most severe conditions. Those receiving moderate support experienced lowest distress and cared for patients with least severe condition
- Family functioning improved with increasing social support

<b>Author/s</b>	Albert, Ashley, Brewer, Brenner, Smith, Waxman		<b>Ref No</b>	<b>CA0129</b>
<b>Title (first 4 words)</b>	Effect of Social Work		<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK		<b>Other (USA)</b>	
<b>User's Long Term Condition</b>	<b>Brain Injury</b>			
<b>Confidence Rating</b>	<b>High</b>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study looks at the benefit of a carer support program via telephone for carers of people with brain injury over the 12 months after discharge. They found that initially contact was for counselling for the carer extending to more family based counselling as the patient moved beyond the initially discharge phase with an increase in enquiries about rehab and nursing home care. The carers who received the service reported significantly less burden than those without and greater mastery of care giving tasks. They also had higher global quality of life ratings.

Reference: Kolakowsky-Hayner, Miner, Kreutzer. Longterm quality and family needs after traumatic brain injury. J Head Trauma Rehabilitation 2001 16: 374-385

Knight, Devereux Godfrey Caring for a family member with a traumatic brain injury Brain Injury 1998: 12:467-481

<b>Author/s</b>	DEGENEFTE, C.E.			<b>Ref No</b>	<b>CA0130</b>
<b>Title (first 4 words)</b>	Family Care-giving (and ) Traumatic Brain		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	T2	T3	<b><u>T4</u></b>	
<b>Location of study</b>	UK		<b><u>Other USA</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	SB		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article draws on an extensive literature to discuss the challenges faced by those providing long term care for family members with traumatic brain injury. Areas reviewed include :

The nature of care needs

Stress and burden experienced

How families cope with care-giving demands

Building on this, the paper concludes with a discussion of what social workers can do to reduce the demands of family care-giving and improve care-givers' quality of life.

No information whatever is given on the approach to the literature review, way it was conducted or the quality, validity and reliability of the studies reported. Nor are theoretical perspectives (such as coping strategies or adaptation) used as a way of structuring the literature.

The paper nevertheless provides a good overview of experiences, needs for support and implications for social work practice.

<b>Author/s</b>	Stebbins & Pakenham			<b>Ref No</b>	<b>CA0132</b>
<b>Title (first 4 words)</b>	irrational schematic beliefs		<b>Year of Publication</b>		2001
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit.review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (Australia)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High		<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

- Care-givers = parents, spouse, siblings
- Methodology = Irrational Beliefs Inventory & Brief Symptom Inventory
- 5 key irrational beliefs: Problem avoidance; Rigidity; Worrying; Demand for Approval; Emotional irresponsibility
- Characteristics related to person with TBI is not related to care-giver stress - not consistent with previous studies. Discrepancy may be because study used single items to measure, but previous studies used a multi-item disability scale.
- Care-givers of people with TBI are vulnerable to high levels of stress & burden
- Reduction in adherence to certain irrational schematic beliefs (worrying + demand for approval ) are likely to reduce psychological stress of care-givers and increase their physical health.

<b>Author/s</b>	Ergh, T.C.			<b>Ref No</b>	<b>CA0133</b>
<b>Title (first 4 words)</b>	Social Support Moderates Care-giver...		<b>Year of publication</b>	2001	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Abstract only. 60 pairs of TBI patients and care-givers studied.

Care-givers with adequate social support adjust better to their new role, and are less distressed than those with low social support, who become increasingly distressed as 'time since injury elapses and patient executive dysfunction worsens'.

Patient neurobehavioural disturbance increases care-giver distress regardless of social support level.

<b>Author/s</b>	Sinnakaruppan, Williams			<b>Ref No</b>	<b>CA0134</b>
<b>Title (first 4 words)</b>	Family carers and the		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High	Medium	Low	<b><u>N/A</u></b>	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article reviews the current literature on the needs of family carers of people with head injury. The article reviews 13 articles. The key findings from the review of carers needs when caring for a person with head injury are:

- Carers need a clear and regular explanation of their relatives condition and realistic prognosis
- Carers need to feel there is hope and know what the future holds
- They need to feel that healthcare professionals care
- Honesty in response to questions
- They need time to themselves outside the house
- A need for understanding of the effects of head injury, community resources and financial assistance
- Assurance that the person with head injury will be cared for in event of the carers death
- Assistance with care: in the home, respite and financially
- Carer stress levels are significantly linked with interpersonal stresses e.g. relationships with friend and the person with HI, independence
- Over two years after injury needs change from medical/ professional ones to include those around community, carer and family support, financial and health information
- These needs are not always met leaving carers misunderstood and isolated. Unmet needs were linked with lower quality of life and greater psychiatric morbidity in carers

- The article concludes that carers needs need to be explored further to ensure service provision can target their needs over time but it does need to be targeted at individual family needs

<b>Author/s</b>	Cummins			<b>Ref No</b>	<b>CA0135</b>
<b>Title (first 4 words)</b>	The subjective well-being of		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	<b>T4</b>	
<b>Location of study</b>	UK		<b><u>Other (Australia)</u></b>		
<b>User's Long Term Condition</b>	<b>General severe disability</b>				
<b>Confidence Rating</b>	High	Medium	Low	<b><u>N/A</u></b>	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article reviews the literature of carer experiences caring for people with all types of severe disability

- Condition e.g. autism vs. cystic fibrosis can determine carer stress levels but there is a ceiling level in carer stress once the disability is severe there is no difference between conditions
- Stress is higher in carers than non-carers
- Carers can suffer depression
- Carers have a severely diminished level of subjective quality of life
- Healthcare systems need to take into account the costs to family well being of caring for a relative

<b>Author/s</b>	Kolakowsky-Hayner, M.A., Miner, K.D., Kreutzer, J.S.			<b>Ref No</b>	<b>CA0136</b>
<b>Title (first 4 words)</b>	Long-Term Life Quality		<b>Year of publication</b>	2001	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other USA</b></u>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	<u><b>Low</b></u>		
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

The principal aim of this study was to assess the long term needs and quality of life of care-givers of people with brain injury. The chosen method was a postal questionnaire asking for completion of the Virginia Traumatic Brain Injury Family Needs Assessment Survey. This was sent to people identified via the 1995 – 1997 records of the Virginia Brain Injury Central Registry.

The study reports diminished quality of life among care-givers after four years, compared to before the injury. Unmet needs persist and the authors claim that these have changed, though this is based on the perception that the rank ordering of needs differs in important respects from that found in studies conducted shortly after the injury – this was a cross-sectional study. After four years Health Information (51.4%) and Involvement with Care (47.9%) needs were most often rated as met. Instrumental Support (31.5%) and Professional Support (28.3%) were most often rated as not met.

The authors use their findings that carers quality of life declines over time, while needs change to signal the importance of professionals recognising and responding to such longer term issues. However, as they acknowledge the study has limitations which call the robustness of their findings into question:

- small (57) and self-selecting sample
- unverifiable (sent and returned by mail) questionnaires
- brevity of the quality of life assessment

In addition, the study's cross-sectional design means that change in needs over time was inferred, rather than directly observed.

<b>Author/s</b>	Tyerman, Booth			<b>Ref No</b>	<b>CA0138</b>
<b>Title (first 4 words)</b>	Family Interventions after Traumatic		<b>Year of publication</b>		
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	Low	<b><u>N/A</u></b>	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article is a review of a how a community service in the UK provides family services to families affected by TBI to help manage the disruption and distress families' experience. The service provides an annual series of educational workshops, follow-up workshops, individual family support, specialist marital counselling. The following carer experiences were raised in the article:

- The 'is this it?' phenomenon initially and long term- is this what I'm faced with
- The need for information and explanation
- Coping with stress and loss
- Sense of obligation and duty to the person with TBI
- Social isolation
- Carers need time and empathy, help to problem solve, opportunities to reflect on their situation and express honest feelings and thoughts and commitment from services for ongoing support and help to adapt long term
- Issues raised by spouses around TBI and marital issues are: is it the TBI?, aggression and unpredictability, dependency, responsibility and decision making, relationships between the person with TBI and the children, reduced communication, restricted leisure/ social life and reduced sexual and emotional intimacy
- Carers need an open door approach from services and not to be treated as patients

- Specialist family services can help to manage short and long term needs of families in coping with the effect of TBI

Reference: Brooks. *The head injured family Journal of experimental and clinical neuropsychology* 13 (1991) 155-188

<b>Author/s</b>	Watanabe, Y. <i>et al</i>			<b>Ref No</b>	<b>CA0139</b>
<b>Title (first 4 words)</b>	The impact of traumatic brain injury....		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		<b><u>Other (Japan)</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic brain injury</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

A comparative, cross-cultural study (England/Japan) examining the impact on family members who had to care for an individual with traumatic brain injury (TBI). The impact on family members is not so well researched in Japan. In Japanese culture, for example, the disgrace associated with some behaviours common to those who have TBI is likely to cause families further stress. Data was generated via face-to-face interview as well as by questionnaire.

- In both cultures families felt a duty to care for the injured relative.
- In both cultures there was discomfort with other people's opinions of the injured relative but in the British sample there was significantly less concern ( $p=0.05$ ) with the opinions of other relatives.
- Both groups reported feeling tired and frustrated by the experience of caring
- The British sample mostly felt that talking to each other or to neighbours or professionals was a useful coping strategy but only one individual from a Japanese family suggested any coping strategy.
- Both cultures valued information and training although awareness of how to access such services was lower in Japan.
- Japanese families reported less stress than British families.

The following reference might be useful:-

Marshall, N.V. *et al* (1998) care-giver burden at six months following severe traumatic brain injury *Brain Injury* 12, 225-238

<b>Author/s</b>	Sinnakaruppan, I., Williams, D.M.			<b>Ref No</b>	<b>CA0140</b>
<b>Title (first 4 words)</b>	Head Injury (and) Family carers		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<u><b>Lit. review</b></u>	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	<u><b>UK</b></u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The reason for assessing this review's quality as 'medium' lies in the minimal information provided on methods and the limited search strategy used – which was apparently limited to standard databases

The review's objective was to identify the available support systems for family carers of head-injured people within the community. The databases searched were: MEDLINE, EMBASE PSYCHIATRY, CINAHL, and PSYCHLIT (years 1987 – 1989).

Only 7 papers were identified. Programmes varied from behavioural to cognitive interventions to help carers adjust to particular problem behaviours in the brain injured person.

Only one study used standard assessment tools. The remainder used a variety of methods including self-report measures and interviews. All interventions were reported as beneficial to carers.

Overall the studies reviewed were found to be limited by biased sampling, non-standardised outcome measures, using subjective methodologies and a lack of control samples. Most studies did not reveal pertinent information regarding the degree or type of head injury or rehabilitation history.

The authors conclude that there is an outstanding requirement for large randomised controlled studies using standardised methodologies to identify efficacious carer programmes.

<b>Author/s</b>	Harris, Godfrey, Partridge, Knight		<b>Ref No</b>	<b>CA0141</b>
<b>Title (first 4 words)</b>	Care-giver depression following traumatic	<b>Year of publication</b>		2001
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK	<u>Other (New Zealand)</u>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>			
<b>Confidence Rating</b>	<u>High</u>	Medium	Low	
<b>Reviewer's initials</b>	HR	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This article analyses the factors that contribute to carer depression. Its key findings are:

- Carers experience distress about behavioural and social problems and adverse effects on families and the adverse changes TBI leads to in these areas
- Adverse effects on the family after TBI is the sole predictor of carer depression with the impact the carer sees that this has on the other members of the family
- If carers appraise stressors as distressing their depression scores will be higher than people who perceive them as less distressing
- The effectiveness of support moderates between adverse effects and depression

<b>Author/s</b>	Swift, Wilson			<b>Ref No</b>	<b>CA0143</b>
<b>Title (first 4 words)</b>	Misconceptions about brain injury		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	<u><b>Qualitative</b></u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	<u><b>UK</b></u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article did not differentiate carers and patients.

<b>Author/s</b>	McPherson, K.M., Pentland, B., McNaughton, H.K.	<b>Ref No</b>	<b>CA0148</b>
<b>Title (first 4 words)</b>	Brain injury: perceived health....	<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative    Qualitative <b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1 <b><u>T2</u></b>	T3	T4
<b>Location of study</b>	<b><u>UK</u></b>	<b><u>Other</u></b> (USA)	
<b>User's Long Term Condition</b>	<b>Brain injury</b>		
<b>Confidence Rating</b>	High <b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	AMC	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This study explores the perceived health and reported strain felt by primary carers (n=70) of individuals with a severe brain injury. Data from semi-structured interviews were analysed via standardised rating scales. Despite awareness that carers need support they continue to complain of being failed by services in terms of understanding needs, responding to crises and providing information.

- There is a correlation between the severity of the brain injury and the perceived health of the carer. Carers in this study scored lower than the general population particularly in physical and emotional health.
- In terms of relationships between carers and sufferers, spouses scored worse than parents in the health domain, especially in reporting bodily pain, vitality and emotional distress.
- Carers generally have an increased incidence of anxiety and depression.
- They are more prone to negative feelings of guilt and anger.
- They experience difficulty in adapting to new roles within the family.

References to follow up might include:-

Payne, S., Smith, P., Dean, S. (1999) Identifying the concerns of informal carers in palliative care *Palliative Medicine* 13, 37-44

Kreutzer, J., Gervasio, A., Camplair, P. (1994) Primary care-givers' psychological status and family functioning after traumatic brain injury *Brain Injury* 8, 197

Kausar, R., Powel, G.E. (1996) Subjective burden on carers of patients with neurological problems as a consequence of precise objective symptoms  
*Clinical Rehabilitation* 10, 159-165

Jones, W.R. (1996) Stressors in the primary care-givers of traumatic head injured persons *Axone*, 18, 9-11

<b>Author/s</b>	Allen, K			<b>Ref No</b>	<b>CA0149</b>
<b>Title (first 4 words)</b>	Pet Dogs Diminish Cardiovascular...		<b>Year of publication</b>	2000	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Abstract only. 60 care-giver spouses with drug controlled hypertension were involved in a controlled experiment where they were assigned pet dogs. Findings demonstrated a therapeutic role for pet dogs.

<b>Author/s</b>	RABKIN, J.G., WAGNER, G.J., DEL BENE, M.	<b>Ref No</b>	<b>CA0156</b>
<b>Title (first 4 words)</b>	Resilience (and) Distress (among) Amyotrophic	<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative    Qualitative <b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1 <b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK	<b><u>Other USA</u></b>	
<b>User's Long Term Condition</b>	<b>Amyotrophic Lateral Sclerosis</b>		
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low
<b>Reviewer's initials</b>	SB	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This was an exploratory study aiming to ascertain the prevalence depressive disorders and symptoms in patients with ALS and their care-givers; and also to identify dimensions of resilience. It claims to be the first study of this population to conduct formal psychiatric evaluations using clinician-administered structured diagnostic interview methods.

The bulk of findings reported relate to the service user and reveal 'striking' findings which contradict the commonly held view that rates of clinical depression among this group are much higher than in the general population, and increase with progressive deterioration. In relation to care-givers, two important findings are flagged.

First, care-givers were as likely to be clinically depressed as patients – and access to psychiatric treatment seemed to be inversely related to care-giver burden.

Secondly, perceived care-giver burden was positively associated (counter-intuitively) with finding positive meaning in care-giving. (The suggestion is made that, with increasing burden the impulse to find meaning grows.)

There is also an important finding on the high concordance of distress between patients and care-givers.

Taken together, these findings lead the authors to point to the importance of responding to psychological distress/depression in care-givers, not only for

their own sakes but because this may lead to improvement in the mental health of the patient.

This is a well-conducted exploratory study. However significant weaknesses include:

Sample recruitment – the majority were participating in a trial at a clinical facility, which might either select more optimistic patients or affect their spirits

Patient characteristics – most were mobile

Self-selection for the study – more optimistic patients might have agreed to participate

Small numbers – 56 patients and 31 care-givers.

<b>Author/s</b>	Kosciulek, J.F.			<b>Ref No</b>	<b>CA0159</b>
<b>Title (first 4 words)</b>	Multidimensional Longitudinal Analysis (of) Family		<b>Year of publication</b>	1999	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other USA</b></u>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a longitudinal study whose purpose was to examine the dimensions that underlie family coping with brain injury over time – in this case a 2 year period. It used a sophisticated mathematical technique (MDS) to group data from a scale developed by the author and used in earlier cross sectional studies with different types of family.

The results indicate both stability in coping patterns and change over time. Consistency was found in relation to one broad dimension, which reflected cognitive versus behavioural coping. In relation to the second broad dimension change was found – from brain injury – focused coping to family to community fit at time one, to seeking professional help versus intra-family coping at time two.

The author concludes that the study's major conclusion is that 'family coping with brain injury' is a complex and dynamic process. Families probably use a variety of coping strategies. Results support a multi-dimensional model for explaining coping among families of individuals with brain injury.

This is an important study, the first longitudinal study at the time. The author suggests that its findings have important implications for service providers, who should assess family coping strategies and use the data 'to guide clinical family intervention, the development of family support services and policy decisions.'

However the study design is flawed in a number of important ways:

- sample selection (using a user support organisation) has created a small (76) atypical, and biased, sample
- there is no baseline or control data
- the time since the original injury is long (mean 7.9) and much adaptation will already have happened (or families broken up).

<b>Author/s</b>	Michael Oddy			<b>Ref No</b>	<b>CA0160</b>
<b>Title (first 4 words)</b>	Carers and Aphasia			<b>Year of publication</b>	Not Known
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain Injury: Aphasia</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This text is a critique on an article from the same journal and the main points are made in the first article which was not provided. However the author reports on the original article and makes the following points: ( I will mark the points which are reported from the article being critiqued (\*) to make them distinct from Michael Oddy's opinions)

- Carers of people with aphasia do not experience a causal link between severity of condition and level of well being (\*)
- Factors that give rise to carer stress: (\* and the authors opinions/ critical analysis of additional articles)
  1. acceptance of change
  2. attributions made to the person with aphasia's (p.w.a) behaviour by the care giver
  3. loss of the sexual relationship
  4. diminished marital satisfaction
  5. spouse no longer seeing the patient as a marital partner
  6. a perceived fundamental change in the person
  7. incompatibility of carer role with a full marital relationship
- The article discusses that the most common form of intervention offered to carers of p.w.a is support groups (\*)
- It highlights that one methodological issue is that carers nearly always express gratitude and positive views

- The article raises the need for the issue of contact between family and medical/social services to be addressed to ensure that care-givers are involved integrally with the rehabilitation process
- The issue is raised that by running professional led support groups carer givers could be put under pressure to continue to care for the p.w.a at home

References: the article has an interesting reference list all the articles maybe of relevance. I suggest you have a look at the article by 'Servaes et al ' from the same volume, I assume its *Aphasiology* , should also be reviewed.

<b>Author/s</b>	Gardener,W. Shatz,P. Hillary, F. Chute,D.			<b>Ref No</b>	<b>CA0162</b>
<b>Title (first 4 words)</b>	The Effect of Behavioural, Personality		<b>Year of publication</b>		
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
	<b>Not clear as abstract only</b>				
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	Low		
	<b>Unable to rate as abstract only</b>				
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study sets out to examine the changes after brain injury: behavioural, personality and emotional, that influence the stability and permanence of primary care giving relationships. Only the abstract was supplied so the key points are drawn from this.

- Loss of self control is the factor that correlated most strongly to changes in care-giver,
- Post injury substance (the abstract does not make clear what this is) lead to changes in care giver particularly away from the carer being a parent or spouse
- High levels of functional independence lead to a change of care giver away from a spouse
- Care-givers are likely to change away from friend or non-parent relative in the first month related to length of coma
- Parents are the most stable carers
- Loss of self-control and substance make most relationships prone to change in care giver

<b>Author/s</b>	Brown, R. <i>et al</i>			<b>Ref No</b>	<b>CA0165</b>
<b>Title (first 4 words)</b>	Distance education and care-giver support.....			<b>Year of publication</b>	1999
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other(Canada)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High	Medium	Low		
<b>Reviewer's initials</b>	AMC			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This paper recognises the importance of the family member in the care-giving role for the long –term well-being of the brain injured person. It further recognises the stresses that family members suffer in this role and sets out to test two methods of offering education and support: the traditional on-site, face-to-face intervention and the telephone support group.

A quasi-experimental design comparing two group types (telephone n=52 and face-to-face N=39) across time (9-10 weeks per group over two years). Three psychometric tools were used to test the mood profile of participants who were caring for an adult with a brain injury on a before during and after basis. The areas addressed were family function, care-giver burden and care-giver distress.

The highly technical nature of this study means that carer experience is heavily mediated by the statistical analyses.

Four hypotheses were advanced.

- 1 participation will have a positive impact on family function
- 2 participation will produce reduction in care-giving burden
- 3 participation will reduce care-giver distress
- 4 participants will report similar levels of satisfaction with the group experience

On point one the FAD (60 item self-assessment checklist) was used to determine family function. There was no significant difference between

telephone groups (TG) and on-site groups (OG) though both groups scored well when compared with non-clinical groups.

On point two the Care Burden Inventory showed that TG reported significantly lower levels of stress and this was maintained over time.

Point three; the OG again reported more distress than the TG. However, across time both groups reported a reduction in distress, even when measured against deterioration in the condition of the injured person.

Point four; high levels of satisfaction were reported by both groups with TG showing slightly better completion and attendance.

For rural dwellers it appears that a telephone support group can be as effective as face-to-face intervention. It is also very cost-effective. The authors want to see more research on why rural groups are apparently so self-sufficient (see CA020).

<b>Author/s</b>	Perlesz et al			<b>Ref No</b>	<b>CA0168</b>
<b>Title (first 4 words)</b>	Impact of Traumatic Brain Injury			<b>Year of publication</b>	1999
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK			Other (USA)	
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High		Medium	<b><u>Low</u></b>	
<b>Reviewer's initials</b>	HA			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Unsure about the robustness of this literature review; no details whatsoever are given about the basis on which the 37 studies included in the review were selected. The review focuses on relatives' stress and burden, and how researchers have gathered and presented their outcome data. It does not discuss carers' experiences of health and social care services. Authors include cross-sectional studies identifying high levels of distress in relatives of people with TBI, as well as longitudinal research tracking relatives' responses for up to 20 years, giving a slightly more comprehensive picture of outcome.

Whilst some studies report that spouses and parents do not experience significantly different levels of stress and burden in caring for a partner or adult child with TBI, many authors continue to suggest that care-giving spouses in TBI populations are at greater risk for distress than care-giving parents. There is a short discussion of different family assessment measures used by TBI researchers, and their respective reported strengths and weaknesses. In the concluding section, the authors state that the findings from the studies included in the review confirm that TBI can have a negative impact on family members, however it is pertinent to note that not all families and family members are necessarily affected in this way.

<b>Author/s</b>	Holland D. and Shigaki C.		<b>Ref No</b>	<b>CA0171</b>
<b>Title (first 4 words)</b>	Educating families and caretakers		<b>Year of publication</b>	1998
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review <b>Other</b>
	Model family educational programme plus 11page bibliographic resource			
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK		<b>Other (USA)</b>	
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>			
<b>Confidence Rating</b>	High	<b>Medium</b>	Low	
	Model may not be generalisable to UK, not evaluated, no carer responses to it reported. However it does attempt to address issues known to be important to families.			
<b>Reviewer's initials</b>	HQ		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Promotes family education as a vitally important aspect of rehabilitation care. Identifies this as a process that must continue beyond the phase where the person with TBI is in hospital or specialist facility.

The intervention described is a response to professional experience with families and research on carer views. It focuses on the provision of information.

People receive different information at different stages

1. ICU
2. (acute) rehab
3. outpatient rehab and community re-entry

e.g. glossary of medical terms and procedures part of phase one, info on lasting behavioural and emotional change following TBI in stages 2 and 3.

Idea of three phases and associated info resources are 'customised' by the rehabilitation psychologist or team responsible for the person with BI.

No info on carer/family reactions to same, though research on family perspectives is cited to support the way the programme has developed to convey appropriate

info at appropriate times (and to help families learn how to seek info for themselves, it is claimed).

<b>Author/s</b>	Holland and Sieglar			<b>Ref No</b>	<b>CA0171b</b>
<b>Title (first 4 words)</b>	Educating families and caretakers		<b>Year of publication</b>	1998	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High	Medium	Low		
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article is a discussion piece proposing a model for educating families to help them adjust to caring for someone with TBI given the changes in the USA healthcare model which means patients spend a very short period in hospital. It is an interesting article but does not have any carer experiences. There is an excellent bibliography of resources for use with families.

<b>Author/s</b>	Gillen R. et al.		<b>Ref No</b>	<b>CA0178</b>
<b>Title (first 4 words)</b>	Distress, depressive symptoms and..	<b>Year of publication</b>		1998
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
	59 care-givers. Structured (telephone) interview and self completion of symptom checklist (twice – 6 months apart)			
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK	<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	HQ	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

39 mothers and 20 spouses

About 45% of the sample were depressed (at each cross-sectional point).

Caseness via DIS-R diagnostic interview

About 1 in 3 individuals were depressed at both points

44% depressed at neither point.

(time since injury 2 to 72 months)

Best (in fact only significant) predictor of depression was a previous (prior to injury) depressive episode.

No relationship with time since injury or severity of injury

No differences between spouse and parent care-givers – possibility of a difference had been predicted

Reports that past research demonstrates:

'Personality changes and decreased emotional control appear to cause greater distress in family members than physical or cognitive limitations.'

However care-giver reports of 'changes in inhibitory control and emotional changes' weren't predictive of depression either.

Therefore one can't rule out the possibility that high rates of prevalence of depression among care-givers of people who experience TBI are a reflection of the fact that people who experience TBI tend to have relatives who are depressed anyway. This is possible, they argue, given evidence that men with alcohol dependence or antisocial personality are over-represented among those who

experience TBI, and other evidence shows that males with these characteristics have an increased incidence of depressed female relatives. Quite a few complex methodological issues here but certainly poses some interesting questions about received wisdom.

<b>Author/s</b>	Hickey, A.M. et al			<b>Ref No</b>	<b>CA0179</b>
<b>Title (first 4 words)</b>	The relationship between post-trauma...		<b>Year of publication</b>	1997	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (Ireland)</b></u>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

The purpose of the study was to assess longitudinally the implications of severe head injury for the quality of life of the injured persons primary carer. Data was drawn from the acute neurosurgical care period to one year post discharge from hospital. This paper is more concerned with psychosocial well-being resulting from the physical and mental changes in the person with SCI rather than experiences of health and social services etc. This paper also evaluates the association between patterns of problem reporting by patients and carers, using *The Psychosocial Adjustment to Illness Scale* (PIAS), the *Schedule for the evaluation of Individual Quality of Life* (SEIQoL), and *The Problem Checklist* (PCL).

- Carer quality of life did not change significantly over the one year period.
- This study also found that (contrary to most of the previous literature on the subject) that the number of problems reported by carers decreased in relation to those reported by the patient over time.

<b>Author/s</b>	McNeil et al		<b>Ref No</b>	<b>CA0182</b>
<b>Title (first 4 words)</b>	Assessing family involvement in TBI		<b>Year of Publication</b>	1997
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit.review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other (USA)</u>	
<b>User's Long Term Condition</b>	Brain injury			
<b>Confidence Rating</b>	<u>High</u>	Medium	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

- Uses Family Involvement Assessment Scale developed, by Barrar, to evaluate family involvement in TBI rehabilitation.
- Supports Barrar (1988) hypothesis that dimensions of support and involvement can be used to describe families. 4 types: involved & supportive, uninvolved & supportive, uninvolved and unsupportive, uninvolved & supportive.
- This study loaded items into the three factor model and these formed 3 subscales: Involved-Rehabilitation (= Barrar's involved family); Supportive (= Barrar's supportive family); Involved-Patient (= Barrar's involvement and supportive, additional information about how family member relates to patient)
- Need to be aware that family member's involvement in rehabilitation process may change due to factors such as patient recovery, rehabilitation program etc

<b>Author/s</b>	Kosciulek, J.F.		<b>Ref No</b>	<b>CA0184</b>
<b>Title (first 4 words)</b>	Dimensions (of ) Family Coping (with) Head		<b>Year of publication</b>	1997
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review    Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other USA</u>	
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study replicates and extends an earlier descriptive study by the same author by recruiting participant families from a different part of the USA (Georgia). The purpose of the study was to test the findings of the earlier study in relation to the dimensions that underlie family coping.

The study was well designed and conducted but its quality is compromised in the following respects:

- its internal validity is compromised by the selection of the 30 coping behaviours used, as opposed to any other group of items
- findings are not generalisable because the sample was not a probability sample, and the study was cross-sectional
- the study did not attempt to assess the utility of different coping behaviours, only their use

The study found that while there were similarities in the coping behaviours used in the earlier study, there were also differences – possibly due to the different social and service contexts of the two samples. Cognitive coping and head injury focused coping emerged as common.

The author draws attention to the need to carry out longitudinal studies and research to assess the utility of different coping strategies. He also draws attention to the value of practitioners assessing family coping behaviours in designing interventions.

<b>Author/s</b>	Gervasio A. et al.			<b>Ref No</b>	<b>CA0186</b>
<b>Title (first 4 words)</b>	Kinship and Family Members...		<b>Year of publication</b>		1997
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
	116 outpatients & family care-givers. Info from hospital records + self completion postal qu.				
<b>Typology</b>	<u>T1</u>	T2	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>		Low	
<b>Reviewer's initials</b>	HQ		Please e-mail this form to <b>Stephen Piper</b> <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Some useful summarising of the literature on distress among care-givers of people with TBI which indicates that findings have been contradictory, in the sense that some have found differences, say between spouses and parents, or in relationships to severity or time elapsed since injury, which others have not.

This study:

89F 27M care-givers. 69 spouses

Distress measured with BSI (Brief Symptom Inventory)

44% caseness overall

Parents/spouses no difference in self perceived stress but spouses sig more likely to fall into caseness category

Time since injury or length of coma not significant as predictors

<b>Author/s</b>	Chwalisz, K et al			<b>Ref No</b>	<b>CA0196</b>
<b>Title (first 4 words)</b>	Support group processes among spouses...		<b>Year of publication</b>	1996	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Abstract only. 5 female care-givers interviewed regarding 'critical events'.  
Results not indicated.

<b>Author/s</b>	Leathem, J. and Wooley, C,		<b>Ref No</b>	<b>CA0197</b>
<b>Title (first 4 words)</b>	Relatives' Perceptions (of) Role Change		<b>Year of publication</b>	1996
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review    Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4
<b>Location of study</b>	UK	<u><b>Other New Zealand</b></u>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>			
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low	
<b>Reviewer's initials</b>	SB	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This otherwise excellent study is rated Medium because, for a quantitative study the sample size is very small (18 parents and 11 partners) and there is a degree of bias in the sample selection methods. In addition, one of the scales used was developed specifically for the study and no account is given of its validation.

The study's main objectives were to examine the nature and extent of role change experience, utilization of and satisfaction with social support and stress levels experienced by both parent and spouse carers and to test the hypothesis that these would differ significantly between the 2 groups, with partners scoring more highly.

The combined parents & partners group experienced moderate levels of stress and role change and a relatively small group reported health problems. Partners reported greater stress, role change and health problems than parents.

Qualitative differences were found between the 2 groups in terms of sources of stress. There was little difference between parents and partners in source, utilization or satisfaction with social support. Positive correlations were found between stress and role change and stress and health problems.

The authors point to the need for further research on stressors after head injury, to lessen burdens and improve families' (and people in different

relationships to the brain-injured person) capacity for involvement in rehabilitation.

<b>Author/s</b>	Carnevale			<b>Ref No</b>	<b>CA0198</b>
<b>Title (first 4 words)</b>	Natural setting behaviour management		<b>Year of publication</b>	1996	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit.review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Helps reduce patient aggression and enhance their control of their rehabilitation

<b>Author/s</b>	Gaudet, L.B. and Pulos, S			<b>Ref No</b>	<b>CA0199</b>
<b>Title (first 4 words)</b>	Concerns after TBI: Reports...		<b>Year of publication</b>		1995
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	<u><b>UK</b></u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Abstract only. Nothing of relevance.

<b>Author/s</b>	Chwalisz and Kisler			<b>Ref No</b>	<b>CA0200</b>
<b>Title (first 4 words)</b>	Perceived Stress: A better		<b>Year of publication</b>	1995	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High		<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article proposes that a perceived stress scale is a better predictor of mental and physical health for carers than the traditional measure of carer burden.

<b>Author/s</b>	Sandra Acorn			<b>Ref No</b>	<b>CA0203</b>
<b>Title (first 4 words)</b>	Assisting families of head injured		<b>Year of publication</b>	1995	
<b>Research methods</b>	Quantitative	Qualitative	<u><b>Mixed</b></u>	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (Canada)</b></u>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High		<u><b>Medium</b></u>	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Care givers of people with a head injury feel a benefit from an education/support programme with other care-givers of people with a head injury. It provides an opportunity to unburden, reduce isolation, support and share.

Isolation is a key theme among care givers along with blame, guilt, anger, unresolved grief, stigma and social withdrawal.

Care givers need practical information such as legal and financial issues as well as family and carer support and education on features and impact of head injury itself.

Care-givers coping styles following an education/ support programme developed into a more positive supportive coping style.

References: There is a really good reference list with this article, 10-15 articles look relevant I suggest you have a look pick of the ones you want.

<b>Author/s</b>	Maitz E. and Sachs P.		<b>Ref No</b>	<b>CA0204</b>
<b>Title (first 4 words)</b>	Treating families of individuals...		<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review <b><u>Other</u></b>
	Description of family therapy in context of family systems theory			
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>	
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>			
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>	
	In the sense that its not evidence of care-giver views			
<b>Reviewer's initials</b>	HQ		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Describes and illustrates family therapy interventions with families of people with TBI. Not an evaluation.

The primary treatment goal after a TBI is to re-establish a workable family structure. A severe TBI compromises family members ability to enact their roles and disrupts the balance of power and authority in the system. Gives case examples to illustrate role changes, role strain, disruptions to power and authority structures and therapeutic intervention to help deal with same. Also discusses power and authority in relation to the treatment team and in the therapeutic relationship. Reports typical conflict over goals if therapist is aiming for 'acceptance' (based on incorrect(?) generalisation from work with families of the terminally ill) and the family are looking for continual 'adjustment' or 'adaptation'. However does not present evidence per se.

<b>Author/s</b>	Hosack, K.R. and Rocchio, C,A.			<b>Ref No</b>	<b>CA0205</b>
<b>Title (first 4 words)</b>	Serving Families (of) Persons (with) Severe		<b>Year of publication</b>		1995
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other USA</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	SB		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

I have rated this article's 'robustness' as low because it is a discussion of the implications of a particular model of service provision in the USA, which has/had a set of particular and quite restrictive conditions for reimbursement – and therefore for the provision of services to support families. It may well be the case that the restrictions mentioned in the article no longer exist.

Given this caveat, this article does contain a very useful account of the support that families are likely to need at different stages of the patient's experience and which is relevant to any country. The discussion is too long to summarise but, as the abstract says, it:

Provides practical and theoretical strategies as to how families and professionals can work through the rehabilitation process.

<b>Author/s</b>	Kosciulek, J.F.		<b>Ref No</b>	<b>CA0206</b>
<b>Title (first 4 words)</b>	Relationship (of) Family Coping (with) Head		<b>Year of publication</b>	1994
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other USA</u>	
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>			
<b>Confidence Rating</b>	High		<u>Medium</u>	Low
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

First exploratory, study of a series of (3) studies exploring strategies families use to cope with a family member's brain injury and the relation of these to family adaptation. Used three instruments to record family socio-demographic data, coping behaviour and general functioning. The analysis used cluster analysis to identify coping strategies families used and multiple regression analysis to examine the relationship between family coping with head injury and family adaptation.

Cluster analysis of 30 coping behaviours yielded a 5-cluster solution, with clusters that were distinct and based on family stress theory and empirical family stress and head injury research. Regression analysis produced a significant result, resulting in the selection of 2 of the 5 family coping variables (positive appraisal and family tension management) which explained 43% of the variance in family adaptation. The study thus found that families use a variety of coping strategies and that 2 of these influenced family adaptation.

This study has serious weaknesses in design which mean that its findings cannot be generalised. These include:

- internal validity is compromised by the selection of the 30 family coping behaviours used in the study – a different list might have produced different results
- ditto the use of frequency of behaviours as a measure of coping
- use of a non-probability sample drawn from a support group, and from participants in an on-going longitudinal study

- use of cross-sectional data to investigate adaptation over time
- lack of a controlled experimental design, which means the study can only be regarded as descriptive, rather than explanatory.

<b>Author/s</b>	Leach, L.R., et al (4 authors)			<b>Ref No</b>	<b>CA0207</b>
<b>Title (first 4 words)</b>	Family Functioning Social Support		<b>Year of publication</b>	1994	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other USA</b></u>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High		Medium	<u><b>Low</b></u>	
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This study sought to examine how changes in family functioning post trauma 'impacted' the adjustment of the individual with TBI. More specifically it sought to test whether poor family functioning was positively associated with depression in that person.

The study found that social support was not predictive of depression – but that effective use of problem solving and behavioural coping strategies by families was significantly related to lower levels of depression in the person with TBI.

This study is, however, very flawed:

- the accounts of family functioning were taken only from the brain-injured person
- the sample is very small, self-selecting, contained larger numbers of women than in the general population of people with TBI, and is dominated by people with low and moderate levels of depression
- it fails to define either coping or social support
- the design lacks a before – baseline – element; and does not use a control

The findings are therefore rather suspect.

<b>Author/s</b>	Allen, Linn, Gutierrez, Willer			<b>Ref No</b>	<b>CA0210</b>
<b>Title (first 4 words)</b>	Family Burden following traumatic		<b>Year of publication</b>	1994	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Burden levels between carers who were parents and spouses were compared in this article. Key findings:

- Both parents and spouses live with significant burden and stress particularly in the post acute period
- Parents are more concerned with lifelong care
- Cognitive disability and social behaviour difficulties have greater association with burden than injury severity or physical disability
- Spouses report a greater lack of personal reward than the parent carers
- Female care givers report higher levels of burden
- Aggressive behaviour is most significantly associated with burden
- The entire family balance is affected by having a person with TBI in the family
- Overall parent or spouse carers do not differ significantly in burden level

<b>Author/s</b>	Greenwood, RJ et al (8 authors)			<b>Ref No</b>	<b>CA0212</b>
<b>Title (first 4 words)</b>	Effects (of) Case Management (after) Head		<b>Year of publication</b>	1994	
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Severe Head Injury</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	SB		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study used a prospective controlled, unmatched, non-randomised design to examine the effects of one model of early case management on patient outcomes, family functioning and provision of rehabilitation. The results were that no significant differences were found, for either patients or family carers, between the group who received this model of case management and the control.

Very little information is provided in relation to the way carers were included in the case-management model, but it appears that, apart from the early provision of advice and information, they did not receive assessments or interventions focusing on their specific needs or characteristics. Moreover the model of case management consisted of an independent case-manager with no budget or strong leverage on services. (At the time of the study this would not be expected to generate significant additional practical or emotional support.)

The paper notes, however, that 19 of the 20 families who received the case-managed service found the case-manager 'helpful' or 'very helpful'.

<b>Author/s</b>	Acorn			<b>Ref No</b>	<b>CA0214</b>
<b>Title (first 4 words)</b>	Head injured survivors: care-givers		<b>Year of publication</b>	1993	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (Canada)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High		<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article evaluates the needs of carers of people with head injury and the availability, usefulness and helpfulness of support groups in meeting these needs. Key points about carers experiences:

- The most stressful issues for carers were the persons decreased memory, problems with decision making, mood swings and long lasting dependency
- Carers need education about head injury and community resources with honest responses to questions. Psychologically they need to know what the future holds, to talk about their feelings, have hope and emotional support.
- They need time off including respite
- They experience poor communication with healthcare professionals
- There needs to be family support groups in rural areas
- Support groups for carers need to provide education, information about services, emotional support, and social support

<b>Author/s</b>	Gottberg, K. <i>et al</i>			<b>Ref No</b>	<b>CA0215</b>
<b>Title (first 4 words)</b>	Multiple sclerosis in Stockholm...		<b>Year of publication</b>		2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		Other ( <b><u>Sweden</u></b> )		
<b>User's Long Term Condition</b>	<b>Multiple sclerosis</b>				
<b>Confidence Rating</b>	High		Medium	<b><u>Low</u></b>	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

A pilot study to gauge patient satisfaction (n = 26) with health care. Data were generated at home visits via structured interview and questionnaire. The contribution of carers to the study was minimal. From this the authors suggest that there is some evidence of dysfunction within family groups where care is provided informally by a family member.

No suitable references were available.

<b>Author/s</b>	Chipchase and Lincoln			<b>Ref No</b>	<b>CA0218</b>
<b>Title (first 4 words)</b>				<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	<b>UK</b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	<b>High</b>		Medium	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This was a 2 stage study which found that carers of people with MS found sources of stress in:

- Changes in the person with MS away from their former self
- The need to change their own personal plans
- Financial strain

Problems with memory and independence in ADL's were found to be predictive of a strained carer. They extended the study to investigate the impact of memory difficulties on the strained and unstrained carer groups and found that:

- Strained carers reported significantly more memory problems in the person with MS than unstrained carers.
- Memory problems had a greater effect on the amount of time strained carers spent alone than unstrained carers with greater effect on the strained carers emotions.
- The strained carers felt less sympathy to the care recipient and wanted coping strategies given to the person with MS to deal with the problem themselves.

Key points for service providers:

- Strategies need to be tried with people with MS to help with the memory difficulties
- Carers of people with memory problems need time alone
- Therapists need to be aware that carers of people with memory difficulties are at risk of strain and need to provide appropriate support

<b>Author/s</b>	Hakim, Bakheit, Bryant, Roberts, et al		<b>Ref No</b>	<b>CA0219</b>
<b>Title (first 4 words)</b>	The social impact of		<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	<b>UK</b>		Other (USA)	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	<b>High</b>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article identified a strong correlation between severity of patient's disability and carer depression anxiety and psychosomatic conditions. The carers experienced changes/impact on their careers i.e. loss of job, becoming part-time, not putting in for promotion, change to lower grade.

<b>Author/s</b>	Aronson,Cleghorn,Goldenberg		<b>Ref No</b>	<b>CA0220</b>
<b>Title (first 4 words)</b>	Assistance arrangements and use		<b>Year of publication</b>	1996
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK		<b><u>Other (Canada)</u></b>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study looked at people with MS and their carers assistance arrangements, needs, and use and satisfaction with services. Carers were found to :

- Be mainly spouses who live with the person with MS
- Have been providing care for an average of 9 years
- Just over half received assistance and were reluctant to use assistance
- Only 4% used respite services
- Carers reported giving more frequent care than the person with MS reported
- More than 90 mins per day were given to personal care, homemaking and communication
- Carers use MS society services finding the newsletters and leaflets the most important service followed by equipment loans, financial assistance, emotional support, referral to community agencies and self help/support groups
- Key finding: carers perceive greater care burden than care recipient
- Greater frequency and length of assistance with ADLS was associated with severity of MS
- More attention needs to be paid to low use of respite service with a preference reported for in home respite care by carers

<b>Author/s</b>	Lackey, N.R., Gates, M.F.			<b>Ref No</b>	<b>CA0222</b>
<b>Title (first 4 words)</b>	Adults' recollections of their experiences.....			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b>Other (USA)</b>		
<b>User's Long Term Condition</b>	<b>General (chronic physical illness)</b>				
<b>Confidence Rating</b>	<b>High</b>		Medium	Low	
<b>Reviewer's initials</b>	AMC			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Demographic changes and changes to the welfare system have meant that children are often the only other people around to help when an adult needs to be looked after in the home.

This retrospective study used a convenience sample (n=51) to explore care-giving activities performed by children for adults with a variety of chronic physical illnesses. It sought to discover the positive and negative effects of the experience.

Purely demographic information reveals that some children began performing caring tasks from as young as age 9, with the duration of caring extending from 8 months to 25 years. Caring activities undertaken range from helping with personal care (feeding, bathing) to assisting with medication (changing dressings, giving medication), to housework (cleaning, shopping) to spending time (reading, talking).

- Carers reported feelings of pride and responsibility but also of feeling helpless due to lack of knowledge, particularly about what to do in a crisis.
- Some carers felt that the experience had brought them closer to their family although where there was more than one child providing care there was potential for conflict.
- Interruption to friendships was reported, with some respondents indicating they lost friends because of their domestic commitments although others report that friends understood and even helped out.
- Those of 'dating' age either didn't or dated early as a means of escaping the home situation.

- When reflecting on the experience respondents thought it had made them more caring as adults. Some, however, still have feelings of resentment or guilt. Some still feel they have to take care of every one and every situation.
- There was a general consensus that children now should be involved in similar situations in order that they are valued as part of the family. Respondents particularly felt that children should have full knowledge of the condition that affects an adult.
- On the parameters of care-giving respondents felt that where a child's education or developmental needs were being curtailed then more outside help should be given.

The study suggests that those who reported negative experiences tended to have been involved in prolonged caring. The authors also suggest that professionals who discharge individuals to care in their own home must ascertain whether children are likely to be involved in delivering this care. More research is needed determine how much is too much.

<b>Author/s</b>	Knight, R.G., Devereux, R.C., Godfrey, H.P.D.		<b>Ref No</b>	<b>CA0223</b>
<b>Title (first 4 words)</b>	Psychosocial Consequences (of ) Caring (for a ) Spouse		<b>Year of publication</b>	1997
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK	<u>Other New Zealand</u>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	SB	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

A well designed, conducted and analysed survey which nevertheless suffers from the following

Convenience sampling, resulting in bias from self selection

Small (55) numbers of respondents

Failure to build adequately on some relevant earlier studies (e.g. Gregory et al)

Cross-sectional design

Lack of a qualitative component

The primary aim of the study was to document the nature of the burden experienced by spouses of people with MS; and to assess whether the factors mediating burden were similar to, or different from, those experienced by care-givers of people with other degenerative neurological disorders or of people with dementia. The behaviours/impairments causing most distress to spouse carers were found to be motor problems, sudden mood changes, partner upsetting other people, incontinence and pain. Consistent with the Lazarus and Folkman model of coping personal coping abilities and satisfaction with social support received were found to mediate the burden of care, and accounted significantly for individual differences of burden.

<b>Author/s</b>	Fernandez et al			<b>Ref No</b>	<b>CA0225</b>
<b>Title (first 4 words)</b>	Predictors of Depressive Symptoms		<b>Year of publication</b>	2001	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	<b>HA</b>		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This three-page article reported on a six-week study aimed to determine the predictors of depressive symptoms among spouse care-givers of Parkinson's Disease (PD) patients. Patient and carer data were collected using standard outcome measures. The authors concluded that the duration of PD appeared to be the strongest predictor of depressive symptoms among spouse-care-givers in the small cohort (n=45) under investigation. The study did not discuss carers' experiences of caring for someone with PD, or include information about health and social care provision.

<b>Author/s</b>	Vedhara, K., <i>et al</i>			<b>Ref No</b>	<b>CA0226</b>
<b>Title (first 4 words)</b>	Chronic stress in nonelderly care-givers.....		<b>Year of publication</b>	2002	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Multiple sclerosis</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

MS spousal care-givers ( n = 41) and a control group ( n = 62) were recruited to investigate whether the immune dysregulation that characterises elderly carers extends to a younger population; the hypothesis being that increased stress can lead to suppressed immune function leading to increased susceptibility to infection/illness.

Two types of data were generated:

a psychological questionnaire measured stress

a saliva sample was taken for hormonal assessment at which time participants were given an influenza injection

at a later time a blood sample was taken for immune assessment

With the emphasis on clinical investigation the carer experience is largely absent here. But from the findings the following results are available:-

- There was only limited evidence of psychological morbidity in MS care-givers compared to non-care-givers. The authors attribute this to the fact that the emotional impact is attenuated in younger people.
- They also suggest that distress due to the role is similarly attenuated due to age.

Caution is need in interpreting these findings. The study could not demonstrate whether younger care-givers have a more preserved immune response or whether they simply have less stress.

The issue of contrasting findings between control/experimental groups is also questioned. The authors consider making comparisons between groups with high/low levels of stress.

References (see next page)

Knight, R.G., Devereux, R.C., Godfrey, H.P.D. (1997) Psychosocial consequences of caring for a spouse with multiple sclerosis *Journal of Clin Exp Neuropsychol* 19, 7-19

Hakim, E.A. *et al* (2000) The social impact of multiple sclerosis – a study of 305 patients and their relatives *Disability and Rehabilitation* 22, 288-293

Vittaliiano P.P. *et al* (1997) Research on psychological and physical concomitants of care-giving: where do we go from here? *Ann Behav Med* 19, 117-123

<b>Author/s</b>	Gulick		<b>Ref No</b>	<b>CA0228</b>
<b>Title (first 4 words)</b>	Coping among spouses or		<b>Year of publication</b>	1996
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK		<b>Other (USA)</b>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	<b>High</b>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article set out to identify the coping strategies of spouse/significant others in caring for people with MS. Key findings:

- Carers tend to employ a systematic planning approach in caring for people with MS but some can become overwhelmed and need to withdraw temporarily
- Dependency determined coping strategies, with more dependency more planning strategies were used. And although seldom used significantly more distancing and escape/anger strategies were used pertaining to recreation/ socialising and communication.
- Carers with their own health problems employed more distancing strategies
- Spouses employ more ambivalent coping strategies compared to significant others possibly because spouses feel more responsibility for their partners dependency needs
- Significant others use more distancing and escape/anger strategies than spouses suggesting less commitment
- Implications for healthcare: Nurses need to explore how dependency needs are met and their impact on the family to enable effective information and counselling of the family.

<b>Author/s</b>	Ybema, J.F. <i>et al</i>			<b>Ref No</b>	<b>CA0230</b>
<b>Title (first 4 words)</b>	Care-giver burnout among intimate partners.....		<b>Year of publication</b>	2002	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK	<u><b>Other (Netherlands)</b></u>			
<b>User's Long Term Condition</b>	<b>Cancer/multiple sclerosis</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>	Medium	Low		
<b>Reviewer's initials</b>	AMC	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>			

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This study adopts a psychological perspective in order to explore the role of 'perceptions of inequity as mediating determinants of burnout' among partners of patients with severe illnesses (cancer N= 106, multiple sclerosis N= 88). The subjective notion of burnout is here preferred to other measures which collapse many variables into one scale. The authors then hypothesise that carers who experience *underbenefit* and *underinvestment* in their relationship will be more prone to burnout. They also appreciate that marital quality as a variable might influence perceptions of inequity in the relationship and so cast it as antecedent in determining burnout. By doing so they note that other causal/theoretical constructs are available.

(The notions of *underbenefit* and *underinvestment* were constructed around domains identified by the participants themselves)

from this sample/study it is possible to deduce that:-

- Partners of cancer patients rated the quality of their relationship significantly higher than those with partners who had MS
- Care-givers who regard their relationship in a negative light experience more inequity
- The relationship between inequity and burnout is identical between the two groups

The authors suggest that depersonalisation and personal accomplishments are two areas that future research needs to investigate. They further feel that a longitudinal study would yield more promising results .

In summary, the heavily statistical nature of the analysis obscures the actual carer experience. A more qualitative approach may have offered more in terms of understanding than the search for causality undertaken here.



<b>Author/s</b>	Hennie Boeije, Mia Duijnste, Mieke Grypdonck, Aart Pool		<b>Ref No</b>	<b>CA0233</b>
<b>Title (first 4 words)</b>	Encountering the downward phase		<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	<b><u>Qualitative</u></b>	Mixed	Lit. review Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK	<b><u>Other(Netherlands and Belgium)</u></b>		
<b>User's Long Term Condition</b>	<b>MS</b>			
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is an excellent article but fits with the articles on individual's personal experience of a long term condition not the carer's experience of caring. There were no points relating to carer experience.

<b>Author/s</b>	Happe S. et al.			<b>Ref No</b>	<b>CA0234</b>
<b>Title (first 4 words)</b>	The association between care-giver...		<b>Year of publication</b>	2002	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
	106 people with PD and care-giving partners – part of a larger study of patients attending outpatient clinics in Germany. Self completion of a depression scale, care-giver burden inventory and a psychosomatic symptom checklist (38% partners were male).				
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other Germany</u>		
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	HQ		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Focus on sleep disturbances. Aim to assess prevalence and causes of sleep disturbances of spouses. Bad sleep defined as disturbed on 3 or more nights a week.

70% of spouses were involved in giving care, 50% on a daily basis

27% of spouses reported frequent sleep disturbances (45% of people with PD themselves had bad sleep)

30% spouses were depressed (scored above levels associated with depression).

As did 52% of patients.

Psychosomatic symptoms assoc with disturbed sleep among care-givers.

Depression scores highly assoc with bad sleep.

Apart from above, sleep disturbance (in care-givers) associated with PD symptom severity; being a female carer; disturbed sleep of person with PD; getting household support; and frequency of care-giving. Heavy involvement in care-giving assoc with bad sleep and excessive tiredness. Bad sleep in spouse not related to depression in patient.

Depression in partners assoc. with depression in patients.

All cross-sectional associations. The sample tended to be biased towards people with mild/moderate symptoms (because drawn from outpatients).

They conclude that interventions which improve sleep of patients would also be likely to benefit carers....

<b>Author/s</b>	Cousins et al			<b>Ref No</b>	<b>CA0237</b>
<b>Title (first 4 words)</b>	Assessing care-giving distress		<b>Year of publication</b>		2002
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit.review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other(USA)		
<b>User's Long Term Condition</b>	<b>Parkinson Disease</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>		Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Use previous measures to develop Care-giver Distress Scale which has Potential to determine the type of intervention needed for a care-giver and provides a profile of psychological distress arising for caring.
- CDS consists of 5 distinct components of potentially negative consequences of caring. It is easy to administer and score. Responses can be used to provide individual profiles to monitor intervention

<b>Author/s</b>	Frazier			<b>Ref No</b>	<b>CA0240</b>
<b>Title (first 4 words)</b>	Book Review of Parkinson's disease: A complete guide for patients and families		<b>Year of publication</b>		
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This was not relevant although the book looks a very useful tool

<b>Author/s</b>	Wolters, E.C., Berendse, H.W.			<b>Ref No</b>	<b>CA0241</b>
<b>Title (first 4 words)</b>	Management of psychosis in Parkinson's...			<b>Year of publication</b>	2001
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (Europe)</b></u>		
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a highly technical paper that considers the extent and treatment of psychotic symptoms in individuals who have Parkinson's Disease (PD). The focus is purely on neuropharmacy and nowhere is the carer experience referred to.

<b>Author/s</b>	Bianchetti et al			<b>Ref No</b>	<b>CA0244</b>
<b>Title (first 4 words)</b>	Care-giver Burden in Alzheimer.....		<b>Year of publication</b>		
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Abstract only. Study comparing care-giver 'burden' in relation to Alzheimer's Disease and Parkinson's Disease. Concludes that AD and PD patients 'induce a comparable objective burden in their care-givers'. Not particularly relevant to this study and probably falls outside target age range (although not specifically stated).

<b>Author/s</b>	Miller,Berrios, Politynska		<b>Ref No</b>	<b>CA0247</b>
<b>Title (first 4 words)</b>	Caring for someone with		<b>Year of publication</b>	1996
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review    Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4
<b>Location of study</b>	<u><b>UK</b></u>		Other (USA)	
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>			
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article evaluates the effects that caring for someone with PD has on the carer:

Relevant findings:

- Carers have raised levels of distress and /or psychological disturbance
- Physical cares are contributing to objective burden
- There was no link between distress etc and social support
- Depression in the person with PD was closely linked with distress and psychological disturbance in the carer

Implications: Services have to look at effective treatment of depression in people with PD

<b>Author/s</b>	Moore, K.A. and Seeney, F.		<b>Ref No</b>	<b>CA0250</b>
<b>Title (first 4 words)</b>	Parkinson's disease: how sufferers...		<b>Year of publication</b>	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review    Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK		<b><u>Other Australia</u></b>	
<b>User's Long Term Condition</b>	<b>Parkinson Disease</b>			
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Abstract only. Australian study.

Study on how 'sufferers' and carers 'cope'.

Both groups are satisfied with the amount and quality of support available .

Both groups would like more subsidised assistance around the house.

Carers exhibited greater use of 'problem-focused coping'.

<b>Author/s</b>	Konstam, V. <i>et al</i>			<b>Ref No</b>	<b>CA0251</b>
<b>Title (first 4 words)</b>	Meaning in the lives of care-givers.....		<b>Year of publication</b>	2003	
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low		
<b>Reviewer's initials</b>	AMC		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

The literature regularly highlights the psychological cost to carers who look after family members with chronic conditions. This study aims to account for why and how some care-givers experience benefits in performing the caring role. Specifically the study investigates how carers find meaning in general terms as well as finding meaning directly related to their care. The study hypothesises that those who can find meaning in these two areas will have increased well-being. Rating scales and checklists were completed by 58 carers and the results subject to statistical analysis.

Results suggest that finding meaning in general is more important than finding meaning specific to the caring role. This is at odds with the emphasis in the care giving literature that focuses on helping care-givers to develop coping strategies.

The authors note that interviews would enhance the data since this would allow for more exploration of how carers experience their world. This would allow professionals to target interventions for carers.

The following references might be worth checking:-

Faran, C.J., Kuhn, D.R. (1998) Finding meaning through caring for persons with Alzheimer's Disease: assessment and intervention In P.T. Wong & P.S.Fry (eds.), *Handbook of Personal Meaning: theory research and applications* (pp.335-358) Hillsdale, N.J.:Elbaum

Noonan, A.E., Tennstedt, S.L. (1997) Meaning in care-giving and its contribution to care-giver well-being *The Gerontologist* 37, 785-794

<b>Author/s</b>	Landoni, Giordano, Guidetti			<b>Ref No</b>	<b>CA0255</b>
<b>Title (first 4 words)</b>	Group psychotherapy experiences for		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b>Other</b>
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b>Other (USA)</b>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	Medium		Low	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article reviews the authors' experiences of group psychotherapy for patients and their families. Relevant observations:

- When the disease is new relatives focus their energies on the patient
- With good family relations there is a low level of criticism and hostility and consideration of the patients needs but where there are poor family relations the disease becomes a vehicle for critical and hostile attitudes
- Psychological support needs to offer: help to bear the emotional load, a listening space, analysis of observed dynamics, rebalancing the family emotions
- Initially relatives focus on the loss of physical autonomy, then the express their own emotional difficulties and some families have difficulty considering how they will reorganise the family dynamics because they cannot work out the disease

<b>Author/s</b>	CARTER, J.H. et al. (30 authors)			<b>Ref No</b>	<b>CA0256</b>
<b>Title (first 4 words)</b>	Living (with a ) Person (who has) PD		<b>Year of publication</b>	1998	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other Canada</u>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study used cross-sectional data to test hypotheses of different kinds about the relationship between three aspects of the care-giver's response to her/his situation and the stage of the disease the person with PD had reached. Very little research had previously been conducted in relation to care-givers' experience over the course of the disease. The three were: role strain; care-giver situation; and care-giver characteristics.

Care-giver strain was found across all stages of the disease, but accumulated significantly as the disease progressed.

The authors acknowledge that the cross-sectional nature of the study and the probably unrepresentative nature of the sample undermine its strength. Further research should address this, and also develop and evaluate interventions which will reduce care-giver strain at different stages of the disease.

Nevertheless the study provides strong justification for clinicians and health/social care professionals to assess the presence of care-giver strain early in the disease's progression, and at intervals as it progresses.

<b>Author/s</b>	ELLGRING, H. et al. (6 authors)		<b>Ref No</b>	<b>CA0258</b>
<b>Title (first 4 words)</b>	Psychosocial Aspects (of) Parkinson's Disease.		<b>Year of publication</b>	1993
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other Germany</u>	
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>			
<b>Confidence Rating</b>	High	Medium	<u>Low</u>	
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study focuses mainly on the person with PD  
 Study design extremely poorly reported, but uses 'questionnaire data'. Found that PD patients experienced stress in five areas, and conclude that social anxiety and a stress-induced increase in symptoms 'clearly result from an interaction of somatic and psychological factors.' Psychological interventions later implemented within an integrated approach to the treatment of people with PD were found to reduce these.

The authors say that relatives of people with PD also experience high degrees of stress and that 'special attention' should be paid to their psychological condition. However the paper does not report research findings that relate specifically to carers/relatives.

<b>Author/s</b>	McRae, Sherry, Roper			<b>Ref No</b>	<b>CA0259</b>
<b>Title (first 4 words)</b>	Stress and family functioning		<b>Year of publication</b>	1999	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>	Medium		Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study looks at the aspects of caring that cause distress among carers of people with PD and explores the relationships between stress and family functioning. They found that stressfulness appears related to aspects of care-giving related to intrapersonal factors e.g. anxiety, fatigue while aspects of care-giving that caused less stress appeared more interpersonal e.g. relative's behaviour on the care giver, family relations.

The article highlights that professionals need to be aware of the stress factors for carers and plan services appropriately.

Carers under high levels of stress reported poorer family functioning than those reporting low levels of stress. Therefore stress is related to family environment which may have a knock on effect on the patient's well being.

Duration of condition was not related to stress and a significant relationship was found between care for older patients and greater family cohesion. Older care-givers appeared related to less conflict.

Impact for healthcare providers:

- Assessing stress and well being of the carer should be a priority for health care providers to identify and provide services for at risk people
- Support groups/ psycho-educational groups may be beneficial
- A needs assessment may show the overriding concerns of the target group
- Respite care is needed

Useful Reference: Davis LL Building a science of caring for care-givers.  
Family Community Health 1992;15:1-9

<b>Author/s</b>	Neva et al			<b>Ref No</b>	<b>CA0261</b>
<b>Title (first 4 words)</b>	Coping style; perceived uncertainty in illness		<b>Year of publication</b>		2001
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit.review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Parkinson Disease</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

- method = IADL - measures degree PD affects carrying out of activities for daily living. Symptom Distress Checklist - 90-item scale used to measure psychological distress Michell Uncertainty in Illness Scale - measures perceived uncertainty in illness across 5 categories: symptoms; diagnosis; treatment; relationship with care-givers; plans for the future. Devised coping strategy scale -
- Findings produced using theory driven regression analysis

## RESULTS

- Patients used emotion-focused coping strategies but not problem-focused coping strategies --> distress
- Patients use of problem-focused coping strategies --> carer distress
- Care-givers uncertainty in illness and emotion-focused coping strategy were significant predictors of distress
- Services should intervene at early stages of patient's diagnosis

<b>Author/s</b>	Walhagen, Brod			<b>Ref No</b>	<b>CA0263</b>
<b>Title (first 4 words)</b>	Perceived control and well-being		<b>Year of publication</b>	1997	
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b>Other (USA)</b>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	<b>High</b>		Medium	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article examines the relationship of patient perceptions of control over aspects of disease with carer burden and well-being. Relevant findings:

- Carers well-being was higher than the people with PD
- Carer burden was associated with severity of PD but not well being
- Perceived patient control over symptoms was associated with carer well being and less carer burden

Implications:

- Helping patient and family in managing symptoms will enhance perceived control and is an important aspect of quality of care which may enhance carer and patient well being
- Intervention needs to focus on care dyad in future
- Carer beliefs about the illness and its management need to be assessed as they influence patient and carers well being
- Need to monitor changes of symptoms over time and the effect these will have

<b>Author/s</b>	DAWSON, S. & KRISTJANSON, L.J.		<b>Ref No</b>	<b>CA0264</b>
<b>Title (first 4 words)</b>	Aping (the) Journey: Family		<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other Australia</u>	
<b>User's Long Term Condition</b>	<b>Muscular Dystrophy or Motor Neurone Disease</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This is a descriptive, qualitative, study which aimed to elicit the needs of relatives caring for people with progressive conditions as they move to, and through, the terminal stage of the illness. It uses these described needs, and participants' reflections on them, to infer that the model of palliative care developed for people with cancer would 'have much to offer' individuals with degenerative neuromuscular conditions and their families.

The study was well conducted and the findings interesting and plausible and point to ways in which the provision of support to family carers of people with MD/MND need to be improved.

Seven 'key findings' are said to emerge from the study:

A need for skilled, expert, support in the later stages of the disease

Gaps in supportive services – notably respite need for 'appropriately paced' information

Differences between carers of people with MD and MND in explicitly identifying need for palliative care (though both wish more and better support in later stages).

Somewhat contradictorily – the finding is reported that health care professionals need to incorporate palliative care in the care plan.

Training for staff in acute hospital settings to improve knowledge of MD and MND

The study's main weaknesses are:

Lack of discussion of what is meant by 'palliative care', and lack of evidence to justify the conclusion that palliative care will necessarily meet the needs identified – the recommendation goes beyond the evidence presented

Poor linkage between the three 'major themes' identified and the seven 'findings' reported in the study

<b>Author/s</b>	Bolmsjon and Hermeren			<b>Ref No</b>	<b>CA0265</b>
<b>Title (first 4 words)</b>	Conflicts of interest: experiences of		<b>Year of publication</b>	2003	
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other ( Sweden)</u>		
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study explores the experiences of carers in caring for terminally ill people with amyotrophic lateral sclerosis and the ethical problems associated with this. Key findings for carer's experiences:

Information:

- Carers felt that information was not adequate enough about ALS and the progress of the disease. They did not like the way the diagnosis was provided. They found professional carers incompetent. Information on available assistance equipment was not adequate

Restrictions:

- Carers experience limited freedom and increased responsibility

The future:

- Carers did not like to think about the future and seldom talked about it
- Carers found thoughts of the future distressing

Relations:

- Carers felt a need to confide in someone

Implications for healthcare: Services need to consider that carers more information about ALS and its progress and someone to confide in

Ethical issues:

Shared decision making is the ideal in trying to solve ethical problems based on communication not information

<b>Author/s</b>	Bolsmjo, I., Hermeren, G.		<b>Ref No</b>	<b>CA0267</b>
<b>Title (first 4 words)</b>	Interviews with Patients, Family.....	<b>Year of publication</b>		2001
<b>Research methods</b>	Quantitative	<u><b>Qualitative</b></u>	Mixed	Lit. review    Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4
<b>Location of study</b>	UK	<u><b>Other</b></u> (USA)		
<b>User's Long Term Condition</b>	<b>Amyotrophic lateral sclerosis</b>			
<b>Confidence Rating</b>	<u><b>High</b></u>	Medium	Low	
<b>Reviewer's initials</b>	AMC	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This qualitative study challenges the view of some professionals in palliative care that sufferers of amyotrophic lateral sclerosis (ALS) perceive their illness in the same way as do their family carers. The study also seeks to contribute to a paucity of literature on this particular subject.

Eight pairs of sufferers/carers were interviewed to generate data. Inclusion criteria demanded that the pairings had been extant for over six months. All respondents lived at home. ALS does not impair memory or intellect but is physically debilitating. All sufferers had impaired speech which precluded the use of recording equipment. One sufferer had lost the power of speech and responded by writing down their thoughts.

Sufferers and carers differ in how they perceive their own needs, in how they view, judge and evaluate the disease, and how they cope with its progress. In summary:-

- Carers tend to want more information about the disease.
- Carers tend to feel insecure.
- Carers feel a great need to talk about the burden of care.
- Some carers tend not to want to think about the future.

Because ALS is a specific condition the authors feel that the conclusions are easily generalised to provide support for other sufferers and their carers.

References to follow up:-

Payne, S. Smith, P, Dean, S. (1999) Identifying the concerns of informal carers in palliative care *Palliative Medicine* 13, 37-44

Higginson, I., Wade, A. McCarthy, M. (1990) Palliative care: views of patients and their families *British Medical Journal* 1:277-281

<b>Author/s</b>	Centers, L.C.			<b>Ref No</b>	<b>CA0268</b>
<b>Title (first 4 words)</b>	Beyond denial and despair.....			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<u><b>Lit. review</b></u>	<u><b>Other</b></u>
<b>Typology</b>	T1	T2	T3	<u><b>T4</b></u>	
<b>Location of study</b>	UK			<u><b>Other (USA)</b></u>	
<b>User's Long Term Condition</b>	<b>General (amyotrophic lateral sclerosis)</b>				
<b>Confidence Rating</b>	High	Medium		<u><b>Low</b></u>	
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

A philosophical/spiritual reflection on the meaning of 'hope' in palliative care, this paper draws on personal care-giving experience and a review of the literature to offer strategies to professionals who cope with individuals who have fatal illnesses.

The author takes a transcendental approach to issues such as hope, despair and denial and advocates a strong spiritual element to the care of the dying person that involves meditation and prayer.

The sincerity apparent in what is a highly subjective view, prompted by loss, might be difficult to reconcile with other times, places and circumstances.

<b>Author/s</b>	Goldstein et al.		<b>Ref No</b>	<b>CA0272</b>
<b>Title (first 4 words)</b>	Attributions, strain and depression...		<b>Year of publication</b>	2000
<b>Research methods</b>	<b>Quantitative</b>	Qualitative	Mixed	Lit. review Other
	Interviews with 19 care-givers, various rating scales			
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	<b>UK</b>		Other (USA)	
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>			
<b>Confidence Rating</b>	High	Medium	<b>Low</b>	
<b>Reviewer's initials</b>	HQ		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

7 (37%) showed anxiety, but none of carers achieved "caseness" for depression (HAD scores), and HAD scores did not correlate with anything (measures of attribution [global/specific, stability/change, internal/external], self-reported control of reactions to partners illness when thinking about partner, strain scores). Self-reported strain did correlate with attribution [global only] and control (in the expected direction).

Internal/external attribution did not relate to depression, strain or anxiety. But it did relate to anticipated coping with likely future distress. Carers with higher self-blame [internal attribution] anticipated coping better... . They can't explain this – its true of patients in, say, SCI but that makes more sense.

Female carers anticipated coping better than males did. For female carers there was an association between number of friends and relatives seen and the extent to which they felt their partners illness was affecting other areas of their life...(a negative assoc. thus suggesting informal support helps).

But the numbers are so small one would not want to over-interpret the data – it really just raises some questions.

<b>Author/s</b>	Jenkinson, Fitzpatrick, Swash, Peto			<b>Ref No</b>	<b>CA0273</b>
<b>Title (first 4 words)</b>	The ALS Health Profile Study			<b>Year of publication</b>	2000
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	<u>High</u>		Medium	Low	
<b>Reviewer's initials</b>	HR			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study examines the quality of life of people with amyotrophic lateral sclerosis and their carers in Europe. Relevant findings were:

- The physical and emotional demands on the patient lead to greater physical and emotional demands on the carer
- Health status of the patient has dramatic effect on the health status of the carer
- Carers have worse health status than the general population
- Services and MND charities need to take into account the impact of MND on the carers as well as the patient

<b>Author/s</b>	Goldstein and Leigh			<b>Ref No</b>	<b>CA0274</b>
<b>Title (first 4 words)</b>	Motor neurone disease: a		<b>Year of publication</b>	1999	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	High	Medium	Low		
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Key findings from this article about the reaction of carers to the diagnosis of MND:

- Families noted lack of support from the doctor and the emotional impact of the diagnosis
- Social support is valuable in helping carers cope with the stress of caring for someone with MND
- In the terminal phase families needed medical support
- Families expressed frustration over the difficulty of getting satisfactory medical information and felt abandoned by the medical services once the diagnosis is given
- Carers indicated that they had little knowledge available to them about MND or available resources
- Families were concerned about the likely course of the illness but expressed helplessness witnessing the course of the disease and the worsening state of the patient
- The families had concerns about the emotional and physical status of the patient
- 15% of families broke up
- Communication difficulties lead to carer frustration

<b>Author/s</b>	Ganzini L. et al.		<b>Ref No</b>	<b>CA0275</b>
<b>Title (first 4 words)</b>	Correlates of suffering in..		<b>Year of publication</b>	1999
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
	91 care-givers structured interviews with them and people cared for			
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other (USA)</u>	
<b>User's Long Term Condition</b>	<b>ALS/MND</b>			
<b>Confidence Rating</b>	High	Medium	<u>Low</u>	
<b>Reviewer's initials</b>	HQ		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Measures of suffering and QoL crude – one question each - 7-point response.  
Also asked about attitudes towards possible life-sustaining treatments (e.g. pain medication, even if death hastened, ventilatory support).

Patient/carer responses significantly correlated for level of suffering, but not QoL.  
'Assessment of patients' suffering by care-givers was accurate' i.e. it corresponded with patients' own reports.

Support or opposition to interventions (like pain relief) which might shorten life not related to perceptions of suffering. True for carers and patients.

Most info in paper is about people with ALS, rather than carers.

<b>Author/s</b>	Goldstein,Adamson,Jeffrey, Down,Barby,Wilson, Leigh			<b>Ref No</b>	<b>CA0276</b>
<b>Title (first 4 words)</b>	The psychological impact of		<b>Year of publication</b>	1998	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	<u><b>UK</b></u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Carers experience anxiety and depression partly linked to functional incapacity of the person with MND
- Carers level of strain correlated with perception of loss of intimacy predicted by cognitive/behavioural and communication changes
- Carers anxiety was greater the shorter their partners duration of symptoms
- Carers used more problem solving and orientation coping strategies when ambulation and alertness was more affected

<b>Author/s</b>	Eliot, Shewchuk, Richards			<b>Ref No</b>	<b>CA0279</b>
<b>Title (first 4 words)</b>	Family Care-giver social Problem solving		<b>Year of publication</b>	2001	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Spinal cord Injury</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This study looks at carers social problem solving abilities and their relationship to adjustment in the first year of care-giving. Relevant findings were:

- Carer negative orientation assessed during inpatient rehabilitation is an indicator of subsequent carer adjustment over the first year of care giving
- Carer with higher negative orientation towards problem solving may show greater distress and depression
- Negative orientation in the carers impair cognitive problem solving performance
- Carers who have more cognitive- behavioural resources exhibit fewer emotional difficulties adjusting to their role
- Carer problem-solving abilities predict emotional and physical health of carer and recipient

Implications for healthcare:

- Interventions are required to help family carers address the everyday routines and tasks needed to run a family

References: Has a massive reference list some may be relevant.

<b>Author/s</b>	Chan, R.C.K., Lee, P.WH., Mak-Lieh, F.		<b>Ref No</b>	<b>CA0280</b>
<b>Title (first 4 words)</b>	Coping with spinal cord injury.....		<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK	<b>Other (Hong Kong)</b>		
<b>User's Long Term Condition</b>	<b>Spinal cord injury</b>			
<b>Confidence Rating</b>	High	<b>Medium</b>	Low	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This cross-sectional retrospective study looked at the impact of care-giving on the spouses (n=40) of persons with spinal cord injury (SCI) (n=66). A plethora of psychometric tests (n=9) were applied to data generated via questionnaire and semi-structured interview.

The authors note from the literature that a good marital relationship is an important factor in the positive psychosocial outcome for the injured person. They also note that Eastern attitudes to disability vary from those in the West.

- Caring simultaneously increases the well-being of the injured person while it reduces it for the carer.
- Caring spouses who were married pre-injury experience more depression than those who married post-injury
- The composition of the extended family often means that the care burden is diluted yet female spouses still feel depressed
- Those couples who experienced marital separation as a result of the injury did so in the early stages. Implications here for professionals in terms of counselling services

<b>Author/s</b>	Boyer et al			<b>Ref No</b>	<b>CA0281</b>
<b>Title (first 4 words)</b>	Prevalence and Relationship of		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b><u>(Paediatric) Spinal Cord Injury</u></b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	HA		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study examined 64 paediatric Spinal Cord Injury (SCI) patients and their parents (64 months; 49 fathers) regarding post-traumatic stress disorder (PTSD). There were 43 families with data from all three members, which was the sub-sample used for the analysis. Data collected using measures. The authors report limitations to the study (small sample; no control group; using a self-report measure of PTSD rather than a structured interview). There was no discussion of issues relating to the provision of health and social care services for carers. Authors reported various associations between PTS-PTSD and family members, e.g. mothers' PTS was strongly related to PTS in their children (patients) and their husbands-partners.

<b>Author/s</b>	Raymond Chan			<b>Ref No</b>	<b>CA0283</b>
<b>Title (first 4 words)</b>	Stress and coping in spouses		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	<u>Mixed</u>	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK	<u>Other(Hong Kong)</u>			
<b>User's Long Term Condition</b>	<b>Spinal cord injury (SCI)</b>				
<b>Confidence Rating</b>	<u>High</u>	Medium	Low		
<b>Reviewer's initials</b>	HR	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>			

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article set out to examine the sources of stress and the patterns of coping of spouses of persons with SCI in the Chinese population in Hong Kong. Key Findings were:

- Sources of stress were: health issues, family/marital interactions, care giving burden and work due to conflict between care giver and employee role
- There were three identified coping models:

**Externals:** spouses with limited coping strategies and limited social support. Had higher depression and care-giving burden. Considered the 'high risk' group. Characterised by being older with longer period of marriage

**Internals:** spouses with adequate coping strategies and social support. The 'well adjusted group'. Scored low on care-giving burden, depression and social role dissatisfaction

**Multi-controls:** mid-range coping strategies and adequate social support. Had mid range adjustment scores and lower scores for depression and emotional care-giving than spouses in the external group. Characterised by being younger with less years marriage than the 'externals'.

The author found that spouse and persons with SCI experience the same processes of stress and adjustment. He proposes that rehabilitation professionals need to attend to both patient and spouses needs to ensure best therapeutic results. Counselling was advocated.

The article also highlights that services need to be culturally relevant for Chinese persons with SCI and their spouses.

References :

Shultz et al *The social psychology of care-giving : physical and psychological costs of providing support to the disabled* J Appl Soc Psychol 1987 17 401-28

<b>Author/s</b>	Holicky, R., Charlifue, S.			<b>Ref No</b>	<b>CA0285</b>
<b>Title (first 4 words)</b>	Ageing with spinal cord injury			<b>Year of publication</b>	1999
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	<u><b>UK</b></u>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Spinal cord injury</b>				
<b>Confidence Rating</b>	High	Medium	<u><b>Low</b></u>		
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

A longitudinal study that describes 225 individuals with spinal cord injury (SCI) and assesses how marital status influences their quality of life. With this focus the carer experience can only be inferred at best.

Results suggest that married individuals (of either gender) with SCI tend to enjoy better quality of life than those who are not married. This ignores the impact of the condition on the carer.

More relevant and better information may be had from  
Gaynor, S. (1990) The long haul: the effects of home care on care-givers  
*Journal of Nursing Scholarship* 4, 208-212

<b>Author/s</b>	Elliot, Shewchuk, Richards			<b>Ref No</b>	<b>CA0286</b>
<b>Title (first 4 words)</b>	Family Care-giver Social Problem solving		<b>Year of publication</b>	1999	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>Spinal cord Injury</b>				
<b>Confidence Rating</b>	High		<u>Medium</u>	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This article considers the impact of carer problem solving abilities on the patient's adjustment and physical well being. Relevant findings were:

- There is a link between the problem solving abilities of the carer and patients psychological and health outcomes
- Impulsive/careless problem solving in the carer was associated with psychological adjustment on discharge and health outcomes at one year may be as they find it harder to adhere to schedules/regimens
- Family members characteristics impact on patient's reactions to severe disabilities and rehabilitation needs to consider psychological interventions for family carers with early detection of those with impulsive/careless problem solving traits.
- Patients in the study who experienced difficulty adjusting appeared to do so due to an awareness of their carers difficulties with coping

References: Again a very long reference list it may have some relevant articles. This one looked quite good:

Aneshensl, Pearlin, Mullan, Zarit, Whitlatch 1995 Profiles in care-giving: the unexpected career San Diego, CA: Academic Press

<b>Author/s</b>	Shewchuk, Richards, Elliott			<b>Ref No</b>	<b>CA0288</b>
<b>Title (first 4 words)</b>	Dynamic Processes in Health		<b>Year of publication</b>	1998	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Spinal Cord Injury</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article investigates the developmental trajectories of health outcomes in carers of patients with SCI. It finds that care-giving can be seen as a developmental process over the initial year.

The study has found that anxiety is the best predictor of the variability in the initial levels of physical symptoms reported by the carers. Physical symptoms also predicted anxiety and depressive behaviour in the carers. Younger carers experience more anxiety and low positive affect initially.

Depressive behaviour was associated with lower positive affect and the authors suggest that this may be due to restricted social contact.

Over time it is the emergence of expressive support that is the best predictor of change in depressive behaviour and anxiety among the carers i.e. more support less anxiety and depression.

<b>Author/s</b>	Scott Richards, J.		<b>Ref No</b>	<b>CA0289</b>
<b>Title (first 4 words)</b>	Care-givers of Persons with Spinal...	<b>Year of publication</b>		1997
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review    Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK	<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Spinal Cord Injury</b>			
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	SP	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Abstract only. 65 care-givers completed questionnaires in hospital, at one month, at 6 months, and one year post discharge. Both descriptive data and 'hierarchical linear modelling techniques' indicated high levels of distress which increased over time.

<b>Author/s</b>	Weitzenkamp, D.A. <i>et al</i>			<b>Ref No</b>	<b>CA0290</b>
<b>Title (first 4 words)</b>	Spouses of spinal cord injury...		<b>Year of publication</b>	1997	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other(USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Spinal cord injury</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>	Medium		Low	
<b>Reviewer's initials</b>	AMC		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The authors note that for many chronic conditions/illnesses there is a body of literature that considers the burden on spouses under headings such as emotional upset, role overload and health issues. They want to discern whether such findings are applicable in the spinal cord injured (SCI) and their spouses. They reason that since SCI sufferers are often younger adults there may be important differences in how people cope.

Participants (n=124) were taken from a longitudinal study into long-term SCI outcomes. The majority (90%) were women. Four established rating scales were used to measure stress, depression, life satisfaction and quality of life. All were subject to statistical analyses. The overall purpose was to quantify how spouses were feeling.

On depression it was found that:-

- Spouses caring were generally more depressed than the injured partner (and more depressed than non-caring spouses).

On Quality of Life and Individual Needs:-

- Caring spouses rated the importance of having children higher than the injured partner

Further analysis showed that it was caring spouses only (n=80) who accounted for these differences (i.e. spouses who didn't perform a caring role reported no difference in needs, depression or quality of life).

Caring spouses reported significantly higher stress, burnout, anger and resentment and poorer well-being.

Despite the equal split between injuries incurred pre and post marriage (38/42) the only discernible difference was that spouses of partners who incurred the injury after marriage complained of more fatigue.

The authors highlight the point that outside help in care-giving will ease the burden ONLY if it is care-giving and NOT the severity of the injury that causes problems.

They are also cautious about the gender imbalance (only 10% male in the sample) and the overall sample size.

<b>Author/s</b>	Calne, S. M. <i>et al</i>			<b>Ref No</b>	<b>CA0298</b>
<b>Title (first 4 words)</b>	Validating a Quality of Life Scale.....		<b>Year of publication</b>	2003	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (Canada)</u></b>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This paper aims to validate the Parkinson's Impact Scale (PIMS) a ten-item, ten areas measure of quality of life for use with the primary care-givers (n=135) of individuals with Parkinson's Disease (PD).

The study found that:-

- Scores altered significantly with disease severity.
- Scores altered significantly with a lapse in the patient's condition
- Carers rated the negative impact of PD most severely in the areas of sexuality, travel and leisure

Potentially useful references might include:-

Berry, R.A., Murphy, J.F. (1995) Well-being of care-givers of spouses with Parkinson's Disease *Clin Nurs Res* 4, 373-386

Carter, J. *et al* (1998) Living with a person who has Parkinson's Disease: the spouses perspective by stage of disease *Mov Disord* 13, 20-28

McRae, C., Sherry, P., Roper, K. (2001) stress and family functioning among care-givers of persons with Parkinson's disease *Parkinsonism Related Disord* 5, 69-75

<b>Author/s</b>	EDWARDS, N.E.		<b>Ref No</b>	<b>CA0301</b>
<b>Title (first 4 words)</b>	Influence of Care-giver Burden on Patients'		<b>Year of publication</b>	
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other USA</u>	
<b>User's Long Term Condition</b>	Parkinson's Disease			
<b>Confidence Rating</b>	High	Medium	<u>Low</u>	
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Study testing the hypothesis that as care-givers perceive that their burden is increasing, the level of management by PD patients of their condition decreases. A significant 'path' was noted between the spouse or patient's perceived burden of care and the patient's management of the disease. The inference made is that as the carer's perceived burden increases s/he is less able to support the PD sufferer's management of the condition – and that rehabilitation nurses can help both to reflect on this and find ways of maintaining disease management by the patient.

Major weaknesses of the study include its inability to test whether, in fact, as the condition progresses and with it the patient's ability to manage the condition the care-giver's burden increases; possible lack of representativeness of the sample; and inability to be sure that the questionnaires were completed independently by patient and care-giver.

<b>Author/s</b>	Anderson, M.I., Parmenter, T.R., Mok, M.			<b>Ref No</b>	<b>CA0304</b>
<b>Title (first 4 words)</b>	The relationship between neurobehavioural....			<b>Year of publication</b>	2002
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (Australia)</u>		
<b>User's Long Term Condition</b>	<b>Traumatic brain injury</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This highly technical and largely methodological study focuses on stress to explore the relationships between neurobehavioral problems associated with traumatic brain injury (TBI), family functioning and psychological distress in care-givers. The literature suggests that neurobehavioral problems are related to stress reaction in carers and this study supports these findings. The study hypothesised that family functioning will mediate the relationship between the neurobehavioural problems of TBI and psychological distress in the care-giver. Data was generated from respondents (sample size n=64) via a series of self-assessment scales and the variables operationalised via established test instruments.

The carers' experience is described mostly in statistical form. From this it is apparent that carers experience distress grouped around behavioural, communication and social problems.

No further insights from actual carer experience was offered.

The authors suggest that gendered and ethnic elements need further study before they can claim more general authority for their findings.

Potentially useful references might include:-

Gillen, R., Tennen, H., Affleck, G. *et al* (1998) Distress, depressive symptoms and depressive disorder among care-givers of patients with brain injury *Journal of Head Trauma Rehabilitation* 13, 31-43

Frosch, S., Gruber, A., Jones, C. *et al* (1997) The long term effects of traumatic brain injury on the role of care-givers *Brain Injury*, 11, 891-906

<b>Author/s</b>	Edwards, N.E., Scheetz, P.S.			<b>Ref No</b>	<b>CA0305</b>
<b>Title (first 4 words)</b>	Predictors of Burden for Care-givers.....		<b>Year of publication</b>	2002	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This inquiry used a cross-sectional design to study the perceived burden of care experienced by cohabiting partners of individuals with Parkinson's Disease (PD). Burden was determined via a rating scale (Zarit Burden Inventory). Four independent variables (Activities of Daily Living/ADLs, perceived social support, psychological well-being and marital satisfaction) were measured and were shown to be significant predictors. Measurement instruments consistently returned alphas of above 0.77.

The care giving experience is reported exclusively in numerical/statistical form. From this it is apparent that:-

- Women in this study reported almost twice the burden as the male care-givers.
- Couples on lower income reported more burden than better off couples.
- The severity of the PD is directly related to increased assistance with ADLs and in turn this increases the level of perceived burden.

The study did not examine the use of support groups and there is conflicting evidence on their efficacy. Respite for care-givers is recommended.

References to pursue might include

Harper, S., Lund, D. (1990) Wives, husbands and daughters caring for institutionalised and non-institutionalised dementia patients: toward a model of care-giving burden

*International Journal of Ageing and Human Development* 30, 241-262

Robinson, K.M. (1997) Family care-giving: who provides the care and at what cost?

*Nursing Economics*, 15(5), 243-247

<b>Author/s</b>	Sander et al			<b>Ref No</b>	<b>CA0307</b>
<b>Title (first 4 words)</b>	Relationship of family functioning		<b>Year of publication</b>		2002
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	<b>HA</b>		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study investigated the relationship of family functioning to patient's progress in a post-acute TBI rehabilitation programme. The hypothesis was that persons from families with unhealthy functioning would show less progress in rehabilitation than those from families with healthy functioning. The sample was small (n=37). Data was collected using two standard outcome measures. The results indicated that family functioning was significantly related to how well patients progressed in post-acute rehabilitation. No discussion about health and social care issues in relation to care-givers.

<b>Author/s</b>	Ganzini L et al.			<b>Ref No</b>	<b>CA0308</b>
<b>Title (first 4 words)</b>	The final month of...		<b>Year of publication</b>	2002	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
	50 care-givers. In person or some self completion				
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>ALS/MND</b>				
<b>Confidence Rating</b>	High	Medium		Low	
<b>Reviewer's initials</b>	HQ		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Mostly focused on carers' reports of patient experience in the last month of life.  
 Only measures which seem to reflect carers experience/views: measure of satisfaction with medical care (for patient); reported assistance given by care-giver with ADLs;  
 72% spouses  
 ADLs: In the month before death carers had given help at least once a week with:  
 Personal care (86%)  
 Finances (82%)  
 Communication with others (82%)  
 Medication (80%)  
 Moving/transferring, hygiene, dressing (all 78%)  
 Toileting (72%)  
 Bathing (64%)  
 Shopping (68%)  
 Cooking (58%)

17 (34%) were dissatisfied with various aspects of medical care. Breakdown (overlapping) is:  
 10 dyspnea management  
 9 pain relief efforts  
 8 information on symptom management

Rest of paper on carers' reports of patient experiences.

<b>Author/s</b>	Ganzini, L., Johnston, W., Silveira, M.J.			<b>Ref No</b>	<b>CA0308</b>
<b>Title (first 4 words)</b>	The final month of life.....			<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Amyotrophic lateral sclerosis</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study aimed to chart the health care experiences and palliative care needs of individuals with ALS in the final month of life. The care-giver experience is then secondary to the main aims and is focused on reporting their own perception of care delivery.

Data were generated from 50 carers via a survey. Relevant here are the findings that:-

- Carers report individuals with ALS do not want to burden their families
- Despite this the carers in this survey were spending up to 11 hours per day with their family member
- Advance care planning was successful in 88% of cases reported here (although the final days of life need a more longitudinal study since there are discrepancies between various reports).
- Advance directives on the other hand were seen by 50% as being either 'helpful' or having no effect on care.
- Carers report very favourably on the involvement of doctors in terminal care
- Carers rated the patient suffering from emotional symptoms at 4 out of 6.
- There was some carer dissatisfaction (33%) with aspects of medical care (dyspnea, pain relief and general symptom management).
- Although most carers reported the patient to be at peace near death distressing symptoms still affect the sufferer, even in a hospice setting.

Reference;

Rabkin, J., Wagner, G., Bene, M.D. (2000) Resilience and distress among amyotrophic lateral sclerosis patients and care-givers, *Psychosom Med* 62, 271-279

<b>Author/s</b>	Thaxton, L., Myers, M.A.			<b>Ref No</b>	<b>CA0310</b>
<b>Title (first 4 words)</b>	Sleep disturbances and their management			<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High		Medium	<b><u>Low</u></b>	
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This paper claims to look at the way care-givers cope with the sleep disturbance of the brain injured person. A lengthy opening section on sleep and insomnia gives way to a catalogue of strategies to promote sleep. These are all of a general nature and relevance is claimed because TBI shortens sleep time and is implicated in the disappearance of deep sleep. A section on the effects/side-effects of prescription and non-prescription medications follows.

At no stage are the actual views of care-givers or their brain injured relatives sought or elaborated.

<b>Author/s</b>	Caap-Ahlgren, M., Lannerheim, L., Dehlin, O.	<b>Ref No</b>	<b>CA0311</b>
<b>Title (first 4 words)</b>	Older Swedish women's experiences.....	<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative <u><b>Qualitative</b></u> Mixed	Lit. review	Other
<b>Typology</b>	T1 <u><b>T2</b></u>	T3	T4
<b>Location of study</b>	UK	<u><b>Other (Sweden)</b></u>	
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>		
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low
<b>Reviewer's initials</b>	AMC	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This qualitative study explores women's perceptions of living with symptoms associated with Parkinson's disease. The carer experience is completely absent.

<b>Author/s</b>	Pitaro & Reggio			<b>Ref No</b>	<b>CA0314</b>
<b>Title (first 4 words)</b>	THE COSTS OF MS			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK_		<b>Other(Italy)</b>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	<b>Medium</b>		Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- First bottom-up study evaluating cost of Multiple Sclerosis in Italy
- Assessed direct and indirect costs of having MS
- Costs were significantly higher for male patients who lost more work.
- Costs also increased with age and disease progression.
- MS is great economic burden in Italian society – indirect costs exceed direct costs
- Care-givers and patients loss of work is significant to Italian economy because unpaid carers are still predominate in Italy. But study suggests that better treatment at early stages of illness can avoid costs increase

<b>Author/s</b>	Loughrun & O'Brian			<b>Ref No</b>	<b>CA0316</b>
<b>Title (first 4 words)</b>	epilepsy liaison nursing			<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SS			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Epilepsy liaison nurse - can be key person in supporting patients and their families, providing information about epilepsy and medication, and liaising with professionals to ensure patient gets appropriate treatment.

Learning Disability Epilepsy Nurse's Forum developed epilepsy nursing assessment tool which gives information about individual's condition and acts as template with which epilepsy care plans can be drawn up.

<b>Author/s</b>	<b>Global Parkinson's Disease Survey Steering Committee</b>			<b>Ref No</b>	<b>CA0320</b>
<b>Title (first 4 words)</b>	Factors impacting on quality .....			<b>Year of publication</b>	2002
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	SP			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Nothing relevant in this report.

<b>Author/s</b>	Craig Alexander, Karen Hwang. Marca Sipski		<b>Ref No</b>	<b>CA0323</b>
<b>Title (first 4 words)</b>	Mothers with Spinal Cord		<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK		<b><u>Other USA</u></b>	
<b>User's Long Term Condition</b>	<b>Spinal Cord Injuries</b>			
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The focus of this study was on mothers with spinal cord injury and the impact it has on marriage, family and children's adjustment. The study evaluates how mothers with SCI adjust to parenting, the marriages and families. It does not have any focus on the carer-recipient dyad. However, there was one relevant finding; that partners of mothers with SCI expressed more life stress than partners of able bodied mothers. The stress was due to situational circumstances beyond their control i.e. disability.

<b>Author/s</b>	Mandler, R.N., Anderson, F.A. <i>et al</i>	<b>Ref No</b>	<b>CA0324</b>
<b>Title (first 4 words)</b>	The ALS patient care database....	<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative    Qualitative    Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1 <b><u>T2</u></b>	T3                    T4	
<b>Location of study</b>	UK	<b><u>Other (USA)</u></b>	
<b>User's Long Term Condition</b>	<b>ALS/Motor neurone disease</b>		
<b>Confidence Rating</b>	High                    Medium	<b><u>Low</u></b>	
<b>Reviewer's initials</b>	AMC	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study focuses on the end of life treatment of individuals with amyotrophic lateral sclerosis. Carer views are not apparent in the paper and therefore it does not meet the criteria for this study.

<b>Author/s</b>	Boston, P., Towers, A., Barnard, D.			<b>Ref No</b>	<b>CA0325</b>
<b>Title (first 4 words)</b>	Embracing Vulnerability: Risk and Empathy.....			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	T2	T3	<u>T4</u>	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>Palliative care</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This largely theoretical article takes one example from a larger case narrative study. It focuses on empathy with the dying person as a therapeutic act and as a process. The authors suggest that empathy, being a complex psychosocial/philosophical concept, tends to be marginalised within the more objective, scientific medical model which has cure as the endpoint of its intervention. This disparity leads to an emphasis on imparting information at the expense of generating understanding.

With reference to the case study carers make the following points.....

- It is possible to learn from the dying person but the experience is always mediated by the professional relationship.
- There are personal risks to carers in getting emotionally involved with dying persons.
- Successful palliative care has a spiritual dimension

<b>Author/s</b>	Perozzo et al			<b>Ref No</b>	<b>CA0347</b>
<b>Title (first 4 words)</b>	Deep brain stimulation			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit.review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b>Other (Italy)</b>		
<b>User's Long Term Condition</b>	<b>Parkinson Disease</b>				
<b>Confidence Rating</b>	High		<b>Medium</b>	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

- Study investigates the behavioural modifications and the relations within a patient's family during 6 months after surgery (treatment for people with Parkinson's Disease )
- Surgery improved motor performances of PD patients
- DBS (deep brain stimulation ) of the subthalamic nucleus was the treatment that resulted in the improvement in motor performances and thus mood of PD patients and care-givers.
- DBS STN treatment results in psychological problems because patients are afraid of returning to pre-operative state. Care-givers showed aggressive behaviour in response to patients psychological dependence.

<b>Author/s</b>	Mark Barber, David Stewart, Donald Grosset, Graeme MacPhee	<b>Ref No</b>	<b>CA0372</b>
<b>Title (first 4 words)</b>	Patient and carer perceptions	<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative <u><b>Qualitative</b></u> Mixed	Lit. review	Other
<b>Typology</b>	T1 <u><b>T2</b></u>	T3	T4
<b>Location of study</b>	<u><b>UK</b></u>	Other (USA)	
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>		
<b>Confidence Rating</b>	<u><b>High</b></u>	Medium	Low
<b>Reviewer's initials</b>	HR	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article has no reference to carer's experience of caring for a person with Parkinson's.

<b>Author/s</b>	Bowen, A. <i>et al</i>			<b>Ref No</b>	<b>CA0429</b>
<b>Title (first 4 words)</b>	Neuropsychological rehabilitation for traumatic brain injury.....		<b>Year of publication</b>	2001	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	<u><b>UK</b></u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Traumatic brain injury</b>				
<b>Confidence Rating</b>	High	Medium	<u><b>Low</b></u>		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This study evaluated the effectiveness of a new rehabilitation service, compared with existing services, for carers of people with traumatic brain injury (TBI). The aim was to reduce neuropsychological sequelae of TBI and to improve outcome for survivors and their carers. 96 carers participated. On admission the injured person was assigned, according to a specified time table, to one of three groups (new service pre-discharge, new service post-discharge and control). Extra recruitment to the first group meant that carer numbers were unequally divided at 41, 28 and 27 respectively. Two outcomes, carers emotional distress and how well informed they felt, were measured 6 months post discharge.

Results show that:-

- The majority of the control group felt poorly informed when compared to both intervention groups. However, this did not reach statistical significance ( $p \geq 0.01$ )
- 52% of the control group showed significant emotional distress after 6 months. This was greater than both intervention groups but again it did not reach statistical significance
- ( $p \geq 0.01$ )

The authors feel that by setting the p value so low they may have committed a type 2 error (not being able to reject the null hypothesis as false). That they did not use the Neyman- Pearson lemma suggests a poor grasp of statistical

significance. These methodological shortcomings reduce confidence in the results.

<b>Author/s</b>	Smith, J.E., Smith, D.L.		<b>Ref No</b>	<b>CA0508</b>
<b>Title (first 4 words)</b>	No map, no guide....		<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other (Canada)</u>	
<b>User's Long Term Condition</b>	<b>Traumatic brain injury</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

A qualitative study that examines the carer experience ( n = 8) of 'the system'. Data generated at interview reveals four main themes that account for the carer experience.

- 1: the search for information
- 2: the search for support
- 3: the need to speak for the survivor
- 4: navigating the system

1 Much of the 'search for information' began at the emergency room where families felt that they were given information but could not relate it to their experience. There was a prevalent feeling that professionals tended to emphasise the seriousness of the injury, thereby denying hope, while all the families wanted was hope.

(see CA142)

2 Care-givers were generally not prepared for the long-term effects. They reported stress, burn-out and giving up, not because they didn't care, but because they couldn't cope.

Speaking of the changes in the injured person they spoke of loss and grief for the person they used to know.

3 care-givers felt the need to advocate for their family member and this frequently brought them into direct conflict with health professionals and sometimes with the TBI individual themselves.

4 one individual reports that they needed someone who knew their way around the system 'because if you don't, you're sunk'.

Much of the conflict here focused on the discharge of the TBI individual. Family members didn't know how to access services.

The authors conclude that family caring can be improved by the introduction of a case manager to co-ordinate the long-term care of TBI survivors and their families.

<b>Author/s</b>	Hellawell, D.J., Signorini, D.F., Pentland, B.	<b>Ref No</b>	<b>CA0528</b>
<b>Title (first 4 words)</b>	Reliability of the relative's questionnaire.....	<b>Year of publication</b>	2000
<b>Research methods</b>	<u>Quantitative</u> Qualitative    Mixed	Lit. review	Other
<b>Typology</b>	T1 <u>T2</u>	T3	T4
<b>Location of study</b>	<u>UK</u>	Other (USA)	
<b>User's Long Term Condition</b>	<b>Brain injury</b>		
<b>Confidence Rating</b>	High	<u>Medium</u>	Low
<b>Reviewer's initials</b>	AMC	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This paper recognises the value of follow-up in cases of traumatic brain injury (TBI) but also notes notoriously low response rates. Due to the marked discrepancy between patient and relative reports the study investigates the test-retest reliability of the relative's questionnaire (RQ) when used in a postal survey (n=81).

Here, however, responses are translated into statistical form and the focus is on what changes relatives/carers perceive in the person with TBI, rather than in their own lives. As such this study doesn't meet the criteria for inclusion here.

<b>Author/s</b>	Meikle, Sebit, Adamolekun			<b>Ref No</b>	<b>CA0539</b>
<b>Title (first 4 words)</b>	The impact of epilepsy		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The was no relevant information in this article

<b>Author/s</b>	Battaglia et al			<b>Ref No</b>	<b>CA0541</b>
<b>Title (first 4 words)</b>	A cost evaluation of MS		<b>Year of publication</b>	2000	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit.review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (Italy)</b></u>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Large body of evidence suggests that Multiple Sclerosis is one of the most expensive neurological diseases (e.g. Whetten-Goldstein et al, 1998). This is because of early onset, long duration and significant impact on employment.

Disease costs are evaluated in terms of:

Tangible costs - direct (cost of drugs, medical visits, assistive devices)  
indirect (loss or reduction in income)

Intangible costs - loss of unpaid position or costs related to health and quality of life

Evaluation assessment results found indirect costs counted for 80% of MS disease costs - highest tangible expense

Informal assistance - second highest tangible expense

Cost-benefit evaluation assessment influences therapeutic decision-making in developing countries.

<b>Author/s</b>	Watanabe, Shiel, Asami, Taki, Tabuchi			<b>Ref No</b>	<b>CA0574</b>
<b>Title (first 4 words)</b>	An evaluation of neurobehavioural		<b>Year of publication</b>		2000
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other(Japan)</b></u>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article looked at the proportions of patients admitted to hospital in Japan and the levels of stress in the carers. The article was let down by the statistical analysis and write up. The authors made claims about their findings which were not supported by the statistical analysis.

Relevant findings: They found that there were fairly high levels of stress in carers and that they might be of increased risk of depression. There were higher levels of strain in carers of more impaired patients.

<b>Author/s</b>	Aarsland,D. Larsen,JP. Karlsen,K. etal		<b>Ref No</b>	<b>CA0602</b>
<b>Title (first 4 words)</b>	Mental symptoms in Parkinson's		<b>Year of publication</b>	1999
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK		<b>Other( Norway)</b>	
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>			
<b>Confidence Rating</b>	<b>High</b>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

The article examined the emotional and social distress of caring for a person with Parkinson's Disease and the effects the mental and motor features of the disease have on this distress. The article's results were:

- Carers of people with PD experience high levels of emotional distress and stress in care-giving
- Spouses were more highly depressed than carers who were children or other carers
- Spouses had low psychological health compared to healthy controls
- Functional impairment was linked to carer stress but not emotional distress
- It is the psychological aspects of PD especially depression, cognitive impairment and behavioural disturbance that lead to the most significant levels of carer distress and stress
- Disease stage and severity of motor symptoms may not influence care-giver stress independent of mental disturbance
- Clinical implications are that the identification and treatment of mental disturbances is of major importance for patient and carer and may enable people to be cared for in their own homes longer
- These findings compare with carers experience of Alzheimer's disease

References:

Carter,J. Stewart,B. et al 1998 *Living with a person who has Parkinson's Disease: the spouse's perspective by stage of disease* Mov. Dis 13, 20-28

Miller,E. Berrios,G. and Politynska,B. 1996 *Caring for someone with Parkinson's Disease: Factors that contribute to distress*. Int. J. Geriatr. Psychiat. 11 263-268

<b>Author/s</b>	Aarsland			<b>Ref No</b>	<b>CA0611</b>
<b>Title (first 4 words)</b>	Range of neuropsychiatric disturbances		<b>Year of publication</b>	1999	
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b>Other(Scandinavia)</b>		
<b>User's Long Term Condition</b>	<b>Parkinsons Disease</b>				
<b>Confidence Rating</b>	<b>High</b>		Medium	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Although this article used a care-giver questionnaire and semi structured interview with carers it was used for diagnostic purposes to identify psychiatric symptoms and dementia not carer experiences.

<b>Author/s</b>	Neufeld et al			<b>Ref No</b>	<b>CA0672</b>
<b>Title (first 4 words)</b>	Life-long history of injuries		<b>Year of publication</b>	1999	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit.review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other(Israel)</b></u>		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	High		<u><b>Medium</b></u>	Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

- Patients who experienced trauma had significantly earlier onset age of epilepsy
- Seizure type is best predictor of sustaining trauma.
- Secondary generalised seizures less likely to be associated with injury

<b>Author/s</b>	Baker, G.A. et al			<b>Ref No</b>	<b>CA0729</b>
<b>Title (first 4 words)</b>	Patients' Understandings of and.....		<b>Year of publication</b>	1999	
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	<b>UK</b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	High	<b>Medium</b>		Low	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The purpose of the study was to discover how well informed sufferers and their carers are about epilepsy. Data was compiled via self-completed questionnaires. Despite the stated aim of the study the carers' experience is entirely absent from the results and discussion.

<b>Author/s</b>	Gosling and Oddy			<b>Ref No</b>	<b>CA0742</b>
<b>Title (first 4 words)</b>	Rearranged marriages: marital relationships		<b>Year of publication</b>	1999	
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	<b>UK</b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High	<b>Medium</b>	Low		
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study looked at changes in marriages after head injury. The following experiences were reported for spouses of people with head injury:

- Marriages were reported to have severe problems
- Sexual satisfaction was rated as lower and they were more dissatisfied
- The partner with head injury was more dependent
- Sexual interest was mainly reported as reduced but elements of coercion were reported
- They felt that their partner felt like a stranger and avoided sex
- They perceived more responsibility
- They experienced gratitude or lack of emotional expression from their injured partner
- The relationship was no longer equal, sharing or providing companionship
- Their sexual relationship felt boring or wrong
- Some partners found it difficult to find a positive in their relationship while others reported continued friendship and mutual affection
- They were realistic about the future
- They were concerned about the effect of their partners injury on the children
- They had limited help
- They spoke of sadness and recognition of their losses

Implications:

- Spouses need help with practical and emotional aspects of coping with added responsibilities
- They need encouragement to have a mutual discussion of their commitment and friendship
- They need to be encouraged to discuss what is acceptable sexually and maybe use techniques such as scheduled feedback and self monitoring

<b>Author/s</b>	Schwartz, and Kraft		<b>Ref No</b>	<b>CA0744</b>
<b>Title (first 4 words)</b>	The role of spouse responses		<b>Year of publication</b>	1999
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review    Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article is about patient experiences not carer experiences

<b>Author/s</b>	DUIJNSTEE, MSH & BOEIJE, HR			<b>Ref No</b>	<b>CA0764</b>
<b>Title (first 4 words)</b>	Home Care (by and for) relatives			<b>Year of publication</b>	1998
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (Netherlands)</u></b>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b> (No info on methods)		
<b>Reviewer's initials</b>	SB		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Note: No info at all on research design or methods. The article draws on a study to point up:

The importance of home care nurses defining family carers as co-workers who experience significant problems in caring and in adjusting to changes in the relationship

The importance of providing timely, preventive, help to carers

The central importance of tailoring both practical and emotional support to the specific 'chemistry' of the relationship and the carers individual needs.

<b>Author/s</b>	Saantos, M.E., Castro-Caldas, A., de Sousa, L.	<b>Ref No</b>	<b>CA0806</b>
<b>Title (first 4 words)</b>	Spontaneous complaints of long-term.....	<b>Year of publication</b>	1998
<b>Research methods</b>	Quantitative    Qualitative <b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3    T4
<b>Location of study</b>	UK	<b><u>Other(Portugal)</u></b>	
<b>User's Long Term Condition</b>	<b>Traumatic brain injury</b>		
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>
<b>Reviewer's initials</b>	AMC	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study sets out to examine the spontaneous complaints of survivors of TBI and to compare these with their relatives' accounts (n = 48). Data was generated by interview and then categorised and subject to statistical analyses. As such the study does not specifically target the carer experience and the responses do not contribute to our understanding.

<b>Author/s</b>	Glozman, J.M., Bicheva, K.G., Fedorova, N.V.		<b>Ref No</b>	<b>CA0854</b>
<b>Title (first 4 words)</b>	Scale of quality of life.....		<b>Year of publication</b>	1998
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review    Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4
<b>Location of study</b>	UK		<u><b>Other (Russia)</b></u>	
<b>User's Long Term Condition</b>	<b>Pakinson's Disease</b>			
<b>Confidence Rating</b>	High	Medium	<u><b>Low</b></u>	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

A very brief paper that begins by recognising the disruption to the quality of life of families caused by a family member with Parkinson's Disease(PD). 30 care-givers completed the Scale of Quality of Life of Care-givers (SQLC). From this the following numerical data is available.

- 23% of carers had to either give up their job or go part-time
- 47% complained that they couldn't attend to other family members as well as previously
- 35% complained that they couldn't leave the person with PD alone

Other than that no further insights are made available.

<b>Author/s</b>	Shackelford M. et al.		<b>Ref No</b>	<b>CA0859</b>
<b>Title (first 4 words)</b>	A comparison of men...		<b>Year of publication</b>	1998
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
	Structured interviews with 128 women and 522 men at least one year post injury. Designed to identify secondary conditions. Response rate 66%.			
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other(USA)</u>	
<b>User's Long Term Condition</b>	<b>Spinal cord injury</b>			
<b>Confidence Rating</b>	High	Medium	<u>Low</u>	
	Not confident it says much about carer views, and the one possibly relevant point is ambiguous.			
<b>Reviewer's initials</b>	HQ		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Males are more likely to have a parent or spouse to assist, females are more likely to get assistance from a paid care-giver or relative who is not a spouse or parent. However it does not make it clear whether this just means that women are just more likely than men to use carers other than spouses or parents, or that spouse/parent carers are actually a minority group of carers where women are concerned. No actual figure given.

Other results not relevant to carers.

<b>Author/s</b>	COHEN, M.			<b>Ref No</b>	<b>CA0940</b>
<b>Title (first 4 words)</b>	Helping at-home Care-givers			<b>Year of publication</b>	1997?
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	<b><u>T1</u></b>	T2	T3	T4	
<b>Location of study</b>	UK			<b><u>Other USA</u></b>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	Medium	Low N/A ?		
<b>Reviewer's initials</b>	SB			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is not a report of research, but a care-giver's account of strategies she developed, and found useful in, seeking help when the demands of caring had become overwhelming.

Three strategies are described:

Writing 'asking-for' letters;

Calling family meetings to recruit more help;

Networking – to talk about the situation and seek practical help and emotional support.

The paper also includes two commentaries on its content.

One, from a professor of nursing, comments on and supports the substance of the account given in the paper, and particularly on: the importance of recognising and responding to the variability of family situations; the possibly unhelpful use of the notion of 'crisis'; and the ethical issue of who bears responsibility for the care of people with very severe impairments. It is not made explicit whether these comments are based on research.

The second explicitly draws on the research literature to support the points made in the paper.

<b>Author/s</b>	Glass C. et al.		<b>Ref No</b>	<b>CA0978</b>
<b>Title (first 4 words)</b>	Estimating social adjustment following	<b>Year of publication</b>		1997
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	<u>UK</u>		<u>Other</u> (also USA)	
<b>User's Long Term Condition</b>	<b>Spinal Cord Injury</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	HQ	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

Tested levels of agreement about changes in social adjustment (before and after injury) of person with SCI. (The majority of questions ask how often negative personality traits are observed). The "modification" is that the scale originally measured current functioning and this one explicitly asks about changes.

Weak evidence that patients identify more problems than relatives, but this is only because patients identify more problems pre-injury.....

Whether people were seeking compensation or not seemed to have no effect on the levels of agreement between partners (but of course this wasn't part of the assessment for compensation).

"Reasonable" level of agreement. Argued that results demonstrate that patients and relatives are on the whole consistent in their judgements about social adjustment pre and post injury.

<b>Author/s</b>	Junque, C., Bruna, O., Mataro, M.			<b>Ref No</b>	<b>CA0986</b>
<b>Title (first 4 words)</b>	Information needs of the TBI...		<b>Year of publication</b>		1997
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (Spain)</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic brain injury</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

The study sets out to evaluate the families' need for information concerning the consequences of TBI. 65 families completed a questionnaire on their perceptions of the patient's condition. The three main changes noted were in cognitive deficits (90%), physical changes (88.9%) and behavioural changes (89.8%).

As such this study does not specifically address the carer experience in terms of how it affects their own lives save for some very general remarks in the discussion.

One reference possibly worth pursuing might be:-

Gleckman, A.D. and Brill, S. (1995) The impact of brain injury on family functioning: implications for sub-acute rehabilitation programmes *Brain Injury*, 9, 385-393

<b>Author/s</b>	Spatt, J., Zebenholzer, K., Oder, W.			<b>Ref No</b>	<b>CA1002</b>
<b>Title (first 4 words)</b>	Psychosocial long-term outcome.....		<b>Year of publication</b>	1997	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other</u> (USA)		
<b>User's Long Term Condition</b>	<b>Severe head injury</b>				
<b>Confidence Rating</b>	<u>High</u>		Medium	Low	
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This largely methodological study focuses on the long-term psychosocial outcomes on individuals who have suffered severe head injury (SHI). Three sources contributed to the assessment: 1) the injured person. 2) carers. 3) a neurologist.

Carers views are considered only in so far as they might contribute to an overall evaluation of psychosocial outcomes. This contribution is apparently particularly effective in providing information on social and behavioural domains where the injured person tends to have impaired judgement. In this case carers' views are purely functional in terms of the overall aim of the study and are not extensively sought or described.

Outcomes were measured on a battery of rating scales and were subject to a variety of statistical manipulation.

The authors conclude that neurologists must make use of carers' assessments in compiling their evaluations of treatment.

<b>Author/s</b>	Hermann, Freyholdt, Fuchs, Wallesch	<b>Ref No</b>	<b>CA1023</b>
<b>Title (first 4 words)</b>	Coping with chronic neurological	<b>Year of publication</b>	1997
<b>Research methods</b>	Quantitative    Qualitative <b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1 <b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK	<b><u>Other Germany</u></b>	
<b>User's Long Term Condition</b>	<b>Parkinsons and stroke</b>		
<b>Confidence Rating</b>	<b><u>High</u></b>	Medium	Low
<b>Reviewer's initials</b>	HR	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article analyses the coping strategies and psychosocial alterations in patients with PD and CVA and their relatives. Relevant findings were:

- Carers of people with PD and CVA employ active coping strategies. Carers of people with PD tended to use more depressive, problem oriented , wishful thinking and minimization coping strategies
- The authors feel the above is due to the knowledge that PD is progressive

<b>Author/s</b>	Beck, L.A., Lovlien, C.A., Twedell, T.M.			<b>Ref No</b>	<b>CA1037</b>
<b>Title (first 4 words)</b>	Care of morbidly obese people.....			<b>Year of publication</b>	1996
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	T2	T3	<b><u>T4</u></b>	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>morbid obesity (with Spinal cord injury)</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The focus of this paper is on morbid obesity where spinal cord injury is a complicating factor. The review looks at patient assessment following trauma and then charts the clinical procedures to be followed up to and including discharge from hospital. The carer experience is only referred to as part of the discharge process. At no stage is the carer experience explored in any detail.

<b>Author/s</b>	Sato A et al.		<b>Ref No</b>	<b>CA01065</b>
<b>Title (first 4 words)</b>	Needs of care-givers of...		<b>Year of publication</b>	1996
<b>Research methods</b>	Quantitative Convenience	Qualitative sample of 21 care-givers (21 out of 58 approached), mail survey. Structured Tool plus 3 open qns.	<b>Mixed</b>	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK		<b>Other (USA)</b>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	High	Medium	<b>Low</b>	
<b>Reviewer's initials</b>	HQ		Please e-mail this form to <b>Stephen Piper</b> <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

MSNA (MS needs assessment tool). Based on conceptual model by Roy (1984)  
Four adaptive modes: physiological; self-concept; role function; interdependence  
35 agree/disagree statements (5 point scale) + 3 open questions on self  
perceptions, advice to others, what nurses could do to help. Not subject to  
reliability testing.

The paper reports a lot of simple frequencies and some correlations but the overall  
numbers are so low and the sample is not representative so omitted here. Needs  
for breaks/relief relatively important, as was wish to get more exercise, and needs  
for help with household chores, and 'help to accomplish all that is expected of me'.  
Minority needed more time for sleep.

Open questions elicited:

Self concept: Would like to be more patient and tolerant; would like to be (feel?)  
more sociable

Share with others: either a. tips to help the patient or exhortation to look after self,  
seek support, not be discouraged

Nurses could help by: teaching care-givers about the disease process; how to do  
technical things (care tasks I guess); info on new developments; listening and  
being understanding.

<b>Author/s</b>	O'Reilly, F. <i>et al</i>			<b>Ref No</b>	<b>CA1066</b>
<b>Title (first 4 words)</b>	The effects of caring for a spouse....		<b>Year of publication</b>	1996	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>			Other (USA)	
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This short report on a large-scale quantitative study sets out to examine whether middle-aged carers of individuals with Parkinson's disease (PD) experience adverse effects on their social, psychological and physical health compared to the rest of the population.

For spouses caring for an individual with PD n= 154. In the control sample n= 124.

Standard tests measured outcomes on these domains and after statistical analysis it was found that:-

- Subjective assessment of care demands can often be a better predictor for future ill-health than objective measures of disability
- GPs should be proactive in identifying those who provide high levels of care
- Severe cases were excluded from this study so the effects may be under estimates

The date of this study suggests that more detailed work may have been undertaken subsequently. The date also precludes any useful references being suggested.

<b>Author/s</b>	Gregory, R.J., Disler, P. Firth, S.			<b>Ref No</b>	<b>CA1143</b>
<b>Title (first 4 words)</b>	Care-givers (of)People (with) Multiple Sclerosis		<b>Year of publication</b>	1996	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK	<b><u>Other New Zealand</u></b>			
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low		
<b>Reviewer's initials</b>	SB	<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>			

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This paper reports the results of a survey carried out in New Zealand, both of people with MS (80) and primary care-givers (31). The paper does not build on, or refer to, previous literature in this field or on caring generally. Methodological aspects of the survey are very poorly reported.

The findings reported are, however, plausible, and echo findings from other studies of carers of people with MS, and with other conditions. So, for example, the impact of MS on carers was found to be considerable, or very considerable; adequate support from external agencies was not frequently present; the carer's quality of life deteriorated over time, and mirrored that of their family member with MS, to a considerable extent. 'The care-giving role is often complex, can be stressful, and may not be well understood by those distant from the actual situation.' Whether carers felt they had a normal life outside caring was a strong predictor of adjustment to their circumstances.

The key role of nursing is emphasised in the paper, though this is reported as an 'impression' from the study rather than an explicit finding.

The study points to the need for more consistent, and better resourced, policies and services for carers. Of particular interest to UK policy makers is the NZ attendant care programme, funded by the Department of Social Welfare, which facilitates the continued employment of some care-givers who might have to reduce working hours or withdraw from employment. This appeared to play a valuable role, even if it was not universally available.

<b>Author/s</b>	Good, D.M., Bower, D.A., Einsporn			<b>Ref No</b>	<b>CA1171</b>
<b>Title (first 4 words)</b>	Social Support: Gender Differences		<b>Year of publication</b>	1995	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other USA</u>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	SB		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

The principal weaknesses of this otherwise well designed and conducted study, acknowledged by its authors, are its reliance on a small, self-selected, convenience sample in a limited geographic area. Probably as a consequence the sample is almost universally white and middle class. Further weaknesses are the small (65) sample size and reliance on self-completed questionnaires, which attracted a relatively low response rate (57%).

The study's purpose was to investigate gender differences in the social support of spouse carers of people with MS. (It drew strongly on Lazarus and Folkman's theory of stress and coping.) Strong gender differences were found: female care-givers scored significantly higher than males on the total number of resources available, perceived social support and the perceived availability of friends and self-help groups.

The authors see the study's importance as lying in its potential to promote effective nursing interventions with the care-giver of the person with MS – though it has similar implications for those assessing needs for, or providing, social care. If the nurse uses knowledge about gender differences (particularly men's lower access to resources and social support), then the care-giver will be strengthened and it will be less likely that families will deteriorate, or even disband, in the face of chronic illness. However, they also draw attention to the potential of tools for assessing the strengths of

networks and social support in general (for women as well as men) and intervening to develop these.

<b>Author/s</b>	Tennant, A., MacDermott, N., Neary, D.		<b>Ref No</b>	<b>CA1183</b>
<b>Title (first 4 words)</b>	Long-term outcome of head injury...		<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review    Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	<b>UK</b>		Other (USA)	
<b>User's Long Term Condition</b>	<b>Traumatic brain injury (TBI)</b>			
<b>Confidence Rating</b>	High	<b>Medium</b>	Low	
<b>Reviewer's initials</b>	AMC		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition*

The sub-title for this paper is 'implications for service planning'. The carer experience is therefore not the main focus. This is supported by the introduction to the methods section which states, 'The principal objective of the study was to ascertain the likely numbers of severely disabled survivors of head injury who required support in the community....'

However, the planning process takes account of the contribution to care made by informal carers and includes their experiences, albeit in statistical/tabulated form.

Data was collected and tabulated in order to provide a model which could act as predictor for quality of life. As part of this process interviews with carers on the subject of quality of life for the brain injured individual revealed similarity with direct reports on issues such as memory loss, ability to concentrate, irritability and headaches. There was disagreement, however, on tiredness and decision-making.

Caring for a brain injured individual who scored poorly on the scale usually meant that the carer was likely to suffer from social exclusion and to suffer from lack of sleep and accompanying fatigue.

The authors conclude that early intervention in the form of counselling to brain injured individuals and their families could have long-term benefits.

<b>Author/s</b>	Berry and Murphy			<b>Ref No</b>	<b>CA1184</b>
<b>Title (first 4 words)</b>	Well-being of care-givers of		<b>Year of publication</b>	1995	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study explores the relationship between disease stage for people with PD and well being in carers. Key findings:

- Carers negative reports of their own health were associated with reports of their partner with PD's diminished physical functioning
- Carers social functioning declined as care needs increased
- Carers social, psychological and financial well being were associated with length of marriage and level of education. Longer marriages and higher levels of education seemed to sustain the carers

Implications discussed in the article:

Health and social services need to recognise that the home is the centre of care. Services need to augment home-care fitting in with family routines and lifestyles during all stages of chronic illness.

<b>Author/s</b>	Hornsey, J.			<b>Ref No</b>	<b>CA1312</b>
<b>Title (first 4 words)</b>	Empowering patient and carer.....		<b>Year of publication</b>	1994	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This brief case study focuses on the end of life strategy adopted by a couple when they knew the man was terminally ill with MND. The decision to die at home and not to have medical intervention was supported by the multidisciplinary team. The carer perspective is absent from the paper.

<b>Author/s</b>	Quine,Lyle,Pierce		<b>Ref No</b>	<b>CA1390</b>
<b>Title (first 4 words)</b>	Stressors experienced by relatives		<b>Year of publication</b>	1993
<b>Research methods</b>	Quantitative	<b><u>Qualitative</u></b>	Mixed	Lit. review    Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4
<b>Location of study</b>	UK		<b><u>Other Australia</u></b>	
<b>User's Long Term Condition</b>	<b>Brain injury</b>			
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>	
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article reports carers' experiences of being used as therapists in an innovative new treatment program with patients in the coma stage of TBI. They met with social workers on an ad hoc basis and discussed current stresses both generally and with the treatment program. Relevant findings were:

- Carer stressors were: domestic, fatigue, financial, long-term implications
- Carers are more concerned with patients condition than treatment particularly severity and extent of injury and future quality of life
- Concern for quality of life increased over time
- Carers found being involved as lay therapists very stressful compounded by poor organisation

<b>Author/s</b>	Engli M and Kirsivali-Farmer K.	<b>Ref No</b>	<b>CA1455</b>
<b>Title (first 4 words)</b>	Needs of family members	<b>Year of publication</b>	1993
<b>Research methods</b>	Quantitative    Qualitative <b>Mixed</b> Very small scale (14) but quantitative methods.	Lit. review	Other
<b>Typology</b>	T1 <b>T2</b> T3                    T4 Nurses are the professional focus		
<b>Location of study</b>	UK	<b>Other Canada</b>	
<b>User's Long Term Condition</b>	<b>Critically ill (with and without brain injury compared)</b>		
<b>Confidence Rating</b>	High	<b>Medium</b>	Low
<b>Reviewer's initials</b>	HQ	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

Follows up a 1984 study which showed families of patients with TBI (in hospital) had higher needs than families of other patients. Based on use of the Critical Care Family Needs Inventory (CCFNI) plus one open question. This study based in ICUs

Not surprisingly response rates were low (36%, 8 cases, with TBI; 26%, 6 cases, otherwise critically ill)

TBI Family members identified as most important - top rank:

*Need for information about treatment and prognosis*

Though most said this need was being met.

This group also identified the following – not on the questionnaire

Transport to hospital for elderly family members; positive reinforcement for the patient and a more restful environment for the patient.

Ranking of top ten need statements (abridged) as on CCFNI (which has 45 need statements)

(I think this gives a picture of some of the things which are important though would not attach a great deal of importance to the rankings per se, as they differ somewhat in other studies.)

To know the prognosis

Honest answers to questions

Assurance that the patient is getting best possible care  
To be called at home if things change  
To feel that hospital personnel care about the patient  
To have a specific person who can visit if they are unable to  
To know how the patient is being treated medically  
To have understandable explanations  
To know specific facts concerning the patients progress  
To see the patient frequently.

<b>Author/s</b>	O Brian		<b>Ref No</b>	<b>CA1456</b>
<b>Title (first 4 words)</b>	Multiple Sclerosis: Health promoting		<b>Year of publication</b>	1993
<b>Research methods</b>	Quantitative	Qualitative	<u><b>Mixed</b></u>	Lit. review Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low
<b>Reviewer's initials</b>	HR		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article found that carers with more dependent care recipients were less likely to promote their own health and look after their own health needs.

Nurses need to be vigilant for this and need to develop interventions that guide carers in providing care to help ease their burden particularly men.

<b>Author/s</b>	O'Brien, M.T.			<b>Ref No</b>	<b>CA1466</b>
<b>Title (first 4 words)</b>	Multiple sclerosis: the role of social support....		<b>Year of publication</b>	1993	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis (MS)</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is a descriptive correlational study that seeks to identify the kinds of social support available to individuals with MS. It does not address the carer perspective/experience.

The most recently cited reference is from 1992.

<b>Author/s</b>	Moss, Casey, stocking, Roos, Brooks, Siegler	<b>Ref No</b>	<b>CA1471</b>
<b>Title (first 4 words)</b>	Home ventilation for amyotrophic	<b>Year of publication</b>	1993
<b>Research methods</b>	Quantitative    Qualitative <u>Mixed</u>	Lit. review	Other
<b>Typology</b>	T1 <u>T2</u>	T3	T4
<b>Location of study</b>	UK	<u>Other (USA)</u>	
<b>User's Long Term Condition</b>	<b>Motor Neurone Disease</b>		
<b>Confidence Rating</b>	High <u>Medium</u>	Low	
<b>Reviewer's initials</b>	HR	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article mainly looks at the benefits of home ventilation for patients but relevant carer experiences were:

- Carers found benefit from home ventilation as it prolonged family life
- Carers found that it tied them down and it was stressful

<b>Author/s</b>	McLaughlin, A.M., Carey, J.L.			<b>Ref No</b>	<b>CA1477</b>
<b>Title (first 4 words)</b>	The adversarial alliance: developing therapeutic.....		<b>Year of publication</b>	1993	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>Brain injury</b>				
<b>Confidence Rating</b>	High	Medium	<u>Low</u>		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This small-scale study attempts to resolve the conundrum apparent in brain injury rehabilitation whereby professionals must simultaneously work positively with families while entertaining doubts over the likely outcomes they can offer. This uncertainty gives rise to conflict. In order to measure the amount of adversarial contact between families and professionals data were generated from a questionnaire, from interview at admission and from a discharge summary form.

From this it becomes apparent that there is increased risk of conflict where:-

- The patient is younger
- The patient has a low level of cognitive function on admission
- The patient has a low level of physical function on discharge

From this the authors have developed protocols for use within their own clinical area. Carer experience is not accessed directly but two scenarios summarise typical responses from families.

The date of the paper precludes the use of any further references.

<b>Author/s</b>	Seibert, P.S et al			<b>Ref No</b>	<b>CA2121</b>
<b>Title (first 4 words)</b>	Brain Injury: Quality of Life's Greatest Challenge		<b>Year of publication</b>	2002	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Older patients reported better quality of life.

Men reported better quality of life than women in terms of their increases in spirituality, better driving ability. Women reported being sadder than men after TBI.

The more severe the injury the more likely relationships would terminate - men were more likely to leave women with TBI although women were more likely to stay with men who suffered TBI.

Patients with TBI reported a low self esteem due to outsiders making decisions for them and not asking for their opinion or giving them choices, this caused a reduction in quality of life.

<b>Author/s</b>	Durrah et al			<b>Ref No</b>	<b>CA2188</b>
<b>Title (first 4 words)</b>	How well are you doing			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit.review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK	<u>Other Canada</u>			
<b>User's Long Term Condition</b>	<b>Cerebral Palsy</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	SS	Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>			

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Identified themes were consistent with previous research. These were service provision in the areas of health, education, recreation, employment, transportation and housing.

Families were frustrated and reported negative experiences of such services, and often felt they were not listened to or valued.

Bureaucracy and lack of funding on time may contribute to service users and their families not obtaining full or adequate information.

<b>Author/s</b>	Chipcase & Lincoln			<b>Ref No</b>	<b>CA2361</b>
<b>Title (first 4 words)</b>	Factors associated with carer strain		<b>Year of publication</b>	2001	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit.review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other(USA)		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High		<b><u>Medium</u></b>	Low	
<b>Reviewer's initials</b>	SS		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Comparative study between strained carers and unstrained carers of people with MS in order to identify if memory loss and cognitive functioning was related to carer strain. Although no significant differences emerged strained carers reported more memory problems than unstrained carers but did not report the frequency or type of memory problems. Further strained carers reported less feelings of sympathy towards the patient with MS than unstrained carers which may be a result of loss of patience due to pressure.

It can be argued that the lack of significant difference between these two groups of carers could be attributed to the interview questions not being sensitive enough.

It is suggested that therapists should be aware that carers of people with MS are prone to memory problems and need support.

<b>Author/s</b>	Connolly, D and O'Dowd, T			<b>Ref No</b>	<b>CA2621</b>
<b>Title (first 4 words)</b>	The impact of the Different ....		<b>Year of publication</b>	2001	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This is a study to measure the association between 'the five categories of disability' (motor, cognitive, behavioural, perceptual, and speech) with 'care-giver *strain*' (the impact on the carer's other roles in work, family and social life etc) and 'care-giver *stress*' (reduced self image, sense of control etc) following brain injury.

Questionnaires were sent to 100 primary care-givers. 70 were used in the final analysis.

Authors suggest a limit to the generalisability of this project due to the selection of the sample from support groups. Also authors feel that a longitudinal study would better serve the changing nature of conditions facing brain injury carers.

+6

Care-givers are more likely to feel low self-esteem if they perceived the impact of the 'disabilities' as being out of their control or being unchangeable.

Results suggested that 'behavioural disabilities' (e.g. increased aggression, restlessness, swearing etc from the brain injured person) was most associated with carer's increased stress level.

<b>Author/s</b>	R c k Chan		<b>Ref No</b>	<b>CA2646</b>
<b>Title (first 4 words)</b>	How does spinal chord injury		<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other China</u>	
<b>User's Long Term Condition</b>	<b>Spinal chord injury</b>			
<b>Confidence Rating</b>	High	<u>Medium</u>	Low	
<b>Reviewer's initials</b>	Ss		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Confucianism ideology still represents a major strand of Chinese thought. It dictates that the man is the protector of the house and brings health and wealth to the family. Therefore disability is considered to be careless, ignorant and living inappropriately. They are considered to be the consequence of divine punishment – not only the individual but the whole family.

Disability is perceived as very negative in Chinese society. It may alter the hierarchical structure of the Five Cardinals.

Spouses found the main stresses to be caused by care-giving – felt trapped, disruption of family interaction, revision of expectations of life quality, social isolation

People with SCI felt they had a very different life and wished they could have the same quality of life as they had before the injury in terms of their relationship with their children, colleagues. They were more likely to have disabled friends as a result of discrimination by nondisabled colleagues.

Suggestions for improving the situation is to include family members in the rehab process from the beginning. Good communication could improve the relationship between people with SCI and spouses - professional intervention may help with this thus reducing barriers put up by Chinese tradition

<b>Author/s</b>	Curtiss, Klemz, Vanderploeg			<b>Ref No</b>	<b>CA2703</b>
<b>Title (first 4 words)</b>	Acute impact of severe traumatic		<b>Year of publication</b>	2000	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		Other (USA)		
<b>User's Long Term Condition</b>	<b>Traumatic Brain injury</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

The study looks at acute changes in family structure after head injury and changes in coping strategies pre and post TBI. Key findings:

- There was a significant change in family balance post injury. Balanced families pre injury became extreme type families after injury and moderately balance families pre-injury showed less cohesion and adaptability after injury
- Post injury the extreme type families showed increased guidance seeking and problem solving coping patterns compared with pre-injury behaviour. This may reflect major role changes and changes in family structure. These families may benefit from family support groups
- Balanced families post TBI used the same coping strategies except they used less emotional discharge and alternative reward seeking which suggested a emotional numbing or over control of emotions
- Moderately balanced families showed little change but did use more emotional discharge, alternative reward seeking and acceptance. This may suggest premature closure which clinicians need to be aware of an provide information on the recovery process
- Midrange families appear to be avoiding the consequences of TBI and are less likely to be involved with the treatment team than any other family type

Service providers need to be aware of families coping strategies and likely changes in family dynamics after head injury and provide appropriate intervention.

<b>Author/s</b>	Koskinen			<b>Ref No</b>	<b>CA3150</b>
<b>Title (first 4 words)</b>	Quality in Life 10 years after		<b>Year of publication</b>		1998
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review.	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other Finland</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SS		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Majority of patients with TBI reported high level of satisfaction therefore good QoL.

Most unsatisfactory domains of life satisfaction were found to be contact with friends, sexuality and leisure activities and social isolation.

Shown decrease in relationships over ten years of injury.

<b>Author/s</b>	Melia			<b>Ref No</b>	<b>CA3475</b>
<b>Title (first 4 words)</b>	Research, consumer involvement, and models of care		<b>Year of publication</b>		1996
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	Low	<b><u>N/A</u></b>	
<b>Reviewer's initials</b>	HM		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This paper reports the issues facing NIDRR (National Institute on Disability and Rehabilitation Research) and its role in encouraging TBI rehabilitation research and the development of TBI model systems of care.

Key issues:-

- development of mechanisms for involving disabled people in research and keeping research relevant to emerging need.
- researching needs of those with secondary conditions
- responding to social policy/service needs of new populations of disabled people
- promoting universal/adaptable design
- evaluating impact of changes in health care policies/organisation

This article does not discuss/report carers' views.

<b>Author/s</b>	Feigin			<b>Ref No</b>	<b>CA3741</b>
<b>Title (first 4 words)</b>	Spousal Adjustment to a Postmarital Disability in One Partner		<b>Year of publication</b>	1994	
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b>Other Israel</b>		
<b>User's Long Term Condition</b>	<b>Spinal Cord/General Neurological</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	HM		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Useful précis of literature on spousal adjustment (N.B. publication date 1994)

An interesting article that is focused on the correlation between the adjustment of disabled/non-disabled partners.

The paper does not address or report carers experiences of services for disabled people.

<b>Author/s</b>	Speer			<b>Ref No</b>	<b>CA3765</b>
<b>Title (first 4 words)</b>				<b>Year of publication</b>	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	<b><u>High</u></b>		Medium	Low	
<b>Reviewer's initials</b>	HM		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

26 PD patient/carer couples completed separate self-administered questionnaires, twice 6 months apart. Average age of patients 70.5 years and carers 67.3 years (predominantly out of the age range of this study). Much of the questionnaires were based on various scales.

The findings relate to carer and patient adjustment (particularly emotional) and do not report carers' views on/experiences of services.

<b>Author/s</b>	Kock and Eilander			<b>Ref No</b>	<b>CA3886</b>
<b>Title (first 4 words)</b>	Patients' outcome and relatives		<b>Year of publication</b>	1993	
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<b>Other (USA)</b>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain injury</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article was not relevant

<b>Author/s</b>	Kreuter, M.			<b>Ref No</b>	<b>CA4118</b>
<b>Title (first 4 words)</b>	Spinal Cord Injury and...			<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<u><b>Lit. review</b></u>	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Spinal Cord Injury</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>		Low	
<b>Reviewer's initials</b>	SP			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This paper summarises literature of the impact of spinal cord injury on patient-partner relationships: the effect on those patients who have an existing relationship at the onset of SCI and the effect on the chances of single SCI patients in establishing a relationship. Partner experiences are not considered although the paper does call for future systematic research to put both the patient and partner problems into perspective and research into predictors and reasons for divorce after SCI.

<b>Author/s</b>	Gervasio A and Kreutzer J			<b>Ref No</b>	<b>CA4184</b>
<b>Title (first 4 words)</b>	Kinship and family members'...		<b>Year of publication</b>	1997	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
	116 co-resident care-givers from outpatients listed on the Medical college of Virginia Brain Injury database. Self completion questionnaires, BSI and info from the database. Qu mailed and then checked over with carer at appointment.				
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	Traumatic Brain Injury				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	HQ		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

89 F 27 M care-givers

44% of care-givers met criteria for 'caseness'. (measured using BSI – Brief Symptom Inventory).

(only 20% showed elevated depression scores, more (around 30%) showed elevated (above popl. norms) scores on scales reflecting psychoticism, hostility and anxiety. This could be because they are feeling overwhelmed, isolated, inadequate, confused, unable to concentrate and as if they might be going crazy. The authors caution against interpreting BSI scale elevations as direct indications of psychopathology.

Levels of self-reported perceived stress (Likert scale) did not differ between spouses and parents, but spouses were significantly more likely to achieve 'caseness'.

Male care-givers of female patients had significantly higher GSI (Global severity index) score than other gender combinations. GSI reflects general psychological distress. Other research apparently suggests male care-givers more likely to use ineffective coping styles, and it's more of a change of role for them.

No significant effects (on GSI or perceived stress) of time since injury or length of coma.

Interpretations of greater 'caseness' among spouses:

- Deprivation of reciprocal and equitable adult relationship, loss of emotional support

- Need to take on additional roles outside gender expectations

- Disruption of sexual relationships

- Parents feel easier about explaining/living with foibles and behavioural problems of their children (i.e. they don't expect to approve of, or be thought responsible for, everything they do), and caring for their children is less of a role change even though it is stressful.

Acknowledges one difficulty is that they have no information about pre-existing problems, and their distributions, and so analysis tends to assume that these were like those in the rest of the population – which may not be true if people with TBI are drawn disproportionately from certain Groups.

Clinical implications : majority of carers did **not** report elevated distress levels; however support groups, individual or marital counselling could be useful for some; need for support for families to continue to be available in the longer term; services may currently be offered in early stages of recovery which people may actually need later; particular attention to the needs of spouses and male care-givers needed.

<b>Author/s</b>	Kosciulek J. and Pichette E.			<b>Ref No</b>	<b>CA4207</b>
<b>Title (first 4 words)</b>	Adaptation concerns of families...		<b>Year of publication</b>	1996	
<b>Research methods</b>	Quantitative	Qualitative	<u><b>Mixed</b></u>	Lit. review	Other
<b>Typology</b>	T1	T2	T3	T4	
	DK not clear, based on Participatory Action Research philosophy, designation of authors not given, but I'd rate it higher on inclusiveness than many.				
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Head Injuries (TBI)</b>				
<b>Confidence Rating</b>	<u><b>High</b></u>		Medium	Low	
	HQ		Please e-mail this form to <b>Stephen Piper</b> <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

Family Adaptation Concerns Questionnaire developed from larger Family Adaptation Concerns Index (from stress and coping theory, the literature and clinical research) by working group of eight family members of persons with BI. Included spouses, parents and siblings.

Each concern rated for importance and satisfaction. Respondents 82 primary caregivers of persons with BI contacted thro' family support groups of Georgia head injury assoc.

24 items chosen for the questionnaire. 22/24 were given scores >50/100 for importance but 20/24 had satisfaction ratings <50/100. So the survey could be said to be about important items where there is quite a bit of dissatisfaction among carers.

Important (>80 average score) areas where satisfaction was highest (average score above 50):

- Friends provide encouragement and support
- Family maintains a positive outlook about the situation
- A support group for families is available (selection bias)
- Family loyalty, unity and cooperation exist

Important areas (scores 75+) where satisfaction was lowest (around 20-40)

Availability of appropriate services for the member with head injury  
Availability of breaks from caring responsibilities  
Appropriate living situation for person with head injury  
Leisure and recreation facilities suitable for member with head injury  
Disruption to family life caused by emotional or behavioural problems by injured family member

Also high dissatisfaction with: Individual members have time for activities outside the home (score 27) tho' not rated so important relative to many other items (score 59)

Suggests from a family perspective the most important threats to successful family adaptation are the lack of suitable services for the injured person, and the persons behavioural and emotional problems, whereas the strengths which contribute to adaptation are within family, or through friendship or peer support.

Described as the beginning step in an agenda-building process to address the adaptation concerns of families of people with head injuries. Future steps are outlined.

<b>Author/s</b>	Kosciulek			<b>Ref No</b>	<b>CA4223</b>
<b>Title (first 4 words)</b>	On identifying Head injury			<b>Year of publication</b>	1995
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain injury</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This study identified that within their population they had five clusters of family types coping with head injury in their family:

- Unpatterned families: family members appear unconnected or separate their normal functioning has been upset by the head injury
- Fragile families: they have dysfunction in problem solving, communication, affective involvement and general functioning and have some problems with family roles. They lack family loyalty and hesitate on depending on the family for support
- Pliant families: they have dysfunction in communication, they have difficulties with exchange of information within the family
- Regenerative families: they function effectively
- Vulnerable families: struggle with information exchange, emotional response and task assignment. Their overall functioning may be prone to deterioration if additional stressors occur

Clinicians need to be aware of how families may react to the impact of head injury

<b>Author/s</b>	Lapham-Randov, N.			<b>Ref No</b>	<b>CA4241</b>
<b>Title (first 4 words)</b>	How the family copes			<b>Year of publication</b>	1994
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	<b><u>T1</u></b>	T2	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Spinal Cord Injury</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b> (not relevant)			Low
<b>Reviewer's initials</b>	SP		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The author writes as both a carer of a spouse with SCI and a health professional (nurse and case manager). She describes the experiences of her family following a SCI to her husband Allen in a motorcycle accident.

- The emotional impact on the family: grief, worries about housing and work, worries about bladder and bowel problems, fear of future uncertainty, and the need to attend to children so that 'we had no time to reflect much about ourselves'.
- Getting through physical rehabilitation: in particular finding rehabilitation beds and even finding physicians who had significant knowledge of SCI.
- Learning: 'gaining a knowledge and understanding of rehabilitation resources and SCI issues has been a long and evolving process'.
- The importance of 'encouraging independence', through not helping too much, house/vehicle adaptation and the use of a service dog. Also, the author suggests that Allen's quick return to paid employment helped the family become a 'regular family' again.
- The importance of maintaining social and recreational lives.
- The importance of dealing with a shift in economic status (although not too downward in this case).

<b>Author/s</b>	Su, Amsters, Carlson			<b>Ref No</b>	<b>CA4281</b>
<b>Title (first 4 words)</b>	The experience and perceptions		<b>Year of publication</b>	2002	
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK		<u>Other (USA)</u>		
<b>User's Long Term Condition</b>	<b>Spinal Cord Injury</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The study looks at the experiences and perceptions of older carers of people with SCI in the community and their implications for service delivery. Key findings:

- All respondents had had to change their lifestyle in response to SCI including reduced social life and holidays, no personal time, loss of contact with friends
- They experience having to plan ahead to leave the house and family have to make appointments to see them
- Wheel chair accessibility has to be part of their planning
- Sleep disturbance is a common experience due to having to provide physical care during the night
- Financial strain was described
- Inability to have a sexual relationship was highlighted
- Carers experienced the dependence of the person with SCI and the prioritisation of their needs
- Carers experience negative changes to their health and experience stress related emotions. Emotional distress/stress was described due to changes in physical abilities of the person with SCI and grief for their loss of physical identity, changes in the person with SCI's health and their frustration and anger. Carers reported worry about leaving the person and what will happen in the future. Other feelings of disappointment, reduced motivation, mental tiredness, and feeling sorry for yourself were described. Some positives were described

- Impact of change over time was described as improving by some people in the study while for others it stayed the same or worsened
- Carers worried about the future and all concerns were for the person with SCI
- They described coping through help from family/friends and through distraction. The person with SCI's positive attitude helped them. Some did describe closing down emotion as a way of coping
- There was a variable response to the support from SCI services with some having assistance and others being uncertain if they have had any support
- Carers are helped by paid carers and respite services
- They felt a crisis help line would have been useful and more services to help with household tasks

The article identifies the following strategies for support services for carers of people with SCI:

- Encourage carers to identify and acknowledge their own physical, social and emotional needs
- Identify and incorporate carers needs and future plans in the long term plan for the person with SCI
- Provide carers with counselling services and educational programs on stress and time management
- Assist carers in regular health promoting behaviour
- Ensure carers are trained in manual handling
- Assist carers to engage in leisure and personal interests to promote a balanced lifestyle
- Assist carers in extending their social network by establishing links with support groups etc
- Carers need to be encouraged to access services themselves not just for the person with SCI

<b>Author/s</b>	Anderson, M.L.			<b>Ref No</b>	<b>CA4362</b>
<b>Title (first 4 words)</b>	Daring Men to be Caring			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	<u>Qualitative</u>	Mixed	<b>Lit. review</b>	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	UK			<u>Other Canada</u>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High		<u>Medium</u>	Low	
<b>Reviewer's initials</b>	SP			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Article based on literature review and regular chapter visits within the MS society in Ontario, Canada. Suggests that the 'dilemma of disability faced by male care-givers' can be summarised in 3 observations.

1. Male care-givers are expected to simultaneously be the care-giver, the primary breadwinner, the childrearer, and to do so without showing any signs of weakness (visible symptoms of stress or emotion).
2. Male care-givers must deal with the perception that as men they are incapable of taking the role of primary care-giver and cannot be trusted to take on such responsibilities. This presumption is particularly predominant amongst professional female care-givers.
3. There is a shortage male care-giver role-models or mentors.

This can result in male care-givers in asking for and receiving less social and professional support than their female counterparts.

<b>Author/s</b>	Thomas, S. and Sweetnam, C.			<b>Ref No</b>	<b>CA4386</b>
<b>Title (first 4 words)</b>	Parkinson's disease caring for the...		<b>Year of publication</b>	2002	
<b>Research methods</b>	Quantitative	Qualitative	<b><u>Mixed</u></b>	Lit. review	Other
<b>Typology</b>	T1	T2	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

This article describes the establishment of a 'Health care for carer's project' with around 1000 PD carers in Cornwall. Draw data from this project and Parkinson's Disease Society 1999 survey.

Carer views expressed.

PDS 1999 Survey

- Out of a list of items the most common 'need' identified was for access to expertise on medical and health issues and the need to talk to a doctor or nurse.
- There were strong demands for information.
- Short respite breaks were a high priority.
- 4 out of 10 felt that caring had adversely affected their health; the most common effects being stress, anxiety, and fatigue.

Cornwall PD carers stated that they wanted

- Carer information groups throughout the county.
- A carer assessment tool so that they could undertake an assessment of their own 'needs' at a convenient time.
- A carer voucher scheme to buy respite care.

- 'A resource file specific to PD for all local GP practices so that they could fully understand the needs of people with PD and their carers'.

<b>Author/s</b>	Gardner, W.			<b>Ref No</b>	<b>CA4388</b>
<b>Title (first 4 words)</b>	The impact of behaviour			<b>Year of publication</b>	2002
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>		Low	
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article is both a literature review and a retrospective study. It is concerned with the relationship between different 'problem behaviours' resulting from brain injury and the breakdown of the primary care-giver relationship. Carers actual experiences or views are not considered. This study found that loss of self control and substance use are the behaviours most likely to cause a breakdown of care-giving relationships.

<b>Author/s</b>	Hobson, P et al			<b>Ref No</b>	<b>CA4391</b>
<b>Title (first 4 words)</b>	The coping methods of...		<b>Year of publication</b>	2001	
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u>T2</u>	T3	T4	
<b>Location of study</b>	<u>UK</u>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	<u>Medium</u>	Low		
<b>Reviewer's initials</b>	SP		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is yet another psychosocial investigation. The aims of this study are to 'explore coping methods employed by PD patients and their carers using Quality of life and depression scales. Carer views as such were not discussed, nor were experiences of health and social services.

- Results suggest that the coping methods of patients and carers were found to be roughly similar with the exception being that patients employed more 'avoidance coping' than carers.
- Depression in carers correlated moderately with both depression and poorer cognitive functioning in patients.
- Impaired cognition in patients was found to have a poor association with increasing depression and avoidance coping in carers.

The paper suggests that additional qualitative work is needed because it is unlikely that the medical symptoms of PD alone cannot explain the multidimensional nature of the patient's and carer's experience.

<b>Author/s</b>	Gold-Spink et al			<b>Ref No</b>	<b>CA4482</b>
<b>Title (first 4 words)</b>	Uncertainty in Illness and Optimism		<b>Year of publication</b>	200	
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<u><b>T2</b></u>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (USA)</b></u>		
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>				
<b>Confidence Rating</b>	High	Medium		<u><b>Low</b></u>	
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

Aim of study: to investigate the psychological consequences of MS within individuals. Further, to examine the psychological effects of MS on intimate partners of MS patients.

Two hypotheses:

1. MS patients and their partners would have difficulty understanding the illness and digesting to it. Levels of optimism relate to levels of adjustment.
2. MS has a negative impact on marital relationships.

**METHOD:**

Center for Epidemiologic Studies Depression Scale - measures frequently and intensity of depression symptoms.

Life Orientation Test - measures dispositional optimism. High scores = high levels of optimism, low scores = low levels of optimism

Dyadic Adjustment Scale - measures marital satisfaction as perceived by each individual in relationship

Mishel Uncertainty in Illness Scale - measures patient's level of uncertainty about the illness, and assesses the amount of ambiguous and complex information received by patient and their partners. High scores = high levels of uncertainty, low scores = low levels of uncertainty.

Activity of Daily Living Self-Care Scale for Persons with MS - assesses what activities patients with MS are able to perform on a daily basis. Measures symptom severity in individuals with MS.

## RESULTS:

A positive relationship between depression and uncertainty. This may be explained by:

1. The fact that depression causes patients to view information as ambiguous.
2. The fluctuating nature of the illness
3. Chronic nature of the illness causes depression

Inverse relationship between patients' optimism and depression.

Strong relationship between patients and partners' high level of uncertainty - because healthcare professional may be providing couples with inconsistent ambiguous information about the disease process.

A trend between patients' level of functioning and level of marital relationship satisfaction. Partners may feel more satisfied when patients have high levels of functioning of daily activities.

The study had several limitations which biased the results. The majority of couples had a high level of relationship satisfaction. The patients had quite mild MS. There was no ethnic minority couples or homosexual couples who participated in the study. This would have probably caused significant differences to the findings.

<b>Author/s</b>	Coombes, R			<b>Ref No</b>	<b>CA4508</b>
<b>Title (first 4 words)</b>	On the shoulders of children			<b>Year of publication</b>	2001
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b><u>UK</u></b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This brief journalistic report describes one case in which a teenager is heavily involved in caring for an older sibling who has epilepsy as well as other disabilities. The report highlights the role played by school nurses in providing counselling and advice for this group of carers.

The teenage boy talks of the difficulties in maintaining a social life because of the heavy demands at home.

No references available.

<b>Author/s</b>	Wollin J and Sato A.		<b>Ref No</b>	<b>CA4538</b>
<b>Title (first 4 words)</b>	An International comparison of...		<b>Year of publication</b>	Undated copy
<b>Research methods</b>	<u>Quantitative</u>	Qualitative	Mixed	Lit. review Other
	MSNA tool plus open-ended questions in self completion mail questionnaire 29 USA 34 AUS recruited thro' membership of vol orgs			
<b>Typology</b>	T1	<u>T2</u>	T3	T4
<b>Location of study</b>	UK		<u>Other (USA &amp; Aus)</u>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis</b>			
<b>Confidence Rating</b>	High	Medium	<u>Low</u>	
<b>Reviewer's initials</b>	HQ		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:

Argues that impacts on care-givers are similar across the 2 different health & welfare systems. Financial hardship (for family) increases with length of years as care-giver.

Most important unmet needs: physiological (e.g. exhaustion, lack of sleep) and role functioning (e.g. needs for help with household chores, finances (i.e. generating income). Relates to Roy (1981) framework.

Health issues: needs for a break, lack of sleep

Half of spouses worked 30+ hours a week (in employment)

Barriers to respite: effort involved in setting it up from formal services; wish to avoid imposing on other family members

Concludes: day-to-day help needed to reduce carer 'burden'.

Difficult in places to distinguish reports of the study from reports of other work, or to draw out the substantive significance of reported results.

Here is a quote to liven up your day:

'There was also a correlation between age of care-giver and years of supporting ( $r=.362$ ,  $p<.01$ ). These responses are reasonable given the chronicity of MS and the likelihood of care-givers getting older the longer they care.'

<b>Author/s</b>	Whetten-Goldstein, Cutson, Zhu, Schenkman			<b>Ref No</b>	<b>CA4551</b>
<b>Title (first 4 words)</b>	Financial Burden of Chronic			<b>Year of publication</b>	2000
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK			<b><u>Other (USA)</u></b>	
<b>User's Long Term Condition</b>	<b>Multiple Sclerosis and Parkinson's Disease</b>				
<b>Confidence Rating</b>	High		Medium	Low	
<b>Reviewer's initials</b>	HR			Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article reviews a series of studies looking at the costs of chronic disease to patients and their carers the figures are all calculated in dollars but the principals are generalisable. The costs to the patients and carers comes from earnings loss for patients, informal care giving, medical expenses, equipment. 19% of the costs of MS were in informal care giving, on average 10 hours per week and 8 hours per week for PD. The costs were great and escalate with time. The financial burden greatly impacts on quality of life

Carers report 2/3 lost out on promotion, pay rises and training because of their caring responsibilities. Once the carer fell off the earning trajectory they did not make up the loss later.

<b>Author/s</b>	Marchi C and Basham M			<b>Ref No</b>	<b>CA4567</b>
<b>Title (first 4 words)</b>	Accepting the PD challenge			<b>Year of publication</b>	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Parkinson's Disease</b>				
<b>Confidence Rating</b>	High	Medium	Low		
<b>Reviewer's initials</b>	HQ		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Not relevant to this study. Information for formal care-givers about the primary symptoms and secondary manifestations of PD.

<b>Author/s</b>	Waite, L.M.			<b>Ref No</b>	<b>CA4617</b>
<b>Title (first 4 words)</b>	Accommodating Parkinson's disease: a review		<b>Year of publication</b>	2000	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		Other ( <b><u>USA</u></b> )		
<b>User's Long Term Condition</b>	<b>Parkinson's disease</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This review summarises aspects of the carer's perspective. The stages of physical decline are well described alongside the adaptations the carer has to make. It is suggested that pre-morbid personality and, in the case of couples, their relationship, can affect the way the patients views themselves. The satisfaction the patient feels with the support is often more important than the numbers of people involved in providing it.

On coping the literature suggests that: studies so far have concentrated on the patient and research on carers has received little attention.

On stress it seems that care-giver depression is related to both the impact and the burden of caring.

Burden appears to reduce when the task of caring is shared by other family members.

Stress increases over time when there is low social support for the carer. Stress is strongly correlated to the degree of physical disability and mental limitation.

The act of care-giving itself is dominated by the 'on-off' demands that characterise the condition.

The care-givers social horizons are restricted the more the disease progresses.

The care-givers need to develop some expertise in administering medication.

Routine can be disrupted by 'spur-of-the-moment' family visits and these can be upsetting for both patient and care-giver if the patient is experiencing difficulties with their symptoms.

In summary, attitudinal stance and psychological adjustment (i.e. coping) have a significant effect on adaptation to the disease by sufferers. More research on the effects on carers is called for.

<b>Author/s</b>	Zeigler E.			<b>Ref No</b>	<b>CA4731</b>
<b>Title (first 4 words)</b>	Psychosocial issues for spouses		<b>Year of publication</b>	1999	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	<b><u>Lit. review</u></b>	Other
	A review of issues with reference to the literature				
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low		
<b>Reviewer's initials</b>	HQ		<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Cites research which indicates:

Behaviour problems in injured person better predictors of psychological distress in spouses than levels of physical impairment. Spouse usually gets to see the worst of the behaviour. Survivor is experienced as a changed person, impacts on intimacy and sexual relationships. Problems with feeling that its not acceptable to express this.

Often means permanent changes in the family role system. Usually spouse has to take over at least some activities undertaken by the other person. If care-giving or supervision is required this may sit uneasily with previous expectations/experience of marital relationship.

Possibility of separation or divorce increases over time with the peak around 5-6 years post-injury (Wood and Yurdakul, 1997). Should not necessarily be seen as a bad thing, can be a positive new beginning for both spouses she says.

Dealing with problems – recognise that progressive recovery over time can take place. Find new sources of social contact for both partners, build a more independent life

Economic impact of head injury more devastating for spouses who care than parents who care (those who are injured are more likely to be men and thus in

general the main wage-earner.) Though for both parents and spouses the number without money to meet basic needs increases (US data).

Friction with in-laws (not documented by research she says but in individual accounts (and clinical experience?).

Isolation and loss of previous friendships (caused by diminishing contact because of unpredictable and difficult behaviour by injured person).

Roles for professionals (though one would have to say this is a professional view even if based on research about the problems experienced): provide the right information at the right time; validate normalcy of needs to grieve; support groups and meaningful activity for injured person; mediate within-family conflict; facilitate appropriate peer support from other spouses; assist access to counselling or psychotherapy.

<b>Author/s</b>	Bromberg et al			<b>Ref No</b>	<b>CA4913</b>
<b>Title (first 4 words)</b>	Ventilator Dependency in ALS			<b>Year of publication</b>	
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK			<b><u>Other (USA)</u></b>	
<b>User's Long Term Condition</b>	<b>ALS/MND</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b> (small sample)			Low
<b>Reviewer's initials</b>	HM			<b>Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a></b>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Small scale pilot study involving four patients who were dependent on artificial ventilation and lived at home and their carers who were interviewed together. Structured interviews, questionnaires and neurological examinations were used.

The findings are largely descriptive i.e. medical condition, use of communication, nature of home care.

The issues identified by carers included the inability to influence disease progression and fear about being able to use the ventilator. Support groups were identified as being helpful. A major area of concern was the cost of ventilators (although this was not a factor in deciding whether to use one) and this is related to the insurance based US health care system./

<b>Author/s</b>	Byers, K			<b>Ref No</b>	<b>CA4946</b>
<b>Title (first 4 words)</b>	One day at a time			<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	<b><u>T1</u></b>	T2	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Epilepsy</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This short first person narrative describes a family whose young son has epilepsy. The seizures are so severe he needs to be hospitalised. Despite a professional background the mother talks of being totally unprepared for the realities associated with caring for her son. The title, One Day at a Time, refers to the constant anxiety of wondering when the next seizure will arrive.

There are no references.

<b>Author/s</b>	McKee			<b>Ref No</b>	<b>CA5030</b>
<b>Title (first 4 words)</b>	Mother knows best			<b>Year of publication</b>	1995
<b>Research methods</b>	Quantitative	Qualitative	Mixed	Lit. review	<b><u>Other</u></b>
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	<b>UK</b>		Other (USA)		
<b>User's Long Term Condition</b>	<b>Brain Injury</b>				
<b>Confidence Rating</b>	High	Medium	Low		
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This is an informal case study of a mother who chose to remove her son with a severe head injury from a rehabilitation setting and to care for him at home.

Key observations:

- The mother felt stress increased over time from her son's psychological and behavioural changes
- She was worried the injury would break up the family as her other son started having behavioural problems at school and her husband bottled up his worries
- She became social isolated
- She could not cope with the stress crying all the time and perceiving that everything she did was wrong
- She felt her son did not readily slot into the system offered by the community and there were no other options were available
- She experienced that letting go of her injured son to enable him to move forward independently was the most difficult stage

<b>Author/s</b>	Hickey, J.V.			<b>Ref No</b>	<b>CA5038</b>
<b>Title (first 4 words)</b>	Family care-givers of severely		<b>Year of publication</b>	1993	
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b><u>T2</u></b>	T3	T4	
<b>Location of study</b>	UK		<b><u>Other (USA)</u></b>		
<b>User's Long Term Condition</b>	<b>Severe head injury</b>				
<b>Confidence Rating</b>	High	Medium	<b><u>Low</u></b>		
<b>Reviewer's initials</b>	AMC		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This very brief study sets out to describe the characteristics of primary family care-givers ( n = 85) of head injured adults, including levels of anxiety, depression and family dysfunction.

Five self-administered instruments were used to generate data over a six month period.

The findings are aimed at professional carers who care for persons with severe head injuries and their families. The actual carer experience is not immediately apparent.

Results are not clearly flagged up but from the discussion it appears that:-

- Care-givers are at risk of long term stress and burnout
- Care-givers can benefit from discussing their problems with family members

The age of the study precludes the use of any additional references.

<b>Author/s</b>	Brady, Goldman, Wandersman		<b>Ref No</b>	<b>CA5047</b>
<b>Title (first 4 words)</b>	Similarities and differences in		<b>Year of publication</b>	1994
<b>Research methods</b>	Quantitative	Qualitative	<b>Mixed</b>	Lit. review Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4
<b>Location of study</b>	UK		<b>Other (USA)</b>	
<b>User's Long Term Condition</b>	<b>Brain injury and mental illness</b>			
<b>Confidence Rating</b>	<b>High</b>		Medium	Low
<b>Reviewer's initials</b>	HR		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>	

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

The article compares the adaptation of three groups of carers: members of a head injury support group, members of a mental illness support group and carers of people with mental illness who do not use a support group. It found that carers did not differ significantly in adaptation strategies between client groups. The mental health support group carers experienced more guilt and stigma. Carers describe coping by use of prayer, faith and acceptance. The members of the support groups felt that they benefited from membership. Many carers reported grief for the loss of patient's potential and personality.

Carers felt that services need to provide increased aftercare, meaningful employment opportunities, avoid over medicating and particularly for head injury establish systemised patient care.

<b>Author/s</b>	Man et al			<b>Ref No</b>	<b>CA5097</b>
<b>Title (first 4 words)</b>	Development and application		<b>Year of publication</b>		2003
<b>Research methods</b>	<u><b>Quantitative</b></u>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	<b>T2</b>	T3	T4	
<b>Location of study</b>	UK		<u><b>Other (Hong Kong)</b></u>		
<b>User's Long Term Condition</b>	<b>Traumatic brain injury</b>				
<b>Confidence Rating</b>	High	<u><b>Medium</b></u>	Low		
<b>Reviewer's initials</b>	HA		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

This article does not discuss carers' experiences of looking after someone with a long term condition, in this case traumatic brain injury (TBI). It builds on previous work relating to the on-going development of the Family Empowerment Questionnaire, and was aimed at exploring the similarities and differences in perceptions of empowerment between rehabilitation professionals and families of TBI clients in Hong Kong. The results showed the differences between rehabilitation professionals and family members on each of the four empowerment sub-scales (Skill, Support, Knowledge and Aspiration), and within individual items of each factor. The authors discuss the clinical implications of the findings.

It is not obvious to me that this study is relevant to the review.

<b>Author/s</b>	Godfrey et al			<b>Ref No</b>	<b>CA5098</b>
<b>Title (first 4 words)</b>	Assessing distress in care-givers		<b>Year of publication</b>		2003
<b>Research methods</b>	<b><u>Quantitative</u></b>	Qualitative	Mixed	Lit. review	Other
<b>Typology</b>	T1	T2	T3	T4	
<b>Location of study</b>	UK		<b><u>Other New Zealand</u></b>		
<b>User's Long Term Condition</b>	<b>Traumatic Brain Injury</b>				
<b>Confidence Rating</b>	High	<b><u>Medium</u></b>	Low		
<b>Reviewer's initials</b>	SS		Please e-mail this form to Stephen Piper <a href="mailto:sp29@york.ac.uk">sp29@york.ac.uk</a>		

*Please write below key points from the text relating to carer's experiences of caring for a person with a long-term condition:*

Identification of 2 factors for the Head Injury Behaviour Scale: items assessing behavioural regulation, and items assessing emotional probably.

HIBS found to have good internal consistency validity. Third or more care-givers consider items comprising HIBS to be present in their injured relative – indicating relevance of items

## APPENDIX 2 'BIBLIOGRAPHY': REFERENCES SOURCED BUT NOT INCLUDED IN THE REPORT

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**APPENDIX 3 SUMMARY TABLES OF REFERENCES INCLUDED IN THE STUDY**

**A4.1 Group A Carers of People with Sudden Onset Conditions**

*A4.1.1 Brain Injury*

Category	T1	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							0205
not rated							
Total no of T1 studies		0			1		

Category	T2	NO. ref numbers (UK)			NO. ref numbers (other locations)		
Confid Rating		Quant	Qual	Mix/other	Quant	Qual	Mix/other
High			0143		0141 1002 0125 0182 0149 0179,	0010	0129 0012 4207 5047
Medium		2621 0133 0199 0196 0528	0014	0003 0140 0074 0742 1183 0148 0070	0198 0128 0184 0206 0159 0186 0178 0132 0304 0197 0508 0574 4184 4223 2703 3150		0211 0210 0200 2121 0126 0171 0214 0203 1455 4355 4731 5097
Low		0429 0212		0110 0016 0168 0123 5030	0127 0207 1477 0307 0136 0986 0121 5038	1390	0162 0310 0120 0204 0165 0806 3886 0171
not rated				0134 0138 0139 0160 0040 0056 0027 0015			0112 3475 3741
Total number of T2 studies		29			59		

4.1.1 Brain Injury (Contd)..

Category	T3	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T3 studies		0			0		

Category	T4	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							0130
not rated							
Total number of T4 studies		0			1		
<b>Total number of studies T1-T4</b>		29			60		

A4.1.2 Spinal Cord Injury

Category	T1	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							4241
Low							
not rated							
Total no of T1 studies		0			1		

Category	T2	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confid Rating							
High					0279 0290 0288		0323 0283
Medium		0978		0019	0286	4281 2646	0289 0280 4118
Low		0285			0859		0281
not rated							
Total number of T2 studies		3			13		

A4.1.2 Spinal Cord Injury (contd).....

Category	T3	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T3 studies		0			0		

Category	T4	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T4 studies		0			0		
<b>Total number of studies T1-T4</b>		3			14		

## A4.2 Group B Carers of People with Intermittent/unpredictable conditions

### A4.2.1 Epilepsy

Category	T1	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							4946
not rated							
Total no of T1 studies		0			1		

Category	T2	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confid Rating							
High			0090	0097	0092	0105 0083	
Medium			0008	0729 0316	0672 0102		0087 0539
Low				4508			
not rated							
Total number of T2 studies		6			7		

A4.2.1. Epilepsy (contd)....

Category	T3	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T3 studies		0			0		

Category	T4	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T4 studies		0			0		
<b>Total number of studies T1-T4</b>		6			8		

### A4.3 Group C Carers of people with progressive conditions

#### A4.3.1 Cerebral Palsy

Category	T1	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total no of T1 studies		0			0		

Category	T2	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confid Rating							
High							
Medium					0082	2188	
Low			0046				
not rated							
Total number of T2 studies		1			2		

A4.3.1. Cerebral Palsy (contd)...

Category	T3	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T3 studies		0			0		

Category	T4	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T4 studies		0			0		
<b>Total number of studies T1-T4</b>		1			2		

A4.3.2 Motor Neurone Disease/Anytrophic Lateral Sclerosis

Category	T1	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total no of T1 studies		0			0		

Category	T2	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confid Rating							
High		0273 0276		0002 0001 0011		0267 0265	
Medium				0026		0264 0265	0321 1471 0156
Low		0272		0013 1312	0275		0324
not rated				0274	0308		0308
Total number of T2 studies		10			11		

A4.3.2. Motor Neurone Disease/Anytrophic Lateral Sclerosis

Category	T3	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T3 studies		0			0		

Category	T4	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T4 studies		0			0		
<b>Total number of studies T1-T4</b>		10			11		

### A4.3.3 Multiple Sclerosis

Category	T1	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated				0067			0940
Total no of T1 studies		1			1		

Category	T2	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confid Rating							
High				0219 0218	0020 0230	0009 0233	0228 1456
Medium			0018 0058	0062 0024 0030	0223 1171 0541 0231 0744	4362	1143 0220 0314
Low					4482 4538		1065 0764 1466
not rated							0255
Total number of T2 studies		7			21		

A4.3.3 Multiple Sclerosis (contd)...

Category	T3	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T3 studies		0			0		

Category	T4	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T4 studies		0			0		
<b>Total number of studies T1-T4</b>		8			22		

A4.3.4 Parkinson's Disease

Category	T1	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High				0007			
Medium		0005					
Low							
not rated							
Total no of T1 studies		2			0		

Category	T2	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confid Rating							
High		0247	0372	0004	0241 0261 0259		0263 0602 0611 1023 3765
Medium		1066 0237 4391		0071 0076 4386	0234 0244 0251 0256 0305 0320	0311	0347 1184 4617
Low					0258 0854	0301	
not rated				0017	0225		0240 0298 4551 4567
Total number of T2 studies		10			26		

A4.3.4 Parkinson's Disease (contd)....

Category	T3	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T3 studies		0			0		

Category	T4	NO. ref numbers (UK)			NO. ref numbers (other locations)		
		Quant	Qual	Mix/other	Quant	Qual	Mix/other
Confidence Rating:							
High							
Medium							
Low							
not rated							
Total number of T4 studies		0			0		
<b>Total number of studies T1-T4</b>		12			26		