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## Summary of the schema used in this report to classify the strength of the evidence

1. **Well-supported practice** – evaluated with a prospective randomised controlled trial
2. **Supported practice** – evaluated with a control group and reported in a peer-reviewed publication
3. **Promising practice** – evaluated with a comparison group
4. **Acceptable practice** – evaluated with an independent assessment of outcomes, but no comparison group (e.g., pre- and post-testing, post-testing only, or qualitative methods) or historical comparison group (e.g., normative data)
5. **Emerging practice** – evaluated without an independent assessment of outcomes (e.g., formative evaluation, service evaluation conducted by host organisation)
6. **Profiles of carer population** (e.g., routine data)
7. **Eligibility for support** (e.g., legislation, policy)
8. **Carers' views** (e.g., surveys, interviews)
9. **Expert opinion** (e.g., peak bodies, government policy)
10. **Economic evaluation** (including service utilisation studies)

## Attachment One

### The policy context

**Table A9 The national policy context**

Reference	Organisation	Policy description
Part VB of the National Health Act 1953 Aged Care Act 1997 Residential Respite Care Manual (Appendix to the Residential Care Manual 1999) Assistance for Carers Legislation Amendment Act 1999	Australian Government	These Acts and the Residential Care Manual (as it relates to residential respite care) cover assistance to people who provided care for frail aged and other people with a disability who have been assessed as requiring nursing home level care.  Additional services in community settings that are substitutable for lower levels of residential care are supported under this legislative framework, in particular care packages and respite services that form an adjunct to the Commonwealth's aged care programs. These form part of the fabric of community care services that are provided by a mixture of national, state and territory and local government programs
Home and Community Care Act 1985	Australian Government	The HACC legislation was a response to series of studies and reports specifically on the frail aged component of primary care and reducing the demand for residential placement from the late 1970s and 1980s It introduced the concepts of a 'balance of care' (institutional and community), expanding 'care options', improved coordination and assessment, a tier of 'basic maintenance and support services' and an explicit focus on the needs of carers.
Home and Community Care Review Working Group (1988). First Triennial Review of the Home and Community Care Program.	(Commonwealth) Department of Health and Family Services	The Review Working Group to Commonwealth, State and Territory Ministers set in train the continuous administrative reform agenda emphasising coordination and planning across programs, and an 'outcomes' focus (p.7). The Review reinforced program boundaries, 'no growth areas' (rehabilitation, post acute, families in crisis, palliative care) and exclusions (supported accommodation, appliances) while calling for greater linkage and coordination (pp 10-11).
National Health Strategy (1991). The Australian Health Jigsaw. Integration of Health Care Delivery. Issues Paper No.1, July 1991.	National Health Strategy	Realignment and consolidation of programs was given specific attention under the National Health Strategy in 1991. Recurring themes were "overlap ... excessive administration ... leading to duplication of services or to significant gaps in services available ... (and) substantial problems" (National Health Strategy, 1991, page 11-12).
National Respite for Carers Program 1996 1997-98 Annual Report for the Department of Health and Family Services, Australian Government Publishing Service, Canberra.	Department of Health and Family Services	Key elements of the 1996 \$280 million Staying at Home Package were implemented, including "approval of a further 500 community aged care packages; improved funding for aged care assessment; expansion of respite care services for carers, particularly those caring for people with dementia; and initiatives to improve continence management." (p.154)
A New Strategy for Community Care – The Way Forward, 2004.	Australian Government Department of Health and Ageing	In August 2004 the Australian Government released <i>A New Strategy for Community Care – The Way Forward</i> , outlining ways of simplifying and streamlining current arrangements for the administration and delivery of aged and community care services. The aim of this strategy was to make it easier for people to access the care that they need.
Consolidation of National Respite for Carers	Australian	With reference to the reform agenda outlined in <i>The Way Forward</i> , a Request for Application (RFA) process took place in 2005 for

Reference	Organisation	Policy description
Program elements	Government, Department of Health and Ageing	consolidating the location and roles of the National Respite for Carers Program, the Carer Information Support Program and Commonwealth Carelink Program.
Carers Australia (2006) Carers of People with a Mental Illness Project. Final Report. Prepared by Julie Nankervis and Dawn Mirapuri for Carers Australia, June 2006.	Carers Australia, Australian Government, Department of Health and Ageing, Mental Health Council of Australia	This report responds to a perceived failure to provide quality mental health services to meet community need, which has resulted in a significant burden on families and carers. Carers find that their role is often very stressful and carries significant risks to their own mental health and wellbeing. The Carers of People with a Mental Illness Project was developed in response to these issues with the primary goal to strengthen the policy capacity of Carers Australia to respond to the needs of carers of people with a mental illness by developing practical solutions to address their needs, raise their profile and obtain recognition. The objectives included a case study of the legislation in the Northern Territory, improved networking and identifying mental health services and/or services in other areas of health and/or disability with successful programs in carer involvement/engagement consistent with the National Practice Standards for the Mental Health Workforce and the National Standards for Mental Health Services,
Development of a carer-specific intake assessment tool, the Carer Eligibility and Needs Assessment (CENA), 2005-2006	Australian Government, Department of Health and Ageing	With reference to the reform agenda outlined in <i>The Way Forward</i> , a Request for Tender was released to develop a carer assessment tool for use by a range of carer support services.

**Table A10 Review of Subsidies and Services in Australian Government Funded Community Aged Care Programs**

Organisation / theme	Comments and recommendations
Aged and Community Services Association <i>Duplication of systems and reporting requirements</i>	An organisation providing all of the following: CACP; EACH; EACHD; HACC/COPS, NRCP (Respite House and in-home respite); TCP; DTC; DVA Nursing; VHC - has to deal with the following: 9 different Guidelines; 6 different Standards; 6 different quality reporting/monitoring processes; 6 different referral and assessment processes; 8 different review and assessment processes; 9 different financial reporting requirements, incorporating various periodic returns; 9 different data reporting requirements; 4 different software requirements; 4 different processes for provision of equipment
Aged Care Assessment Services, Victoria <i>Lack of flexibility</i>	Flexible and responsive in home respite and residential respite to enable carers to be able to access a reasonable break from their caring role. Carers often respond better to respite services that are flexible in their nature and also provide culturally appropriate workers. Respite is often only able to be provided at times dictated by the service providers which are not always when the carer requires the break.
Australian Institute of Health and Welfare <i>Gaps in the evidence base</i>	Significant gaps in available data ... constrain the value of the Review at the present time and this inadequate evidence base may adversely affect the efficacy of reforms that flow from the Review.  Some data are collected but are not available to the wider research and policy community in either unit record or summarised format (e.g. the National Respite for Carers Program minimum data set). Sometimes this is due to concerns about data quality; at other times because no processes have been developed to support the release of unit record data.  Some data are difficult to access and to make maximum use of. For example the complexity of access and permission procedures to obtain several data sets and undertake data linkage, even within the 'safe environment' offered by the AIHW Act, produce long delays, high costs and less than timely results...

Organisation / theme	Comments and recommendations
	<p>The technical means to undertake such data linkage have been in place for some time ... However, implementation of a fully functional linked national database would require appropriate financial resources.</p> <p>A comprehensive study of unmet need for formal and informal assistance within the older population, by type of assistance, is strongly recommended as a means to investigate the adequacy of existing community aged care programs and services. Such a study would draw on data from the ABS Survey of Disability, Ageing and Carers.</p>
<p>Carers Australia</p> <p><i>Gaps and overlaps and needs in the future</i></p>	<p>Fragmentation of the services system in most states and territories, together with complexity of targeting, eligibility requirements and the services that can be delivered within different programs makes the services system difficult both to understand and to access for most carers and consumers.</p> <p>Consideration of means for consolidating the services system beyond the common arrangements. This requires progressive reductions in the development of separately targeted small funding programs and in the distribution of small amounts of program funding to a wide variety of agencies.</p> <p>Some carers are reluctant to transfer to CACPs due to possible reduced services and higher fees than those being received under the HACC program.</p>
<p>Catholic Health Care</p> <p><i>Support for carers as one of the principles of a community care system</i></p>	<p>The principles of a good community care system include: enhancing and supporting carers; carers as co-clients; care partnerships: integration of formal and informal care; coordinated, easy to navigate; provide optimal approaches to the provision of information to consumers, carers, providers. Community care should be preventive, therapeutic, and restorative or supportive; and services which support older people include services which support carers to maintain their caring role.</p>
<p>Department of Health and Human Services Tasmania</p> <p><i>Service gaps and overlaps</i></p>	<p>In theory, each program has its own discrete role. .. basic level support services to maintain an individual's independence (HACC), higher level of community care for individuals who would otherwise require low or high level residential aged care (CACP and EACH packages). Other Australian Government programs (i.e. NRCP and residential respite) then aim to provide separate but complementary services. However in practice, both anecdotal and formal reports show that service gaps and overlaps are common. The variation in services provided under the various program types is so significant that clients ultimately receive an amount of care that can range from one to 50 hours per week</p>
<p>Department of Families and Communities</p> <p>South Australia</p> <p><i>Service gaps and overlaps</i></p>	<p>Family and other informal carers will always be critical to the success of community care and keeping people at home rather than in more expensive and restrictive institutional care options. Carer support and respite are both relevant. Currently, there are few carer support services in terms of quantity and variety. This is an area that warrants further consideration.</p> <p>Of immediate concern is the number of different programs providing respite, the variation and overlap between them, and the lack of a system to assess relative need and equity of service provided... Some programs currently have caps, but there is no system to identify cross program usage. Again anecdotal evidence suggests that this occurs more for younger people.</p> <p>The need for respite is more related to carer circumstances than to the level of caree needs. Assessment for respite provision needs to be based around the carers' needs, although the needs of the caree are central in determining how the care should be provided.</p>
<p>Queensland Health</p> <p><i>Service gaps and overlaps</i></p> <p><i>Education and training for carers</i></p>	<p>Carer burnout is an ongoing problem when carers are only eligible to receive a community care subsidy for a maximum of 56 days respite care per financial year with a maximum of 28 days leave to use as social leave. This amount of respite is often insufficient ... (and) support should be available when the carer reaches a stage of 'not coping'.</p> <p>Amalgamate the programs for respite such as the National Respite for Carers Program and respite through the HACC Program, into one program that offers a range of respite options that can be delivered by a variety of service providers operating at the local level.</p> <p>In amalgamating respite programs ... there should be recognition of those programs which also provide respite to carers of people with a disability. Any amalgamation should ensure these carers are not disadvantaged.</p>

Organisation / theme	Comments and recommendations
	Education and Training for Carers to access appropriate information, advice and support ... that have a preventive / restorative function and are not limited to tertiary interventions are required ... through the establishment of an education/training program to inform carers of the progression of certain conditions (e.g. dementia); healthy ageing programs; self advocacy programs, and community and primary health options.
Uniting Care Ageing NSW and ACT <i>Importance of residential respite and anomalies in costs</i>	<p>A great many packaged care recipients also have live-in or informal carers. Indeed, the success of many services in maintaining care recipients at home is only made possible by the presence of a carer working in partnership with the service provider. On average, some 57% of CACP care recipients and 90% of EACH care recipients have such a carer.</p> <p>The importance of residential respite should not be underestimated ... over 50% of residential respite users are also accessing community care programs, such as HACC and CACPs.</p> <p>Centre based day care respite also often plays an essential role in supporting carers, including those of packaged care recipients. However, program boundaries and varying interpretations of "full cost recovery" policies often cause inequitable and prohibitive cost problems for CACP and EACH service providers when seeking to access such services. Additional funding needs to be provided to CACP and EACH provider to overcome this anomaly.</p> <p>Increase the Carers Allowance by at least 10%.</p> <p>Explore and/or pilot the concept of merging lower level packaged care (CACP) and residential low care into an "interchangeable" single subsidy scheme.</p>
Victorian Department of Human Services <i>Improve access to restorative services</i>	<p>Reducing complexity for clients and carers by simplifying the system rather than requiring case management to navigate the complexities of the system.</p> <p>Victoria proposes that residential respite care for older people should remain with the residential aged care program as a fully Commonwealth-funded program, and that access to residential respite should be coordinated through ACAS.</p> <p>Merge the Day Therapy Centre program and NRCP into HACC Basic on the grounds that the services delivered, the client groups served and the participating agencies all align closely with HACC Basic rather than being focused on clients in the 'package care' tier. Victoria's preferred option is for DTC funding to be folded into HACC Basic to allow for the coherent development of allied health services through HACC and state-funded health programs.</p>

**Table A11** *Legislation and policy in the States and Territories*

State	Legislation and Policy	Scope	Description and comments
<b>Victoria</b> Department of Human Services, Aged Care Branch (2006)	Action Plan 2006-2009 Recognising and supporting care relationships for older Victorians.	Includes associated action plans for disability, mental health and aged care	Aim is to improve recognition of and support for care relationships through policy and service development and delivery.
DHS Aged Care Services Division	Victorian Aged Care, Support for Carers Program (SCP)	Support for Carers Program provides in home, out of home, and emergency carer respite, and support services, for older carers and carers of older people.	This program is delivered through a range of carer respite and support organisations, and Carers Victoria.
DHS Victoria Disability Services Division (2006)	Reflects the principles of the Victorian State Disability Plan 2002-2012	The original 'Help for Carers' for the disability sector was released in September 2002 (re-written and updated)	Catalogue of policies and principles emphasising resources for carers and planning for the future, plus information on community supports for people with a disability and their families.
<b>NSW</b> NSW Government (2007)	NSW Carers Action Plan 2007-2012	Whole of government: ageing, community support, health, education, transport, employment and industrial relations	Five year action plan includes the NSW Carers Program 2000 covering services and special grants and a cross agency plan. Has five areas with Priorities for Action.

State	Legislation and Policy	Scope	Description and comments
NSW Parliament	NSW Mental Health Act 2007	For mental health patients under compulsory treatment orders	Provides a definition of a primary carer and gives effect to the rights of carers to be kept informed. Describes obligations of hospitals and mental health facilities to notify the primary carers of patients and detained persons of proceedings under the Act and to include them in care planning.
Mental Health and Drug and Alcohol Office (NSW Health), Australian Government and Carers NSW 2006	Family and Carer Mental Health Program NSW	Families and carers of people with a mental health problem, carer MH support groups and networks, service providers and NGOs	Operates in 3 Area Health Service regions to support carers, improve service responsiveness and consumer outcomes. Contains 6 programs that include information and education, young carers and Kooris
<b>South Australia</b> Parliament of SA (2005)	SA Carers Recognition Act 2005	Provides a definition of the term 'carer', outlines a 7-point Carers Charter	Formalises consultation with carers as an obligation of public sector agencies.
SA Department of Families and Communities (2006)	SA Carers Policy: Supporting Carers.	Describes the policy, SA Carers Charter and principles	Charter and Principles are described along with evidence for why they are important and practical pointers on how agencies can assist carers.
<b>Western Australia</b> Parliament of WA (2004)	WA Carers Recognition Act 2004	Whole of government – shows how departments will work in partnership with carers Defines carers, establishes the 4 point Carers Charter Established the Carers Advisory Council	Charter covers: respect and dignity; obliging recognition in the assessment, planning, delivery and review of services; views of carers as well as care recipients taken into account; having complaints taken into account.
WA Aged Care Advisory Council reporting to the Minister	WA Carers' Action Plan	The Carers' Action Plan fits within the strategic framework of the State Aged Care Plan for Western Australia 2003-2008	The issues and needs of carers warranted a separate Action Plan.
Carers WA (2003) August 2003	Carer Involvement Framework.	A literature review was undertaken to inform the Framework	Framework identifies a number of key issues of relevance to carers, service providers and agencies.
<b>Tasmania</b>	Tasmania Disability Framework for Action 2005-2010	Whole-of government framework for Tasmanians with disabilities	Supporting, valuing and promoting the roles of families, guardians and carers.
Tasmanian Government Disability Framework for Action	The Tasmanian Companion Card	Tasmanians with a disability who require assistance from a companion to participate at community venues and activities.	Aims to foster human rights by removing some of the barriers to participation in Tasmania's social, cultural and economic life for people with a disability.
<b>Queensland</b>	Queensland Government Carer Recognition Policy 2003 and Carer Action Plan 2006-10	Whole of government – shows how departments will work in partnership with carers	Key initiatives: Carers as partners in care; Ageing carers; Young carers; Work / life balance; Information for carers.
Carer Action Plan	Queensland Companion Card and Carer Card	People with attendant care support and who will need this level of support lifelong.	The Carer Card and Companion Card will allow free admission for their chosen companion at participating venues and activities.
<b>Northern Territory</b>	NT Carers Recognition Act 2006	Whole of government – shows how departments will work in partnership with carers	The Schedule to the Act includes the NT Carers Charter with 8 points.
<b>Australian Capital Territory</b> Department of Disability, Housing and Community Services	Caring for Carers Policy 2003	Three-year plan of action to enhance government and community support for the estimated 43,000 ACT carers.	A collaborative approach across government.
ACT Government Caring for Carers in the ACT - A Plan for Action 2004-2007 is the sequel to the policy.	2005-06 Progress Report on the Implementation of Caring For Carers in the ACT - A Plan for Action 2004-07	Shows government has consolidated and progressed the implementation of the Action Plan in its second year of operation	Takes stock of all the initiatives that are currently in operation that aim to improve the lives of carers in the community.

## Attachment Two

### Summary of the review literature of the needs of carers

**Table A12 Summary of the review literature of the needs of carers**

Reference	Review scope	Outcomes	Results	Service implications	Research implications
<b>General</b>					
Guberman N, Nicholas E et al. (2003) <i>Impacts on practitioners of using research-based carer assessment tools: experiences from the UK, Canada and Sweden with insights from Australia. Health and Social Care in the Community</i> Vol 11, No. 4, pp. 345-355.	Selected sample of tools for assessing the situation of the carers of adults who are ill, elderly or have disabilities from Canada, the UK and Sweden, with emphasis on the professional practice of assessors. All tools were tested in agency-based studies.	Examined the development of tools and used focus groups to explore how these tools worked in agencies	The results reveal that the use of carer assessments can lead to changes in the appropriateness of intervention by informing practitioners of issues which are given little attention, but which impact on the adequacy of interventions to the service user.	Across the projects, most workers found that the tools facilitated a more comprehensive, in-depth and carer-focused assessment. Use of carer assessment tools can lead to more appropriate interventions	The tools highlight important information which can provide a rationale for current intervention with carers and contribute to future service development.
Houde SC (2001) <i>Men providing care to older adults in the home. Journal of Gerontological Nursing</i> Vol.27, No.8, pp.13-19.	Discussion in relation to male caregivers reported from the literature	Includes results of studies looking at interventions to support male caregiver	Having a male caregiver increases the risk of nursing home placement. Little information available related to the needs of the male caregiver.	Nurses should play a role in developing interventions to support male caregivers	Evaluations of the effectiveness of interventions targeting males is important
Houde SC (2002) <i>Methodological issues in male caregiver research: an integrative review of the literature. Journal of Advanced Nursing</i> , Vol.40, No.6, pp.626-640.	Male caregivers. Gender differences in caregiving experience, and interventions. 127 articles during 1997-2000 excluded articles from saw or OT journals, not research studies or testing of an instrument. 36 articles reviewed- 13 qualitative, 22 quantitative, one both. P627. This is not a systematic review but a discussion in relation to caregiver gender reported from 9	Not detail available on outcome measures	"Men provide approximately 28% of the care in the home to functionally impaired elders in the USA..." p626 "Men have not been studied adequately because of limitations in sampling design, with too few men in many caregiving samples" p634	Approx 1/3 carers are male (USA) - potentially similar rates in Australia - need to develop services which are responsive to their needs. Males reported fewer behavioural problems with spouses; males had higher mutuality ratings than females;	Little information available related to the needs of the male caregiver. "In summary, there is a need for an increase in caregiver research that analyses differences by gender and family relationships ..."p639

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	cross-sectional studies				
Hunt C (2003) <i>Concepts in Caregiver research Journal of Nursing Scholarship</i> Vol 35 No. 1 pp27-32	Reviews carers experiences of caring - positive as well as negative aspects	Non-standardised measures of positive aspects of caregiving	Although earlier studies focused on negative aspects of caregiving, more recent research has also included positive aspects. ' p27 Positive aspects include: caregiver esteem, uplifts of caring ('events that make one feel good, make one joyful, or make one glad or satisfied..' p29); caregiver satisfaction; finding or making meaning through caregiving; gain in the caregiving experience. It may include any positive return to the caregiver as a result of the caregiving experience'. p29	Routine review of the caregiver needs to be included in community nursing practice	More research on positive aspects of caregiving
<b>Cancer/palliative</b>					
Given BA, Given CW and Kozachik S (2001) <i>Family support in advanced cancer. CA: A Cancer Journal for Clinicians</i> . Vol. 51, pp. 213-231.	This is not a systematic review but a discussion paper describing the needs of family carers looking after advanced cancer patients at home and reviewing the evidence for several types of interventions to support carers. Two examples of education models are presented: COPE (Houts and colleagues) and a program for health care teams (Barg and colleagues). All family caregivers, some differences between the needs of spouses and others are discussed	Self-efficacy, mastery, sense of control and competence. Knowledge and skills in the techniques and strategies of providing care at home. Health related QoL (SF-36).	Spouse carers typically receives less assistance from secondary carers than non-spouses. As demands increase over time, primary carers tend to seek supplementary care rather than completely handing over responsibility for any tasks. Carers want detailed and specific information tailored to their unique situations and psychosocial needs, as well as to the physical care needs of their patients. Older carers report more problems with physical demands of caring, while younger carers tend to have more emotional difficulties. Virtually all studies find elevated levels of depressive symptoms among family carers. There is also elevated risk of poor physical health, which increases with duration of caring. Carers report fatigue and inadequate time for sleep and self care. Evidence is mixed on the relationship between level of care required (i.e. patient need) and carer distress. Pre-existing family problems or mental health issues tend to exacerbate carer burden.	Lack of skill and knowledge contributes to carer distress. Adequate education for carers, tailored to their needs, may help reduce the need for psychotherapy. They do not want large amounts of non-specific information, however. Few carers use formal home care (domestic assistance) services; those who are highly stressed need help to enlist formal and informal support. Home care delivered to patients increases their independence and thus reduces demands on carers. Ideally, a case manager within the care system would be responsible for helping families utilise community resources.	There are no reports in the literature describing caregivers' acquisition of (secondary) assistance as disease progresses and the demands of care increase. It is unclear what constitutes a 'therapeutic dose' of social or instrumental support for family caregivers. There is a need to define good patient outcomes and develop standards of care. "Research is needed to demonstrate that investing time, providing information and working with families to provide home care leads to demonstrably better patient outcomes at lower costs with less professional time overall." p229
Hodges LJ, Humphris GM and Macfarlane G (2005) <i>A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. Social Science</i>	All family carers for cancer patients. Databases included Psycinfo, Medline and Cancer Lit. Included were papers dealing with cancer patients and their carers, recording levels of psychological distress for both groups, reporting a statistical estimate for each group and/or a correlation between the levels of		A total of 21 separate samples were identified and entered into a meta-analysis. Findings indicated a significant positive correlation between patient and carer self-reported psychological distress (Z=6.94, p<0.0001). The relationship appeared strongest among male patients and female caregivers, although this was based on just one study. Overall the correlation is moderate, which suggests that in some couples there may be no relationship, or a negative correlation, between the distress experienced by the patient	"...the carer is as likely to experience psychological distress as the cancer patient ... Clinical attention should therefore consider the patient-carer dyad as the 'clients of care'" p 9. "It could be possible to devise a clinical model of response with which interventions and support	

Reference	Review scope	Outcomes	Results	Service implications	Research implications
and <i>Medicine</i> , Vol.60, pp.1-12.	distress in each group, and using the same measures of distress in both groups.		and their carers. "It is most likely a subgroup of patients and carers exist who are vulnerable to or at higher risk of suffering from psychological distress" p9 Female patients reported significantly more distress than male carers.	could be targeted at critical stages (e.g., for carers during treatment), and early intervention with the patient, carer or the dyad could prevent later development of psychological distress in both members." p10	
Kinsella G, Cooper B, Picton C and Murtagh D (2000) <i>Factors influencing outcomes for family caregivers of persons receiving palliative care: toward an integrated model. Journal of Palliative Care</i> , Vol.16, No.3, pp.46-54.	All family caregivers - factors such as age, gender, health status, SES, ethnicity and culture, and relationship to patient are variables in the proposed model		This paper presents an integrated model (the 'Stress Process Model') for understanding the relationships between carer demands, outcomes and determinants of outcomes for home-based palliative caregivers. The model includes 'background and context' variables such as carer characteristics, relationship with patient, living arrangements and availability of formal support services. Stressors are defined as external demands and changes in the lives of caregivers that have the potential to threaten wellbeing. Psychosocial resources include social support, family functioning and coping strategies. Outcomes are responses to caregiving and encompass emotional, physical and social wellbeing in the short term (proximal outcomes) and longer term (distal outcomes).		Longitudinal studies are needed in order to distinguish causal pathways. There is a need to develop subjective appraisal measures that capture individual carers' appraisals of the objective stressors and their associated strains. The main areas of appraisal identified in previous research are 'role overload', 'role captivity' and 'loss of relationship with the patient'. The current review adds 'loss of self', 'role orientation', 'adequacy of social support' and 'adequacy of coping'.
<b>Chronic conditions</b>					
McKeown LP, Porter-Armstrong AP, Baxter GD (2003) <i>The needs and experiences of caregivers of individuals with multiple sclerosis: a systematic review. Clinical Rehabilitation</i> , Vol.17, No.3, pp.234-248.	24 studies. To appraise recent studies on the needs and experiences of caregivers of individuals with MS. Inclusion criteria: primary studies focusing on caregivers of individuals with MS, English language, published in peer-reviewed journals, 1990-April 2002. Caregiver themes: responsibilities; effect of providing care; how carers cope with the demands of caring; support systems.	Caregivers: all standard domains (e.g., strain, personal resources, physical health, stress, coping, social network and support, family and life satisfaction, caring tasks).	Minority (7) reported reliability and validity of instruments: questionnaires: postal, face-to-face structured interviews and focus groups. Impact on MS caregiver's life: detrimental effects on physical and psychological well-being, social life, work life, financial situation, quality of life; increasing care recipient dependency, years of caring: increasing negative effects on health and health promoting behaviours; differences in male and female coping strategies and social support seeking; differences in rural and urban social support seeking. Social support: beneficial effects on carers' mood, general health and family life. Poor use of community resources.	Maintenance of caregiver health is a critical factor in enabling carers to continue to provide care. Professionals should: regularly and routinely assess needs of carers, encourage caregivers to look after their own health, advise on health-promoting behaviours, facilitate social support, provide caring skills.	Need to develop disease specific assessment instruments validated for populations of MS carers, to enable comparisons to be made across studies, improve understanding of the caring process, and facilitate reliable and valid measurement of the outcomes of interventions with people with MS and their carers.

Reference	Review scope	Outcomes	Results	Service implications	Research implications
<b>Dementia</b>					
Black W, Almeida OP (2004) <i>A systematic review of the association between Behavioural and Psychological Symptoms of Dementia and burden of care.</i> <u>International Psychogeriatrics</u> Vol.16, No.3, pp.295-315	Systematic review and meta-analysis of 30 cross-sectional data and 12 longitudinal studies looking at association between Behavioural and Psychological Symptoms of Dementia (BPSD) and carer burden & depression and 5 studies examining relationship between BPSD and institutionalisation.. No. reviewed: 30 articles in the review of cross-sectional data and 12 in the systematic review of longitudinal data, and 5 studies examining relationship between BPSD and institutionalisation. Inclusion criteria; referenced journals between Jan 1990 and Dec 2001; informal caregivers; valid measures of caregiver burden, psychological distress or depression; valid measure of BPSD; data available for both BPSD and PSC; diagnosis of dementia using well-established diagnostic criteria.	Admission to residential care; Depression; Caregiver Stress; & General Health Question: association between Behavioural and Psychological Symptoms of Dementia (BPSD) and carer burden, depression and rates of institutionalisation of people with dementia	"Half of the studies investigating the association between BPSD and burden in a multivariate analysis identified BPSD as the variable most strongly correlated with caregiver burden" p309 "This review confirmed the existence of a good cross-sectional relationship between BPSD and burden of care, moderate association between BPSD and GHQ scores, and poor to moderate association between BPSD and depression scores. It remains unclear which factors best predict PSC (psychological sequelae of caring) or the institutionalisation of patients over time, although currently available evidence suggests that caregiver variables may be more important than care-recipient variables" p311	focus on services which enhance caregivers skills/abilities to care for people with dementia	Link between BPSD and PSC demonstrated. "For this reason, we would suggest that cohort studies would be better suited to clarifying the factors that more closely predict the development of clinically relevant PSC, service utilization or institutionalization.." p311
Brodady H and Green A (2002) <i>Who cares for the carer? The often forgotten patient.</i> <u>Australian Family Physician</u> . Vol. 31, No. 9, pp. 833-836.	This is not a systematic review but a research synthesis for the benefit of GPs, explaining the needs of carers and the role of the GP in providing support to carers of patients with dementia. Care coordination. All family carers of people with dementia	Time attending to ADLs and IADLs Carer well-being Care recipient admission to RACF	Carers experience poor physical and psychological health, social isolation and financial costs. Assistance with ADLs and IADLs takes an increasing amount of time as the disease progresses (4.6 hours/week for normal aging person, additional 8.5 hours/week for mild dementia, additional 17.4 and 41.5 hours/week for moderate and severe dementia respectively). Admission to RACF is more likely when carers are distressed and when they are not the spouses of patients (i.e. adult children) and tends to be precipitated by increasing time spent caring for the patient, clinical fluctuations, patient misidentifications and nocturnal deterioration. Emotional liability of the patient is the strongest predictor of impaired wellbeing in the carer. Protective factors include greater perceived support and emotion-focused coping skills.	The author outlines practical measures that GPs can take to assist carers at different stages of the illness, from diagnosis and referral to community self-help groups, to management of behavioural and psychological symptoms, to assistance with basic daily care and dealing with grief, guilt and family tensions.	1

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Cuijpers P (2005) <i>Depressive disorders in caregivers of dementia patients: A systematic review</i> <u>Aging and Mental Health</u> Vol.9, No.4, pp.325-330	Caregivers with a diagnosis of a major depressive disorder. 10 studies met inclusion criteria, comprising 790 carers. Inclusion Prevalence of Dx depression, Studies up til 1 May 2004; Exclusion: studies that reported symptomatology of depression. Only one study used representative community sample, the rest used selective and unrepresentative samples	Depression	Prevalence rates range from 0.15-0.32, which is considerably higher than is found in community studies among the elderly' p329 'The studies examining the incidence of depressive disorders again confirm that caregivers have a highly increased risk of getting a depressive disorder..' p329 'No clear indicators were found that prevalence rates differ for differing types of caregivers, although the number of studies comparing types of caregivers was too small to reach definite conclusions'.	And it may be very well possible that depressive disorders are not detected by professionals and are considered to be a 'normal' reaction to a very stressful situation, while adequate treatments are available'.p330	.. we have to know how often these disorders occur, and what chance a non-depressed caregiver has to get a depressive disorder in the next year.' p330 ; Risk factors, prevention and treatment.
DiBartolo MC (2002) <i>Exploring self-efficacy and hardiness in spousal caregivers of individuals with dementia</i> <u>Journal of Gerontological Nursing</u> (2002) Vol.28, No.4 pp.24-33	Spousal carers of people with dementia. Self-efficacy and hardiness of spousal carers		"..personality characteristics (e.g. self-efficacy, hardiness) deserve further consideration to explain why certain caregivers persevere longer under similarly stressful circumstances" pp30-31 "Gerontological nurses ..can identify pertinent personality characteristics and promote adaptive responses to the stresses of caregiving. This, in combination with the usual discharge planning and educational interventions ... can contribute to a more positive appraisal of the caregiving situation and maximise quality of life for both the caregiver and the care recipient...(which) may also better ensure that both.. reap the lesser-known positive rewards" p31	Role of nurses in identifying carers needs, as well as the characteristics of carers (self-efficacy, hardiness), and therefore put in place appropriate strategies matched to the individual needs.	Refinement of measures of hardiness, and implications for supporting caregivers.
Dunkin J, Anderson-Hanley C (1998) <i>Dementia Caregiver burden: A review of the literature and guidelines for assessment and intervention</i> <u>Neurology</u> Vol.51, No.1, Supple 1 pp.S53- S60	Determinants of positive and negative outcomes in caring - how and why some caregivers adapt over time whereas others do not.	Adaptation to caring demands - positive and negative outcomes of caring; determinants of institutionalisation and frequency of behavioural problems of people with dementia.	" Recent theorists have put forth the notion of caring gain and have proposed that it be conceptualized as not merely the absence of negative outcomes, such as burden, but rather as the presence of feelings of satisfaction, personal growth, and the idea that caregiving can provide enhancement and enrichment of the caregiver's life ...some caregivers are able to find personal meaning through caregiving ..." pS54"Caregiver and family assessment should be an integral part of any thorough dementia work-up and, for relatively little effort, can be instrumental in improving the quality of life for both patients and their families" pS59	Assessment of carers should include the following key issues: ethnic and cultural status; knowledge base; social support; psychiatric symptomatology and burden; and family conflict. Interventions should include: education; support groups; respite care; family therapy; individual treatment e.g., psycho-social/therapy.	
Gottlieb BH, Wolfe J (2002) <i>Coping with family caregiving to persons with dementia:</i>	Canadian review of 17 studies that relate the ways of coping employed by family caregivers of people with dementia to their health and morale.	Coping measures & measures of health and well-being	Due to the use of cross-sectional designs, the adoption of different coping and outcome measures, the lack of specificity and the incomparability of the target stressors, the reliance on retrospective reports and the use of inappropriate	..pre-screening of caregivers along the dimensions of support-seeking and emotion-focused coping may yield better matches	" ...incorporating personality and other dispositional variables in the models that are proposed and tested" p339

Reference	Review scope	Outcomes	Results	Service implications	Research implications
<i>a critical review</i> <u>Aging and Mental Health</u> Vol.6, No.4, pp.325-42	International. Primary caregivers of individuals with multiple sclerosis (MS), majority spouses. Samples sizes: 9-345. Majority used convenience samples: caregivers recruited from membership lists of societies and voluntary organisations. 17 empirical studies that relate the ways of coping employed by family caregivers of people with dementia to their health and morale. Inclusion distinct measure of the coping responses of family caregivers of community dwelling, older adults with dementia to one or more measures of the caregivers' health or well-being. Exclusion purely descriptive accounts of caregiver coping, and studies that combined samples of people with dementia caregivers with other illnesses or disabilities.		response formats , among other limitations, the interpretability of the cumulative body of empirical findings on caregiver coping is questionable" p325 "The centrality and ubiquity of coping, both when the alarms of life are sounded and when stress is characterized by grinding and persistent adversity, require more concerted and refined efforts to appreciate its role in matters of human health and well-being" p.340	for community intervention or for the emphasis of interventions' p340	"Studies need to be 'more faithful to and build upon the transactional theory' i.e., emphases on stressor and stage specificity, the dynamic, changing character of coping efforts that unfold over time, and the influence of the larger social context on adaptational outcomes. p340 "investigators could systematically vary the ways the caregivers spend their time.. (during periods of respite, e.g., positive event, or education and training) p 340
Hughes JC et al. (2002) <i>Carers, ethics and dementia: a survey and review of the literature</i>	Main (primary) non-professional carers of people with dementia. Literature search using various databases and qualitative study (survey of ten volunteers with statements and case scenarios)		Much literature about ethics re dementia. However, 'These ethical issues are identified and discussed primarily from the perspectives of the professionals involved, or from a social or legal perspective. Almost no attention has been paid to ethical issues from the perspective of carers' p.36 Only one study found that reports family carers' ethical views (Pratt et al. 1987) "There is a broad range of ethical issues facing the non-professional, main carers of people with dementia. ...It is noteworthy that when carers focus on issues which solely involve either the person with dementia or others ... these issues are seen by professionals too. But when carers involve themselves in their perspective, the ethical issues become less predictable and more varied ... We can speculate that these ethical issues contribute to 'carer burden' and the psychosocial impact of dementia..." pp.39-40	Greater awareness of ethical issues facing carers and the relationship to carer burden and psychosocial impact - which professionals can help carers to deal with. p.40	"It appears worthwhile, therefore, to pursue more systematic research, both qualitative and quantitative, into the ethical issues that arise for the main, non-professional carers of people with dementia from the perspective of those carers." .p40
Janevic MR, Connell CM (2001) <i>Racial, ethnic and cultural</i>	Race, ethnic and cultural differences in caring experience. 21 US studies based on 18 samples		"As a group, the studies ... suggest that there may be differences in the stress process, in psychosocial outcomes, and in variables related to service utilization among	US review - but may have relevance here. Service providers need to be mindful of the impact	Review of US studies - but may have relevance in Aus. What are the effects of

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<i>differences in the dementia caregiving experience: recent findings</i> <u>Gerontologist</u> Vol.41, No.3, pp334-347	published between 1996 and 2000; Inclusion articles that compared two or more racial, ethnic, cultural, or national groups on variables related to the dementia caring experience. Exclusion articles that focused on just one racial, ethnic or cultural group, and book chapters, unpublished dissertations, and empirical studies that did not have ethnic differences as the main question.		caregivers of different racial, ethnic, national and cultural groups; however, the origin of these differences is unclear, as is the extent to which they can be generalized beyond the samples employed in a given study." p345 "Knowledge and attitudes regarding health and social services are also critical topics to explore within a qualitative research paradigm, in order to determine the specific nature of structural and cultural factors affecting service use and to improve outreach efforts to diverse groups of caregivers" p346	of culture, race and ethnicity on experience/needs of carers.	ethnicity, culture and race on caring? Knowledge and attitudes of service providers.
Kneebone I.I. & Martin P.R., (2003) <i>Coping and Caregivers of people with dementia</i> <u>British Journal of Health Psychology</u> Vol 8, pp1-17	Carers of people with dementia. 16 studies - 12 cross-sectional and 4 longitudinal, review of research based on Lazarus & Folkman's (1984) stress and coping model to establish implications for interventions aimed at improving caregiver adjustment.	Depression, indexes of life satisfaction, caregiver burden.	Overall, the research on coping in caregivers to people with dementia to date provides evidence that a general tendency to problem-solving and an acceptance style of coping is likely to be advantageous.' p 13 'Alternative research designs may have the potential to have a greater impact on caregiver adjustment than the investigations reviewed in this paper'. p14	Clinicians...should work with their clients to develop problem-solving responses to the difficulties they face, where solutions are available.(otherwise where) solutions may not exist, clinicians should encourage caregivers to adopt an acceptance style of responding.' p13	.. the ability of the research to inform the clinician for intervention purposes with any specificity remains severely limited'. p14. Need for 'longitudinal studies of specific caregiver problems that consistently incorporate measures of coping strategies particular to caring and the specific problems that arise for the caregiver.' p14 'Alternatively, perhaps what is needed is a radical revision of methodology and perspective. e.g., caregivers monitor their coping responses to particular problems... coping strategies and mood responses could also be frequently/continuously measured in relation to particular stressors...' p14
Pinquart M, Sorensen S (2004) <i>Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a</i>	60 studies Inclusion informal CGs of older adults; associations of caring stressors and uplifts with indicators of SWB were reported as correlations or statistical measures that can be converted to	Subjective well-being (SWB) assessed by scales measuring positive affect and life satisfaction.	...caregiving stressors show stronger associations with CG (caregiver) depression when with SWB (subjective well-being). Thus, many CGs can protect their SWB as long as there is enough time left for alternative pursuits that may cause the SWB, and/or as long as they experience the uplifts of providing care..." "providing more care does not	developing and maintaining sources of positive affect may counteract some negative effects of caring and thus protect CG's well-being and mental health' p447	..more research is needed on correlates of SWB of informal CGs' 447

Reference	Review scope	Outcomes	Results	Service implications	Research implications
<i>meta-analytical comparison</i> <u>Ageing and Mental Health</u> Vol 8, No.5, pp.438-49	correlations; studies were in English or German or in a language that they were able to obtain a translation	Care recipients: ADL & IADL; cognitive problems; behaviour problems; Amount of care (hrs/week); Caregivers: number of caring tasks; measures of perceived uplifts of caring assessed perceived gains and benefits and enjoyable aspects of care giving.	necessarily impair the SWB of the care receiver, probably as long as other social roles and activities that are sources of positive affect are not too restricted..... Developing and maintaining sources of positive affect may counteract some negative effects of caregiving and thus protect CG's well-being and mental health" p447		
Pinquart M, Sorensen S (2007) <i>Correlates of physical health of informal caregivers: a meta-analysis</i> <u>Journals of Gerontology Series B-Psychological Sciences and Social Sciences</u> Vol.62, No.2, pp.126-37	176 studies on correlates of caregiver physical health published or presented between 1986 and 2006. 48% focused on dementia caring, 18% on physically frail adults, and 34% on both dementia and other caregivers. Inclusion informal carers of older adults, associations of study variables with physical health were reported as correlations or as other effect size measures, and studies were written in English, German or easily translatable.	health status; education; income; support - informal and formal; carer burden; residence; length of time in caring role; number of caring tasks; .	"Higher age, lower socioeconomic status, and lower levels of informal support were related to poorer health... Associations of caregiving stressors with health were stronger among older samples, dementia caregivers, and men" p126 " First, caregiving -related stressors affect caregivers' physical health ...Second, feeling depressed is more strongly associated with caregivers' physical health than the absolute levels of caregiving demands. Third higher caregiving demands have a stronger impact on the physical health of older caregivers, dementia caregivers, and men, thus suggesting that these are additional risk factors for practitioners to be aware of". p132 "We conclude that psychological interventions should not only target caregivers' psychological health but also include physical health promotion, such as offering opportunities for exercise, nutrition improvement, and preventive care visits". '(W)e need more triangulated, objective assessment approaches to explain the health consequences of informal care	Physical health needs of caregivers need to be addressed. Older carers, and men at higher risk.	Need more triangulated, objective assessment approaches to explain health consequences of informal caring more fully, also, longitudinal studies that test for mediators of the relationship of caregiver stressors and burden with physical health. i.e., which health habits mediate the observed relationship between stressors and physical health, and which forms of illness are most likely to be influenced by caring stressors?
Torti F. M. et al. (2004), <i>A multinational review of recent trends and reports in dementia caregiver burden</i> <u>Alzheimer Disease &amp;</u>	Carers of people with dementia. 93 articles that addressed 5 key questions re relationship people with dementia and carer burden, from North America, Europe, Australia & Asia ie:1) Do aspects of		Characteristics that influence carer outcomes are the types of personal care tasks required, the hours of care each day and the amount of supervision needed. In addition, behavioural problems are more burdensome than physical problems. Carers who live with the care recipient exhibit increased depression and anxiety.' p100. Q1) Netherlands	Critical difference in cultural expectations, which must be understood if effective interventions are to be undertaken." p 107 '.some interventions that combine a	Need for larger scale studies 'that evaluate interventions in adequately powered research studies. Future research should test culturally appropriate interventions

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<p><u>Associated Disorders</u> Vol 18 No. 2 pp 99-109</p>	<p>dementia affect depression/psychosocial burden; 2) do characteristics of carer independently predict degree of burden? 3) psychological and/or physical status of carer impact on outcome of dementia; 4) support systems or interventions make a difference? ; 5) interventions directed at people with dementia make a difference?</p>		<p>study showed less severe dementia associated with negative experiences - possibly due to less predictable clinical behaviour of people with dementia. p102 Q2) 'female caregivers .. are more stressed in the caregiving role... and spouses experienced less burden than non-spousal caregivers'. p103 Q3) 'Amount of caregiving time and impaired sense of identity of caregivers predicted the breaking point, as did patients' clinical fluctuations, nocturnal deterioration and mis-identification of the caregiver.' p104 Q4) 'Social participation is associated with greater caregiver life satisfaction however .. can be a source of stress if they are perceived to be inadequate' p104 In contrast to the mixed picture presented in many US studies, an Australian study strongly supports caregiver intervention' p106.- (Brodsky et al. 1993) Q5) psychosocial and pharmacological interventions - 'The results showed improved psychosocial health-related quality of life in those randomized to the memory clinic intervention, although not all of the psychosocial instruments used detected this improvement p107(Loguidice D et al. 1999)</p>	<p>number 9of different approaches are successful in reducing caregiver burden and delaying time to nursing home admission.' p108</p>	<p>tailored to the needs of these groups that combine methods demonstrated to be effective in reducing burden and improving caregiver outcomes." P 108</p>
<p>Vitaliano P, Zhang J, Scanlan JM (2003) <i>Is Caregiving hazardous to one's physical health? A meta-analysis</i> <u>Psychological Bulletin</u> Vol.129, No.6 pp.946-972</p>	<p>23 studies that compared physical health indicators in family caregivers of people with dementia to health indicators in no caregivers who were generally matched on age and sex. Inclusion data bases search of reports of caregivers of people with dementia and physical health problems or illnesses or physiology; English only; till 2001Exclusion non-data based, non-dementia carers; didn't have health or physiological data; lacked non-carer comparison group</p>	<p>Physiological indicators - stress hormones and neurotransmitters and immunologic, cardiovascular and metabolic functioning. Health indicators - self-reported health.</p>	<p>"Caregivers had a 23% higher level of stress hormone and a 15% lower level of antibody responses than did non-caregivers....doubly prospective studies of caregiving should be performed to clarify the causes of such added risk ... By helping caregivers to maintain their health, such interventions should also help care recipients and society" p966</p>	<p>Assessments that rely solely on self-reports will lead to a targeting of resources away from some caregivers (e.g. men) who may be unwilling or unable to express their distress (Lutzky &amp; Knight 1994 p518) " P966</p>	<p>Research design should include assessments of individual differences and other health indicators, target high risk caregivers and be used to develop cost-effective treatment for those who can profit most from interventions.</p>
<b>Disabilities</b>					
<p>Cummins RA (2001) <i>The subjective well-being of people caring for a family member with a severe disability</i></p>	<p>Carers of relative with severe disability within their family. Carer of relative with severe disability within their family. Approx 4000 from Aust Centre for QOL form the basis for</p>	<p>Stress, depression and QOL</p>	<p>"Care givers of people with severe disability are at extreme risk of being highly stressed, clinically depressed, and with a subjective QOL that is way below normal... Children with disability have a higher risk of abuse... and it would not be surprising to find ... a relationship to the degree of family</p>	<p>Increased public expenditure directed to the care of people with severe disability is needed.</p>	<p>Although increased expenditure and allocation of public resources is advocated, whether this involves support for care inside or outside the</p>

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<i>at home: A review.</i> <u>Journal of Intellectual &amp; Developmental Disability</u> Vol.26, No.1, pp.83-100.	systematic search. Begins with historical review, 12 previous reviews, 8 qualitative studies, 8 comparing different forms of disability, 17 studies measuring stress and distress, 8 on subjective QOL, 7 on other measures of subjective well-being. Central questions: examine consequences of providing care on family members. Consequences are stress, reduced QOL and depression		stress". Advocates increased public expenditure directed to the care of people with severe disability, aiming to reduce caregivers' high risk of stress, clinical depression, and abnormally low QOL.		family is an issue that remains undetermined.
<b>Frail aged</b>					
Goldstein NE and Morrison RS (2005) <i>The intersection between geriatrics and palliative care: a call for a new research agenda.</i> <u>Journal of the American Geriatrics Society</u> , Vol. 53, pp. 1593-1598.	This is not a systematic review but a discussion paper describing the potential for using palliative approach with frail older people and outlining a research agenda. All carers for frail aged, including spouses and adult children	Paper looks at all types of outcomes for carers (and patients) including anxiety, depression, mortality, quality of life, needs and burden.	"If the field of geriatrics is to encompass the needs of all older adults, it needs to actively integrate within it the principles of palliative care and promote and support the development of new investigators in palliative care research."	The majority of scales used to assess caregiver burden have been developed for patients with dementia or cancer; older patients with heart or lung disease have different care needs.	Research required to examine burden in caregivers of geriatric patients with end-stage organ failure, especially given that these individuals tend to be adult children with families of their own.
<b>Mental illness</b>					
Kuipers E, Bebbington PE (2005) <i>Research on Burden and Coping Strategies in Families of People with Mental Disorders: Problems and Perspectives.</i> In Sartorius N et al. (Eds) (2005) <u>Families and Mental Disorders</u> . John Wiley & Sons	Carers of people with mental illness. 500 articles (criteria were "carer" and "burden" from 2000 to 2003). Also analysed British data on the mental health of carers aged 16 years or older in England, and the extent to which caring impacted upon their health (from British General Household Survey, 2000)	Carer burden	Crucial for carers to feel that they can take a break or have some respite, that they are not alone, and that their social support is effective. Likewise, it is important that they do not perceive caring as having had a negative impact on other parts of their life.	Services should routinely address carer inputs (not just carer burden), carer needs and the role carers can play in long term care.	Methodological problems of research are discussed - lack of consistent outcome measures.

## Attachment Three

### Summary of the study literature of the needs of carers

**Table A13 Summary of the study literature of the needs of carers – general**

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Bittman, M Hill, T and Thomson, C (2007) <i>The Impact of Caring on Informal Carers' Employment, Income and Earnings: a Longitudinal Approach. Australian Journal of Social Issues</i> 2007, 42, 2: 255-272.	Results for carers from a longitudinal study that examined the effect of caring on employment, hours worked and earnings, as part of a broader project that aims to map the longer term effects on carers' life circumstances	General outcome measures (self-rated health and life satisfaction) of carers	Results in line with the ABS estimate of 12.5% of the adult population, and the proportion reporting intensive care responsibilities stays stable across all waves – being relatively small at 3-4% of females and 2% of males. The ABS estimate is that primary carers represent 2.4% of the adult population. “This suggests that it is difficult to combine even a moderate amount of caring with full-time employment.”	Any caring may lead to exclusion from the labour market, and the loss of income is significant. As caring responsibility intensifies the rate of full-time employment falls. Only 10 to 15 per cent of carers who have intensive care responsibilities work full-time. Implies programs for working carers will be targeted at those with fewer care responsibilities	Important to continue investigating what sustains people in the dual roles of employment and caring to minimise the effects on those prepared to care
Briggs H and Fisher D. (2000) <i>Warning – caring is a health hazard. Carers Association of Australia. Canberra, 2000</i>	Reviews results of the 1999 national survey of carer health and wellbeing. Included reference to previous reviews.	Health and well-being levels of practical support received by carers and tasks and impacts of carer roles	A profile of carers in Australia based on 1449 surveys, including variation between different groups	That carer needs be taken into account in all service systems	Support further research into how, and to what extent, the needs of carers are being met in the formal health and community care sector.
Chambers M, Ryan AA, Connor SL (2001) <i>Exploring the emotional support needs and coping strategies of family carers. Journal of Psychiatric and Mental Health Nursing, Vol. 8, No.2, pp.99-106.</i>	UK: Northern Ireland. 14. Family carers: 2 males and 12 females caring for relatives with different medical conditions and needs. Duration of caring: 2-10 years. Some employed full-time or part-time. Sample: purposive, selected from known family carers in a local health board area.	Semi-structured focus group interviews. Interview guide questions based on previously identified needs of family carers: carers' support needs, emotional impact of caring and coping strategies, plus issues raised by participants. Qualitative, exploratory, part of a larger project: Assisting Carers Using Telematics Interventions to meet Older persons Needs (ACTION).	Themes: 1) Support needs: informational, communication with other carers by phone and support group re: loneliness and practical tips. 2) Emotional impact: fear of future t; guilt and sense of responsibility: reasons for not using respite; anger about complexity of accessing financial assistance. 3) Coping strategies and adaptation: trial and error learning; greatest difficulties: care recipient's health deterioration, antisocial behaviour, mood swings or aggression.	Preparation for caring: information on services and training prior to hospital discharge. Professionals should provide support, advice, carer participation in decision-making; inform carers of right to separate assessment of their ability to care. Develop support groups for empathy, social contact and sharing of practical information/tips in problem-solving.	Findings corroborate previous quantitative research.
Edwards NI and Meara J (1999) <i>Care of disabled</i>	UK - reviews national statistics and concepts of needs and interventions from	No specific outcome measures - uses a mixture of survey data and	No specific results, as not a systematic review and describes a number of	General policy prescriptions for services, respite and appliances	None reported

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<i>older people in the community</i> <u>Reviews in Clinical Gerontology</u> 9; 363-369.	a collection of studies	policy documents	general policy prescriptions		
Eurofamcare Consortium (2005) <i>Services for supporting family carers of older dependent people in Europe</i> . Institute for Medical Sociology, Hamburg	Summary of main findings from the Eurofamcare study conducted by 8 research groups and based on 6 national surveys.	Perceived burden, state of health and quality of life	The family caregivers reported the need for help in areas of domestic (92%), emotional/psychological/social (89%), mobility (82%), financial management (80%), organising and managing care and support (79%), health care needs (79%), physical/personal care (66%), financial support (36%)	More equally distributed services of greater flexibility and more individualised. Hard to provide more for caregivers when clients have unmet needs	These findings have to be integrated with a follow up survey and future analyses need to classify caring situations.
Farkas, J. I. and C. L. Himes (1997). <i>The influence of caregiving and employment on the voluntary activities of midlife and older women</i> . <u>Journals of Gerontology Series B-Psychological Sciences &amp; Social Sciences</u> Vol 52, No. 4 ppS180-9.	1988 National Survey of Families and Households (incl. questions re assistance provided to seriously ill or disabled co-residential and non-coresidential kin members, friends and nonrelatives): respondents aged 35-74 who provided information on their voluntary activities.	duration of caring, and intensity	The study 'evaluated the extent to which midlife and older women caregivers reduce their participation in voluntary activities. From the results of this study we conclude that women do not reduce their outside activities in response to additional caregiving requirements, and in some cases, caregiving is associated with higher levels of participation.' pS187. 'The higher levels of social participation among caregivers ... cast some doubt on the notion that caregivers suffer a 'loss of self' in the caregiving role. Even when those caregivers who provide the most intensive care are examined, supplemental activity participation is not reduced.' pS188	While no researcher denies the added stress that occurs when the caring role is added to the lives of women, caring women, especially those who are employed, appear to be coping remarkably well.	Additional research on the ways in which women are selected into, and out of, the role of carer, the ways in which they use a variety of roles to compensate and complement one another, and the successful strategies they employ for managing their time and responsibilities is likely to improve our understanding of the needs of caregivers and the types of support most beneficial to them.' p S187
Hancock P, Jarvis J and L'Veena, T (2006) <i>Barriers to Respite Services: A Case Study of a Sub-group from an Older Carer Program in Western Australia</i> . <u>Australian Journal of Primary Health</u> 12, 2: 113-123	WA with 62 older carers in the Red Cross Older Carers Program. Older Carers Program is run by Red Cross WA and provides case management and access to respite	In depth semi-structured interviews	High levels of overall satisfaction but some sub-groups needed more tailored services to meet their needs, particularly rural and single parents and high need care recipients. Barriers were values and attitudes (duty, not admitting weakness, and feelings of guilt) and practical problems (lack of information, confusion regarding services, availability, quality, transport and finances).	Highlights importance of recognising diversity of needs. Barriers to accessing respite can be overcome by earlier detection of those experiencing problems. Better liaison between older carers, GPs and respite providers. Fewer options are available in rural settings	More of this type of research should be focussed on the needs of indigenous groups and CALD communities.

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Harris NM, Thorpe R, Dickinson H, Rorison F, Barrett C and Williams C (2004) <i>Hospital and after: experience of patients and carers in rural and remote north Queensland, Australia. Rural and Remote Health</i> , Vol.4, no.246, no page numbers (online).	Family caregivers of people in rural and remote areas who have been discharged from hospital following surgery and require further care and rehabilitation in the community. Four vignettes are presented, based on in-depth qualitative interviews with 12 patients and 12 carers discharged from Townsville General Hospital into rural and remote communities in north Queensland, Australia.	In-depth qualitative interviews focusing on social, economic and cultural impacts of early discharge from hospital into rural and remote communities. Patients and carers were contacted during the hospital stay and 2-5 weeks after discharge. The carers and patients in the study were not necessarily related.	"The four stories described reveal the high financial and emotional costs, for patients and carers, of negotiating a healthcare system a long way from home. Challenges faced included inadequate admission planning, excessive accommodation and transport costs, and lack of post-discharge support services in home communities, as well as business failure, marital and family strain. There was an over-reliance on carers who lacked medical caring expertise, had other major commitments (family and work) and who may have had a tenuous and uncertain relationship with the patient."	Discharge processes need to ensure patients and carers are linked to adequate support services in their home communities. There is also a need to improve communication about admission, travel benefits, accommodation options and care requirements following discharge.	None referred to by authors
Lee C (2001) <i>Experiences of family caregiving among older Australian women</i> <u>Journal of Health Psychology</u> 6, 4: 393-404	Reports on results from the Australian Longitudinal Study of Women's Health (ALSWH) 40,000 women over 20 years in three cohorts (young, middle aged and old)	Women are surveyed every three years about their health and well being and social circumstances.	Reports on the caring experiences of women in the older cohort	Informs the understanding of needs of women carers for carer support programs	Contribution to the overall understanding of women caregivers' needs
Lee C and Porteous J (2002) <i>Experiences of family caregiving among middle-aged Australian women</i> <u>Feminism and Psychology</u> 12, 1: 79-96	Reports on results from the ALSWH mid age cohort	Women are surveyed every three years about their health and well being and social circumstances	Reports on the caring experiences of women in the mid age cohort	Informs the understanding of needs of women carers for carer support programs	These results have been followed up with more specific reports to draw out implications for carer support programs
Lee C and Gramotnev H (2007) <i>Transitions into and out of care-giving: Health and social characteristics of mid-age Australian women</i> <u>Psychology and Health</u> 22: 193-209	Reports on results from the ALSWH mid age cohort	Women are surveyed every three years about their health and well being and social circumstances	Reports on the characteristics of women in the mid age cohort who report having made transitions into and out of care-giving	Informs the understanding of needs of women carers for carer support programs at points of transition into and out of caring roles	These results have been followed up with more specific reports to draw out implications for carer support programs
Northcote J and Hancock P (2005) <i>Differences in Satisfaction Ratings of</i>	177 clients of Red Cross Carer Respite Centres in WA. Older Carers Program is run by Red Cross WA and provides	In depth semi-structured interviews	Half the respondents found a barrier to accessing respite and a third of the carers of children with disabilities felt	More attention to younger people with disabilities as these not well integrated into CRC activities.	More extensive quantitative research on why people do and do not use respite in

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<i>Carer-Respite Services between Carer Types: Results of a Western Australian Evaluation. Australian Journal of Primary Health</i> 11, 3: 88-94	case management and access to respite		their needs were not being positively met by the CRC.		order to understand the differences in the levels of satisfaction between groups of caregivers
Pearce T (2000) <i>Being an Indigenous carer. Aboriginal and Islander Health Worker Journal</i> . Vol.24, No.1, pp. 21-22.	This is an opinion piece written by an Indigenous health worker who is also a carer for a child with a disability and a wife who was ill.	None used	The author sees the caring role as an intrinsic part of caring and development in family relationships. Existing health programs are seen as unhelpful because they do not take into account the values and styles of Aboriginal culture and represent an agenda of forced assimilation into the mainstream.	The author is critical of institutional placement the lack of alternatives that make it easier for those people to support their family members. He argues that Aboriginal men could play a far greater role in providing care given the opportunity and appropriate support by government, policy makers	None described
Schofield H, Herrman H, Bloch S, Howe A & Singh B (1997). <i>A profile of Australian family caregivers: diversity of roles and circumstances. Australian and New Zealand Journal of Public Health</i> 21(1):59-66	Based on a state-wide random population survey of 26,000 households, from which self-identified carers were selected (N= 976) and interviewed to create a socio-demographic profile including the duration of caring	Characteristics of care recipients and their difficult behaviours, as well as the carers' physical and emotional wellbeing, their need for assistance and use of informal and formal supports	Findings reflected the heterogeneity of both caregivers and care recipients, and the diversity of their roles and circumstances. Differences with non-caregivers physical health and emotional well-being	Routine review of the caregiver needs to be included in community care, particularly to redress the information gaps, and for information to be available from GPs	Highly consistent with the ABS survey results and has a useful evidence base for program development Routine review of the caregiver needs to be included in community
Tamiya, N., K. Yamaoka, et al. (2002). <i>Use of home health services covered by new public long-term care insurance in Japan: impact of the presence and kinship of family caregivers. International Journal for Quality in Health Care</i> Vol 14, No. 4, pp. 295-303.	Japanese study of whether the presence of a family caregiver impacts service use following introduction of long-term care insurance.	Cross-sectional, mailed, self-administered questionnaire survey to family caregivers of 237 applicants for long-term care insurance with a caregiver, and 33 applicants without a caregiver	The use of major services may be decided more by the needs of caregivers than by the care level of the recipient.	Attention be given to including the caregivers role in long term care services	None described
van Exel J, Moree M, et al. (2006) <i>Respite care: An</i>	273 informal carers in the Netherlands (both users and non-users of respite	Questionnaire addressed characteristics of carer, the care	Found that one out of three informal carers that presented themselves at a	Respite care has been demonstrated to be an effective	"To assess the actual effectiveness of respite care,

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<p><i>explorative study of demand and use in Dutch informal caregivers.</i>  <i>Health Policy</i>, Vol.78, No.2-3, pp.194-208.</p>	<p>services).</p>	<p>recipient, and the care giving situation, in terms of objective and subjective burden, well-being and process utility.</p>	<p>regional support centre currently use respite. "The care giving experience and need for respite was shown to depend on characteristics of the caregiver, care recipient and the care giving situation... To sum up, our results indicate that respite care meets the needs and desires of many caregivers, it appears to be effective in reducing caregiver burden, and users are fairly satisfied with the respite they receive. Still, current programmes could do better in reaching the caregivers most in need (and vice-versa!)" p205.</p>	<p>and sometimes health budget-saving way of reducing carer burden, however, less is known about carers' needs and desires regarding support.            "Two main challenges for policy are, first, to identify and direct funds at efficient respite care programmes and, second, to develop an information strategy that helps caregivers overcome the obstacles they perceive for using respite care, in particular care recipient resistance (and sometimes their own)" p205.</p>	<p>a longitudinal design would be more appropriate. In addition, such a design would make it possible to investigate the optimal quantity of respite care supply and to classify which caregivers benefit most from (different types) of respite care...., as well as assessment of the cost-effectiveness of respite care." p205. Study didn't really differentiate between types of respite care in results.</p>

**Table A14 Summary of the study literature of the needs of carers - cancer and palliative care**

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<p>Albinsson L and Strang P (2003) <i>Differences in supporting families of dementia patients and cancer patients: a palliative perspective.</i> <i>Palliative Medicine</i>, Vol. 17, pp. 359-367.</p>	<p>Health care providers attending national courses (4 courses on dementia, 1 course on palliative care). Total sample was 437 (316 from dementia care courses and 121 from palliative care course). Participants in the courses were expected to be experienced and motivated staff seeking new information. Over 60% of those attending the dementia courses had worked in the area for more than 5 years; the corresponding figure for the palliative care course was 50%.</p>	<p>Participants were asked to respond to open-ended questions: "What are the two most important measures for supporting families of late-stage dementia patients/severely ill cancer patients in a palliative phase?"</p>	<p>Both staff groups felt the most important intervention was to listen to family members and provide information, though listening was emphasised more in the palliative group (significant to <math>p &lt; 0.001</math>). Staff in dementia care felt that support groups for families, respite care and education were essential, along with trying to relieve family members' feelings of guilt. Staff in palliative care focused more on the importance of being available, creating a sense of security and supporting the family after the patient's death.</p>	<p>Health professionals regard good communication and listening as essential components of support for family caregivers in both dementia and palliative care. Their opinions about the need for other types of support differ according to diagnosis, probably because of the different trajectories of the illnesses.</p>	
<p>Brazil K, Bedard M, Willison K and Hode M (2003) <i>Caregiving and its impact on families of the terminally ill.</i> <i>Aging &amp; Mental Health</i>, Vol.7, No.5, pp.376-382.</p>	<p>151 family caregivers to palliative patients (who had died), recruited over a two-year period through two community nursing agencies in an urban region of the province of Ontario, Canada (response rate 51%). 79% were women, 66% were spouses, average</p>	<p>Structured quantitative interviews. Patient characteristics included demographics, diagnosis, ADLs. Carer characteristics included demographics, employment status, health status, caring experience (Caregiver Reaction</p>	<p>Almost all carers (89%) reported that the patient had experienced some functional restriction and required assistance with ADLs. The physical demands of caring increased substantially in the last three months of life. Increased patient need for assistance with ADLs was the</p>	<p>Findings suggest that interventions should focus on reducing the amount of physical care provided by family carers.</p>	<p>None reported</p>

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
	age 61 years.	Assessment)	strongest predictor of greater caregiver burden. There was a strong association between greater burden and poorer self-reported physical health.		
Brazil K, Bedard M, Krueger P, Abernathy T, Lohfeld L and Willison K (2005) <i>Service preferences among family caregivers of the terminally ill. Journal of Palliative Medicine</i> , Vol. 8, No. 1, pp. 69-78.	Canadian study of service preferences amongst 373 caregivers of the terminally ill.	Telephone interviews at two points in time - when the terminally ill person was designated as palliative, and 5 months later.	The five services caregivers reported as the most valuable included: in-home nursing care (90.7%); family physicians (45.6%); medical specialists (46.4%); housekeeping (23.6%); and, religious support (11.3%).	The five services they would have liked to receive more of were: housekeeping (13.1%); caregiver respite (10.2%); in-home nursing care (8%); personal support workers (4.6%) and self-help/support groups (3.8%)	None reported
Cameron JI, Franche RL, Cheung AM and Stewart DE (2002) <i>Lifestyle interference and emotional distress in family caregivers of advanced cancer patients. Cancer</i> . Vol.94, No.2, pp.521-527.	44 family caregivers to advanced cancer patients, recruited through a hospital oncology program in Toronto, Canada (response rate 46%). 57% were women; 86% were spouses, average age 56 years.	Structured quantitative interviews. Emotional distress (Profile of Mood States short form), lifestyle interference (Caregiving Impact Scale; Caregiver Activity Restriction Scale), amount of care provided (Caregiver Assistance Scale, developed for this study)	Purpose of the study was to examine whether lifestyle interference mediates the relationship between the act of providing care and the negative emotional consequences. This was supported by the data analysis: more lifestyle interference was associated with greater carer distress, regardless of the level of care provided.	Family caregivers' inability to maintain participation in valued activities and interests is associated with increased emotional distress. Therefore, home care policies that provide services in the home or respite care would be expected to alleviate distress by enabling carers to have more time for themselves.	Other factors associated with emotional distress, such as mastery, social support and coping skills, could be explored in order to build a more comprehensive model of caregiver emotional well-being.
Kelly B, Edwards P, Synott R, Neil C, Baillie R and Battistutta D (1999) <i>Predictors of bereavement outcome for family carers of cancer patients. Psych-oncology</i> . Vol.8, pp.237-249.	178 family carers of palliative patients with a cancer diagnosis, recruited at the time of referral to a hospice homecare service (Mt Olivet) in Brisbane, Australia. 76% were female, 60% were spouses, mean age 57 years (range 22-87)	Measures were taken at the time of referral (time 1) and following the death of the patient, on average 4 months post-bereavement (time 2). Time 1 variables were carers' physical and psychological symptoms (DSSI, GHQ, and Guilt Scale), social functioning (including a Life Events Inventory), adjustment and coping, past health and psychosocial history, quality of relationship with patient. Patient measures (Karnofsky, MMS, QL index, DSSI, GHQ, and Suffering Index) were also taken at Time 1.	The main predictor of caregiver bereavement outcome was the level of psychological distress at time of referral. More concurrent adverse life events, lower levels of practical assistance and the quality of the relationship with the patient (lower levels of 'care') also predicted poorer carer health and wellbeing shortly after bereavement. Individual factors that predicted bereavement outcomes included experiences of childhood separation from parental figures, previous experiences of bereavement and individual coping styles (accepting responsibility and avoidance of emotion).	The breakdown of cancer diagnoses in the sample reflected the most common malignancies (i.e. gastrointestinal and lung cancers) in the Australian community, particularly among males, who made up three-quarters of the patient group. However, there was a very low rate of breast cancer diagnoses among the sample (which was representative of the overall proportion of cancer diagnoses among those referred to this hospice home care unit). This pattern of referral (i.e. lack of	None reported

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
		At Time 2, carers' physical and psychological symptoms were assessed again, along with bereavement symptoms (Impact of Events scale, Bereavement Phenomenology Measure)	There was a significant association between greater importance of religiosity/spirituality at time of referral and poorer carer health following bereavement.	referral) requires further investigation "and may reflect patterns of care of women, and of breast cancer patients, in this community" p246.	
Kissane DW, McKenzie M, Bloch S, Moskowitz C, McKenzie DP, O'Neill I. (2006) <i>Family focused grief therapy: a randomized, controlled trial in palliative care and bereavement. Am J Psychiatry.</i> 163(7):1208-18.	After screening of 257 families of patients dying from cancer: 183 (71%) were at risk, and 81 of those (44%) participated in the trial. They were randomly assigned (in a 2:1 ratio) to family focused grief therapy (53 families, 233 individuals) or a control condition (28 families, 130 individuals).	The primary outcome measures were the Brief Symptom Inventory, Beck Depression Inventory, and Social Adjustment Scale. The Family Assessment Device was a secondary outcome measure. Analyses allowed for correlated family data.	The overall impact of family focused grief therapy was modest, with a reduction in distress at 13 months. Significant improvements in distress and depression occurred among individuals with high baseline scores on the Brief Symptom Inventory and Beck Depression Inventory. Global family functioning did not change. Sullen families and those with intermediate functioning tended to improve overall, whereas depression was unchanged in hostile families.	Family focused grief therapy has the potential to prevent pathological grief. Benefit is clear for intermediate and sullen families. Care is needed to avoid increasing conflict in hostile families.	"Bereavement care should begin during palliative care and should include screening to aid recognition of high risk families, who become the focus in a family-centered model of care. However, replication of this trial is needed before we can confidently call for the inherent place of our model in palliative care." (p.2617)
McGrath P, Patton MA, Olgivie K, Rayner R, Holewa H (2006) <i>"It's very difficult to get respite out here at the moment": Australian findings on end-of-life care for Indigenous people. Health and Social Care in the Community.</i> Vol.14, No.2, pp.147-155.	MNH&MRC funded study exploring carer needs, including need for respite care or day care. 72 interviews conducted (patients = 10; carers = 19; Aboriginal healthcare workers = 11; healthcare workers = 30 and interpreters = 2) in 4 geographical areas in the Northern Territory	Naturalistic observation study	Findings reflect a serious need for Indigenous respite services, coupled with a severe deficiency in the present availability of these services, especially within rural and regional areas. Lack of local respite services was documented to be negatively impacting upon the ability of carers to fulfil their caring duties and was found placing undue physical, emotional and economic stress upon carers, patients and their families. Lack of access to local respite services was found to be forcing rural and regional patients to relocate to metropolitan areas away from family, community and land to which strong ties are held. Also lack of respite services was found to obstruct patients' and carers' wishes for death to occur in the local community.	Tackle the obstacles preventing local respite services being established in areas close to where patients and carers live. Obstacles to the provision of respite care to Indigenous Australians: beliefs about families looking after their own, resourcing restrictions, limited staff availability in local areas, and problems with hostel use in metropolitan areas. For residential respite services, outstations could be a convenient and attractive location. Also, other families in the community could be supported to provide respite in order to provide an alternative to having to relocate patients to the metropolitan centres.	None reported
Payne S, Smith P, Dean S (1999) <i>Identifying the</i>	A cross-sectional study of 39 (15 male & 24 female) informal carers (families and	Psychological morbidity - General Health Questionnaire (GHQ);	33 (84%) reported above normal levels of psychological distress and 16 (41%)	There is a need to develop effective ways to offer emotional	Longitudinal study of carers

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<i>concerns of informal carers in palliative care.</i> <u>Palliative Medicine</u> , Vol.13, No.1, pp.37-44.	friends of cancer patients receiving palliative care in the community) recruited from 2 areas in southern England (Portsmouth and Swindon). Carers mean age was 60 years old (range 35-89 years) with majority between 55 and 74 years.	Caring burden - Carer Strain Index; semi structured interviews - perceptions of caring	experienced high levels of strain related to caring. Younger age and being female were found to be correlated with psychological morbidity and strain. Perceptions - participants reported life restrictions, emotional distress and limited support. The present study indicates that carers below 60 years if age and women may be the most in need of additional support.	and physical support for relatives not only to sustain their role as informal carer but also to maintain their mental and physical health.	
Proot IM, Huijer Abu-Saad H, Crebolder HFJM, Goldsteen M, Luker KA and Widdershoven GAM (2003) <i>Vulnerability of family caregivers in terminal palliative care at home: balancing between burden and capacity.</i> <u>Scandinavian Journal of Caring Sciences</u> . Vol.17, pp.113-121.	13 family caregivers for palliative patients at home in the Netherlands, 11 were women, 9 were spouses, mean age 51 years (range 28-80)	Open-ended interviews using a guide developed through previous interviews and review of the literature. Topics encompassed the experiences, difficulties and needs of family carers and the service provision and adequacy in addressing these difficulties and needs. Data were analysed using the constant comparative method as described in grounded theory.	Factors that increased carers' vulnerability (to fatigue and eventual burnout) were increasing physical and mental burdens, fear of the future and inability to plan, restriction of their normal activity patterns and habits, and the loneliness experienced as a result of holding back information from the patient to protect them from emotional distress. Factors that that decreased vulnerability included continuing previous activities, including work, setting limits on their involvement (e.g., by refusing to be trained to give injections if this is too distressing) and receiving good support from family, friends and professionals.	Good support from home care professionals falls into three categories: instrumental, emotional and information related. Instrumental support needs to be available to relieve physical burden (e.g., when the caregiver is ill or has been sleep deprived due to caring for the patient at night). Emotional support concerns support in keeping control, in continuing one's own activities and social contacts, and in maintaining (realistic) hope. "Being included by the providers in the care of the patient and being involved in the decision making process is highly supportive for family caregivers." (p.119)	None described
Stajduhar KI (2003) <i>Examining the perspectives of family members involved in the delivery of palliative care at home.</i> <u>Journal of Palliative Care</u> . Vol.19, No.1, pp.27-35.	12 dying patients, 13 family members caring for them and 47 people who had provided care at home to family members who had since died. 78% of family caregivers were women, mean age 58 years, 22% working full time, 15% working part time, 7% took leave of absence from work to provide care. 33% were spouses and 70% shared a household with the patient. 67% of patients had a diagnosis of cancer.	Data included participant observation field notes, interviews and documents (e.g., news stories, policy statements, and government reports) published in Canada 1990-2000. A total of 130 hours of observation were conducted in the homes of 13 palliative caregivers. Open-ended interviews were conducted with 31 people. Transcripts were	The decision to provide care at home was influenced a belief that privacy and self-determination could be maintained there. Care at home would be better than in hospital, but may cost more (e.g., for analgesics, home support etc). Home environments and family relationships changed, carers experienced a loss of their core identities (as spouses, children etc) as the care role became a 'job' they had to do.	Reduce the number of different health care providers entering the home and improve communication among health care agencies. Health care professionals could educate family caregivers about what changes to expect in the home environment to prepare them better. Professionals visiting the home need to be able to develop respectful and	None described

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
	Study also included a secondary sample of health care providers (n=28) and administrators (n=10).	read and entered into NVivo for analysis. Almost half the caregivers were asked to respond to the emerging analysis to validate the findings.	There was a loss of privacy as the home was constantly visited by different health care professionals.	collaborative relationships with family caregivers. Some carers felt exploited by the health care system, particularly when they could not get access to the help they needed.	
Stajduhar KI, Davies B (1998) <i>Palliative Care at Home: Reflections on HIV/AIDS Family Caregiving Experiences.</i> <u>Journal of Palliative Care</u> , Vol.14, No.2, pp.14-22.	Canadian study in-depth interviews examined the day-to-day experiences of 7 family members (aged 31-65 years) providing care at home for their dying loved one with HIV and/or AIDS		Findings reflects a significant need for interventions designed to provide direct and effective support for family members care for a loved one with HIV/AIDS. Care givers use various strategies to deal with the demands of care giving.	Easy and prompt access to health care services esp. home care services was an essential factor that allowed caregivers to continue to care for their loved one at home.	Paper suggests that studies addressing caregivers' needs and their perceptions of helpful behaviours from health care providers would clarify how to design and implement effective support programs for those caring for a dying loved one at home.
Stajduhar KI, Davies B (2005) <i>Variations on and factors influencing family members' decisions for palliative home care.</i> <u>Palliative Medicine</u> , Vol.19, No.1, pp.21-32.	Family members (13) providing care to a palliative patient at home, bereaved family members (47) and with health care providers (25). Canadian.	Part of a larger ethnographic study. Canadian. Data from participant observations and in-depth interviews with family members (13) providing care to a palliative patient at home, interviews with bereaved family members (47) and interviews with health care providers (25).	Decisions are characterised by three types: uninformed decisions (little consideration to implications) – caregivers - felt unprepared for their roles; indifferent decisions (- reluctantly agreed to provide care at home)- caregivers also unprepared, placed own needs aside, and felt little or no choice in the decision for home care; and negotiated decisions (for home care with the dying person) - caregivers seemed to cope better with caring, felt they had a choice in decision-making and, in general, were more satisfied with their decisions.	Findings suggest interventions are needed to enhance caregivers' choice in the decision-making process, improve care for the dying in hospital and consider the development of alternative options for care. The paper made suggestions about ways to assist families in making negotiated decisions -e.g. healthcare providers mediating discussions.	None described
Terry W, Olsen LG, Wilss L and Boulton-Lewis G (2006) <i>Experience of dying: concerns of dying patients and of carers.</i> <u>Internal Medicine Journal</u> , Vol. 36, pp. 338-346.	18 family caregivers of palliative patients (who had died) took part in focus groups. 16 were women, time since the death of the patient ranged between six months and 4 years. Interviews were conducted with 36 patients of the palliative care service, 13 were women, mean age 68 years (range 44-92), and none were connected with the carers involved in this study. Most died within 5	Three focus groups were conducted using a schedule of open-ended questions over a 90-minute period. Patient interviews were conducted after admission to the palliative care service and consisted of a series of open-ended questions with follow-up specific questions.	Some fundamental differences between patients' and carers' views, particularly in the areas of privacy and autonomy. While patients expressed a wish to retain control over decision making and keep certain information about their illness and their emotions private, carers believed they should be provided with complete information, even when the patient explicitly refused to share this	Health professionals may need to be more open with carers about what information can and cannot be provided (p345). Carers had detailed and practical concerns about medication and wanted help in establishing simple, robust routines that would not break down under fatigue and emotional strain. They wanted written information,	None described

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
	days of giving the interview.		with them. They saw themselves as the most reliable sources of information about the patient, and as stakeholders in their own right in decisions about managing the illness. "Carers demanded recognition of their role and access to information about the patient was valued as confirming recognition of the carers' role by health professionals." (p.340)	with sample medication charts and an 'algorithmic approach' to common dosing dilemmas. Most said they would have benefited from more support and more information. "Many said they should have had support 'forced upon them' because they were tired and not able to assess their own needs." (p.343)	
Visser G, Klinkenberg M, Broese van Groenou MI, Willems DL, Knipscheer CPM, Deeg DJH (2004) <i>The end of life: informal care for dying older people and its relationship to place of death.</i> <u>Palliative Medicine</u> , Vol.18, No.5, pp.468-477.	56 persons who have been primary caregivers of older relatives in the last three months of their lives completed a written questionnaire. Part of the Longitudinal Aging Study Amsterdam (LASA) an ongoing study on physical, cognitive, emotional and social functioning of older people in the Netherlands.	Face to face interviews with the relatives was used to collect data on the care receivers. Functional limitations of the care receivers were assessed using a questionnaire. Information was collected on chronic diseases. For the informal caregivers data was collected on: socio-demographic characteristics; informal care tasks; availability of other caregivers.	Informal caregivers provide a considerable amount of personal, household, and management care. Secondary informal caregivers and formal caregivers assisted resident primary care givers less often. Primary caregivers who felt less burdened, who gave personal care more intensively, and/or who were assisted by secondary carers, were more likely to provide informal end-of-life care at home until the time of death. Concluding that informal care at the end of life of older people living in the community is complex, since the care required is considerable and highly varied, and involves assistance from secondary informal caregivers, formal home caregivers as well as institutional care.	More attention is needed to help informal caregivers, since resident caregivers are disadvantaged in several respects (i.e. health, income, assistance from their cares) compared to non-resident caregivers, interventions by formal caregivers should also be directed towards these persons, enabling them to bear the burden of end-of-life care. Demographic results included: men received informal care mostly from their spouse, whereas women obtained most informal care from their daughters or daughter-in-law; primary informal caregivers were predominantly female.	Burden of informal care is one of the most important factors associated with home death. Paper suggests that to increase the opportunity for older people to die at home, more research is needed that identifies conditions under which formal caregivers may optimise informal end-of-life care, and reduce the perceived burden of informal end-of-life caring.
Zapart S, Kenny P, Hall J, Servis B, and Wiley S (2007) <i>Home-based palliative care in Sydney, Australia; the carers' perspective on the provision of informal care.</i> <u>Health and Social Care in the Community</u> Vol 15(2), pp. 97-107.	82 informal carers of patients registered with two palliative care services in Sydney.	Interview schedule, SF36 used on carers and open ended questions about impact and supports needed	Domestic assistance, personal care, medications management and organisational tasks were where help was most needed. Carers' mental health scores were lower than the Australian norms. The extra support required was for information, in-home respite, help with household tasks and financial support.	"The present study supports the view that effective support for carers must recognise the pre-existing relationship between carer and recipient, and the differing needs of individual carers.' (Abstract p. 97)	"The conceptualisation of care-giving must recognise the duality of stress and satisfaction that comes from the established relationship ... The challenge for service providers is to find the means to identify the carer's support needs .. " (p.106)

**Table A15 Summary of the study literature of the needs of carers - dementia**

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Armstrong M. (2000) <i>Factors affecting the decision to place a relative with dementia into residential care</i> <u>Nursing Standard</u> (2000) Vol.14, No.16 pp.33-7	UK study of 4 carers of relatives with dementia - convenience sample of the author's caseload. Semi-structured interviews with carers of people with dementia prior to nursing home placement and four months after placement	Semi-structured interviews - five themes emerged from transcripts: challenges of caring for someone with dementia (physical problems, personal care, challenging behaviour, communication); the personal needs of carers (knowledge and information, personal space, someone to listen, wellbeing of the person with dementia); formal help; support of family and friends; and, carer well being (p.35)	"The prime reasons given for placing their relative into residential care were wandering, aggression, incontinence and physical dependency, although these problems were compounded enormously by the other themes discussed here (i.e., challenges of caring, personal needs of carers, formal help, support of family and friends, and carer wellbeing)"p36 "All carers were adamant about the need for information, knowledge and education'. (p.36)	Carers ...would benefit (from)...increased day care and home respite sitting services; services should be increased at Christmas; and support staff should be knowledgeable about the specific needs of people who have dementia and their carers" (p.33)	None reported
Brodady H, Gresham M and Luscombe, G (1997) <i>The Prince Henry Hospital dementia caregivers' training program.</i> <u>International Journal of Geriatric Psychiatry</u> ,12:183-192.	96 persons less than 80 years old with mild to moderate dementia and their cohabiting caregivers.	MMSE, CDRS (Clinical Dementia Rating Scale; Hughes et al., 1982), IADL and ADL Measures of formal and (indirectly) informal or social support were recorded by caregivers keeping a health diary of all health care visits and medication use for both themselves and the care receiver, as well as rating both frequency of and satisfaction with personal and telephone contacts.	When the training groups were compared with the memory retraining group, caregiver training had a significant effect in delaying nursing home admission and there was a trend towards training delaying patient death (p.189)	"Our impression from our pilot groups was that once the dementia has progressed to the later stages, the benefits of training, education and other approaches diminish for both caregiver and patient. However, early in the course of the dementia, training may have a preventative aspect and may be cost-effective in delaying the need for residential care. If confirmed, this has important implications for policy. For example, it may be effective to divert funds from residential care budgets to caregiver training programmes." p.191	Future research might benefit from a careful comparison of the comprehensive programme described and a targeted, more selective approach. With the latter, the particular needs of individual caregivers would need to be carefully analysed and a tailored package of interventions (delivered) ... so that these can be prescribed accurately (Brodady and Gresham, 1992). P.191
Brodady H, Thomson C, Thompson C and Fine M. (2005) <i>Why caregivers of people with dementia and memory loss don't use services,</i> <u>International Journal of Geriatric</u>	The findings of a literature review were used to develop a typology of caregivers' non-use of services, and then this was applied to a sub-sample of 109 carers of people in the community with dementia or memory loss, in order to investigate the reasons for not using	Use and non-use of community services were key independent variables, and the study examined the characteristics of carers and care recipients related to those factors. Typology of non-use showed key factors were:	The main reason for non-use was perceived lack of need, followed by care recipient resistance. One in three dementia caregivers were not receiving any services, and one in four used only one service; very few were using multiple services. The presence of a	Priorities for action are raising community awareness on the availability of services, normalising service use, de-stigmatising dementia and encouraging processes of referral.	Shows how a typology of service use and non-use can be applied to an existing sample where carer and care recipient characteristics are well described. Used a range of carer

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<u>Psychiatry</u> , :20:537-546.	services. The typology was applied to data from the Victorian Carers Program comparing service users and non-users.	managing at the moment; reluctance to use services; service characteristics impede use; and don't know of the existence of services.	physical disability in the care recipient was significantly associated with service use. GPs did not fill the role of coordinating services. Service availability or affordability were not identified as major impediments to service use.		characteristics, mainly demographic, but not stress or burden or sustainability of the relationship.
Bruce, D. G., G. A. Paley, et al. (2005). <i>Physical disability contributes to caregiver stress in dementia caregivers</i> . <u>Journals of Gerontology Series A-Biological Sciences &amp; Medical Sciences</u> Vol 60, No. 3, pp 345-9.	Australian study of 91 carers of people who had been referred by their family physicians for the first time for formal support services or memory evaluation, to determine whether physical disability contributes to caregiver stress. Study conducted between April and December 2001.	Health status and disability (SF-12) and interview re caregiver knowledge and attitudes of dementia, duration and extent of caring, access to services, demographic data, specific questions re health (i.e., health problem/type/medications) and whether they were feeling stressed.	As a group, carers had SF-12 MCS scores lower than population levels, and a substantial proportion (20%) had MCS ( <i>mental component summary</i> ) scores consistent with moderate or severe mental health problems.' p348 'Most caregivers, especially older ones, reported having physical health problems and were taking medications...it seems likely that physical disability contributed to caregiver stress rather than vice versa..	"It is conceivable that attempts at lessening the impact of physical disability could benefit the mental health of caregivers.' p348	(W)e found that caregivers who declined to participate were usually too stressed or burdened to become involved in research studies, and thus our data probably underestimate the true mental and physical health burden of these persons. Similarly, we studied caregivers relatively early in their caring "career",..' p349
Cahill SM and Shapiro MM (1998) <i>"The only one you neglect is yourself": Health outcomes for carers of spouses or parents with dementia. Do wives and daughter carers differ?</i> <u>Journal of Family Studies</u> , Vol.4, No.1, pp.87-101.	91 female caregivers for family members with dementia: 60 wives (mean age 70 years) and 31 daughters (mean age 52 years). Sample was part of a major longitudinal study of carers. Recruitment was through four health and social care agencies, therefore all these carers were in contact with service providers. 13 carers (including 12 daughters) were employed and another 13 (including 12 spouses) had given up paid work in order to provide care. A subset of the sample (n=36) who later placed their relatives in RACF were re-interviewed within a few months of the placement. Study took place in Queensland, Australia.	In-depth qualitative interviews focusing on six major questions: (1) how healthy were participants when they first became carers, (2) what type of new health problems did they experience which caring, (3) how did dementia care impact on their quality of life, (4) what type of service support and income maintenance benefits did they receive, (5) to what extent did they believe that their own health had been adversely affected by caring, and (6) did a decline in carers' health lead to decisions about placing their relatives in a nursing home?	Almost three-quarters had at least two diagnosed health problems. Spouses were more likely than daughters to acquire new health problems after the caring role was adopted. Caring was mentally and physically exhausting for most respondents. There were additional negative impacts on quality of life - three-quarters of the sample reported that they were so trapped by the caring role that they could not plan ahead, 71% reported excessive tiredness and 68% said their social lives had been negatively affected. Nursing home placement tended to occur as a result of a crisis	Three-quarters used formal day care services, and 40% had domiciliary nurses visit, but very few used home help or meals on wheels. "No service listed was available at weekend or at night, a time when carers reported their needs were often most acute." p95 "Service providers need to play a more proactive role in counselling and advising carers about better care options, including the appropriateness and timing of nursing home placement." p99. Less than half received the domiciliary nursing benefit and only four carers received the carer payment. "These findings lead us to question the somewhat discretionary decision-making basis by which such a payment is	The research suggests that spouses are a particularly vulnerable group, disadvantaged by their health and the lack of service supports. There is a need to examine their experiences in more detail.

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
				made available in Australia. In other countries where similar style benefits are available, eligibility is based on medical and dependency needs and not on nursing care need." p99	
Hooker, K., S. Bowman, et al. (2002). <i>Behavioral Change in Persons With Dementia: Relationships With Mental and Physical Health of Caregivers</i> <u>The Journals of Gerontology</u> Vol 57, No. 5, pp453-460	Carers of people with dementia who had visited the Oregon Alzheimer's Disease Centre in Portland, Oregon, between 1992 and 1997. 102 responded to questionnaires, of which 90 provided additional behavioural information about the patient in a follow-up telephone interview.	<i>Care Recipient:</i> cognitive impairment (MMSE and neuro-psychiatric disturbances (Cummings, 1997 and Cummings et al. 1994). <i>Carers:</i> Physical health, mental health (depression - CES-D, affect - Bradburn Affect Balance Scale, & life orientation - Scheier & Carver 1985), stress (perceived stress scale & carer experiences - Zarit et al. 1998).	"The primary findings of this study are that two conditions are strongly associated with worse mental and physical health for the caregiver: a) the amount of increase in problematic behaviours among persons with dementia and b) caregiving for someone who is in a long-term care setting." The finding that residence in long-term care setting would be associated more highly with stress is an unexpected result ...	Assessment and treatment of behavioural disturbances can reduce stress in carers. '... the very symptoms for which effective interventions are available are those that are most distressing for caregivers. 'e.g. depressed mood and disruptive behaviours. P458-9. ' (W)e advocate for the incorporation of standard repeated behavioural measures (such as the NPI) into the protocol testing for persons with dementia so that rate of change in behaviours can be assessed over time.' p459	"Future research should also be targeted toward a more narrowly focused understanding of the psychopathological behavioural domains and trajectories of change therein.'
Houde , Susan Croker (2002) <i>Methodological issues in male caregiver research: an integrative review of the literature</i> <u>Journal of Advanced Nursing</u> Vol 40, No. 6 pp626-40	Male caregivers. Gender differences in caring experience, and interventions. 127 articles during 1997-2000. 36 articles reviewed- 13 qualitative, 22 quantitative, one both. P627		"Men provide approximately 28% of the care in the home to functionally impaired elders in the USA..." p626 "Men have not been studied adequately because of limitations in sampling design, with too few men in many caring samples" p634	Approx 1/3 cares are male (USA) - potentially similar rates in Australia - need to develop services which are responsive to their needs.	"In summary, there is a need for an increase in caregiver research that analyses differences by gender and family relationship ..."p639
Leong J, Madjar I and Fiveash B (2001) <i>Needs of family carers of elderly people with dementia living in the community.</i> <u>Australasian Journal on Ageing</u> . Vol.20, No.3, pp.133-138.	94 family caregivers of people with dementia, more than 2/3 were women, 89% lived with the care recipient, mean age 65 years (range 45-97). From this group, a purposive sample of 10 carers was drawn for interviewing (5 women, 5 men). Study was conducted in NSW, Australia.	Questionnaires: Family Carer Need Survey (modified from the Home Carer Need Survey) which covers 42 need items in 8 domains. Respondents assess each need item twice (for importance and for degree to which need is being met) on 5-point Likert-type scales. Semi-structured interview schedule.	The six highest ranked unmet needs named by carers were (1) to know someone will provide care if I become ill, (2) a telephone hotline I could call if I needed further information, (3) to have time for myself, (4) ways to deal with my stress, (5) to have physical rest, and (6) ways to deal with my feeling of being trapped. The interviews revealed that carers took on the responsibility largely because no-one else was available or	"Respite was one of the most frequently mentioned needs." p136 Carers want "services to be more flexible, responsive and available when needed, rather than involving delays or lengthy periods on a waiting list." p136 Health care professionals (GPs, community nurses, members of ACATs) can help by arranging and facilitating family conferences, a	

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
			willing. Carers were willing to provide care for many months or years but needed to know that immediate help was available when needed.	telephone hotline, 'crisis teams' for after-hours and weekends, and short-term respite care for carers overwhelmed by their responsibilities	
McConaghy R and Caltabiano ML. <i>Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being</i> <u>Nursing and Health Sciences</u> (2005) Vol.7, No.2, pp.81-91	Australian Study (north Queensland) of 42 carers of people with dementia, age range 21 -88 (mean 62). 95% were clients of Homecare Dementia Services Far North Queensland. Findings presented in this paper are part of a larger study that investigated perceptions and experiences of rural families caring for a mentally ill relative. Survey questionnaire booklets distributed by mail (27 respondents - but 4 were late and not included) and in face to face interviews (19) Response rate was 28.2%	Survey questionnaire including demographic section and five instruments common to caregiver literature: Satisfaction with Life Scale (Dietner et al. 1985); Radloff's (1997) Centre for Epidemiological Studies Depression (CES-D) Scale; COPE (Carver et al. 1989); Short Form (SF) 12v2 (Ware et al. 1996 - health status) and Caregiver Burden Scale (Zarit et al. 1980)	Well-being, burden and depression: Gender differences: '...there was no statistically significant difference between males' and females' use of emotion coping strategies in this study" p89; "...satisfaction with life increased the longer the amount of time the carer had been in that role" p89; "The findings from the current study indicate that carers of persons with dementia in North Queensland are at risk of developing psychological and physical ill health and this risk can be directly attributed to the burden associated with caring" p90	"Of significance ... Is the finding that depression failed to make a significant contribution to carer well-being...Health professionals and providers of respite services should be cognisant of the fact that carers may down play their feelings of despair" p 88	None reported
Miyamoto Y, Ito H, Otsuka T and Kurita H <i>Caregiver burden in mobile and non-mobile demented patients: a comparative study</i> <u>International Journal of Geriatric Psychiatry</u> (2002) Vol.17, No.8, pp.765-73	Japanese RCT of 379 primary caregivers of people with dementia - mobile vs. non-mobile - living in the community. Random sample of day care units in psychiatric hospitals - carers of 4 dementia clients asked to participate in a survey in-person, and to complete questionnaires.	burden - Zarit Caregiver Burden Interview; cognitive function - MMSR; ADL - Japanese version of Personal self-Maintenance Scale (PSMS); behaviour - Troublesome Behaviour Scale (TBS);	"The caregivers of the mobile demented patients were experiencing greater burden because of the higher levels of patients' behaviour compared to the caregivers of the non-mobile patients. The difference in exhibited behaviour and frequency of behaviour between the groups was likely to explain the gap of the perceived burden between the groups" p772	None reported	None reported
Nuendorfer M, McKee J et al. (2001). <i>A Longitudinal study of the relationship between levels of depression among persons with Alzheimer's Disease and levels of depression among their family caregivers</i> , <u>The Journals of Gerontology</u> ; Vol.56B,	353 persons with dementia and their caregivers; Ohio, US. Observational study to examine impact of depression in person with dementia on caregivers living in the community, between Oct 1992 and March 1999.	Measures included duration of illness, ADLs and IADLs and depressive symptoms	"More patient depressive symptoms were associated with caregiver depression at baseline, and an increase in patient depressive symptoms was associated with an increase in caregiver depression." pP312	"Findings from this study suggest that treatment of patient depressive symptoms may improve the quality of life for patients and for their family caregivers. They also support interventions for caregivers early in their family members' illness when caregivers' depression may be high due to their family members' depressive symptoms and initial	None reported

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
No.5, pp.301 - P313				signs that their family member is becoming more dependent" pP312	
Pot A, Zarit S, Twisk J, Townsend A. <i>Transitions in Caregivers' use of paid home help: Associations with stress appraisals and well-being</i> <u>Psychology and Aging</u> (2005) Vol.20, No.2, pp.211-9	US study, 264 caregivers who completed 3 interviews during one year period. Previous US study on psychological benefits of adult day care - this study uses the control group data of primary family caregivers from north-east Ohio region and two counties in Pennsylvania bordering Ohio. Baseline, 3 months and 12 months data collection.	Caregiver distress - 'Stress process model of caregiving' - (Pearlin et al. 1990); Depression - Centre for Epidemiological Studies Depression Scale - CES-D); Positive Affect - 'Positive and Negative Affect Schedule (Watson, Clark, and Tellegen 1988); Feelings of Overload (Pearlin 1990); Feelings of Worry and Strain (Zarit et al. 1998); Patterns of home care use; Health - 5 point scale; Behaviour - 'Revised Memory and Behaviour Problems Checklist (Teri et al. 1992 Zarit et al. 1998); ADLs - (Lawton and Brody 1969); and, Demographics	"Results of this naturalistic observation study showed that the onset of paid home care was associated with increases in family caregivers' feelings of worry and strain and a worsening in positive affect." (p.216)	"The results of this study suggest that receiving paid home care may not be enough to unburden the family caregiver. Paying attention to family caregivers' concerns when they accept paid home care ... may be necessary for paid home care to become successful in relieving family caregivers' burden." (p.218)	None reported
Proctor R, Martin C and Hewison J. <i>When a little knowledge is a dangerous thing ....: a study of carers' knowledge about dementia, preferred coping style and psychological distress</i> <u>International Journal of Geriatric Psychiatry</u> (2002) Vol.17, No.12, pp.1133-9	UK study of 50 carers and patients attending day services. Questionnaires and patient symptom measures were administered to carers by the main researcher; questionnaires were left with carers to complete independently and collected later.	Socio-demographic information; clinical characteristics of patients i.e., cognitive function (MMSE);behaviour (Dementia Behaviour Disturbance Scale - DBDS and functional ability (Barthel); Carers knowledge about dementia (Dementia Quiz - Gilleard and Groom 1994), coping style (Miller Behavioural Style Scale - MBSS 1987), strain (Machin Strain Scale) and anxiety/depression (Hospital Anxiety and Depression Scale - HADS)	"The findings show that there was an association between increased knowledge and higher levels of anxiety... (however it seems that only biomedical knowledge about dementia that was predictive of anxiety for the carers in the present study" (p.1137)	"It is clear that education about dementia needs to be delivered in a supportive and sensitive environment where it is possible for carers to explore ideas and share emotional reactions." (p.1138)	None reported
Rockwood K, Fay S, Song X, MacKnight C and Gorman M (2006) <i>Attainment of treatment goals by people with</i>	Canadian study of 130 patients with Alzheimer's disease receiving galantamine or placebo in a RCT design, using Goal Attainment Scaling (GAS) to determine the extent to which	Primary outcome measures were GAS scores as assessed by clinicians, patients and caregivers. Secondary outcome measures included the	In the intention-to treat analysis, the clinician-rated GAS scores showed a significantly greater improvement in goal attainment among patients in the galantamine group than among those in	Shows usefulness of the GAS method in practice settings. "The primary efficacy measure was the GAS instrument, an individualized outcome measure in which goals	Shows usefulness of the GAS method in research. "Clinicians, but not patients and caregivers, observed a significantly greater

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<i>Alzheimer's disease receiving galantamine: a randomised controlled trial.</i> <u>Canadian Medical Association Journal</u> 174 (8):1099-105.	the intervention met the goal of treatment as assessed by clinicians, patients and caregivers	cognitive subscale of the Alzheimer's Disease Assessment Scale (ADAS-cog), the Clinician's Interview-based Impression of Change plus Caregiver Input (CIBIC-plus), the Disability Assessment for Dementia (DAD) and the Caregiving Burden Scale (CBS).	the placebo group. The patient-caregiver-rated GAS scores showed a similar improvement in the galantamine group, however, because of the improvement also seen in the placebo group, the difference between groups was not statistically significant	are set and then followed over the course of a trial. The goals are personalized (i.e., people set goals according to their own needs). What is standardized is the extent of their attainment, which can be either "no change," or "much better" (or "much worse") than expected." (p.1100)	improvement in goal attainment among patients with mild to moderate Alzheimer's disease who were taking galantamine than among those who were taking placebo." (Abstract)
Rockwood K, Black S, Bedard M-A, Tran T and Lussier I (2007) <i>Specific symptomatic changes following donepezil treatment of Alzheimer's disease: a multi-centre, primary care, open-label study.</i> <u>International Journal of Geriatric Psychiatry</u> 22: 312-319.	This Canadian, 24-week, open-label, multi-centre study investigated the clinical meaningfulness of treatment with donepezil, and translated from standardized measures to primary care settings. 101 primary care patients, - changes in a 19-symptom checklist were assessed in relation to changes in standardized scales of cognition, activities of daily living, behaviour, and caregiver burden.	Top Symptoms (TOPS) checklist and standard measures of cognition (ADAS-cog) (Rosen et al., 1984) activities of daily living (DAD) (Gelinis et al., 1999), behavioral symptoms (NPI) (Cummings et al., 1994), overall effective performance (FRS) (Feldman et al., 1995), and the Caregiver Activity Survey (CAS) (Davis et al., 1997). Mini-Mental State Examination (MMSE) (Folstein et al., 1975), and the Clinician's Global Impression of Change plus caregiver input (CIBIC) (Olin et al., 1996)	Three symptoms were reported in more than 80% of patients by both clinicians and caregivers: problems in remembering, (97%), temporal orientation (89%), and repetitiveness (85%). Five others overlapped on each of the clinician and caregiver 'top ten', including cognitive activation, spatial orientation, leisure, attention, and apathy. Caregivers reported that symptoms did not improve in 55 patients, whereas 27 and 19 patients showed some and most symptoms improving respectively.	"One way to help bridge the gap between what standardized instruments measure and what can be observed in practice is to have physicians and patients/ caregivers separately set individualized goals for treatment. The extent to which goals are attained can be standardized using Goal Attainment Scaling (GAS) (Kiresuk and Sherman, 1968)." (p.313) "These data suggest that, in primary care, there is merit in having a symptom checklist that gives caregivers a role, and in then having physicians help advise them about their responses." (p.318)	"A symptom checklist allowed clinically meaningful profiles to be identified, but revealed different estimates of response between clinicians and caregivers. Both agreed that improved executive function was the most common response. A symptom checklist can help translate between standard measures and everyday practice." (p.313)
Schneider J, Murray J, Banerjee S, Mann A. <i>Eurocare: A cross-national study of co-resident spouse carers for people with Alzheimer's disease: 1 - Factors associated with carer burden</i> <u>International Journal of Geriatric Psychiatry</u> (1999) Vol.14, No.8, pp.651-61	European study - 14 EU countries; cross-national profile of co-resident spouse carers	Socio-demographic information; Client Service Receipt instrument (CSRI; Beecham and Knapp 1992); Carer Burden Inventory (CBI - Zarit et al. 1980); General Health Questionnaire - 12 (GHQ-12; Goldberg and Hiller 1979) and four open questions investigating the difficulties and rewards associated with caring, perceived public reaction and the carers' perception of the support received.	"The most striking finding is a highly statistically significant association of behavioural disturbance with increasing carer burden ... due to ... behavioural deficits (such as stubbornness, unco-operative behaviour and apathy) rather than behavioural excesses (such as aggression, restlessness or lability of mood)." p654 "This study confirms the high level of burden and mental distress in spouse carers .... (and) suggest avenues for the primary and secondary prevention of burden by addressing	"These data suggest the possibility that individually based interventions (psychological, educational, social or pharmacological) focused on these areas of difficulty may be of particular help in the secondary (treatment) and tertiary (minimization) prevention of carer burden" (p.659) Individually tailored interventions - psychological, educational, social and pharmacological) may be	Lack of association between mental distress and carer burden - which is at odds with other studies (Draper et al. 1992)- they may have different determinants and perpetuating factors, and so might require different responses. (pp.659-660)

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
			clinical issues (e.g. behavioural disturbance); public attitudes and education (e.g. negative social reactions); economic support for carers (e.g., financial dissatisfaction); and higher-risk groups (e.g., younger spouse carers). (p.660)	useful in preventing carer burden.	
Schultz, R et al. <i>End-of-life care and the effects of bereavement on family caregivers of persons with dementia</i> <u>New England Journal of Medicine</u> (2003) Vol.349, No.21 pp.1936-42	Part of REACH study - US RCT of 217 family caregivers of people with dementia during the year before the patient's death, and assessed caregiver's responses to the death. 20 co-resident spouses caring for people with dementia, who had been diagnosed within a 12-36 month period prior to study, were recruited in 14 EU countries. Sample in each country recruited by a professional experienced in dementia care and research. Semi-structured questionnaire translated into requisite languages.	Socio demographic data; ADL (Katz et al.1963); IADL (Lawton et al., 1969); burden (Revised Memory and Behaviour Problems Checklist); depression (CES-D); as well as no. hours per day caregivers were 'on duty', medication for depression and anxiety, and questions post-death of people with dementia re pain they had felt before death, was death a relief, preparation for death & use of and need for bereavement services.	The caregivers showed remarkable resilience in adapting to the death of their relatives ... only a minority of caregivers reported using or needed bereavement-related services...In contrast, caregivers whose relatives were institutionalised did not show this recovery from depressive symptoms .It is possible that they grieve for the loss of the patient before death. Implications of these findings: 1) Relationship between context in which death occurs and effects of bereavement - i.e., 'When death was preceded by a protracted and stressful period of caregiving, the negative effects ... may be substantially lessened'; 2) Need for support after death is limited	Grieving starts before death of people with dementia; interventions and service resources may be most beneficial just prior to the death of people with dementia. This possibility suggests that clinicians and scientists should view bereavement not only as a phenomenon that affects caregivers after the death but also as one that affects many caregivers before the death occurs" (p.413)	Relationship between bereavement and service usage prior to death of people with dementia; what interventions can be put in place pre-death which will have most benefit and assist caregivers with post-death bereavement
Thommessen, B., Aarsland D. et al. <i>The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease</i> <u>International Journal of Geriatric Psychiatry</u> (2002) Vol 17, No. 1, pp78-84.	Norwegian study using data on patient-spouse couples from studies of patients with stroke (36 couples), mild dementia (92 couples) and Parkinson's disease (58 couples).	Relatives' Stress Scale.	Problems in spouses across groups: carer stress, household routines, holidays, constraint on social life, sleep disturbances. Stroke and Parkinson's: striking association between patients' reduced cognitive function and spouses higher burden; weak association with dementia.	Psychosocial burden evident for carers of people with stroke and Parkinson's as well as dementia	Intervention studies needed to explore the importance for caregiver burden of detecting and being better able to cope with cognitive impairment in such patients' (i.e., stroke, dementia & Parkinson) (p.83)

**Table A16 Summary of the study literature of the needs of carers - disabilities**

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Adams D and Allen D (2001) <i>Assessing the need for reactive behaviour management strategies in children with intellectual disability and severe challenging behaviour</i> . <u>Journal of Intellectual Disability Research</u> Vol.45, No.4, pp.335-343.	Children with intellectual disability and severe challenging behaviour, and their carers. 54 children referred to a specialist behavioural support service in the UK.. Views obtained were those of specialist health personnel which may be very different to the immediate carers of the children; population studied represented a skewed sample of children with more severe problems. Aim of study was to identify the most common topographies of challenging behaviour amongst a cohort of children with ID and challenging behaviour from a service. Also, to identify the need for training in reactive behaviour management.	contained 5 scale items covering behavioural frequency, severity of injuries, degree of management problems, and intrusiveness of typical carer response and perceived efficacy of response. Questionnaires were completed via interviews with the members of the support team who knew each child best (not immediate family caregiver).	Study revealed a high prevalence of aggressive behaviour within a sample of children with ID referred for a specialist behavioural intervention. Prevalence rates were more comparable to prevalence rates for individuals with more severe problems; to be expected as children referred to service were likely to present with more severe difficulties. No significant associations were found between prevalence, and age, sex or degree of ID. Challenging behaviour overall begins to increase markedly in late adolescence before diminishing once more in mid-adulthood. Males more likely to have challenging behaviour and rates typically increase in accordance with rates of intellectual impairment. Serious consequences for carers, siblings and other children.	Reactive behavioural management strategies used for adults may be appropriate and effective for children approaching adult size (e.g. existing adult removal procedures and restraint procedures), but not for children of smaller stature. More carer training in reactive behavioural management strategies appears necessary (as well as more attention to appropriate strategies for children). Use of reactive physical interventions to interrupt aggression was common (the fact that they are used at same rate across age bands and that most were improvised by carer rather than having been introduced via formal training, raises ethical and health concerns).	Implications for adapting adult service's training to meet the needs of children requires further investigation, and conclusions made in this paper require more support. Validity of conclusion diminished by various factors including: small sample size; retrospective and descriptive study; assessment of ID not based on formal measures and measure of informant reliability lacking..
Chung P, Garfield C et al. (2007) <i>Need for and Use of Family Leave Among Parents of Children With Special Health Care Needs</i> . <u>Pediatrics</u> Vol.119, No.5, pp.e1047-e1055.	Children with special health care needs and their parents. 1105 telephone interviews conducted. In Chicago and Los Angeles. Study specifically investigated paid leave for caring, and carer financial benefits	Carer stress, use of respite care services	Results described time taken off work and types of benefits received by parents. Availability of paid leave increases the odds of taking time off for a carer role.	Paid leave has clear benefits for carers.	Scope for more work that crosses over to income support or income support as part of a multi-modal approach
Dew A, Llewellyn G, et al. (2004) <i>Post-parental care: a new generation of sibling-carers</i> . <u>Journal of Intellectual and Developmental Disability</u> Vol.29, No.2, pp.176-9.	Sibling-carers of people with disability.	Short research paper examines issues surrounding post-parental care, and implications for sibling-carers once their parent-carers have passed away. Subsequent to NHMRC funded project on carers of people with a disability.	It is critical to address issues associated with sibling-carers due to the ageing population of parent-carers, and the extended life expectancy of people with a disability.	"Together researchers and service providers are well advised to develop knowledge about sibling-carers in advance of increasing pressure to have in place appropriate policy, service and practice responses to the demise of the current generation of older parent-carers". (p.178)	"An outstanding issue requiring investigation is the impact on service agencies of dealing with sibling-carers ... The issue of how post-parental care is negotiated and organised within a family context attains greater urgency".

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Higgins DJ, Bailey SR, et al. (2005) <i>Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder</i> . <u>Autism</u> Vol.9, No.2, pp.125-37.	Parents/caregivers of a child with autism spectrum disorder (ASD). 53 caregivers of a child with ASD from Victoria, Australia were surveyed.	Behavioural measures, family functioning (Family Adaptability and Cohesion Evaluation Scales), Marital Quality and marital happiness (Quality Marriage Index), Self-esteem (Rosenberg Self-Esteem Scale), Coping Strategies (adapted Coping Health Inventory for patients)	Results suggest that these caregivers had healthy self-esteem, although they reported somewhat lower marital happiness, family cohesion and family adaptability than did norm groups. Coping strategies were not significant predictors of these outcome variables. Results highlight the need for support programmes to target family and relationship variables as well as ASD children and their behaviours, in order to sustain the family unit and improve quality of life for parents and caregivers as well as those children.	Meeting the need for effective support programmes to target family and relationship variables as well as ASD children and their behaviours in routine practice will likely be expensive.	Evaluation of support programmes to target family and relationship variables as well as the ASD children and their behaviours are required.
Maes B, Broekman TG, et al. (2003) <i>Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems</i> . <u>Journal of Intellectual Disability Research</u> Vol.47, No.6, pp.447-55.	Children or adults with intellectual disability (ID) and behavioural or psychiatric problems that live at home, and their families/caregivers. 66 participants in the study. In Belgium/Holland.	Severity of problems and caring family burden. Instruments: Reiss Scales to evaluate degree and nature of clients' psychiatric and behavioural problems, (Reiss Screen for Maladaptive Behaviour, and Reiss Scales for Children's Dual Diagnosis). Nijmegen Family Situation Questionnaire to measure the subjective load parents bear in rearing or living together with their child.	Parents consider the psychiatric or behavioural problems of their child to be an extra burden and feel it more difficult to raise and manage such a child. This impels them to change the situation and to call on the help of external services.	Implies consistent approach to including carer views in assessments	Future studies might look for impact of consistently describing carer views in assessment systems
Martin DM, Roy A, et al. (1997) <i>Health gain through screening - users' and carers' perspectives of health care: developing primary health care services for people with an intellectual disability</i> . <u>Journal of Intellectual and Developmental Disability</u> Vol.22, No.4, pp.241-9.	People with an intellectual disability and their carers. In the UK. Aim of study was to gather the experiences, expectations, and opinions of people using primary health care services for adults with an ID.	Satisfaction surveys, carers' questionnaire, users' focus groups	There are difficulties in getting the views of care recipients about primary health care and carer involvement can assist	Carer involvement in primary health care consultations would be useful	Carer satisfaction with primary care given to people with ID should be built into studies of how GPs work with this client group.

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Shugarman LR, Buttar A, et al. (2002) <i>Caregiver attitudes and hospitalization risk in Michigan residents receiving home- and community-based care.</i> <u>Journal of the American Geriatrics Society</u> Vol.50, No.6, pp.1079-1085.	527 individuals eligible for home and community based services (HCBS), and their caregivers. Study focused on carers with declining health, distress and dissatisfaction with support. In Michigan, United States.	Primary outcome was hospitalisation after admission to HCBS. Key measures were caregiver attitudes (distress, dissatisfaction, and decreased caregiver ability) and HCBS participant characteristics (cognition, functioning, diseases, symptoms, nutritional status, medications, and disease stability). Minimum Data Set for Home Care (MDS-HC) was used.	"Found a strong association between carer dissatisfaction (caregiver dissatisfied with the level of care the home care participant currently receiving) and an increased likelihood of hospitalisation. HCBS participant ... [conditions] ... were also associated with increased hospitalisation. Poor food intake and prior hospitalisation were associated with hospitalisation and death" p1079.	"Several of the characteristics significantly associated with increased hospitalisation... are potentially amenable to interventions... [i.e.] Caregiver concerns can be identified, and support and counselling may be offered. Alternatively, caregiver dissatisfaction may be an indicator that the patient's needs exceed the ability of the caregiver/home care system to provide for them and that a higher level of care is warranted" (pp.1083-84)	"Need for follow-up outcome studies and practice-change interventions in home- and community-based care to increase caregiver support, offer aggressive pain management, and monitor for unstable disease" (p.1084)

**Table A17 Summary of the study literature of the needs of carers - frail aged**

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Lopez, J., J. Lopez-Arrieta, et al. (2005). <i>Factors associated with the positive impact of caring for elderly and dependent relatives.</i> <u>Archives of Gerontology &amp; Geriatrics</u> Vol 41, No. 1, pp 81-94.	Spanish study of 111 informal caregivers of dependent older people looking at predictors of positive aspects of caring for Spanish carers	Stressors - such as duration of caring and dependence, behavioural and memory problems of care recipient; Appraisal - i.e., burden (Zarit) Caregiver resources - self-esteem, social support, satisfaction with support, coping strategies; Caregiver problems - depression, anxiety, anger, changes in healthy behaviour such as sleep patterns, fitness etc. Positive aspects of caring was assessed by the Caregiving Satisfaction Scale (Lawton et al. 1989).	"The outcomes related to these positive emotional aspects ( <i>of caring</i> ) are the following: a better previous affectionate relationship between the caregiver and the care recipient, less use of venting as a coping strategy, being a caregiver by ones' own decision, maintaining the same amount of leisure time than before becoming a caregiver, and not working outside the home. All these factors are related to caregiver characteristics, not to those of the care-receiving subjects. ' p92	(A) better understanding of the positive aspects of caregiving, and the related predictors for caregivers of elderly dependent subjects, could help health professionals to not only try to avoid the numerous negative problems associated with subjects and their caregivers, but to strengthen the positive aspects also to be found in caregiving. '(p.92)	More research to focus on ways to strengthen the positive aspects to be found in caring
Travis SS, McAuley WJ, et al. (2007) <i>Factors associated with medication hassles experienced by family caregivers of older adults.</i>	Older people (55 years old and over) and their long-term caregivers who provide medication assistance. Sample consisted of 156 informal caregivers recruited from seven states and several types of settings (i.e. adult day services,	The dependent outcome variable is the total FCMAHS score (instrument consists of 24 items and 4 subscales: Information seeking/Information sharing; Safety Issues; Scheduling	More intense hassles are associated with the level of a caregivers' education (people with high school education or higher experience more hassles) and ethnicity (White and Hispanic carers perceived the highest hassle levels),	Providers prescribing medications should pay attention to the complexity of medication administration regimens as this variable has a significant impact on overall hassle scores. FCMAHS	More research is needed. The ethnic group/FCMAHS association is worthy of additional research with larger involvement of Hispanic caregivers...

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<p><u>Patient Education and Counseling</u> Vol.66, No.1, pp.51-57.</p>	<p>case management services) - representing rural and urban, large and small, and ethnically diverse programs.</p>	<p>logistics; and Polypharmacy).</p>	<p>greater medication complexity, and the mental functioning of the care recipient (carers of persons in the mid-range of mental impairment experience more intense hassles). These variables can be used to identify carers who may be at risk of experience medication administration hassles, increased stress, and potentially harmful situations for their care recipient p56.</p>	<p>seems to be a useful research and applied tool.</p>	<p>Larger samples will be needed to fully explore how caregiver education and FCMAHS are associated... important as we begin to think about caregiver educational interventions to manage or reduce medication administration hassles...</p>
<p>Covinsky KE, Eng C, Lui LY, Sands LP, Sehgal AR, Walter LC, Wieland D, Eleazer GP and Yaffe K (2001) <i>Reduced employment in caregivers of frail elders: impact of ethnicity, patient clinical characteristics and caregiver characteristics.</i> <u>The Journals of Gerontology</u>, Vol. 56A, No. 11, pp. M707-M713.</p>	<p>Total of 4592 'potentially working' family caregivers of 2806 patients with dementia who were enrolled at the 11 sites of the Program of All-Inclusive Care for the Elderly (PACE) in the US. Of the caregivers, 62% were women, 36% lived with the patient, mean age was 45 years and most were the adult children of the patients. Mean age of patients was 78 years, 73% were women and about half were white.</p>	<p>Primary dependent variable was whether or not a caregiver reduced the number of hours they worked or quit working in order to provide care for the patient. Data were also collected about patients' dependency in five ADL, continence, problem behaviours, cognitive function and presence/absence of dementia, co-morbid medical conditions, use of paid help for personal care or domestic chores and enrolment in adult day care.</p>	<p>Data were collected through interviews administered by social workers at the time of admission to PACE. Overall, 22% of potentially working caregivers had reduced their work hours or quit working. Caregivers who were most likely to have reduced their working hours in order to provide care were: daughters or daughters-in-law of the patient, caregivers for older patients, and caregivers who lived with the patient and had no other caregivers living with the patient.</p>	<p>The patient characteristics that predict a reduction in caregiver employment are the same characteristics that predict nursing home placement (ADL dependence, stroke, dementia with behavioural disturbance). This supports the hypothesis that "the family's willingness to accept income loss may save the public the expense of nursing home care"</p>	<p>Almost no data are available on the economic costs of caring</p>
<p>Hughes, S. L., A. Giobbie-Hurder, et al. (1999). <i>Relationship between caregiver burden and health-related quality of life.</i> <u>Gerontologist</u> Vol 39, No. 5, pp 534-45.</p>	<p>Carers of veterans who qualified for home care</p>	<p>4 variables were considered: 1) caregiver characteristics; 2) care recipient characteristics related to caregiver burden (functional &amp; cognitive status); 3) objective and subjective caregiver burden; and 4) 8 subscales of SF36 for Health Related Quality of Life (HRQOL).</p>	<p>A spousal relationship and low income were consistently associated with poorer scores for almost all the HRQOL subscales, underscoring the importance of these variables. p 543</p>	<p>The objective demands of caring could cause symptoms of depression and could decrease both the energy required and the opportunity to engage in social activities... diminished functioning in these domains may be precursors of physical illness that are stress related.' (p.544 )</p>	<p>Question of whether caregiver burden affects health status through diminishing vitality and mental health functioning which ultimately results in diminished performance in more distal health domains.' (p.544)</p>
<p>Witt E, Chenoweth L, Jeon Y-H (2004) <i>Respite services for older persons and their family carers in southern Sydney.</i> <u>Collegian</u>, Vo.11, No.4, pp.31-35.</p>	<p>18 primary family carers for Australian older people with chronic degenerative diseases, in southern Sydney. 83% females, aged 49-86 years. Purposive random sampling from community health services client list.</p>	<p>Survey: demographic data, semi-Structured interviews. Health care providers and respite care providers: surveys, semi-structured focus group discussions, some individual interviews.</p>	<p>1) Deteriorating health and well-being; 2) Lack of communication between carers, health professionals, respite service providers; 3) Little knowledge of respite availability and scope; demand greater than availability. 4) Utilisation of respite: used all forms, 2/3 frequently used</p>	<p>Need to improve: referral service processes, training for staff in managing clients, communication with clients and carers, timely access for short-notice/unplanned respite. Reluctance to access respite services perceived to offer</p>	<p>Non-English speaking carers excluded from study – noted as important area for future research.</p>

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
			planned centre-based services, residential used infrequently, but for longer periods, referral services inefficient and often not user-friendly; negative experiences of in-home respite: inadequate staff levels, knowledge and skills, post-respite client's adjustments/ reactions difficult for carer to manage, access referral only when desperate/ emergencies, some prefer to directly access respite services – bypass referral service.	poor quality care: concern by carers that care recipients need to have a positive experience of respite, home or centre-based.	

**Table A18 Summary of the study literature of the needs of carers – mental illness**

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Cleary M, Freeman A, et al. (2005) <i>What patients and carers want to know: an exploration of information and resource needs in adult mental health services. Australian and New Zealand Journal of Psychiatry</i> Vol.39, No.6, pp.507-13.	People with mental illness and their carers. 207 people with mental illness in the inpatient setting were interviewed, 200 in community settings, and 50 of their carers. A 3 month study period, in a Sydney inner-city catchment area .Study investigates the extent of carer involvement, and differing perceptions of patients and carers regarding information and resource needs (in inpatient and community settings) through face-to-face interviews.	Versions of the discharge planning survey and the community care survey were developed from a previous study. Inpatient survey asked about satisfaction with discharge, the provision of discharge-related information, confidence in managing mental health problems post-discharge and information requirements. Community setting survey asked about helpfulness of information provided, confidence in managing mental health problems and information requirements. Carer surveys had demographic information, rating of satisfaction with involvement, the info provided to them, confidence in patient managing patient's mental health problems and information requirements.	Importance of facilitating active carer involvement in mental health care is clear. In hospital settings, over 50% of carers reported info was not provided, and when it was many found it unhelpful. Similar results for community settings, although percentages of patients and carers rating info as helpful were higher. Carers have a more positive view of hospital care when they feel informed, have opportunity to discuss treatment and know its aims, furthermore, family involvement is reassuring for many patients. Patients in hospital and community settings were more confident than carers in managing their mental health. Patients' and carers' perspectives differed in terms of priorities for more info (carers want more info than patients). However, both patients and carers consistently wanted more info about what to do when the patient becomes unwell, medication and medication side-effects and community	Inadequate information is a source of dissatisfaction among health service users - info should be given at the right time, should be able to be easily understood and based on assessed need. Regular communication and info exchange during process of treatment can potentially increase carers' confidence, prevent feelings of exclusion and improve resilience and coping strategies. Additionally, "research suggests that linking patients to community services while they are in hospital, improving communication between hospital and community teams and increasing carer involvement in discharge planning are essential strategies in navigating the high-risk transition from hospital to the community".	Results may have been affected by recall bias. Carer response rate was poor. Level of carer availability and support may vary in settings with different cultural and socioeconomic characteristics (outside Sydney). There is now a new carer support program piloted in three Health Areas and comparisons between areas with and without this program in a subsequent study may highlight if there is any impact for carers of the new program.

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
			resources.		
Hodgson O, King R, et al. (2002) <i>Carers of mentally ill people in Queensland: their perceived relationships with professional mental health service providers: report on a survey.</i> <u>Australian e-Journal for the Advancement of Mental Health</u> Vol.1, No.3, pp.219k.	Carers of people with mental illness. 157 questionnaires completed by carer of person with diagnosed mental illness receiving treatment in Queensland, Australia. Study set out to explore the expectations and actual experiences of families and other carers of mentally ill people with respect to community mental health service provision. Specifically to discover the level of satisfaction they have in relation to key components of mental health service delivery particularly in the relationship between carers and the principal service provider.	Single cross-sectional survey using a comprehensive questionnaire was distributed throughout Qld. 66 items in the questionnaire covered: demographics; carer expectations and experiences of service delivery regarding carers involvement with mental health services and also regarding quality of relationship and communication between carers and mental health professionals; and effect of medical versus non-medical service provision on service delivery experiences. A 'Mental Health Professional and Carer Quality of Relationship Scale' was developed was developed to measure carer perceptions of service quality.	Areas of concern and dissatisfaction included: lack of provision of info and advice on treatment; failure to discuss treatment with carer or involve carer in treatment planning; lack of assistance to carer in coping with problems; poor response to crisis situations; lack of info to the carer about trends in service provision, medication; rehabilitation, social services, job opportunities, etc. Although carers rated service providers highly for professional respect, friendliness and positive outlook, they were dissatisfied with levels of access to service providers. Perception that service providers didn't communicate with them, provided little or no info on the treatment process, rehab and resources, was excluded in treatment and discharge planning and didn't meet their expectations of service provision.	Need for more active intervention in order to make the realities of service provision more consistent with policy objectives. Important for service providers not to exclude carers.	Unlikely this sample was representative of carers of mentally ill people in Qld, however findings are consistent with other studies. Further research on the problems of communication between carers and clinicians is needed, with more representative sampling.
Lauber C, Eichenberger A, et al. (2003) <i>Determinants of burden in caregivers of patients with exacerbating schizophrenia.</i> <u>European Psychiatry</u> Vol.18, No.6, pp.285-289.	Relatives (caregivers) of schizophrenia patients. 64 relatives or "significant others" of persons with schizophrenia providing support at home were interviewed. In Zurich. Investigates caregiver burden 2 weeks before hospitalisation, and ways to better counter burden.	Semi-structured "Interview for Measuring the Burden on the Family", assessing topics such as demographics, behaviour of the affected, objective and subjective burden, social life and leisure of carer, relationship between affected and caregiver, financial consequences, etc.	The most important predictor of burden is burden in the relationship between caregiver and affected care recipient. Threats, nuisances, time spent with affected, and burden due to restricted social life and leisure activities were additional predictors, but not aggression and substance abuse. Biggest burden for carer is during acute stage of illness. Family support programs should be developed to help relatives to better cope with these burdens, and thus to improve relatives' well-being.	Family support programs should be developed to help relatives to better cope with these burdens, and thus to improve relatives' well-being. Programs should focus on coping with disturbing behaviour (especially threats and nuisances), but also needs of relative regarding leisure activities	Programs focussed on coping with disturbing behaviour should include comparisons of single and multiple interventions and at different time periods post hospitalisation
Levine IS and Ligenza LR (2002) <i>In their own voices: Families in crisis. A focus group study families of persons with</i>	Family caregivers of people with serious mental illness during crisis. 55 families interviewed.	Interview of families regarding their needs as carers.	Few families report that they obtain the supports they need during the early years of their relative's illness. Based on dialogues with families, two sets of recommendations are presented to	Descriptive study suggests educational strategy for care givers and service providers	May be useful to test the impact of information packages for carers and service providers on routine practice

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
<i>serious mental illness. Journal of Psychiatric Practice</i> Vol.8, No.6, pp.344-353.			improve the timely provision of services and supports: one set for families and the other for mental health policymakers		
Lloyd C and King R (2003) <i>Consumer and carer participation in mental health services. Australasian Psychiatry</i> Vol.11, No.2, pp.180-4.	Carers of people with mental illness.	N/A	Describes barriers to involvement and practical ways to involve consumers and carers. Solutions: information, education, carer surveys and forums, and participation in service development, research and evaluation.	"We suggest that it is time to move beyond paying lip service to consumer and carer participation and actively explore strategies to increase their participation in a meaningful way". P184	Suggests active involvement of consumers and carers in surveys and research, including assisting in conducting research within the mental health service.
Mathews-Cowey S (2000) <i>Too much responsibility, too little help: family carers and the rural mental health care system. Journal of Family Studies</i> Vol.6, No.2, pp.267-71.	Individuals with mental health problems and their family caregivers, in rural areas. 43 focused in-depth interviews conducted with families in rural Victoria (the Loddon Southern Mallee Region).	Interviews based on carer experience. Key issues were: inadequate support from mental health services, such as lack of psychiatrists, hospital care, and case managers.	"Virtually unanimous among these carers that the mental health care system in rural communities is under-resourced". (p.270) Difficulties accessing hospital in the larger rural centres, and almost impossible to receive adequate hospital care in other rural areas. Particularly in other rural areas, problems due to early discharge and limited follow-up and support from case managers (only had resources to respond to crisis events). Therefore, families have to provide care for which they do not necessarily have the knowledge, skills or emotional energy	The National Mental Health Strategy, which proposed a comprehensive system of care, has not been fully implemented in rural Australia. Access to (and provision of) a comprehensive formal mental health services must be improved, especially in rural areas, otherwise mental health of family and client is jeopardised. Too much responsibility placed on families.	"Further research needed to determine whether and how rural communities are disadvantaged in relation to mental health care services compared to urban areas and the impact that this has for families and clients".
Ostman M, Wallsten T, et al. (2005) <i>Family burden and relatives' participation in psychiatric care: are the patient's diagnosis and the relation to the patient of importance? International Journal of Social Psychiatry</i> Vol.51, No.4, pp.291-301.	People with mental illness and their caregiver relatives. Longitudinal study has 3 periods of investigation: 1986, 1991, and 1997. Interviews with 455 close relatives to a total sample of 623 patients. In Sweden.	Semi-structured questionnaire focused on burden of relatives, their need for support, and participation in care. Measured relatives own subjective feelings.	Relatives showed burdens in several of the aspects measured. In only 1 aspect of the investigated burden items was a difference found between different diagnostic subgroups. Relatives of patients with affective disorder more often had to give up leisure time. However, spouses showed more burdens & more often experienced sufficient participation in the patient's treatment than other subgroups while siblings more seldom experienced burdens & more seldom felt that their own needs for support had been met by the psychiatric services..	Services should more effectively and routinely explore the needs of informal carers and the differences between the types of care givers. Being a close relative, and living together with a severely mentally ill person in an acute situation, is one factor of importance for experiencing burden and participation in care, contradicting the conventional wisdom which differentiates between diagnoses	Within each diagnostic subgroup there were differences between subgroups of relatives. Future studies might look for impact of consistently describing carer views in assessment systems

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Phillips M (2004) <i>Mental health and harmony for Indigenous clients and carers. Aboriginal and Islander Health Worker Journal</i> , Vol.28, No.2, pp.30-31.	Family caregivers of Indigenous people with mental illness, stakeholders (Indigenous people who had contact with others who had a mental illness, through their work or through family members) and Indigenous health workers	Semi-structured interviews were conducted as part of an evaluation of the Integrated Mental Health Service (IMHS) at Mt Isa, north-west Queensland.	"It was found that the lack of cultural knowledge and understanding actually contributed further to the stress for Indigenous families. Participants displayed anger at not being supported by IMHS. They felt abandoned due to not being visited in the home and little or no 'follow up' was carried out." p31. Providers at the mental health service were reluctant to provide a service to clients who presented to A&E smelling of alcohol, sometimes with tragic consequences. Some non-Indigenous clients also complained of a lack of support.	The researcher planned to continue working with service providers and communities to find practical solutions tailored to local issues and to change health policy for the benefit of the district.	
Rooney R, Wright B, et al. (2006) <i>Issues faced by carers of people with a mental illness from culturally and linguistically diverse backgrounds: carers' and practitioners' perceptions. Australian e-Journal for the Advancement of Mental Health</i> Vol.5, No.2, pp.166KB.	Carers of people with mental illness (from a CALD background), and their practitioners. In-depth interviews with carers of 9 clients with mental illness from CALD backgrounds (Italian, Vietnamese, Indian and Spanish-speaking). In Australia. Study examines the perceptions of CALD background carers regarding the conceptualisations of mental health/illness, stress and support, stigma, and pathways to seeking help. Carers' and treating practitioners' perceptions of these issues are then compared.	Interview based on satisfaction (non-standardised).	Highlighted difficulties experienced by CALD carers include lack of involvement in the treatment process and dissatisfaction with treatment, insufficient communication from health professionals, lack of understanding about mental illness, lack of support, increased stress, and a lack of understanding of explanatory models between carer and practitioner. Difficulty in accessing informal support networks is shown, carers generally coped within their own families. A conflicting finding was carers reporting lack of family support while practitioners reported carers receiving excellent family support.	Suggested that CALD explanatory models of mental health/illness must be incorporated into best practice care: better compliance in treatment, fewer dropouts, and greater satisfaction with treatment. These findings support the integration of both Western and CALD explanatory models in the treatment of mental illness ... Culturally sensitive mental health management involves practitioners and workers at the service delivery level understanding more about the clients' explanatory models".	Study only had 9 carers and practitioners from 4 CALD backgrounds, so further research is needed to investigate whether these results are supported in other cultural contexts and with more members of similar cultural backgrounds. Further exploration of coping strategies for CALD carers is needed.
Spear J (2003) <i>A new measure of consumer expectations, perceptions and satisfaction for patients and carers of older people with mental health problems. Australasian Psychiatry</i> Vol.11, No.3, pp.330-3.	Older people with mental health problems and their carers. Sample consisted of 115 consecutive patients (median age 74 years), in Western Australia. Patients from Peel and Rockingham Mental Health Services for Older People, covering a socially and economically disadvantaged mixed metro and rural population. Aim of study	Scale has 3 sub-scales: expectations; perceptions; and satisfaction. 2 measures used to evaluate validity of CEPAS - the Clinical Global Impression scale (CGI) is a global outcome measure, and the Client Satisfaction Questionnaire (CSQ-8) is a widely used measure of	CEPAS was found to be an appropriate, acceptable and brief scale, an adequate measure of patient and carer expectations, perceptions and satisfaction. Appropriate for 49% of clients and 51% of carers. Overall satisfaction had a significant association with the measure of satisfaction (CSQ-8) and the measure of outcome (CGI).	"CEPAS could complement other indicators of patient satisfaction"	"Satisfaction surveys alone are insufficient for engaging patients or discovering what they really feel about their experience of mental health care. Surveys can be supplemented with patient focus groups and other qualitative methods ...

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
	was to develop and evaluate the Consumer Expectations, Perceptions and Satisfaction Scale (CEPAS), supposed to be an appropriate, acceptable, brief and valid new measure for older people with mental health problems.	patient satisfaction within mental health services.	CEPAS addresses some methodological concerns about patient satisfaction measures, and has less positive skewness than the CSQ-8.		CEPAS have potential utility in other settings and age groups but further research is needed before it can be recommended for general use".
Wooff D, Schneider J, et al. (2003) <i>Correlates of stress in carers</i> . <u>Journal of Mental Health</u> Vol.12, No.1, pp.29-40.	Carers of people with mental illness. 64 carers interviewed. UK. Explored care coordination in the context of other mental health interventions	Carers' experiences of caring, carer stress, impact of caring on carers, and the service user's level of impairment. Interview used "Experience of Caregiving Inventory", which includes General Health Questionnaire-12, Life Skills Profile (assessing severity of impairment in self-care and social interaction), Global Assessment Scale, Health of Nation Outcomes Scales, Brief Psychiatric Rating Scale, etc	Carers were sometimes better judges than care coordinators of user impairment. Their experience reflected the independently rated severity of service users' problems. When carers were aware of care plans, they felt less negative about caring. Even in above-average mental health services, carers lacked information about: care plans, medication and complaints procedures. This evidence can be used in allocating resources such respite care, family therapy and CBT to carers. These findings have implications for how mental health services might improve their provision for carers, for instance, involvement in care planning may help carers to cope.	Services should more effectively and routinely explore the needs of informal carers and the differences between care givers in terms of their family situation, to incorporate into care plans	Future studies might look for impact of consistently describing carer views in assessment systems in order to improve care planning

**Table A19 Summary of the study literature of the needs of carers – stroke and brain injury**

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Gan C, Campbell KA, Gemeinhardt M, McFadden GT (2006) <i>Predictors of family system functioning after brain injury</i> . <u>Brain Injury</u> , Vol.20, No.6, pp.587-600.	Canadian. Family carers Acquired Brain Injury (ABI). No: 148 family caregivers within the same household who had enrolled in a community-based support program. ABI patients: trauma and non-traumatic.; mild brain injury: 12%, 15% moderate, 73% severe to very severe.	General Scale of the Family Assessment Measure III (FAM-III) Problem Check List and Patient Competency Rating Scale. Caregiver Strain Index.	Mothers, spouses, siblings and family unit: significant distress in family functioning compared to norm. Poorer family system functioning related to higher caregiver strain and client gender (female). Spouses were generally more distressed than parents in all domains. Biggest problem for caregivers may centre on the role changes in the family.	Treat the whole family system, not just patient and primary caregiver. Interventions should focus on role changes, alleviating role strain, collaborative family problem-solving. Support groups: families catered for in simultaneous needs groups (one-stop shop) positively evaluated.	Differences in family stress levels may be related to the role of the injured person within the family and severity of injury. <i>Limitations</i> : retrospective design; availability and quality of data; different versions of tests, inconsistent testing; no pre-injury measures of family system functioning.

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
van den Heuvel E, de Witt LP, Schure LM, Sanderman R, Jong BM (2001) <i>Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention.</i> <u>Clinical Rehabilitation</u> , Vol.15, No.6, pp.669-677.	Netherlands: 4 regions. Objectives: 1) to identify which caregivers of stroke patients living at home experience highest levels of strain and at risk of burn-out, 2) to investigate how support for caregivers of stroke patients could be organised and when support should be offered. Recruitment: through health professionals, hospitals, community and stroke organisations, and the media. Home-based interview with patient and caregiver separately.	Caregiver Strain Index; Short Form-36: mental well-being, vitality; Psychological consequences of stroke (Schure). Short version Utrecht Coping List; assertiveness: researcher developed questionnaire; social support: adjusted version Social Support List-Interaction; satisfaction with social support: adjusted version Social Support List-Discrepancy. Short Form-36: physical functioning.	<i>Caregiver strain</i> : younger; severe stroke; changes in patient's cognitive, emotional and behavioural functioning; dissatisfied with social support. Lower mental well-being associated with: females; poor physical health; patient with severe emotional, cognitive, and behavioural changes; little confidence in knowledge about patient care; little use of coping strategy 'confronting'; dissatisfied with social support. Highest risk of burnout: younger female caregivers of patients with severe consequences from stroke.	Caregivers' strain: re: inability to find time for themselves. <i>Prevention of burnout programs</i> target: women, younger caregivers, in poor physical health, caring for a patient with severe emotional, cognitive & behavioural disturbances. Education & support programs for caregivers should include: self-efficacy, using the coping strategy 'confronting', and mobilising suitable social support. Offer to all caregivers, regardless of time since occurrence of stroke.	"Compared with other diseases stroke causes the highest care needs." Therefore, <i>dementia findings</i> of no relationship between consequences of the disease and caregiver strain are <u>not</u> relevant to stroke. [Conflicting statements in results about influence of amount of social support received. Note: This study is mentioned in most of the stroke reviews.]
Thommessen, B., Aarland D. et al. (2002) <i>The psychosocial burden on spouses of the elderly with stroke, dementia and Parkinson's disease</i> <u>International Journal of Geriatric Psychiatry</u> Vol 17, No. 1, pp.78-84	Norwegian study using data on patient-spouse couples from studies of patients with stroke (36 couples), mild dementia (92 couples) and Parkinson's disease (58 couples).	Relatives' Stress Scale.	Problems in spouses across groups; carer stress, household routines, holidays, constraint on social life, sleep disturbances. Stroke and Parkinson's: striking association between patients' reduced cognitive function and spouses' higher burden; weak association with dementia.	Interventions needed to address psychosocial burden and coping skills of carers of people with stroke and Parkinson's Disease, as well as dementia.	Intervention studies needed to explore the importance for caregiver burden of detecting and being better able to cope with cognitive impairment in such patients' (i.e., stroke, dementia & Parkinson's)(p.83)

**Table A20 Summary of the study literature of the needs of carers - other chronic conditions**

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Aoun S, Kristjanson L and Oldham L (2006) <i>The challenges and unmet needs of people with neurodegenerative conditions and their carers.</i> <u>Journal for Community Nurses</u> 11, 1:17-20	Included 373 carers of people with Motor Neurone Disease, Multiple Sclerosis and Parkinson's disease identified in a national survey.	This paper reports on the qualitative aspect of the survey and describes the comments made by carers and associated demographic characteristics	Highlighted the need for novel, tailored and flexible models of care for each of the disease groups. Eight elements of improved support services are about care planning and navigating service complexities	Suggestions for improved support were better coordination of services and partnership with the support organisations and better help with palliative care	
Ellgring JH (1999) <i>Depression, psychosis and dementia: impact on the family</i> <u>Neurology</u>	German survey of 158 caregivers of people with Parkinson's Disease as a result of the emergence of depression, psychosis or dementia in a person with	No specific measures noted	"The influence of depression, psychosis and dementia on the behaviour, emotions and cognitions of caregivers must not be disregarded. ...To support	"Psychoeducation interventions can play a pivotal role in restoring lost meaning to the lives of chronic PD caregivers ... Stress	Are psychosocial interventions different for people with AD or PD?

Reference	Carer population	Outcome measures	Results	Service implications	Research implications
Vol.52, No.7 Suppl.3 pp.S17-20	Parkinson's disease.		families enduring these hardships, a few cursory words of advice from a physician will not suffice. Rather, thorough psychological counselling and an opportunity to share experiences with others in the same situation are often needed."p20	prevention programs can also improve the way in which patients and caregivers cope with the daily demands ..." (p.S20)	
Scott LD, Arslanian-Engoren C (2005) <i>The decision to care: a life-altering experience.</i> <u>Home Health Care Management &amp; Practice.</u> Vol.17, No.2, pp.130-135.	USA. Primary caregivers of individuals who had been liberated from prolonged mechanical ventilation (PMV). No.: 8 (out of 15 who had participated in quantitative phase of the study). Gender: females. Ages: 37-70 years (mean = 54.12 years). Relationship to care recipient: family.. Length of care provision: 3 months to 3.5 years. Daily time spent caring: 1.50 to 24 hours (average 9 hours). Employment: 6/8. Purpose: to explore the choices and challenges of family caregivers for patients liberated from PMV. Design: qualitative part of a larger descriptive study to explore complex caregiving. Content analysis to identify emerging themes.	<i>Telephone interviews</i> using a pre-established set of guiding questions to establish consistency: (a) What was the caregiving experience like for you? (b) What were the expectations and realities of the caregiving experience? (c) What were the rewards and challenges associated with caregiving? and (d) If given the opportunity, what advice should be given to a new caregiver?	<i>Themes: Caregiving experience:</i> physically exhausting, emotionally stressful, required lifestyle change. <i>Expectations and realities:</i> similar to expectations, different from expectations. <i>Rewards:</i> recovery (of loved one) having loved one at home, gratifying experience. <i>Challenges:</i> emotional toll of providing care, change in family dynamics. <i>Advice to new caregivers:</i> need for adequate preparation, ask for help, lots of love, take one day at a time, treat person with dignity, and take care of self. (Table 2, p.132) Although given advice for self-care, had difficulty using self-care strategies for themselves. Dual roles of caregiver and employment: often competing, precipitated physical and mental fatigue, potential to adversely affect both caregiver and work performance.	Need for adequate preparation for caring role and external support. "it is imperative that home health care nurses facilitate an effective transition to the caregiving role, serving as conduits for caregiver education and skill acquisition and advocating for the development of vital infrastructures that will provide resources, reassurance, and respite from burdensome caregiving challenges." (p.134) "... Evidence-based interventions are urgently needed that will augment the caregiving-care receiving experience for patients and families." (p.134)	Although the number of participants was limited, "...descriptions of the caregiving experience among survivors of PMV are consistent with those in other technologically dependent populations. ... [suggesting that] consistent themes are inherent in the complex caregiving experience and are not isolated occurrences specific to a given patient population. (p.134)
Williams AK, Young J, Nikoletti S, McRae S (2004) <i>Reasons for attending and not attending a support group for recipients of implantable cardioverter defibrillators and their carers.</i> <u>Journal of Nursing Practice.</u> Vol 10, No.3, pp.127-133.	Australia. 11 Primary family caregivers of people with implantable cardioverter defibrillators (ICDs) on the patient list of a Perth hospital. Age: =18 years old.	Semi-structured interviews on the realities and implications of coping with a life-threatening condition.	4 major themes: re: attending a support group: providing information, connecting with others, helping others, attendance issues: age and location – inaccessibility for rural people. Younger people's non-attendance: perceptions that group focused on circumstances and experiences of older people, preference to avoid thinking about the condition and 'get on' with their lives.	Meet the needs and circumstances of different groups and individuals. 1) more frequent support group meetings; 2) alternative strategies to address younger peoples' needs, lifestyles and concerns: e.g. web sites and newsletters, 3) strategies to address needs of rural people: e.g. web sites, newsletters, non-metropolitan group support sessions.	Further research into benefits of support groups and factors for selecting appropriate psychological strategies to meet individual needs. [Research could evaluate internet support/chat groups for younger people.]

## Attachment Four

### Summary of reviews of interventions by type of intervention

#### Multi-component interventions

**Table A21 Summary of reviews of multi-component interventions**

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Acton GJ, and Kang J, (2001) <i>Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis</i> <u>Research in Nursing &amp; Health</u> Vol 24, No. 5 pp349-360	Dementia. Meta-analysis of 24 studies (comprising 27 treatment groups) published between 1982 and 1999 which tested an intervention to reduce the burden of caregiving. 17 studies used treatment and control groups & 7 used a one-group pre-test/post-test design. Interventions included: support group, education, psycho-education, counselling, respite and multi-component	Burden - Burden Interview (Zarit & Zarit 1990) in 18 studies & Burden Scale (Montgomery et al. 1985) in 4	This meta-analysis indicates that, overall, interventions designed to reduce caregiver burden had no effect on burden, and in some cases the effect of the intervention on burden was negative or the control group burden scores improved more than those of the treatment group'. p356 (discussion re 'blanketing subjects with a variety of services and interventions... it is not clear that more really is better'. (p 356) "...it is critical to identify outcomes most likely to be changed by intervention. Burden, a multidimensional and global concept, may not be the best outcome to demonstrate the effectiveness of caregiver interventions' (p.358) '...perhaps researchers should address such positive outcomes as meaning making, transcendence, well-being, and life satisfaction. It may be that an intervention cannot change the perception of burden yet may be able to help caregivers find meaning in the experience or transcend the negativity while acknowledging the burden remains unchanged.'	Multi-component interventions appear to offer more benefit for caregivers, however it is not clear that more is better	Need to look at positive outcomes of caring instead of negative (burden) which is unlikely to change due to the degenerative nature of dementia. E.g., meaning making, transcendence, well-being, and life satisfaction.' The results of this study show that burden may be too global and multidimensional to be affected by interventions' (p. 358)
Acton, G. J. and M. A. Winter (2002). <i>Interventions for family members caring for an elder with dementia. Annual Review of Nursing Research</i> Vol 20, pp149-79.	Dementia. Family members caring for older person with dementia. 73 published and unpublished research reports of interventions, conducted by nurse researchers or researchers from other disciplines.	Burden, depression, knowledge	Key findings show that approximately 32% of the study outcomes (burden, depression, knowledge) were changed after intervention in the desired direction.		Several problematic issues were identified including small, diverse samples; lack of intervention specificity; diversity in length, duration, and intensity of the intervention strategies; and problematic outcome

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Bhogal SK, Teasell RW, Foley NC, Speechley MR (2003) <i>Community Reintegration After Stroke. Topics in Stroke Rehabilitation</i> , Vol.10, No.2, pp. 107-129.	Canada. 17 Studies. Family caregivers. Published literature. Carer information: inconsistent: in 5 trials patients were 60+ years old, tended to be younger than patients. Randomised controlled trials: evaluated interventions on family education, leisure therapy, community reintegration, social support, caregiver burden and depression.	All standard caregiver domains plus standard patient outcome measures	Caregivers' depression and psychological morbidity: affects 1/3 to 1/2 of caregivers; associated with stroke severity, caregivers' health, lower socioeconomic level, patient care time, patient's behaviour and mood, younger patients, smaller social network. Older, healthier caregivers with higher incomes less depression and psychological strain. Rehabilitation outcomes: affected by family function and spousal conflict. Family education: strong evidence of positive benefit from active educational-counselling. Strong evidence outcomes not improved by information packages and workbooks.	Caregiver stress, burden and health: associated with social and emotional support, family functioning, social and leisure activities. Information ineffective without an educational or counselling context: teach active skill development e.g. problem-solving, best in family contexts. Service provision focus on: needs of younger caregivers and stroke patients, vary re: education levels; addressing high levels of caregiver psychological depression and morbidity.	measures. Similarities to caregiver outcomes in dementia and spouses in nursing homes research re: stress and burden, inadequacy of education and skill training. Evaluations of programs targeting families and caregivers in: education and counselling, skill development, family leisure activities, community reintegration.
Boschen K, Gargaro J, Gan C, Gerber G, Brandys C (2007) <i>Family interventions after acquired brain injury and other chronic conditions: A critical appraisal of the quality of the evidence. NeuroRehabilitation</i> , Vol. 22, No. 1, pp. 19-41.	Canada. 31 studies. Acquired Brain Injury (ABI). Randomised controlled trials. 6 types of family interventions for ABI and similar populations: educational, telephone/internet, multiple models, case management, counselling/therapy, support group/peer support. Assess re: published hierarchy of levels of evidence; current best practice; evidence of enhancing family coping and adjustment.	Questionnaires on wide range of carer domains including, e.g., resources and stress, anxiety and depression; and general health.	Literature lacks methodological rigour. No strong research evidence supporting any specific intervention method for family caregivers of individuals with ABI (Acquired Brain Injury) or any of the other [similar] chronic condition groups surveyed (dementia, stroke, mental health, childhood chronic illnesses), although an abundance of anecdotal descriptive, and quasi-experimental support exists in the rehabilitation literature.	Few interventions designed to support the family system. Common themes: support for well-coordinated multi-component interventions integrated across community-based service delivery systems; role for case management, health professionals and peers. Effective family support requires family-directed services, available long-term. Can reduce health system costs.	Few rigorous studies available. Future studies to identify and compare effective family interventions and outcomes across studies; use validated assessment tools; longitudinal studies, as ABI is a lifelong condition and families need long-term support. Depression, anxiety and adjustment: require ongoing interventions and assessment at intervals.
Brodaty H, Green, A, Koschera A (2003) <i>Meta-analysis of psychosocial interventions for carers of people with dementia Journal of the American Geriatrics Society</i> Vol 51 (5) pp 657 - 664	Informal carers of people in the community. 30 studies (34 interventions) over 17 year period of RCTs or quasi-experimental trials which included intervention & non-intervention groups. Aim of study was to review the evidence for the outcome of caregiver interventions (excl. respite - which is patient-targeted	Psychological morbidity, and burden	CG interventions have modest but significant benefits on CG knowledge, psychological morbidity, and other main outcome measures (such as coping skills and social support). .... Statistically, the only feature that emerged as significant was involvement of the patient in addition to the CG in a structured program, such as teaching the CG problem-solving skills in the care of the patient. (Teri et al. 1997) The small numbers of subjects in a large number of trials may have militated against the emergence of other features that appear qualitatively important: practical support for	problem-solving skills as well as education/training - and inclusion of people with dementia in that process	"The quality of research is advancing, but there is considerable room for methodological improvement." p663 More rigour i.e., randomised, controlled, blind outcome assessments, follow-ups for at least 6 months, and use of well-validated and reliable outcome criteria measuring

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	intervention). Dose effect included.		the CG, involvement of the extended family, structured individual counselling, and a flexible provision of a consistent professional to provide long-term support" p 663		outcomes proximally (burden, knowledge) and distally (depression, QoL). Interactions with drug therapies.
Farran, C. J. (2001). <i>Family caregiver intervention research: where have we been? Where are we going?</i> <u>Journal of Gerontological Nursing</u> Vol 27, No. 7, pp38-45.	Overview of key research themes in caregiver intervention literature from 1980 - 2000, with a particular focus on psychosocial interventions, and suggests directions for future research.		These...findings suggest that caregivers benefit from information, support from others, assistance in learning more about specific caregiving skills, and encouragement for maintaining a program of self-care (p44) Research study designs, sampling intervention and measurement issues continue to be key issues for researchers, as well as magnitude, dose, duration and integrity of interventions (p43). Growing attention to the importance of health services utilisation, positive aspects of caregiving and multicultural issues (p42).	"Nurses play a major role in identifying family caregivers, assessing their needs, intervening with both the impaired family member and the caregiver, and evaluating the outcome of this care." (p.44)	Continued need for improved study methods and designs e.g. prospective/longitudinal studies, and post-caregiving studies, use of technology (p.43), physical and immunological aspects of carer health (p.44).
Forster A, Smith J, Young, Knapp P, House A, Wright J (2007) <i>Information provision for stroke patients and their caregivers (Review)</i> . <u>Cochrane Database of Systematic Reviews</u> , No. 3, pp. 1-39.	UK. No. studies: 9 completed trials, 8 ongoing studies. Evaluated information, education programs and counselling. <i>Inclusion criteria:</i> randomised controlled trials. Also included some studies of matched pair design and studies which breached randomisation procedures.	Knowledge about stroke and stroke services; impact on health, especially mood; social activities; satisfaction with information; perceived health status; quality of life; service contacts or health professional contacts.	<i>Variable quality</i> of trials, attrition problems, limited comparable outcome measures, received additional information from authors. Only 3 centres obtained patients' views and opinions prior to developing the intervention. General 'effectiveness' of information provision not conclusively demonstrated. Information combined with education sessions improved knowledge; more effective than simple provision of a booklet or leaflet. Little evidence of an association between information and education provision and emotional outcomes. Education associated significantly with preventing deterioration in family function in problem-solving, communication and global family function.	Provision of information as print materials: little effect needs to be part of education and/or counselling program. Poor understanding of stroke, its consequences and available support is poor; important for compliance with secondary prevention and longer-term psychosocial outcomes. Focus on providing information based on identified needs, clear aims, and appropriate teaching strategies in conjunction with clinical practice. Address issues of attendance, accessibility and acceptability of education programs.	Importance of using comparable measures and reporting carer characteristics, sample size, intervention details. Relationship between increased knowledge of stroke, improved patient recovery and carer adjustment. Evidence of successful education strategies including: appropriate, accurate, timely information and advice about stroke.
Given BA, Given CW and Kozachik S (2001) <i>Family support in advanced cancer</i> . <u>CA: A cancer journal for clinicians</u> . Vol. 51, pp. 213-231.	Cancer/palliative care. This is not a systematic review but a discussion paper describing the needs of family carers looking after advanced cancer patients at home and reviewing the evidence for several types of interventions to support carers. Two examples of education	Self-efficacy, mastery, sense of control and competence. Knowledge and skills in the techniques and strategies of providing care at	Spouse caregivers typically receive less assistance from secondary caregivers than non-spouses. As demands increase over time, primary caregivers tend to seek supplementary care rather than completely handing over responsibility for any tasks. Caregivers want detailed and specific information tailored to their unique situations and psychosocial needs, as well as to the physical care needs of their patients. Older carers report more problems with physical demands	Lack of skill and knowledge contributes to carer distress. Adequate education for carers, tailored to their needs, may help reduce the need for psychotherapy. They do not want large amounts of non-specific information, however. Few carers use formal home care (domestic assistance) services: those	There are no reports in the literature describing caregivers' acquisition of (secondary) assistance as disease progresses and the demands of care increase. It is unclear what constitutes a 'therapeutic dose' of social or instrumental support for

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	models are presented: COPE (Houts and colleagues) and a program for health care teams (Barg and colleagues). All family caregivers, some differences between the needs of spouses and others are discussed	home. Health related QoL (SF-36).	of caring, while younger carers tend to have more emotional difficulties. Virtually all studies find elevated levels of depressive symptoms among family carers. There is also elevated risk of poor physical health, which increases with duration of caring. Carers report fatigue and inadequate time for sleep and self care. Evidence is mixed on the relationship between level of care required (i.e. patient need) and carer distress. Pre-existing family problems or mental health issues tend to exacerbate caregiver burden.	who are highly stressed need help to enlist formal and informal support. Home care delivered to patients increases their independence and thus reduces demands on carers. Ideally, a case manager within the care system would be responsible for helping families utilise community resources.	family caregivers. There is a need to define good patient outcomes and develop standards of care. "Research is needed to demonstrate that investing time, providing information and working with families to provide home care leads to demonstrably better patient outcomes at lower costs with less professional time overall." (p.229)
Goldstein NE and Morrison RS (2005) <i>The intersection between geriatrics and palliative care: a call for a new research agenda. Journal of the American Geriatrics Society</i> . Vol. 53, pp. 1593-1598.	Frail aged. This is not a systematic review but a discussion paper describing the potential for using palliative approach with frail older people and outlining a research agenda. All carers for frail aged, including spouses and adult children	Paper looks at all types of outcomes for carers (and patients) including anxiety, depression, mortality, quality of life, needs and burden.	"If the field of geriatrics is to encompass the needs of all older adults, it needs to actively integrate within it the principles of palliative care and promote and support the development of new investigators in palliative care research."		Research still needs to be conducted to examine burden in caregivers of geriatric patients with end-stage organ failure, especially given that these individuals tend to be adult children with families of their own. Similarly, the majority of scales used to assess caregiver burden have been developed for patients with dementia or cancer; older patients with heart or lung disease have different care needs.
Harding R, Higginson IJ (2003) <i>What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. Palliative Medicine</i> , Vol.17, No.1, pp.63-74.	Systematic review of interventions for carers of patients using home cancer and palliative care services. Using the databases. 22 interventions were identified - home nursing care (4), respite services (3), social networks and activity enhancement (2), problem solving and education (3), and group work (10). Of the 22		There was a lack of outcome evaluation designs, small sample sizes and a reliance on intervention descriptions and formative evaluations. The current evidence contributes more to understanding feasibility and acceptability than to effectiveness. Carers report high satisfaction with home care services (nursing or hospice) but users still have high levels of psychological morbidity and unmet need. Similarly, carers are satisfied with respite care in the form of 'sitting services' provided by professionals or volunteers. High quality evaluation data are lacking	"The service conceptualization of the carer as co-worker rather than client is problematic and leaves unmet support needs." p63	Paper suggests that methodological challenges may mean alternatives to 'pure' RCTs should be considered. Practitioners and evaluators must prioritise the further development of intervention studies. "The detection of improvements in (carer stress) scores may be

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	papers, 9 were services specifically for carers, and only 6 of the carers' interventions had been evaluated - RCT (2), single group methodology (3), facilitator feedback (1).		for either of these interventions. An 'activation program' was effective in increasing carers' social activity in the last few months of the patients' lives. One-to-one psychoeducational interventions have been rigorously evaluated, but findings are mixed. Carers groups have been shown to increase knowledge but not necessarily improve psychosocial adjustment. There are also significant recruitment difficulties.		clouded by the baseline scores of those who choose to attend ... It has been suggested that carers are not under severe stress when they access interventions, and that they do so to gather information to assist them in advance of the situation worsening" (p.71)
Kennet, J., L. Burgio, et al. (2000). <i>Interventions for in-home caregivers: A review of research 1990 to present. Handbook on dementia caregiving: Evidence-based interventions for family caregivers</i> . R. Schulz. 61-125. xiii.	Dementia. This review provides context for the rest of the book which focuses on issues of theory, measurement, treatment implementation and public policy regarding dementia caregiver intervention research. 40 manuscripts obtained, published between 1990 and 1997, including full range of methodologies i.e., case studies, quasi-experimental designs, panel studies and randomized trials, obtained through computerised searches and responses from leading researchers.	Knowledge of dementia; cognitive skills; behaviour, affect; social and physical environment;	Anyone expecting to find a silver bullet solution to alleviating caregiver distress will clearly be disappointed... There is no single, easily implemented and consistently effective method for eliminating the stresses of caregiving.' p79 'There exists strong consensus among researchers that all caregivers are likely to benefit from enhanced knowledge about the disease, the caregiving role, and resources available to caregivers. Once the informational needs have been met, the caregiver may additionally benefit from interventions that train the caregiver in general problem solving skills ... (Also) there may be important synergies achieved by simultaneously treating the care recipient...and/or altering the social and physical environment of the caregiver/care recipient dyad.' p79	The literature clearly points to one overriding conclusion, namely that interventions which are comprehensive, intensive, and individually tailored are likely to be more effective than those that are not.' (p.79)	Two main challenges for researchers: 'One concerns the choice of outcomes and the other concerns methods for identifying the optimal mix of intervention components for a particular caregiver.' (p.121) What is needed are large studies with diverse populations to explore the complex interactions among caregiver and care recipient characteristics, treatment components and methods of delivery.' (p.121)
Lee J, Soeken K, Picot SJ (2007) <i>A Meta-Analysis of Interventions for Informal Stroke Caregivers. Western Journal of Nursing Research</i> , Vol. 29, No. 3, pp. 344-364.	4 studies: 3 European, 1 USA. Interventions for improving mental health of caregivers conducted by treatment personnel: education/skills training, family support & functioning, psychosocial, support groups. Published studies, peer reviewed. English language. Randomised controlled designs.	Measure of mental health: SF-36 only.	Across the 4 studies, the intervention was effective in improving the mental health of informal caregivers. Effect and quality ratings of educational program interventions were larger than support programs. Education programs used more focused content. Goals of support programs may have been too broad. Effect size for a-theoretical intervention studies was larger than for theory-based studies; had larger sample sizes, therefore carried more weight in the analysis.	More education programs needed, based on results from 2 high quality randomised studies. Important to have good quality interventions to improve caregivers' mental health, as mental health decline (burden, depression and strain) is one of the most commonly reported problems of informal caregivers.	Research mental health re: ethnicities and cultures; long term effects. Design: controlled, double-blind; describe dosage, period, and content, theory base; immediately post-discharge. Meta-analyses: effects and effectiveness of: telephone, internet, home visits. Outcomes: depression or burden.
Lui M H L, Ross FM, Thompson	11 studies: 6 RCTs and 2	Physical health,	Few studies examining carer problem-solving.	Need to develop appropriate	Research problem solving

Reference	Review scope	Outcomes	Results	Service implications	Research implications
DR (2005) <i>Supporting family caregivers in stroke care: a review of the evidence for problem solving</i> . <i>Stroke</i> , Vol. 36, Issue 11, pp. 2514-22.	qualitative. Education/skills training and psychosocial interventions. Sample no. 71. Recruited post hospital discharge. Longitudinal: measuring short- and long-term outcome effects.	psychosocial well-being; problem-solving abilities; coping strategies; family functioning; stroke knowledge; perceived health status; burden, stress, depression, role preparedness, satisfaction with services, social support, use of social services.	Interventions benefited: females, younger, better confidence in knowledge. Types of interventions: specialist nurse visits, telephone, social problem-solving, and psychosocial. Effective problem solving skills enhanced caring abilities and reduced depression. Lacked evidence to support reported effects of teaching problem solving: reducing stress, promoting physical health or patient's physical recovery. Teaching with telephone follow-up more effective than home visits. Limitations: focus on outcome evaluation of problem-solving interventions, not process. Lacked: definition of 'problem-solving'; baseline assessments; proper randomisation; blinding; caregivers characteristics. Small sample sizes, non-standardised and variable outcome measures.	interventions targeted to family caregiver problem-solving abilities, to improve caregiver health and stroke patient functional recovery; but needs to be linked to research evidence.	as a complex intervention; links between processes and outcomes involved; use mixed quantitative and qualitative designs to evaluate implementation and outcomes. Effectiveness of interventions re: carer wellbeing. Measure impact of patients' depression, behavioural abnormalities, functional abilities on carers' problem-solving abilities, physical health, and psychological health.
McKevitt C, Redfern J, Mold F, Wolfe C (2004) <i>Qualitative studies of stroke: a systematic review</i> . <i>Stroke</i> , Vol. 35, No. 6, pp. 1499-1505.	95 studies. Some studies included Asians and Afro-Americans. Aims: To identify the scope of published qualitative studies of stroke conducted to 2002; relevance to development and delivery of services for people with stroke. English language; published in peer-reviewed journal to end of 2002; any qualitative method). Most papers focused on stroke patients/survivors, not carers.	Mostly one-off open-ended interviews. Types of observational studies: observational, descriptive, development and evaluation of interventions.	11 studies on carers' experiences and needs. Descriptive study of rehabilitation service 1-year post-stroke: late therapy provided continuity of care and respite for carers. Caregiver strategies: to increase own competence, creating own solutions for patient's functional loss, constructing meaning for 'recovery', spiritual beliefs and practices. Needs for support: information about long-term implications of stroke, availability of community services. Specialist nurse intervention: qualitative results more positive compared with RCT more negative results; intangible aspects of nursing care: concern, attention, empathy and interest, combined with emotional and practical support. General contribution: recording human experience of stroke; identify: perceived needs; differences in priorities between patients, carers, and professionals; barriers to best quality care; gaps in services. Limitations: small-scale, one off-interviews. Interview-based studies: actual practices may differ from what was reported	Carers' solutions: access to advisors, opportunity for regular reassessments of patient, improved access to day care and respite care, carer support groups, access to emergency calls for support. Need to be adequately consulted and considered by professionals. UK study of patients' and carers' experiences of obtaining information post-stroke: dissatisfied, wanted individualised information related to clinical questions, practical issues, and issues related to services and resources. Service problems identified in studies: delays in seeking and accessing acute care, some aspects of care not equitably provided, inadequate information, lack of satisfactory longer term care.	Meta-analysis to pool qualitative research findings and multi-site investigations, especially re: service delivery evaluations. UK Medical Research Council: greater utilisation of qualitative research, in conjunction with RCTs of complex interventions, in studies to explain the social processes involved in delivery and uptake of an interventions. Equity and access to care: ethnographic observational methods preferable to interviews.
Nelis, S. M., C. Quinn, et al. (2007). <i>Information and support interventions for informal caregivers of people with</i>	Dementia. Cochrane review - Inclusion criteria: RCTs; Quantitative evaluations of interventions; use of	Caregivers: Psychological well-being, physical well-being, caregiver	This is a description of the methods and protocol - no results		Meta-analysis will allow us to synthesize the valid retrieved studies and to summarise the findings on

Reference	Review scope	Outcomes	Results	Service implications	Research implications
dementia [Protocol] Cochrane Database of Systematic Reviews Issue 2.	standardised measures; English language; peer-reviewed, include a follow-up time-frame. Exclusion criteria: specific psychotherapeutic interventions e.g. cognitive behaviour therapy; respite as intervention; non-dementia; >1 intervention; qualitative studies; paid carers.	knowledge and skills, social outcomes, caregiver strain & caregiver satisfaction; Care recipients: mood and psychological well-being; behavioural problems; nursing home admission.			the effectiveness of information and support for caregivers of people with dementia.' (p.5)
Patterson T.L., & Grant I (2003) <i>Interventions for caregiving in dementia: physical outcomes</i> <i>Geriatric Psychiatry</i> Vol 16, pp629-633	Carers of people with dementia. Psychological and physical health consequences of being a dementia carer, and interventions to reduce negative health consequences	Review of studies with multiple measures	Intervention studies designed to reduce distress have shown modest success, but have largely ignored physiological outcomes. .... Inconsistent findings may result from a failure of interventions to target the needs of caregivers. ' p 631 Important to recognise growing literature re positive aspects of caring, 'Interventions designed to reduce the stress of caregiving have mixed this segment of the population with more vulnerable caregivers (which) may be why the effects of these interventions have been relatively modest.' (p.632)		"Studies should include outcome measures that match intervention targets" p631 " The challenge for the field is to identify specific profiles that predict who these vulnerable caregivers are." (p.632)
Peacock, S. C. and D. A. Forbes (2003). <i>Interventions for Caregivers of Persons with Dementia: A Systematic Review</i> <i>CJNR: Canadian Journal of Nursing Research</i> Vol 35, No. 4, pp88-107.	Dementia. 11 studies rated strong (out of 36) which gathered and synthesized information on interventions designed to enhance well-being of caregivers of people with dementia.	Review of studies with multiple measures	No one intervention had a significant impact on the well-being of carers. Although several interventions have been shown to be of benefit to caregivers, non-significant findings were more common.'	Several interventions have been shown to be of benefit to caregivers, (None were described in the abstract that was accessed for the review and a full text copy was not received.)	Systematic reviews are an important means of guiding consumers and practitioners in making evidence-based decisions.
Pinquart, M and Sorensen, S. (2006) <i>Helping caregivers of persons with dementia: which interventions work and how large are their effects?</i> <i>International Psychogeriatrics</i> Vol 18, No 4, pp577-95	Dementia. Meta-analysis of 127 intervention studies with dementia caregivers, published between 1982 and 2005. "We ask, first, which average effects of interventions are found on caregiver burden, depression, indicators of positive subjective well-being (SWB), ability/knowledge of caregivers, symptoms of CRs (care recipients) and the risk of	Psychoeducational; cognitive-behavioural therapy; counselling/case management, general support, respite, training of the care recipient.	"We conclude ... first, interventions with caregivers for patients with dementia have, on average, small but meaningful effects on reducing burden and depressive symptoms, and increasing ability/knowledge and SWB (subjective well-being) and, for a subset of interventions, reducing the risk of institutionalisation....Second, because multi-component interventions had only few effects, future research is needed regarding how the complexity of interventions relates to treatment effects and which combination would have the largest effects." 3rd - need for longer term follow-ups; 4th "more measures		Future research is needed regarding how the complexity of interventions relates to treatment effects and which combination would have the largest effects." 3rd - need for longer term follow-ups; 4th "more measures are needed on the positive aspects and outcomes of caregiving, for example on SWB and

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	institutionalisation. Second, we compare effects of different forms of intervention such as caregiver education, general support, and respite. Third, ...impact of study characteristics ...such as group-based versus individualized interventions" (p.579)		are needed on the positive aspects and outcomes of caregiving, for example on SWB and finding benefits in the caregiving role" (pp.592-3)		finding benefits in the caregiving role"(pp.592-3)
Pusey H, & Richards D (2001), <i>A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia</i> <u>Aging and Mental Health</u> vol 5, No. 2, pp 107-119	30 RCTs or controlled trials without randomisation reported in English language journals; 2 US studies using technology based interventions (computer network providing carers with education, decision, support and communication; and a network of telephone support; 14 studies evaluating group formats; and 9 studies of individualised interventions; 5 studies of a specific mode of service configuration (i.e., which used a range of interventions)	Psychological health (including depression, guilt, anger, frustration, rage, hostility, stress and anxiety) physical health QOL (including perception of burden).	"... there is no evidence to support the use of psychosocial interventions that utilize 'technology ... However, due to methodological weakness it should also be stated that there is no strong evidence of their ineffectiveness'. p 114 "The evidence from .. group-based interventions is fairly weak. Although a number of studies report successful interventions ... these results are subject to numerous and critical methodological weaknesses. Brodaty and Gresham (1989) offer the 'best' evidence of effectiveness. "p 114." Once again, due to consistent methodological weakness, there is no strong evidence that suggests the efficacy of individual interventions" p115 "Using the present evidence, it is clear that the 'strongest' case is for individualised interventions, particularly psychological therapies: p 115 "There is a dearth of strong evidence to support the efficacy of any service delivery model. A particular weakness with these studies was the lack of random allocation." (p.115)	The methodological flaws.. do not necessarily reflect the actual relationship between the intervention and outcomes: "Targeting an intervention to a specific population is likely to be more productive than trying to provide blanket support to all carers" Successful interventions feature a behavioural element focussing on problem solving and strategies for behaviour management' (p.117)	Need for high quality intervention studies - with larger sample sizes, and randomised allocation. Future research should concentrate on carers with identified needs, e.g., those who score above a specified level of depression'. (p.117)
Redfern J, McKeivitt C, Wolfe CDA (2006) <i>Development of complex interventions in stroke care: a systematic review.</i> <u>Stroke</u> , Vol. 37, No. 9, pp. 2410-19.	67 stroke studies, 1 Australian. Published evaluations of complex interventions in stroke prevention and management. Designs: 40 RCTs, 27 quasi-experimental, observational or qualitative. <i>Inclusion criteria:</i> definition of complex interventions: educational or psychosocial	53 standardised published scales: single item questions plus 15 author-developed scales.	Primary and secondary prevention studies were significantly less likely to have been evaluated in RCTs than recovery studies. Interventions evaluated in RCTS were significantly less likely to influence primary outcomes compared with other designs. "Studies with large numbers of primary outcomes (5 or more) were statistically less likely to be completely successful than those with fewer outcomes ... but were also less likely to fail..." (p.2413) No evidence that theoretical development was associated with success in primary outcomes. Observational or quasi-experimental studies tended	"Lack of clarity about the mechanisms by which interventions work makes it difficult to pool the results of similar studies in systematic reviews or meta-analyses, because although intervention components appear similar, we do not know whether interventions are delivering similar 'packages' of care. ... it is of concern that so few studies reported an appropriate literature review or considered established theory. ...	Note on blinding: in complex interventions it is impossible to conceal from intervention recipients or providers whether or not they have received the intervention. Such interventions may also present ethical difficulties attributable to the requirement that researchers withhold the intervention from some

Reference	Review scope	Outcomes	Results	Service implications	Research implications
			to yield better outcome success than RCT designs, may be due to publication bias, journals less likely to publish non-significant results for observational or quasi-experimental studies than for RCTs.	complex health interventions seem to be developed based on ad-hoc assumptions, and evaluated using methods where at the end of the study it is impossible to understand the reasons for success or failure. ...An evaluation of intervention implementation (process evaluation) could have enlightened our understanding." (p.2417)	groups/patients.
Schultz, R et al. (2002) <i>Dementia caregiver intervention research: In search of clinical significance</i> <u>Gerontologist</u> Vol 42, No 5 pp589-602	Dementia. Informal carers of people in the community. 50 articles reporting the results of 43 distinct studies, 27 of which used random assignment of interventions. Inclusion community dwelling people with dementia; focus was on intervention with cg and/or cr; quantitative data available for at least one clinically relevant outcome; comparative statistics evaluating between- and/or within-group differences. Excluded case studies and qualitative/descriptive reports	Symptoms, QOL and social significance. Social significance included residential care placement, patient longevity, patient functional status, service utilisation and time spent on caring tasks	"Overall, the data suggest that there is evidence of clinically significant outcomes in the caregiver intervention literature. ... Interventions show promise of achieving clinically significant outcomes in improving depressive symptoms, and, to a lesser degree, in reducing anxiety, anger and hostility....(and) some impressive and clinically meaningful effects have been demonstrated for delayed institutionalization of the care recipient. " p598 "There exists strong consensus that all caregivers are likely to benefit from enhanced knowledge about the disease, the caregiving role, and resources available ... caregivers might additionally benefit from training in general problem-solving skills, as well as from interventions that target managing care recipient behaviours or caregivers' own emotional response to caregiving." (p.599)	Dementia training needs to include problem-solving skills, as well as behaviour management, plus dealing with caregivers' emotional responses.	..there is room for increased methodological rigour in caregiver intervention research...' p599.. '...the development of a standardized taxonomy for characterizing and measuring multi-component psychosocial interventions ...We recommend a core set of outcomes be included in all interventions studies (ie, symptomatology, QOL, Social significance and social validity). ...researchers should set as their goal the achievement of reliable and clinically significant outcomes. preferably in multiple domains.' (p. 599)
Sinnakaruppan I, Williams DM (2001) <i>Head injury and family carers: a critical appraisal of case management programmes in the community.</i> <u>International Journal of Rehabilitation Research</u> , Vol. 24, No. 1, pp. 35-42.	7studies. Interventions: education/skills training, psychosocial, family support/functioning. Little information on patients or carers. Programs varied from behavioural to cognitive interventions to help family carers adjust to head injured	Validated standard tests to researcher developed questionnaires. Mostly self report measures and interviews. Psychological well-being, self-esteem,	Few studies of support and education programs specifically for family carers. Some programs were beneficial to carers. Limitations: 3 studies details of interventions – nature of training and support critical factor in determining outcomes. No consistency in outcome measures used or methodology. Majority small, unrepresentative, biased samples. Little information on patients: extent of disability, previous rehabilitation – important re: association between	Education/support programs: to complement professional therapy; include carer management techniques; from hospital and outpatient rehabilitation to post rehabilitation phases. Standardised information; flexible design to address individual carer needs; 'guided study' format to suit informal home practice.	Authors recommend large controlled clinical studies to identify optimal training and support programs that effectively reduce psychological distress in carers and improve their ability to cope and adjust to their head-injured relative.

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	person's problem behaviours. Professionally led programs.	coping strategies; target behaviours baseline and percentage change measures.	disabilities, behaviour of patient, and carer psychological burden. In one study: a statistically significant difference in the use of supportive coping techniques following the support program.	Support groups: helpful re: carer educational and psychological needs; not helpful: in teaching adjustment, family communication skills, and addressing concerns about patients' future.	Findings limited by lack of details, outcome measures, and controls. Use standardised methodologies appropriate for carers of the head-injured.
Sörensen S, Pinquart M and Duberstein P (2002) <i>How effective are interventions with caregivers? An updated meta-analysis. The Gerontologist</i> , Vol. 42, No. 3, pp. 356-372.	Frail aged. Inclusion criteria: care recipients aged 60 years or over; study compared intervention with control condition and reported outcomes in terms of caregiver burden, well-being, knowledge or symptoms; statistics could be converted into effect sizes; language = English, German, French or Russian; peer-reviewed. There were 78 eligible studies. Meta-analysis of 78 studies - no. of participants in studies ranged from 4 to 2268. On average, 69% were women, 50% were spouses, 14% reported their ethnicity as 'non-White'. More than half the studies (61%) focused only on care for dementia patients.	Outcome measures included: caregiver burden, self-rated depression, subjective well-being, uplifts (sources of satisfaction), ability and knowledge, and care receiver outcomes.	Taken together, all caregiver interventions produced a significant improvement (between 0.14 and 0.41 SD units) in caregiver burden, depression, subjective well-being, satisfaction, ability/knowledge and care receiver competence. Psycho-education and psychotherapy had a significant effect on all outcome variables. Multi-component interventions had significant effects on burden, well-being and knowledge. Respite was effective for reducing burden and depression and enhancing well-being. Individual interventions had stronger effects on burden and wellbeing, while group-based interventions had larger effects on care receiver competence. (It should be noted that social support outcomes were not included in the meta-analysis.) People caring for a dementia patient were less likely than others to benefit from interventions. Studies with a higher proportion of spouse caregivers (vis-à-vis adult children) tended to find smaller improvements in burden, depression etc but greater improvements for care receiver symptom	Analyses suggest that the older the care recipient, the more the caregiver is likely to benefit from interventions that either free up their time or provide emotional support. Group settings are beneficial for learning how to influence care recipients' behaviour, possibly because of mutual learning and exchange of experiences. Individual interventions appear more effective in reducing depression and burden, possibly because they can be tailored to each caregiver' specific concerns.	Greater objective burden at pre-test (ie hours of care required and years providing care) is linked with greater knowledge increases and improvements in care receiver symptoms at post-test, but less reduction in burden and depression. This may indicate that where levels of caring are high and cannot be changed (e.g., with dementia patients), psychological outcomes are less amenable to change.
Stoltz, P., G. Uden, et al. (2004). <i>Support for family carers who care for an elderly person at home - a systematic literature review. Scandinavian Journal of Caring Sciences</i> Vol 18, No. 2, pp111-9.	Frail aged. 36 articles derived from Medline database search (out of initial 734 references, 333 retrievals) which reviewed the available scientific evidence on support for family carers. Support defined as 'any services, assistance, education, information, attitude, lay or professional persons provision for the benefit of the family carer.' (p.112)		Studies interweave <i>why</i> family carers are in need of support as well as <i>how</i> to support them.' p 113 '(F)amily carers fear social isolation..' p 116 Family carers also ..'desire respite. However, it is difficult to show that family carers actually benefit from this.' p 116 'Family carers' fear of isolation and explicit wish to network with peers could perhaps emphasize the social dimension .. Rather than the current instrumental approach in service provision.' p117 (I)t appears that care and services are 'given' to family carers, rather than being negotiated and individually tailored to their needs.' (p.117)	Discrepancies between the views of professionals/decision makers and family carers: 'It seems as the professionals' view on support is dominant in service provision, family carers may have another point of view regarding what constitutes support for them.' (p.117)	

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Vernooij-Dassen, M. and M. Downs (2007). <i>Cognitive and behavioural interventions for carers of people with dementia [Protocol]</i> . Cochrane Database of Systematic Reviews Issue 2.	Dementia. Cochrane review - RCTs. No restrictions to length of trial and number of measurements and assessments.	Psychological morbidity and stress of carers including depression and anxiety; quality of life of carers; and carers' perceptions of their fulfilment including burden and competence.	Report on the review protocol - no results		
Visser-Meily A, van Heugten C, Post M, Schepers V, Lindeman E (2005) <i>Intervention studies for caregivers of stroke survivors: a critical review. Patient Education and Counseling</i> , Vol. 56, No. 3, pp. 257-267.	22 studies (1 Australian). Most randomised clinical trials, clinical trials or uncontrolled trials with pre- and post-test measurement. Language: English, German or Dutch. Sample size: 20 - 170. Time: immediately after stroke - few years after. Patients' ages: 60+ (mean age mostly 70+).	9 outcome domains for caregivers: 1) quality of life, 2) emotional state, 3) burden, 4) family functioning, 5) social activity in daily life, 6) coping, 7) satisfaction with care, 8) knowledge, 9) social support.	<i>Four main intervention approaches:</i> specialist services, (psycho) education, counselling, and peer social support. Counselling: 3 out of 4 studies showed a positive overall effect, even up to 3 years after stroke - increased confidence in knowledge about patient care, increased use of active coping strategies. Negative effects: early discharge - even when supported; require more emphasis on individualised needs of caregivers instead of offering pre-structured programs, active problem-solving strategies and promotion of support-seeking behaviour. Trend towards lower burden, without statistical significance. Difficult to change strain, wellbeing or emotional status of caregivers in a positive way.	Counselling beneficial for caregivers at risk of becoming stressed, depressed, socially and functionally dependent; offered shortly after stroke, when stress levels are high. Telephone counselling follow-up, after problem-solving training in hospital, effective and less time consuming alternative. "more emphasis should be placed on individualized needs of the caregivers instead of offering a pre-structured programme." (p.266) Interventions should aim to promote active problem-solving strategies and support seeking behaviour. Review sheds doubt on the effectiveness of emotional support as a strategy to reduce caregiver strain.	Future interventions should be targeted to compare: (1) caregivers at risk for burnout and caregivers with a lesser risk profile; (2) different types of counselling (personal vs. telephone, individual vs. group); (3) interventions in different phases of caring (acute, subacute, chronic); respite care; ongoing or booster sessions; effects of caregiver intervention on care recipient.
Yin T, Zhou Q and Bashford C (2002) <i>Burden on family members. Caring for frail elderly: a meta-analysis of interventions. Nursing Research</i> , Vol. 51, No. 3, pp. 199-208.	Frail aged. Focus was on group and individual interventions to reduce caregiver burden. 18 studies of group interventions were included, and 8 studies of individual interventions (3 of these were also included in the meta-analysis of group interventions because the studies investigated the effectiveness of both types). The total combined sample size was 1970 family caregivers of frail	Caregiver burden measured by various standardised and non-standardised instruments including Zarit Burden Interview, Caregiver Strain Index, Caregiver Burden Inventory and Subjective and Objective Burden Scale.	Almost all the group interventions (93%) involved education plus peer support. Some also included specialised group counselling, respite care and stress management. Duration ranged from 2 weeks to 1 year. The weighted mean effect size for group intervention studies was 0.41 (95% CI 0.32-0.51) indicating a moderate, positive treatment effect on caregiver burden. Effect sizes varied widely between studies, particularly among the quasi-experimental studies (which tended also to report larger effects than the controlled studies). For the individual interventions, the weighted mean effect size was 0.48 (95% CI 0.30-0.67). This was reasonably	None described	"Further experimental studies of large scale and high quality designs are needed to produce more definitive conclusions about the real strength of various interventional strategies." (p.207)

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	elderly people; 79% were women, 86% were 'white', mean age was 60 years. More than half of the care recipients (54%) had dementia.		homogeneous (that is, the studies reported similar sized effects). This type of intervention mainly consisted of psychosocial counselling.		

## Psychosocial /counselling interventions

**Table A22 Summary of reviews of psychosocial and counselling interventions**

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Charlesworth, GM (2001) <i>Reviewing psychosocial interventions for family carers of people with dementia</i> <u>Aging and Mental Health</u> Vol.5, No.2, pp.104-106	Dementia Psychosocial interventions. Review of two systematic reviews of psychosocial interventions for family carers of people with dementia - Cooke et & Pusey and Richards. "That search strategies on the same topic should produce different results is damaging to the credibility of the review process. To increase the validity of reviews, search strategies must be as rigorous as possible" p104		"The differences between the two (well conducted systematic) reviews demonstrate the heterogeneity of psychosocial interventions, and highlight the difficulties of searching for primary research in a 'non-medical' field. ...the available evidence suggests that psychosocial interventions can be effective - especially those that are theory-based with a coherent and explicit rationale. However, there needs to be a much greater emphasis on targeting interventions according to specific characteristics of the carer and the person with dementia'. (p.106)	Role of nurses in identifying carers needs, as well as the characteristics of carers (self-efficacy, hardiness), and therefore put in place appropriate strategies matched to the individual needs.	
Cooke, DD et al. (2001) <i>Psychosocial interventions for caregivers of people with dementia: a systematic review</i> <u>Aging and Mental Health</u> Vol.5, No.2, pp.120-35	Dementia 40 studies <b>focus</b> on the components of psychological/ psycho-educational interventions for dementia caregivers, and how successful they are in producing positive outcomes. <b>Inclusion</b> qualitative evaluation of psychosocial interventions and focus on improving caregivers psychological well-being and/or social well-being. 15 intervention components	Knowledge; psychological well-being (e.g., depression, mental health); caregiver burden (e.g. Zarit); social outcomes (support needed); general (QOL,satisfaction) Caution: small sample size, variety of outcome measures, and lack of control groups in designs.	"Overall, there is little evidence that interventions consistently produce benefits for caregivers in terms of improved caregiver psychological well -being or caregiver burden" p 129 " The efficacy of interventions is greater when caregivers' knowledge of illness is considered as an outcome" p130 "The findings suggest that the inclusion of social components in interventions or a combination of social and cognitive component appears to be relatively effective in improving psychological well-being" p132 However - 'An intervention is unlikely to influence a particular outcome if baseline scores on the dependent measure are relatively low' (i.e., need to be significantly/severely depressed initially for change to be measurable). (p.131)	Improvement in knowledge appears to be unrelated to psychological or social outcomes. The findings of the review suggest that the inclusion of social and cognitive components appears to be relatively effective in improving psychological well-being' (p.132)	Need for follow-up assessments: 'Caregiver interventions may require a delay before their effects become apparent' p129 '...a systematic approach to investigations of interventions with caregivers is required, where components are carefully contrasted in appropriately designed studies of sufficient size.' (p.132)

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Kneebone I.I. & Martin P.R., (2003) <i>Coping and Caregivers of people with dementia</i> <u>British Journal of Health Psychology</u> Vol 8, pp1-17	Carers of people with dementia. 16 studies - 12 cross-sectional and 4 longitudinal, review of research based on Lazarus & Folkman's (1984) stress and coping model to establish implications for interventions aimed at improving caregiver adjustment.	Depression, indexes of life satisfaction, caregiver burden.	Overall, the research on coping in caregivers to people with dementia to date provides evidence that a general tendency to problem-solving and an acceptance style of coping is likely to be advantageous.' p 13 'Alternative research designs may have the potential to have a greater impact on caregiver adjustment than the investigations reviewed in this paper'. (p.14)	Clinicians...should work with their clients to develop problem-solving responses to the difficulties they face, where solutions are available....(otherwise where) solutions may not exist, clinicians should encourage caregivers to adopt an acceptance style of responding.' (p.13)	.. the ability of the research to inform the clinician for intervention purposes with any specificity remains severely limited'. p14 i.e., need for 'longitudinal studies of specific caregiver problems that consistently incorporate measures of coping strategies particular to caregiving and the specific problems that arise for the caregiver.' p14 'Alternatively, perhaps what is needed is a radical revision of methodology and perspective. e.g., caregivers monitor their coping responses to particular problems... coping strategies and mood responses could also be frequently/ continuously measured in relation to particular stressors...' (p.14)
Low JTS, Payne S, Roderick P (1999) <i>The impact of stroke on informal carers: a literature review</i> <u>Social Science &amp; Medicine</u> , Vol. 49, No. 6, pp. 711-25.	Stroke/brain injury. Authors: UK. International. Psychosocial interventions. Some Australian studies. Carer sample: caring for elderly stroke survivors (55 years+). Carers: predominantly female 60 years+, spouse or adult children. 31 relevant studies identified: 29 dealt exclusively with stroke carers, 2 studies – with both dementia and stroke carers. <i>Objectives:</i> a) to evaluate the impact of stroke on informal carers' quality of life, b) to identify factors which help	Psychological health and carer burden, physical health, stroke knowledge, social health: social adjustment and engagement, carer satisfaction and life satisfaction, carer's perceived needs, satisfaction with services, post-discharge needs, and educational needs.	Most studies focused on carers' psychological health and the negative impact of stroke with interventions showing mixed results. Depression: some found higher levels, others similar to normal population levels. Carers' ability to cope was enhanced by use of positive coping strategies and more stroke information (concrete approaches). Variables important in predicting degree of carers' psychological morbidity/emotional impairment: 1) cognitive and behavioural abnormalities caused by patient's stroke: incontinence, language impairment, demanding behaviour; 2) carers' morale (mixed results) related to: degree of stroke survivors' physical disability/mobility; 3) carers' own physical health;	Although ... "most carers were generally satisfied with health services, the few interventions directed at improving carer outcomes showed mixed results." (p.711) Differences in stroke and dementia: sudden onset of stroke – little time to adapt, vs. dementia – time to adapt to changes; even though parallels in age and problems of coping with 'patient's/survivor's' cognitive impairment, behavioural problems, mood disorder and communication difficulties. Focus in the research of carers'	"Future studies should broaden their research question to evaluate quality of life, using standardised measures ... [and] either a longitudinal or randomised control design to improve the robustness of results. <i>Outcome measures:</i> More studies are needed evaluating the effectiveness of health services on carers' quality of life." (p.711). Need studies on impact of domiciliary delivery of stroke

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	carers to cope with their caring role, c) to evaluate health service provision for stroke carers.		4) carers' own psychological state prior to stroke and level of optimism; 5) quality of carer's relationship with stroke survivor: poor relationship related to higher perceptions of burden and negativity in their caring role and life situation; 6) longitudinal studies: significant predictors related to carers' psychological morbidity can vary with time. Initial stages of caring related to: stroke survivor's depression, stroke severity, concerns about future medical care. Later stage related to: carer's own health, income, age. Coping enhanced by: teaching positive coping strategies, concrete measures: post-discharge support, counselling, information about stroke, practical help. Information provision prior to discharge found to be insufficient – needs to be associated with other support strategies.	perceptions of in-patient stroke services; carers' perceived needs for services and satisfaction with services. Areas of dissatisfaction: communication with nursing staff or discharge plans; lack of sufficient information on: allowance entitlements, post-discharge service needs, carers' domiciliary support, provision of aids and adaptations; information about reducing risk of another stroke; insufficient support in dealing with their own emotional and personal problems, especially in dealing with lifestyle and role changes.	rehabilitation. <i>Carer population:</i> lack of information on target population socio-demographic characteristics;. Issue of using control groups: unethical to withhold care or services. Need precise definition of 'carer' and to identify relationship of carer to the care recipient.
Martire LM, Lustig AP, Schulz R, Miller, Ge, Helgeson, VS (2004) <i>Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness.</i> <u>Health Psychology</u> , Vol.23, No.6, pp.599-611.	No. studies: 70. Family caregivers: average sample size 87, average age 59.1 years (excluding 2 large studies). Cross-literature meta-analytic review of interventions involving a family member, focusing on both patient and family member. Inclusion criteria: Randomised controlled trials; published in peer reviewed, English language journals to October 2002: adult populations; evaluations of a family psychosocial intervention for a physician diagnosed medical illness; living independently at home; comparison of family intervention with usual patient medical care; report data for 1 of 9 psychosocial and physical health outcomes, not disease-specific. Includes intervention effects at	Family caregivers: depression, anxiety, relationship satisfaction, caring burden	Carers: positive effects for burden, depression and anxiety; strongest for non-dementing illnesses and interventions targeting only the family member and addressed relationship issues. Statistically significant aggregate effects were generally small in magnitude.	Improvements in family carer depressive symptoms and burden may have reduced the risk of carer mortality. Family carers of dementia patients face increasingly uncontrollable stressors and difficult to improve their mental health through psychosocial interventions. Family interventions beneficial in reducing carer burden and anxiety, especially when content focused on emotional needs and relationship issues.	Illness-specific interventions for patients including family caregivers, compare with patient-focused interventions; long-term or lagged effect of interventions including family caregivers; include conceptual models and impact on design and development of intervention and materials; gender; health of carer in relation to perceived support; relationship satisfaction; patient physical co-morbidities and dependency; use of moderators (characteristics, p.603); identify mechanisms to benefit mental and physical health.

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	first follow-up.				
Pilling S, Bebbington P, et al. (2002) <i>Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy</i> . <u>Psychological Medicine</u> Vol.32, No.5, pp.763-782.	People with mental illness, specifically schizophrenia, and their families. Only RCTs considered for inclusion in analysis. Reviewing 2 psychological interventions in schizophrenia: Family intervention and Cognitive Behaviour Therapy. Family intervention: 18 studies involving 1467 patients. CBT: 8 studies involving 528 patients. There is considerable variation in content and application of these psychological interventions.	Death, mental state, relapse, re-admission, burden, expressed emotion, medication compliance and acceptability of treatment	Family therapy, in particular single family therapy, had clear preventative effects on the outcomes of psychotic relapse and readmission, in addition to benefits in medication compliance. CBT produced higher rates of 'important improvement' in mental state and demonstrated positive effects on continuous measures of mental state at follow-up. CBT also seems to be associated with low drop-out rates.	Supports the use of both family interventions and CBT	Both interventions, CBT and family intervention should be further investigated in large trials across a variety of patients, in various settings. The factors mediating treatment success in these interventions should be researched.

## Respite and day care

**Table A23 Summary of reviews of respite and day care**

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Flint A (2005) <i>Effects of respite care on patients with dementia and their caregivers</i> <u>International Psychogeriatrics</u> Vol.7, No.4, pp.505-517	Dementia 4 RCTs derived from search of English language articles between 1975 and 1994. <b>Inclusion</b> original research, controlled trial, dementia population, and one outcome measure.	rate of institutionalisation, carer burden	Based on the results of controlled studies, there is little evidence that respite care for a patient with dementia significantly affects caregiver burden or delays institutionalisation of the patient. In fact there is some suggestion from uncontrolled trials that utilising respite services may increase the rate of institutionalization.' p515 However - data far from conclusive due to small number of studies and methodological and conceptual problems. p515 Despite this, many caregivers report 'high levels of satisfaction with respite services' p516	Respite care should be matched to the needs of the caregiver, and of sufficient frequency and duration to be clinically meaningful.	Studies should be controlled and of sufficient size to detect differences; type of respite care should be well defined, matched to the needs of carers and be of sufficient frequency and duration to be clinically meaningful; clearer definition of the outcome of respite and using appropriate measures.
Gaugler J and Zarit S (2001) <i>The effectiveness of adult day services for disabled older people</i> . <u>Journal of Aging and Social Policy</u> Vol.12, No.2,	Disabled adults / older people, and their caregivers. Respite or day care. Paper reviews research that determines the effectiveness of adult day	Admission to residential care, QOL, caregiver stress, client functioning,	Elderly clients are largely satisfied with adult day services and seem to enjoy improvements in psychosocial functioning. Also, family caregivers seem to benefit from utilising adult day services over time. However, adult day programs act more as a	"Experts should pay special attention to the program content, timing, and targeting of adult day programs in order to improve overall effectiveness."	"Researchers must gain a greater understanding of effectiveness by utilizing larger samples, incorporating more rigorous

Reference	Review scope	Outcomes	Results	Service implications	Research implications
pp.23-47.	services in improving client functioning, alleviating caregiver stress, and delaying nursing home placement; considers strengths & limitations of the research. Typically an elderly client attends an adult day program for 2 or 3 days a week for about 5 hours a day. However, adult day care does not refer to a homogenous set of activities, services or programs, nor does it serve a generic population. As such, interventions have been classed as either 'medical' programs or 'social' programs.	caregiver adaptation and timing of institutionalisation.	supplement to informal assistance than a substitute for nursing home care, and the functional status of clients is often not affected.		experimental designs, and evaluating different types of programs (that is, social models) as well as multi-component approaches."
Ingleton C, Payne S, Nolan M and Carey I (2003) <i>Respite in palliative care: a review and discussion of the literature</i> . <u>Palliative Medicine</u> , Vol.17, pp.567-575.	Palliative care. All family caregivers for palliative patients and for carers of adults with chronic conditions. Search identified 260 papers, of which 28 related directly to adult respite care in specialist palliative care.	Studies were largely concerned with descriptive accounts of respite programs, guidance on referral criteria or evaluating effects on patients but not carers. In their discussion, the authors drew on wider literature on carers of adults with chronic disease.	No empirical studies evaluating the impact of respite care provided by specialist palliative care services on carer outcomes were found.	There is a need to know how 'respite' facilities are construed and utilized (p573) Studies should take into account the assumptions of professionals when dealing with caregivers, and the lifestyle choices, experiences and life stages of carers.	Any future evaluation of respite care needs to take into account the dynamic nature of caring, which changes as the patient's physical and psychological health and dependency/function fluctuates. At least three aspects should be evaluated, namely the extent to which respite functions to (1) reduce physical and psychological morbidity, (2) enhances wellbeing and perceived control and (3) enhances choice, which may include the decision to cease caring.
Lee H & Cameron M (2004) <i>Respite care for people with dementia and their carers</i> <u>Cochrane Database of Systematic Reviews</u> , Issue.1, Art	Dementia 3 RCTs which compared respite care with a control intervention for people with dementia. Grant 2003: 60 hrs in-home respite	Rate of institutionalisation; burden, psychological stress and health, physical	"Analysis of the data showed no significant effects on caregiver outcomes and there was no evaluable data for people with dementia" p7 Number of methodological issues - interventions and outcomes were too dissimilar so data couldn't be pooled.	No meaningful conclusions can be drawn with the available evidence.	need for better quality research - ie, consistent approaches to randomisation, blinding, drop-out rates, etc and

Reference	Review scope	Outcomes	Results	Service implications	Research implications
No.:CD004396.	over 2 week period; Lawton 1989: 3 types of respite over one year period with some paying/subsidised/free; Wishart 2000: weekly visiting/walking program for people with dementia, 2.5 hrs, for 6 weeks.	health, economic impact and quality of life, QoL, abuse	'These results should be treated with caution, however, as they may reflect the lack of high quality research in this area rather than an actual lack of benefit' p1		longer duration of intervention (given the prolonged and degenerative nature of the disease);
Mason A, Weatherly H, et al. (2007) <i>A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers.</i> <u>Health Technology Assessment</u> Vol.11, No.15, pp.1-176.	Same study as reported in Mason et al. (2007a) in JAGS. The searches were unable to discriminate between services for the carers and the care recipients, although in most circumstances terms such as 'respite' and 'break' did refer to the carer.	Caregiver outcomes across all studies included burden, depression and knowledge and quality of life measures.	"The literature reviewed in this report suggests that respite for carers of frail older people generally has a small effect upon carer burden and carer mental or physical health. There is tentative evidence that some carers benefit more than others. However, carer satisfaction levels for all types of respite are generally high and carers appear to be more satisfied with respite than with usual care. The study found no robust evidence that respite either benefits or adversely affects care recipients, or that it delays entry to residential care. Economic evidence suggests that day care is at least as costly as, and may be considerably more expensive than, usual care." (p.73)	"There are difficulties recruiting frail older people: trials may suffer high attrition rates either because of the death or institutionalisation of the care recipient or because of carer exhaustion. Lessons from trials of palliative care may help to inform this issue." (p.78)	The quasi-experimental studies had methodological weaknesses and findings that may be more to do with the design of the study than the benefit of respite.
Mason A, Weatherly H, Spilsbury K, Golder S, Arksey H, Adamson J and Drummond M (2007a) <i>The effectiveness and cost-effectiveness of respite for caregivers of frail older people.</i> <u>Journal of the American Geriatric Society</u> , Vol. 55, pp. 290-299.	37 databases were searched for studies assessing the effect of community-based respite on caregivers of frail elderly people relative to usual care or to another support intervention. Of the 12,927 titles and abstracts screened for relevance, 379 full text copies were obtained, along with 91 references identified via bibliography checking. A total of 10 RCTs, 7 quasi-experimental studies and 5 uncontrolled studies were included.	Caregiver outcomes included burden, depression and knowledge and quality of life measures. Care recipient outcomes included delay in admission to institutional care.	There is some evidence that respite provides a small benefit to caregivers of frail aged people in terms of reducing burden and improving mental and physical health. Evidence from quasi-experimental studies is generally more positive than evidence from well-controlled studies. Caregivers are satisfied with all types of respite and prefer it to usual care. There is no reliable evidence to show that respite care delays entry into residential care. No adverse effects of respite on care recipients have been demonstrated.	"The existing evidence base does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn and is unable to inform current policy and practice." (p.297) There is also a need to explore reasons for poor uptake of respite services.	The challenge is to design a well-controlled study with findings that can be applied beyond the local context. This is difficult because respite is complex: "it is difficult to identify the 'active' ingredients and to determine how these interact" (p.297). The primary research need is for good pilot studies that can inform full-scale controlled trials. These pilots would identify target groups, establish clear definitions of respite services and determine the main outcomes to be measured. The authors

Reference	Review scope	Outcomes	Results	Service implications	Research implications
					suggest a mix of qualitative and quantitative methods within a study. Longitudinal data on service use could complement these studies.
McNally, S., Y. Ben-Shlomo, et al. (1999). <i>The effects of respite care on informal carers' well-being: A systematic review</i> . <u>Disability and Rehabilitation: An International Multidisciplinary Journal</u> Vol. 21, No. 1, pp 1-14.	Carers of people with a chronic illness or disability. 29 studies were found following a literature search of 'Psyclit', 'Medline' and Social Science Citation Index computerised databases, followed by a search of the reference sections of relevant studies.		There was little evidence that respite intervention has either a consistent or enduring beneficial effect on carers' well-being.	A more 'carer-centred' approach is required in both the provision and evaluation of respite care intervention. This approach would address the experiences of both caregiver and care-recipient during the respite period	The majority of the work conducted has been methodologically poor.
Payne M (2006) <i>Social objectives in cancer care: the example of palliative day care</i> . <u>European Journal of Cancer Care</u> , Vol.15, No.5,pp.440-447.	Literature review in all databases for the National Health Service by Dialog Datastar for the terms "day care" and 'palliative care' and a hand search of St Christopher's Hospice Library and King's Fund Library in London during July and August 2004. Table 1 pp442 - sets out an analysis of references to various aspects of social and creative care.	NICE Guidance (NICE 2204a) - identifies 5 aspects of palliative day-care provision: medical care, nursing care, emotional and spiritual support, social support and services for families and carers	Success in achieving social objectives is likely to depend on first identifying interventions that are designed to lead to specifiable and therefore potentially measurable outcomes. Examples from this literature review would be interventions designed to: increase social interaction; decrease isolation; provide reassurance about future care arrangements; promote personal growth; and promote a sense of control of the illness experience. This article discussed findings in day care programs/centres but in the context of social objectives rather than outcomes of the interventions. However, there are some references that give findings. Eg, the article refers to an ethnographic study - found that the day centre made it possible for patients to discuss impending death with people sharing the same experience, whereas they sometimes found it difficult to do so with relatives and carers. Another article referred to showed that day centres were a useful point of contact for assessment and intervention in cases of elder abuse. Another article referred to was a Birmingham study that showed that there may be under-utilisation of day care by people from minority ethnic groups.	"..missing aspect of day-care provision in more recent literature: whether carers and family members participate in the day centre or have services provided for them". "the assumption that merely by providing day care, appropriate respite for carers is achieved may need further exploration. It would seem likely that explicit care plans to meet carers' needs separately from and additional to the needs of patients need to be developed, with clear objectives that may then be tested" (pp.445)	Evaluation has focused on health care rather than social outcomes - need to have better precision in specifying social objectives in a way that might be evaluated (pp.445)

## Family support, including home care

**Table A24 Summary of reviews of family support, including home care**

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Cuijpers P (1999) <i>The effects of family interventions on relatives' burden: A meta-analysis.</i> <u>Journal of Mental Health</u> Vol.8, No.3, pp.275-285.	Relatives of psychiatric patients. 16 studies reviewed. Effect studies of family intervention with schizophrenia. Criteria was that study had to investigate effects of an intervention for relatives of psychiatric patients, and had to use at least 1 outcome measure that could be seen as an element of carer burden. Studies had to report at least pre-test and post-test data.	Relatives' psychological distress; relationship with the patient; family functioning	Length of family intervention is key to interventions' effectiveness on carer burden (long-term interventions with 12 sessions or more are effective, less than 10 sessions had little effect).	Family support interventions must have an extended duration (at least 12 sessions) if they are to have any significant effect.	More research needed to determine what is most predictive of success of family intervention. I.e. Not necessarily number of sessions, possibly length of time of total intervention.
Joy CB, Adams CE, et al. (2004) <i>Crisis intervention for people with severe mental illnesses.</i> <u>Cochrane Database of Systematic Reviews</u> (4): CD001087.	People with severe mental illness. All randomised controlled trials of crisis intervention models versus standard care for people with severe mental illnesses	Service utilisation, satisfaction with treatment, clinical outcome, social outcome, and cost of treatment.	Crisis/home care reduces the number of people leaving the study early, reduces family burden, and is a more satisfactory form of care for both patients and families. No differences in death or mental state outcomes found. All studies found home care to be more cost effective than hospital care but all data were skewed or unusable. No data on staff satisfaction, carer input, compliance with medication and number of relapses were available.	No data on carer input suggests crisis intervention should routinely address carer inputs (not just carer burden), carer needs and the role carers can play in long term care.	If home care crisis treatment (coupled with an ongoing home care package) is to be widely implemented it is apparent that more evaluative studies are needed to ensure that this is a prudent use of resources.
Pharoah F, Mari J, Rathbone J, Wong W. (2006) <i>Family intervention for schizophrenia.</i> <u>Cochrane Database of Systematic Reviews</u> 2006 Issue 4. Art.No.CD000088. DOI: 10.1002/14651858.CD000088.pub2.	Schizophrenia patients and their relatives. 43 studies in total, this includes 15 added in the 2005-6 update. These 15 new studies include data from another 1765 participants	Suicide and all causes of mortality, Service utilisation, Clinical measures of the person with schizophrenia. No outcomes measured for family or carers.	Family intervention may decrease the frequency of relapse, although some small but negative studies may not have been identified by the search. Family intervention may also reduce hospital admission - and this finding is a change to the previous equivocal data reported in 2002.. It may improve general social impairment and the levels of expressed emotion within the family. No data to suggest that family intervention either prevents or promotes suicide.	Family interventions generally supported as they may prevent relapse and may improve general social impairment and the levels of expressed emotion within the family. No data to suggest negative impacts. Family intervention may also encourage compliance with medication but does not obviously affect the tendency of individuals/families to drop out of care	Cannot be confident of the effects of family intervention from the findings of this review - more research needed.
Pitschel-Walz G, Leucht S, et al. (2001) <i>The effect of family interventions on relapse and rehospitalisation in</i>	Schizophrenia patients and their relatives. 25 intervention studies were meta-analytically examined regarding the effect of including	Relapse rates	The main result of the meta-analysis was that the relapse rate can be reduced by 20% if relatives of schizophrenia patients are included in the treatment. If family interventions continued for longer than 3	Psycho-educational family interventions are clearly beneficial. Duration of family intervention is critical - must be at least 3 months.	Future research should focus on and evaluate the process of integrating family interventions into the clinical

Reference	Review scope	Outcomes	Results	Service implications	Research implications
<i>schizophrenia--a meta-analysis. Schizophrenia Bulletin</i> Vol.27, No.1, pp.73-92.	relatives in schizophrenia treatment. The studies investigated family intervention programs to educate relatives and help them cope better with the patient's illness. The patient's relapse rate, measured by either a significant worsening of symptoms or re-hospitalisation in the first years after hospitalisation, served as the main study criterion		months, the effect was particularly marked. Furthermore, different types of comprehensive family interventions have similar results. The bifocal approach, which offers psychosocial support to relatives and schizophrenia patients in addition to medical treatment, was clearly superior to the medication-only standard treatment. The effects of family interventions and comprehensive patient interventions were comparable, but the combination did not yield significantly better results than did a treatment approach, which focused on either the patient or the family. Psycho-educational interventions are essential to schizophrenia treatment.	Psycho-education for patients and their families should become a basic part of a comprehensive psychosocial treatment package offered to all schizophrenia patients.	routine and examine long term effects in more detail. Also, other important effects of family intervention (reduced burden, expressed emotion, improved knowledge of schizophrenia, improved QOL and costs to society) should be investigated (not just relapse and re-hospitalisation rates, as examined in this review).

## Educational and psycho-educational interventions

**Table A25 Summary of reviews of education and skills training**

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Allen D (1999) <i>Mediator analysis: An overview of recent research on carers supporting people with intellectual disability and challenging behaviour. Journal of Intellectual Disability Research</i> Vol.43, No.4, pp.325-339.	People with intellectual disability and challenging behaviour and their carers (both informal and formal carers). Reviews factors that may impact on effectiveness of behavioural interventions for people with ID and challenging behaviour... It focuses on carer attitudes and beliefs, carer emotional responses, and on more general setting conditions which seem to enhance or reduce intervention effectiveness. Literature search including key terms 'learning disability', 'mental handicap', 'mental retardation', 'ID', 'challenging behaviour', 'families' and 'staff'. Number of articles reviewed is not specified.	Impact of carer attitudes, beliefs and emotional states on behavioural intervention effectiveness is measured. Explores key setting conditions which are likely to impact on carers' (formal and informal) ability to implement behavioural interventions	Interventions based on a functional analysis of target behaviour are generally likely to produce superior outcomes. If the full potential of natural carers as agents of behavioural change is to be realised, it appears a far more systemic perspective on functional analysis is needed. In addition to immediate-behaviour-consequence relationships, the cognitive and emotional states of mediators, reciprocal reinforcement systems, and the ecological and cultural systems under which interventions are introduced seem to deserve far greater attention. Behavioural interventions with client could be enhanced by utilising additional psychological approaches with carers.	Important implications for clinical practice are principally concerned with the nature of functional analysis and with the need to combine therapeutic strategies in order to maximise intervention outcomes.	A clear need for more research on parental beliefs which parallels that undertaken with paid carers, and an equivalent need for research on professional attitudes to and assumptions about carers (an important influence on intervention effectiveness). A need for studies which evaluate comparative effectiveness of multi-component packages of support, and investigation of independent variables which are critical to intervention success. Finally, studies tend to focus separately on behavioural, emotional or cognitive

Reference	Review scope	Outcomes	Results	Service implications	Research implications
					aspects of supporting people with ID and challenging behaviour, but research that bridges the 3 strands is needed.
Hassiotis A and Hall I (2004) <i>Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with learning disabilities</i> . <u>Cochrane Database of Systematic Reviews 4</u> : CD003406	Adults and children with intellectual disabilities exhibiting outwardly-directed aggressive behaviour, and their carers. databases were searched using a strategy combining 'Learning', 'disabilities', 'behaviour' and 'treatment' (or synonyms) to late 2002. Three RCTs included (UK and USA). Treatments varied between studies (i.e. anger management based on modified relaxation, social skills training based on behavioural techniques, problem solving and assertiveness training and anger management using cognitive-behavioural principles).	Standardised instrument: reduction in aggressive behaviour); improvement of mental state; i adaptive functioning; reduction in care needs; and improvement in QOL. Other outcomes were medication; frequency of service use; user satisfaction data; and negative effects such as death or side-effects.	Results should be treated with caution; however, review suggests that behavioural and cognitive behavioural techniques have the potential to reduce outwardly directed aggression in people with ID with variable results. Improvement in measures of emotional distress and adaptive functioning compared with control group were seen post-treatment but no significant differences were found at 3 month follow-up (assertiveness and problem solving interventions). A 3-week relaxation training significantly reduced disruptive behaviours in participants. Both carers and participants found anger management beneficial after 9 weeks training and continued to do better after 3 month follow-up.	Insufficient evidence that cognitive behaviour and behaviour interventions are efficacious on their own in the long-term management of outwardly directed aggression. These interventions are relatively resource-intensive.	More research needed on the efficacy of these interventions. "Clearer evidence would be provided by larger RCTs of well-defined interventions over a longer timeframe ... Comparison RCTs with other interventions such as psychotropic medication and systemic therapy would add significantly to the evidence base and promote improved clinical decision making. Primary outcome measures should include not only reduction in aggressive behaviour but also QOL and cost efficacy". (p.8)
Lui M H L, Ross FM, Thompson DR (2005) <i>Supporting family caregivers in stroke care: a review of the evidence for problem solving</i> . <u>Stroke</u> , Vol. 36, Issue 11, pp. 2514-22.	Stroke/brain injury. Authors: Hong Kong, UK. Education/skills training and psychosocial interventions. 11 studies: including 6 RCTs and 2 qualitative. International. Caregivers of people with stroke. <i>Aims</i> : 1) to identify and describe studies examining the effectiveness of teaching problem-solving skills to caregivers in stroke care, 2) to identify any gaps in the evidence base, and 3) to recommend avenues for additional research.	<i>Family caregivers</i> : cognitive, physical, psychosocial well-being; Cognitive measures: Physical measures:.. Psychosocial: Lack of standardisation of outcome measurement instruments, some newly developed instruments with insufficient evidence	Overall few studies examining variables associated with caregiver problem-solving abilities. One study examined characteristics of caregivers who benefited most from the intervention: female, younger showed better confidence in knowledge. Intervention models and approaches included: specialist nurse visit, telephone social problem-solving, and psychosocial interventions. ... "teaching effective problem solving skills was found to be useful in enhancing caregiver problem-solving abilities and reducing depression. ... most intervention studies did not describe the details of the intervention or give evidence to support the effects of teaching problem solving in reducing caregiver stress or promoting their physical health or the physical recovery of the stroke patients. ...	Need to develop appropriate interventions targeted to family caregiver problem-solving abilities, to improve caregiver health and stroke patient functional recovery; but needs to be linked to research evidence.	Studies need to: measure at baseline to evaluate improvement and provide comparison data across studies; include characteristics of family caregivers. <i>Research required</i> : to explore problem solving as a complex intervention, investigating the links between processes and outcomes involved, using mixed quantitative and qualitative designs. More research needed to

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	<i>Inclusion criteria:</i> studies that examined problem-solving skills of family caregivers in stroke care or evaluated educational interventions for family caregivers' problem-solving skills in stroke care.	of validity and reliability.	teaching with telephone follow-up contact was found to be more effective than home visits." (p.2521).		establish the link between caregiver problem-solving abilities and stroke patient functional recovery.
Smith, M. et al. (2004) <i>History, development and future of the Progressively Lowered Stress Threshold: A conceptual model for dementia care</i> <u>Journal of the American Geriatrics Society</u> Vol.52, No.10 pp.1755-60	Dementia Education/skills training. Carers of people with dementia living in the community		"Extensive testing... Supports the use of the PLST model in decreasing depression, diminishing uncertainty and unpredictability associated with dementia caregiving, lessening caregiver appraisals of stress and burden while promoting levels of satisfaction, and reducing caregiver reactions to behavioural symptoms. ... additional study is needed to establish whether the PLST model consistently produces positive behavioural outcomes for persons with ADRD (people with dementia)" p1759	Key elements of Progressively Lowered Stress Threshold (PLST): ongoing education; assist with development of routines and strategies that enhance behaviour; help simplify day to day care tasks; assist with problem-solving strategies; assist locating community resources and developing social networks,; provide ongoing emotional support and counselling; case management.	Use PLST in assisted living settings, combining psycho-educational interventions with pharmacological treatment of agitated residents, and examine physiological outcomes and genetic risk factors.

## Other interventions

**Table A26 Summary of reviews of other interventions**

Reference	Review scope	Outcomes	Results	Service implications	Research implications
Brodady H and Green A (2002) <i>Who cares for the carer? The often forgotten patient.</i> <u>Australian Family Physician</u> Vol.31, No.9, pp.833-836.	This is not a systematic review but a research synthesis for the benefit of GPs, explaining their roles in providing support to carers of patients with dementia. Care coordination. All family carers of people with dementia		Carers experience poor physical and psychological health, social isolation and financial costs. Assistance with ADLs and IADLs takes an increasing amount of time as the disease progresses (4.6 hours/week for normal aging person, additional 8.5 hours/week for mild dementia, additional 17.4 and 41.5 hours/week for moderate and severe dementia respectively). Admission to RACF is more likely when carers are distressed and when they are not the spouses of patients (i.e. adult children) and tends to be precipitated by increasing time spent caring for the patient, clinical fluctuations, patient mis-identification and nocturnal deterioration. Emotional liability of the patient is the strongest predictor of impaired wellbeing in the carer. Protective factors include	The author outlines practical measures that GPs can take to assist carers at different stages of the illness, from diagnosis and referral to community self-help groups, to management of behavioural and psychological symptoms, to assistance with basic daily care and dealing with grief, guilt and family tensions.	None described

Reference	Review scope	Outcomes	Results	Service implications	Research implications
			greater perceived support and emotion-focused coping skills.		
Reid D, Laliberte-Rudman D, et al. (2002) <i>Impact of wheeled seated mobility devices on adult users' and their caregivers' occupational performance: A critical literature review.</i> <u>Canadian Journal of Occupational Therapy</u> Vol.69, No.5, pp.261-280.	Wheelchair users and their caregivers. Review of 46 studies, of an initial 282 potential articles. 10 were qualitative, and 36 quantitative. 7 studies included caregivers. Only 1 study directly investigated the impact of caring for wheelchair user on caregiver. Focus of review is examining body of knowledge concerning impact and effectiveness of wheeled seated mobility on wheelchair users and their caregivers.	Competency of recipient. ADLs, IADLs, quality of life	Methodological limitations of pooled results in drawing conclusions beyond performance of tasks to engagement in occupations	None described	The existing body of research is limited (inadequate attention to engagement in occupations). Potential for more research on impact of mobility aids on carers.
<b>Palliative care interventions</b>					
Adams M (2005) <i>Patient and carer satisfaction with palliative care services: a review of the literature.</i> <u>ACCNS Journal for Community Nurses</u> Vol.10, No.2, pp.11-14	Palliative care. Respite or day care. Four electronic databases were searched for peer reviewed and unpublished research reports, along with an internet search via Google. Limited to studies in English, 1993-2003, focus on palliative care outcomes for patients and carers. 70 articles were retrieved, 30 were included.	Satisfaction with end-of-life care (patients and carers)	Family members were assuming carer roles that require complex assessment and monitoring, administration of medicines etc. These responsibilities have a considerable impact on the health and well-being of carers, including fatigue, anxiety, depression and reduced ability to concentrate. The most important issues relevant to carers have been identified as pain and symptom management; preparation for death; communication with the physician; and an opportunity to achieve a sense of completion. Patients, carers and their families are more satisfied with services when they have a clear understanding of the patient's condition and treatments and the services available. Financial costs of caring can impose significant strain.	"Poor communication between service providers, in particular between hospital providers and home care providers, was found to be of major concern for patients and carers. A direct result of the lack of collaboration of specialist services and GPs was unnecessary stress for patients, carers and their GP ... In view of the fact that home care has been identified as the preferred setting for the delivery of palliative care, it seems prudent to support and maintain GP involvement in patient care." (p.14)	There was a lack of research relating to specific ethnic or cultural groups and to Aboriginal and Torres Strait Islander people.
Given BA, Given CW and Kozachik S (2001) <i>Family support in advanced cancer.</i> <u>CA: A cancer journal for clinicians.</u> Vol.51, pp.213-231.	This is not a systematic review but a discussion paper describing the needs of family carers looking after advanced cancer patients at home and reviewing the evidence for several types of interventions to support carers. Two examples	Self-efficacy, mastery, sense of control and competence. Knowledge and skills in the techniques and strategies of	Spouse caregivers typically receive less assistance from secondary caregivers than non-spouses. As demands increase over time, primary caregivers tend to seek supplementary care rather than completely handing over responsibility for any tasks. Caregivers want detailed and specific information tailored to their unique situations and psychosocial needs, as well as to the physical care needs of their patients. Older	Lack of skill and knowledge contributes to carer distress. Adequate education for carers, tailored to their needs, may help reduce the need for psychotherapy. They do not want large amounts of non-specific information, however. Few carers use formal home care	It is unclear what constitutes a 'therapeutic dose' of social or instrumental support for family caregivers. There is a need to define good patient outcomes and develop standards of care. "Research is needed to

Reference	Review scope	Outcomes	Results	Service implications	Research implications
	of education models are presented: COPE (Houts and colleagues) and a program for health care teams (Barg and colleagues). All family caregivers, some differences between the needs of spouses and others are discussed	providing care at home. Health related QoL (SF-36).	carers report more problems with physical demands of caring, while younger carers tend to have more emotional difficulties. Virtually all studies find elevated levels of depressive symptoms among family carers. There is also elevated risk of poor physical health, which increases with duration of caring. Carers report fatigue and inadequate time for sleep and self care. Evidence is mixed on the relationship between level of care required (i.e. patient need) and carer distress. Pre-existing family problems or mental health issues tend to exacerbate caregiver burden.	(domestic assistance) services; those who are highly stressed need help to enlist formal and informal support. Home care delivered to patients increases their independence and thus reduces demands on carers. Ideally, a case manager within the care system would be responsible for helping families utilise community resources.	demonstrate that investing time, providing information and working with families to provide home care leads to demonstrably better patient outcomes at lower costs with less professional time overall." (p.229)
Goldstein NE and Morrison RS (2005) <i>The intersection between geriatrics and palliative care: a call for a new research agenda. Journal of the American Geriatrics Society</i> . Vol.53, pp.1593-1598.	This is not a systematic review but a discussion paper describing the potential for using a palliative approach with frail older people and outlining a research agenda. All carers for frail aged, including spouses and adult children	Paper looks at all types of outcomes for carers (and patients) including anxiety, depression, mortality, quality of life, needs and burden.	Describes the potential for using a palliative approach with frail older people and outlines a research agenda. The majority of scales used to assess caregiver burden have been developed for patients with dementia or cancer; older patients with heart or lung disease have different care needs.	"If the field of geriatrics is to encompass the needs of all older adults, it needs to actively integrate within it the principles of palliative care and promote and support the development of new investigators in palliative care research."	Research still needs to be conducted to examine burden in caregivers of geriatric patients with end-stage organ failure, especially given that these individuals tend to be adult children with families of their own.
Higginson IJ, Finlay IG, Goodwin DM, Hood K, Adrian GK, Cook A, Douglas HR, Normand CE (2003) <i>Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? Journal of Pain and Symptom Management</i> . Vol.25, No.2, pp.150-168.	Palliative care. 10 electronic databases (to 2000), 4 relevant journals, associated reference lists and the grey literature were searched. All PCHCT evaluations were included. 44 studies evaluated PCHCT provision - home care (22), hospital-based (9), combined home/hospital care (4), inpatient visits (3), and integrated teams (6). Much evidence was of moderate /poor quality - studies were mostly Grade II or III quality.		Mostly focussed on patient outcomes. There were 13 studies with caregiver outcomes (page 154 has list). For caregiver outcomes, the funnel plot indicated a greater degree of publication bias and heterogeneity than for patient outcomes. Therefore it is difficult to infer any 'true effect size'; one large study and the overall results (Table 5) showed no effect on outcomes. Only 3 studies reporting caregiver satisfaction could be included (meta-analysis). All indicated a small benefit from the team. From the meta-synthesis results - one of the most consistent effects was of improved satisfaction for carers and. to a lesser extent, for patients when services were compared to conventional or non-hospice services. This finding was strongest for home care services - where most studies were found.		
Payne M (2006) <i>Social objectives in cancer care: the example of palliative day care.</i>	Palliative care. Literature review in all databases for the National Health Service	NICE Guidance (NICE 2204a) - identifies 5 aspects	Success in achieving social objectives is likely to depend on first identifying interventions that are designed to lead to specifiable and therefore	"..missing aspect of day-care provision in more recent literature: whether carers and family members participate	Evaluation has focused on health care rather than social outcomes - need to

Reference	Review scope	Outcomes	Results	Service implications	Research implications
<p><u>European Journal of Cancer Care</u>, Vol.15, No.5, pp.440-447.</p>	<p>by Dialog Datastar for the terms "day care" and 'palliative care' and a hand search of St Christopher's Hospice Library and King's Fund Library in London during July and August 2004. Table 1 pp442 - sets out an analysis of references to various aspects of social and creative care.</p>	<p>of palliative day-care provision: medical care, nursing care, emotional and spiritual support, social support and services for families and carers</p>	<p>potentially measurable outcomes. Examples from this literature review would be interventions designed to: increase social interaction; decrease isolation; provide reassurance about future care arrangements; promote personal growth; and promote a sense of control of the illness experience. This article discussed findings in day care programs/centres but in the context of social objectives rather than outcomes of the interventions. However, there are some references that give findings. E.g. The article refers to an ethnographic study - found that the day centre made it possible for patients to discuss impending death with people sharing the same experience, whereas they sometimes found it difficult to do so with relatives and carers. One study found day centres were a useful point of contact for assessment and intervention in cases of elder abuse. Another found that there may be under-utilisation of day care by people from minority ethnic groups.</p>	<p>in the day centre or have services provided for them". "the assumption that merely by providing day care, appropriate respite for carers is achieved may need further exploration. It would seem likely that explicit care plans to meet carers' needs separately from and additional to the needs of patients need to be developed, with clear objectives that may then be tested" (pp.445)</p>	<p>have better precision in specifying social objectives in a way that might be evaluated (pp.445)</p>
<p>Snyder C (2005) <i>Assessing the subjective impact of caregiving on informal caregivers of cancer patients</i>. In: Lipscomb J, <u>Outcomes assessment in cancer: measures, methods and applications</u>. New York, Cambridge University Press, pp. 329-345</p>	<p>Informal caregivers for cancer patients. Most were women and frequently they were the wives or daughters of cancer patients. Two literature searches were conducted to identify articles relevant to subjective caregiver impact related to cancer. Searches covered the period 1966-2001, limited to English language studies. A total of 72 articles were reviewed.</p>	<p>More than 50 different instruments to measure subjective caregiver impact were identified.</p>	<p>The purpose of the review was to identify commonly used measures of carer outcomes and develop a conceptual model of carer impact. Many studies used two or more instruments. Some of the most commonly used were the Depression scale and the State-Trait Anxiety Inventory, also Beck Depression Inventory and General Health Questionnaire. Other instruments measured specific domains such as fatigue, family function and social support. Some form of the MOS SF-36 was often used to measure health status. Purpose designed questionnaires were also identified.</p>	<p>None described</p>	<p>This is a useful reference for people designing studies because it shows what outcome measures are commonly used.</p>

## Attachment Five

### Summary of the study literature on interventions by type of intervention

#### Multi-component interventions

**Table A27 Summary of studies of multi-component interventions**

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Gitlin, L. et al.(2003) <i>Effect of multi-component interventions on caregiver burden and depression: the REACH multisite initiative at 6 month follow-up</i> <u>Psychology and Aging</u> Vol .8, No.3, pp.361-374	1 - Well supported practice	Dementia	REACH study - Resources for Enhancing Alzheimer's Caregiver Health - US RCT of 9 active and 6 control sites on caregiver burden and depression. Recruitment goals were based on power analyses for detecting different effect sizes for the different intervention strategies.	Professional backgrounds varied (OT, psychologists, SW and counsellors). 15 interventions across 6 sites - e.g. Skills training, telephone-linked computer support, environmental skill building program; behaviour and enhanced care; family based multi-system in-home intervention; coping with caring and enhanced support groups; information and referral - all interventions were responsive to the particular cultural backgrounds. 6 to 12 to 24 months duration. Revised Memory and Behaviour Problems Checklist (RMBPC); Centre for epidemiological Studies - Depression Scale (CED-S); demographic and background measures and characteristics	"..there is no single, easily implemented, and consistently effective method for eliminating the multiple stresses of providing care to people with dementia." "This suggests that a multi-component intervention that includes elements that target different aspects of caregiving experience (e.g., affective responses, behavioural burden, and unsafe physical environment) might be most beneficial. ...the challenge for future research will be to match the interventions with specific target populations" (p.372) Need to target interventions to needs of caregivers; Thus, future research is needed to test a multi-component intervention approach tailored to match specific characteristics of caregivers and their needs in order to maximize benefits.' (p.372)
Quayhagen M.P., et al. (2002) <i>Coping with dementia: evaluation of four non-pharmacologic interventions</i> <u>International Psychogeriatrics</u> Vol.12, No.2 pp.249-65	1 - Well supported practice	Dementia	103 participant dyads randomly assigned to one of four interventions or wait-list control group. Pre and post intervention (@ 3 months)	4 interventions: cognitive stimulation - 1 hr for 5 days per week; dyadic counselling - marital/couples therapy including both dyads; dual supportive seminar groups - 7 sessions group work; early-stage day care - respite and education/training for caregivers Marital satisfaction - 24 item Marital Needs Satisfaction Scale (Stinnett et al. 1970); Emotional status - Brief Symptom Inventory (Derogatis & Spencer 1982); Morale - Geriatric Centre Morale Scale (Lawton et al. 1982); Health status - Health Assessment Scale (Rosencraz and Pihlblad 1970); Memory and Behaviour Problems Checklist Part B (Zarit et al. 1985); Coping Strategies Inventory-Revised (Quayhagen & Quayhagen 1988); Social Support Questionnaire (Shaefer et al. 1981) & six item semi	"In conclusion, although the authentic comments of the caregivers support the validity of these interventions ... more definitive quantitative findings to support the differentiation of group potentials would have been helpful. Other benefits that were more selectively derived.. such as providing mental stimulation and enhancing emotional involvement of participants, could guide future program revisions." (p.263)

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
				structured questionnaire	
Yaffe, K., P. Fox, et al. (2002). <i>Patient and caregiver characteristics and nursing home placement in patients with dementia</i> <u>Journal of the American Medical Association</u> Vol 287, No. 16 pp.2090-7.	1 - Well supported practice	Dementia	US Study - Medicare Alzheimers' Disease Demonstration and Evaluation (MADDE), 1989 to 1994. 5788 ethnically diverse community dwelling persons with advanced dementia.	In-home and community based services and case management were provided to people with dementia and their carers over a 2 year period. Trained interviewer conducted in-home assessment of carer and care recipient. Random assignment of 2/3 (n= 3859) into development cohort; and 1/3 validation cohort (n=1929). Primary outcome measure was time to nursing home placement, assessed by interviews at 6,12,18, 24 & 36 months. Carer measures: burden (Zarit), depression (Geriatric Depression Scale) Adel (Katz) & IADL (Lawton). Care recipient measures: cognitive (MMSE), ADL (Katz), general health and behaviours.	In our cohort of 5788 ethnically divers patients with advanced dementia, we found that patient and caregiver characteristics were independently predictive of nursing home use and that consideration of patient and caregiver characteristics together predicts long-term care placement better than consideration of either patient or caregiver characteristics alone.' (p. 2096) 'Some of the patient and caregiver variables that were associated with risk of nursing home placement, such as patient's living status, level of functional and cognitive impairment, and caregiver age, are not readily amenable to interventions.' (p. 2096) 'A comprehensive support and counselling intervention for spouse-caregivers of patients with Alzheimer disease reduced time to nursing home placement by nearly 1 year compared with those not receiving the intervention.' (NB, average 3 year rate of NH placement) (p. 2096) 'Interventions .. such as reduction of caregiver burden or difficult patient behaviours could lead to greater patient independence and formal cost savings'. (p.2096) These results demonstrate 'the importance of considering the patient and caregiver as a unit'. (p. 2096) 'Difficult behaviors are common in dementia ....However, often these behaviors are undertreated by physicians, and little education and few behavioral strategies are offered to caregivers.' (p. 2096) Our findings document the need to consider the patient and caregiver as a unit in studies of interventions or nursing home placement'. (p.2096)
Bedard, M., D. W. Molloy, et al. (1997). <i>1997 IPA/Bayer Research Awards in Psychogeriatrics. Associations between dysfunctional behaviors, gender, and burden in spousal caregivers of cognitively impaired older adults</i> <u>International Psychogeriatrics</u> Vol 9 No. 3, pp 277-90.	4 - Acceptable practice	Dementia	111 patients of a geriatric clinic with memory problems and their spousal caregivers.	Participants and caregivers underwent a standardised baseline assessment, and carers provided with education about dementia and interventions to reduce burden, with follow-up visit (1-12 months) with patients' condition and caregiver burden re-evaluated. Outcomes: status and progression of condition (Reisberg stage); Patients' mood, cognition, behaviour, and function; Caregivers health, time demands from caregiving, support from others & carer burden (Zarit et al. 1985)	"We have shown that dysfunctional behaviors and caregiver burden are highly variable within individuals." (p.285) "Whereas some patients and caregivers may benefit from our intervention, the situation in others may deteriorate sufficiently to negate any beneficial effects of the intervention' (pp.285-6). '...(W)e found that male caregivers were more likely to report reductions in burden than female caregivers.' (p.286) 'We cannot conclude that our intervention produced the changes observed or that it failed to reduce burden. Valuable information can, however, be derived to better understand factors that may explain not only burden but changes in burden.' (p.286) 'Although it is tempting to conclude that dysfunctional behaviors cause burden, association alone does not establish causality" (p.287). Future studies will have to address the issue of causality if effective interventions to reduce burden are to be developed.' (p.287) These need to be long-term i.e., dysfunctional behaviours of early stages compared to functional decline/continence of latter stages; cumulative impact of behaviours on burden etc.

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Gitlin, L et al. (2006) <i>Enhancing Quality of life of families who use adult day services: Short- and Long-term effects of the adult day services plus program</i> <u>The Gerontologist</u> Vol.46, No.5 pp.630-639	4 - Acceptable practice	Dementia	US study of 'impaired adults' (majority dementia) attending 3 adult day centres in Philadelphia; between 2002-2004 129 caregivers at baseline, 106 after 3 months, 74 at 6mths, 58 at 12mths	care plan, education, counselling etc and emotional support by family service director on average 1 hour per moth Depression - CED-S; Burden - Zarit; Memory and problem behaviour - Zarit & Zarit Memory and problem Behaviour scale; well-being - Perceived change index (Gitlin 2003), service usage and NH placement	"..systematically combining caregiver care management with ADS is not only feasible but results in clinically significant public health benefits ... (and) ....without systematically targeting the concerns of family caregivers, (delay in NH placement) may not be fully achieved" (p.639)
Hoskins, S., Coleman, M, McNeely D (2005) <i>Stress in carers of individuals with dementia and community mental health teams: An uncontrolled evaluation study</i> <u>Journal of Advanced Nursing</u> Vol.50, No.3 pp.325-333	4 - Acceptable practice	Dementia	UK study of 26 carers using time series design over 2 year period	Psych Nurse and SW from community mental health team; joint assessment and care co-ordination; respite, carers support group; domiciliary assistance; Multi-disciplinary team joint assessments, in home, conducted by community psych nurse and SW; Caregiver Strain Index (CSI - Robinson 1983) administered baseline, & 3mths & 6 months.	Limitations to study - size, uncontrolled, "The interventions provided by the CMHT were significant in reducing carer stress.." p331 "The importance of working collaboratively ... Joint needs assessment was found to be of paramount importance in providing the correct and most appropriate interventions, which in this study proved to be a success" ".. the importance of respite care was reinforced by the results of the study (p.331)
Corcoran, M. A. and L. N. Gitlin (2001). <i>Family caregiver acceptance and use of environmental strategies provided in an occupational therapy intervention.</i> <u>Physical &amp; Occupational Therapy in Geriatrics</u> Vol 19, No. 1, pp 1-20.	5 - Emerging practice	Dementia	Study of environmental strategies that were used by 100 family carers of people with dementia.	Occupational Therapists provided 5 x 90 minute home visits to identify caring issues and generate environment-based solutions. E.g., de-cluttering, installing grab bars and hand rails. Outcomes: Number and types of caregiver issues which were the focus of the intervention, strategies introduced, and whether these were accepted and utilised.	Caregivers were willing to try a total of 1,068 strategies, of which 81% were subsequently used independently. "Caregivers used a greater number of strategies that modified the task and social environment than the objects layer of the environment." (p.20)

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Friedman, S. M., D. M. Steinwachs, et al. (2006). <i>Informal Caregivers and the Risk of Nursing Home Admission Among Individuals Enrolled in the Program of All-Inclusive Care for the Elderly</i> . <u>The Gerontologist</u> Vol 46, No. 4, pp456-463.	5 - Emerging practice	Frail aged	Informal caregivers of participants of the Program of All-Inclusive Care for the Elderly (PACE)	US study using secondary data from 3,189 participants of the PACE program, a community based system of preventative, primary, acute, and long-term care that cares for dually eligible (Medicare and Medicaid) older adults who qualify for nursing home care. PACE provides extensive formal services, including day care, home care, and meals. Caregivers are provided with education, provision of formal care that reduces burden short (e.g. day centre) and long respite care. Time from enrolment onto PACE to a long-term nursing home admission (i.e., >30 days).	"Once participants were enrolled in PACE, the presence of a caregiver was not associated with the hazard of admission to a nursing home.." (p.462) "One possible explanation is that PACE is able to tailor formal services to compensate for the presence or absence of informal care.' (p.462) It could also be that 'this is a self-selected group (i.e., <i>joining PACE</i> )...These caregivers may represent a particularly dedicated group of individuals'. (p463) "Individuals without caregivers, or those who have caregivers in one of the several high-risk categories for burnout ... are not at increased risk for institutionalization.' (p 463) This suggests that this program, through its multidisciplinary approach to caregiver and patient support, may be meeting needs in this population that, if unmet, may lead to nursing home admission.' (p 463)

## Care coordination

**Table A28 Summary of studies of care coordination**

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Béland F, Bergman H, Lebel P, Clarfield AM, Tousignant P, Contandriopoulos A-P, Dallaire L (2006) <i>A system of integrated care for older persons with disabilities in Canada: Results from a randomized controlled trial</i> . <u>Journal of Gerontology</u> , Vol.61A, No.4, pp.367-373.	1 - Well supported practice	Frail aged	Canada. 1230 community-based disabled persons over 64 years of age and their caregivers.	<i>Aim:</i> to assess the impact on hospitalisation and institutionalisation of integrated community-based health and social services for older community-based disabled people, delivered by a multidisciplinary team: System of Integrated Care for Older Persons (SIPA). <i>Design:</i> randomised controlled trial. Controls received the usual care. Package of coordinated services tailored to needs delivered over 22 months. Assessments at baseline (t0) and at 12 months (t1). <i>Caregivers:</i> satisfaction and burden assessed at t1. Caregiver questionnaires: Client Satisfaction Questionnaire (CSQ-8) and Zarit Burden Scale.	Most important overall impact was in reducing acute hospital utilisation (by 50%) and institutionalisation for participants with increased ADL disability. Caregiver satisfaction after 12 months was significantly higher for SIPA than for controls. No differences in caregiver burden between the 2 groups. Reduction in 'bed-blockers' in acute hospitals: effect of reserving access to acute hospital and emergency department beds and services for the general public, and reducing use of hospital as a 'conduit' for nursing home (institutional) placement. Future research on caregivers: role in the service model and education/skill development required.

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Callahan, C. M., M. A. Boustani, et al. (2006). <i>Effectiveness of Collaborative Care for Older Adults With Alzheimer Disease in Primary Care: A Randomized Controlled Trial</i> <u>Journal of the American Medical Association</u> Vol 295, No. 18, pp 2148-2157.	1 - Well supported practice	Dementia	Focus of study was on people with dementia living in the community who had a caregiver also willing to participate in the study.	Intervention patients and their caregivers received collaborative care management for a maximum of 12 months (initially bimonthly visits, then monthly) by a team led by their primary physician and a geriatric nurse practitioner who served as the care manager. All intervention patients were recommended for treatment with cholinesterase inhibitors unless contraindicated. Caregivers and patients also received education on communication skills, caregiver coping skills, legal and financial advice, patient exercise guidelines, and caregiver guide provided by local Alzheimer's Association. Baseline assessment by telephone, repeated at 6, 12 & 18 months - included Neuropsychiatric Inventory (NPI); ADL; health care resource use; caregiver satisfaction; frequency of initiation for any of the caregiver education and nonpharmacological management of behaviour symptoms. Memory and Behaviour Problems Checklist was completed by caregivers each visit (initially bimonthly, then monthly for up to 1 year).	We have demonstrated that this comprehensive approach results in clinically significant improvements in behavioral and psychological symptoms of dementia ( <i>which</i> ) are accompanied by a reduction in caregiver stress.' (p2154) 'We found no evidence that the intervention improves or worsens cognition, activities of daily living, or rates of nursing home placement.' (p. 2154) 'The strength of the intervention is believed to be due to its comprehensive and integrated approach.' (p.2155) Estimated annual cost = \$1000 per client (based on caseload of 75) plus set up costs. Medication costs for cholinesterase inhibitors = \$1200 per year; medication for management of behavioural and psychological symptoms of dementia = \$250-\$400 per year. Achieving guideline-level dose and duration of the intervention required a care manager who supported the patient's caregiver and physician and adhered to recommended treatment protocols. The intervention demonstrates that care for patients with Alzheimer disease can be improved in the primary care setting but not without substantial changes in the system of care.' (p.2156)
Dobrof J, Ebenstein H, Dodd SJ, Epstein I, Christ G and Blacker S (2006) <i>Caregivers and professionals partnership caregiver resource center: assessing a hospital support program for family caregivers.</i> <u>Journal of Palliative Medicine</u> , Vol. 9, No. 1, pp. 196-205.	5 - Emerging practice	Cancer/palliative	US study of family carers of people with chronic or palliative illness.	This is a hospital-based support program delivered by social workers. Interventions focused on emotional impact of caring and resource issues including referral to community services. In approximately 75% of cases, social workers followed up with caregivers to ensure they received ongoing support. Evaluation focused on challenges facing caregivers, how social workers intervened and results of their interventions. Few details are available in the abstract.	From the perspective of the social workers, their interventions enhanced caregivers' abilities to cope with their situations. Future research could focus on how to engage caregivers who are isolated or too overwhelmed to ask for help.
Eloniemi-Sulkava, U et al. (2002) <i>Emotional reactions and life changes of caregivers of demented patients</i>	1 - Well supported practice	Dementia	Finnish RCT of 2 year intervention program of community care support for carers of people with dementia living in community	The RCT involved the provision of a case management service, delivered by a dementia family care coordinator, which included access to physicians, organising care, services and support, including advocacy, psychological support and counselling for family caregivers and patients with dementia. As the end, caregivers were asked how	"..cessation of caregiving had different consequences for caregivers in the supported and control groups, as well as for spouse and non-souse caregivers. The cessation provided less relief to spouse caregivers, even tending to give rise to negative life changes... evidence that the support program during community care also seemed to have long-term effects and helped the caregivers to return to a normal life with more

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<p><i>when home caregiving ends</i>  <u>Aging and Mental Health</u> Vol 6, No.4, pp343-349</p>				<p>their lives had changed, and which factors predicted their emotional reactions and life changes. Semi-structured interviews with carers of people with dementia during Feb 1999, based on the results of a previous study. Sociodemographic data, emotional reactions of caregivers from point of cessation of caring, and life-changes after caring</p>	<p>leisure activities" (p.348)            Spouse caregivers are more likely to have 'emotional reactions of loneliness, depressive feelings and sorrow' following cessation of caregiving whereas 'non-spouse caregiving was linked with feelings of relief' (p.348) - different supports needed pre- &amp; post-care for these sub-groups of carers.            Clarify what supports/interventions might most benefit/prepare spouse carers in/for their post-care lives.</p>
<p>Gaugler J. E., et al. (2005) <i>Early community-based service utilization and its effects on institutionalization in dementia caregiving</i>  <u>The Gerontologist</u> Vol 45, No 2, pp177-185</p>	1 - Well supported practice	Dementia	<p>US study, using an experimental research design with random assignment of caregivers to treatment and control groups, comprising 4,761 dementia caregivers over a 3 year period.</p>	<p>The intervention involved case management (including assessment of carers and care recipients) and care planning, including a range of community-based services largely reimbursed by Medicare. Clients not covered by Medicaid paid a 20% co-payment for the services, to 'instill a sense of cost consciousness' (p179). Interviews were conducted by trained nurses or social workers every 6 months over 3 year period, including a range of outcome measures, including service utilisation rates and institutionalisation of the care recipient.            Institutionalisation; community based service utilisation; socio demographics; primary objective stressors - functional and cognitive status - ADL and IADL (Lawton &amp; Brody 1969); behaviour (Zarit, Orr and Zarit 1985); MMSE; Primary subjective stressors - Zarit burden scale; Global well-being Geriatric Depression Scale</p>	<p>"For particular types of services, earlier use during the course of dementia caregiving is likely to exert more benefit than if community based long-term-care utilization is delayed." (p.184) "...instead of offering extensive services as a tertiary benefit unlikely to reverse or delay the trajectory toward institutionalization, adopting a preventive strategy so that caregivers can adapt to the challenges of dementia care earlier may result in more cost-effective approach to community based long-term-care.." (p.184)            ...early community-based long-term-care utilization in dementia caregiving context can potentially mitigate the upheaval that occurs during the early stages of informal long-term care and even delay nursing home placement...' (p.183) 'Formal in-home care provision during the potentially tumultuous early stages of dementia caregiving may offer the assistance, support, and possibly even the guidance necessary to delay institutionalization. In contrast, stand-alone adult day services may not be as flexible in providing individually tailored care to families at different points in the dementia caregiving career, although the respite these services provide may still delay nursing home placement' (p.185)            ...few studies examine the importance of timing for community-based long-term-care service use or other events that may have long-term implications for families and their elderly relatives with dementia....Such refinement to the stress process would add considerably to our dynamic conceptualizations of dementia caregiving over time.' (p.185)</p>
<p>Pickard S and Glendinning C (2002) <i>Comparing and contrasting the role of family carers and nurses in the domestic health care of frail older people.</i></p>	8 - Carers' views (surveys, interviews)	Frail aged	<p>Frail older people and their older carers and also their professional carers (nurses working in the home). Sample consisted of 24 carers across 2 UK health authorities and 24</p>	<p>Paper examines the health care activities currently undertaken by older carers of older frail people and the way in which they work with, and supported by, professional nurses in the home. It compares and contrasts the approaches of both groups to care-giving for this client group. Interviews with both carers and nurses. Interviews supplemented by observation of care-giving episodes. Interviews explored: "professional roles and</p>	<p>Range of roles performed by nurses, but mainly complex activities, very unlikely to be low-tech activities (nurses hardly have responsibility for personal care). In most cases, professional support was not offered to people with dementia and the type of care required by these people left to family carers. Family carers carried out a wide-range of activities, ranging from less complex aspects of personal care to technical and highly complex care, which significantly overlapped with the kind of tasks performed by nurses. "Data indicated that family carers were generally</p>

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<u>Health and Social Care in the Community</u> Vol.10, No.3, pp.144-50.			nursing professionals. The two care groups were spread equally over the both sites (six carers of frail older people plus six carers of frail and demented older people in each site). Both carers and care recipients had to be at least 70 years old.	caring activities; carers' feelings towards care-giving activities; professional support for carer; impact of caring on health/well-being of carer; and the 'assumptive worlds' of both carers and care-givers."	not involved explicitly in a process of decision-making and planning over care-giving ... meaning of teamwork [between professional and family carers] may not be able to do things together so much as to work in such a way that each are able to do their allocated tasks in a process that may be described as complementary" (p.147). Carers don't appear to be 'real partners' in the provision of care. "What is needed is the establishment of a 'real team', in which process an understanding of the approach, roles and experiences of both parties involved is essential", as well as inclusion in decision-making and care planning. This process "could involve, among other things establishing a carer's protocol, and setting out a framework for cooperation and decision-taking between carer, user and primary care professional". (p.150)
Teng J, Mayo NE, Latimer E, Hanley J, Wood-Dauphinee S, Côté R and Scott S (2003) Costs and Caregiver Consequences of Early Supported Discharge for Stroke Patients. <u>Stroke</u> , Vol.34, No.2, pp.528-36.	1 - Well supported practice	Stroke/brain injury	Canadian study. Based on characteristics of stroke patient No. 114 (18 lost during study): Gender: 37 women, 77 men Age: average age of 70 years (range: 28-89 years) Home intervention = 58 Control: usual care = 56	RCT. Intervention - Home care group: received a 4-week tailor-made home program of rehabilitation and nursing services. Control - Usual care group: current practices for discharge planning and referral for follow-up services. Outcomes from 2 time periods: 1) from randomisation to end of 4-week intervention period, 2) follow-up from end of intervention to 3 months after randomisation. Interviews on use of rehabilitation and home care services; health professionals recorded no. of visits with patients; analysis of costs to healthcare system during the study time frame. Caregiver assessments: Burden Index: Personal Strain Index and Role Strain Index. Stroke patients: SF-36 Physical Component Summary.	"One likely mechanism through which ESD reduced costs was that the home care team identified healthcare problems early and dealt with them before they required emergency care or rehospitalisation" (p.534). Research hasn't focused on impact of ESD on caregiver burden - impact may be health service dependent eg. mix of services, delivery modes. Questions: Will reduced caregiver burden stay lower over time? Length of time home support services required? What types/qualities of home care services are required? Qualitative data: on caregiver burden, caregiver needs. Do services meet caregiver needs for support and impact? Costs of reduced caregiver burden and greater clinical effectiveness not measured. Study did not compare ESD with another type of organised and coordinated rehabilitation program - these may have been key issues responsible for better outcomes.

## Psychosocial and counselling interventions

**Table A29 Summary of studies of psychosocial interventions**

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Lavoie, JP et al. (2005) <i>Understanding the outcomes of a psycho-educational group intervention for caregivers of persons</i>	1 - Well supported practice	Dementia	Canadian study of 30 family carers of people with dementia who were part of the experimental group of a RCT; these carers had	15 x 2 hour weekly sessions comprising cognitive appraisal and coping strategies; Revised Memory and Behaviour Problems Checklist (RMBPC); which measures frequency of behavioural and memory problems of people with dementia and caregivers reactions to these problems; Also, burden (Zarit)	"Results showed that participants' reactions to their relative's behaviour problems decreased by 14%, compared to a 5% decrease in the control group ( $p=0.04$ ). The frequency of behaviour problems also decreased ... (and) the difference was maintained six months after the end of the program. Furthermore, participants' psychological distress scores decreased by 7%, compared to a 5% increase in the control group."

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<i>with dementia living at home: A process evaluation</i> <u>Aging &amp; Mental Health</u> Vol.9, No.1 pp.25-34			high to severe levels of burden		(p.27) 'These positive effects can be explained by the psycho-educational intervention's intensity, characterized by its high number of meetings (15) and its focus on coping strategies for relatives' dysfunctional behaviours'. (p.31) '..Participants found the learning of reframing to be particularly important and effective.' 'The process evaluation of the psycho-educational group intervention helped us to understand the major role played by reframing in decreasing the disturbing behaviours of persons with dementia and the associated stresses experienced by their caregivers. It also revealed that certain psycho-educational interventions which include reframing can play a 'major role' in decreasing the behaviours of people with dementia and associated stresses for caregivers. Need for better understanding of the change mechanisms introduced by psycho-educational interventions.
Schultz, R et al. (2006) <i>Predictors of complicated grief among dementia caregivers: a prospective study of bereavement</i> <u>American Journal of Geriatric Psychiatry</u> Vol .4, No.8 pp.650-8	1 - Well supported practice	Dementia	Part of REACH study - US study involving 217 bereaved caregivers who were part of a multi-site RCT testing feasibility and effects of various psychosocial and skills training interventions on the health and well-being of caregivers of people with dementia	Caregivers were randomised to either active treatment or control condition after baseline assessment; caregivers were assessed at 6, 12 & 18 months and post death of people with dementia. Primary outcome measure was the 19 item Inventory of Complicated Grief (Prigerson HG et al. 1997) which was administered at all available measurement points post-death	"Our data indicate that reducing caregiver burden, treating depression before the death of the loved one, and providing supportive psychosocial or skills training caregiver interventions may help the caregiver better manage the sequelae of death" (p.657) "Family members caring for relatives with advanced disease would not only benefit from traditional caregiving interventions designed to ease the burden of care, but would also benefit from pre-bereavement treatments that better prepare them for the impending death of their loved one" (pp.657-8) Most deaths are preceded by chronic disease/disability and family involvement in caregiving. '....reducing caregiver burden, treating depression before death of loved one, and providing supportive psychosocial or skills training caregiver interventions may help the caregiver better manage the sequelae of death' (p.657). Clarification of types & dosage of pre-bereavement interventions best enable caregivers to better manage sequelae of death.
Yip KS (2003) <i>The relief of a caregiver's burden through guided imagery, role-playing, humor, and paradoxical intervention.</i> <u>American Journal of Psychotherapy</u> Vol.57, No.1, pp.109-121.	8 - Carers' views (surveys, interviews)	Mental illness	Carers of people with mental illness. Specifically, women caring for their husbands. (Hong Kong)	Use of guided imagery, role-playing, humour, and paradoxical intervention. Carer burden	Dialogue between a wife and counsellor shows that this intervention eased her worry, anxiety, and frustration engendered by caregiving. The intervention made the wife feel normal and relaxed in facing the "symptoms" of her husband's mental illness. It also revived her patience, hope and strength in the process of rehabilitation Services should more effective and routinely explore the needs of informal carers and the supports that would help them Value of this study is limited considering it was a one-off study with only 1 subject.

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Venables D, Clarkson P, Hughes J, Burns A, Challis D (2006) <i>Specialist clinical assessment of vulnerable older people: outcomes for carers from a randomised controlled trial.</i> <i>Ageing &amp; Society</i> , Vol. 26, No.6, pp.867-882.	8 - Carers' views (surveys, interviews)	Frail aged	UK. 142 informal carers of older people in 2 social service areas of England. July 1998 to November 2000, older people referred to the study.	<p><i>Design:</i> randomised controlled trial of a specialist clinical assessment (of care recipients) additional to the standard assessment by local social services care managers.</p> <p><i>Purposes</i> to identify: whether the carers of those who received the enhanced assessment experienced improved outcomes; the relative influence on carer distress of: the behaviour of older people, the characteristics of carers, and services received; which groups could gain the greatest health and social-care benefits.</p> <p><i>Inclusion criteria:</i> older people judged by care-managers to be eligible for permanent placement in a care home and their informal carers.</p> <p>Carer interviews at baseline and after 6 months.</p> <p><i>Report</i> on diagnosis, care needs and treatment options to social services care-manager.</p> <p>Paper is a secondary analysis of results from a previous publication.</p> <p>Standardised assessment instruments: modified version of Social Behaviour Assessment Schedule (SBAS); the 12-item General Health Questionnaire (GHQ-12); a relatives' satisfaction scale based on the Client Satisfaction Questionnaire (CSQ-8). Carers' rating over the last month of 21 problematic behaviours or attributes of the older person and the associated distress of the carer.</p>	<p>Carers in the experimental group: overall level of distress was significantly reduced and distress associated with 2 attributes of the care recipients: under-activity and requirement for physical care. 3 changes of behaviour of care recipients had significant positive associations: wandering, risk of falling, and negative mood. Incontinence, physical disability, all carer-related and service-related factors had no significant association. Change in negative mood state of the care recipient from baseline (depression) level was the only factor to significantly predict change in carer distress – effect in experimental group only. <i>Serious limitation of this study.</i> the authors were unable to provide information on services delivered as a follow up to the clinical assessment report.</p> <p>Therefore, although they speculate on the reasons for the differences in the experimental and control groups, they have no evidence to support their conclusions: that new services should concentrate on the 'cared-for-person', rather than services directed to the carers. Authors' recommendation of psychiatric assessment of care recipients for undetected depression and treatment, as beneficial in alleviating carer distress, is based on previous literature. It is of concern that sweeping statements about changes in service provision can be made based on a randomised controlled trial which omits information on the intervening variables. The authors suggest that future studies should target the symptoms of care recipients, e.g. to examine the effects of interventions designed to uncover and treat unaddressed psychiatric symptoms, particularly depression.</p>

## Respite and day care

**Table A30 Summary of studies of respite and day care**

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Lawton, M., E. Brody, et al. (1989). <i>A controlled study of respite service for caregivers of Alzheimer's patients.</i> <i>The Gerontologist</i> Vol 29, No.1, pp 8-16.	1 - Well supported practice	Dementia	642 caregivers of people with Alzheimer's	Half offered formal respite care.	<p>Over 12 months, families with respite care maintained their impaired relative significantly longer in the community (22 days).</p> <p>Although respite was ineffective for caregiver burden and mental health, satisfaction was very high. Although not a strong intervention, respite care can increase caregivers' quality of life.</p>

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Gaugler J. E., et al. (2003) <i>Adult day service use and reductions in caregiving hours: effects on stress and psychological well-being for dementia caregivers</i> <u>International Journal of Geriatric Psychiatry</u> Vol 18, No1, pp55-62	4 - Acceptable practice	Dementia	US study, three month longitudinal data from 400 Adult Day Care services	Impact on respite - in person interviews administered at baseline, 3months, and one year Outcome measures - caregiving hours: ADLs, IADLs, behaviour memory problems on a typical day; Psychological well-being - CES-D (depression), Hopkins Symptoms Checklist (anger)	"...adult day service use is potentially effective in reducing caregivers' emotional and psychological distress...." (p.59)
Grant I, et al. (2003) <i>In-home respite intervention reduces plasma epinephrine in stressed Alzheimer caregivers</i> <u>American Journal of Geriatric Psychiatry</u> Vol 11, No. 1 pp62-72	4 - Acceptable practice	Dementia	US study of 55 spousal caregivers testing whether providing in-home respite was associated with reduction in both psychological and physiological indicators of stress	2 week respite intervention (random assigned). Follow-up testing 1 month post intervention Assessments in home, 2 visits - comprehensive interview and physiological assessment, including experimental stressor tasks; Mental health - Structured Interview guide for the Hamilton Depression and Anxiety Scales and the Brief Symptom Inventory; Catecholamine levels (emotional stress is a trigger); BP and Heart rate; Sociodemographic data;	".. The study provides preliminary evidence that a simple respite intervention may be useful in reducing sympatho-adrenal-medulatory arousal in a subgroup of caregivers who may be considered vulnerable to deleterious health outcomes by virtue of being placed under unusually burdensome caregiving circumstances in the context of inadequate social support" (p.70)
Holm S and Ziguras S (2003) <i>The host-homes program: an innovative model of respite for carers of people with dementia.</i> <u>Australasian Journal of Ageing</u> . Vol. 22, No.3, pp.140-145	4 - Acceptable practice	Dementia	7 carers for older people with dementia; 6 were women, two were spouses (5 were daughters) of the care recipient, 1 was from a non-English-speaking background. Data were available for 18 care recipients, 15 were women, average age 81.5 years.	Care was provided for 4-6 recipients in the home of an experienced care worker. Groups met for approximately 6 hours (9am-3pm) once a week. Care recipients were picked up and dropped off home again by the care workers or volunteers. Care recipients attended for an average of 17 weeks (range 1-45) and the main reason for ceasing attendance was admission to a RACF. The service was targeted to those for whom centre-based respite care was less appropriate, such as those with severe dementia, hearing or mobility problems or those who found it difficult to establish relationships. Care workers were supervised by centre-based managers and provided with training, home modifications and supplies. Interviews with staff and carers, observation of the groups and informal chats with care recipients, attendance records, care recipient demographic information and costs of the program.	The cost of providing host-home respite was almost 40% cheaper than in-home care, but both services cost more than centre-based care (day and overnight) because of the higher staff-client ratios. Both carers and care recipients appreciated the small-group setting and homelike environment, which allowed the formation of friendships with other regular attendees and some tailoring of activities to suit the care recipients' interests. Staff felt they were able to pay greater attention to the needs of individual care recipients and to monitor and respond to changes in their health or behaviour. "The model may be particularly suitable for people of non-English-speaking background and for Aboriginal groups because it may allow more culturally sensitive options such as careworkers from the same background, appropriate activities and culturally specific food. However, such models would need support from a larger organisation, perhaps an existing respite service, for staff support and training, financial management, central monitoring and accountability." (p.144) There is a need to establish Australian government standards for host-home programs (which operate on a similar model to family day care for

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
					children). This would avoid potential problems relating to inadequate supervision or exploitation of staff and encourage/maintain high quality care.
Lee, D.; Morgan, K; Lindsay, J <i>Effect of institutional respite care on the sleep of people with dementia and their primary caregivers</i> <u>Journal of the American Geriatrics Society</u> Vol.55, No.2 pp.252-8	4 - Acceptable practice	Dementia	UK study of 33 dyads; 6 weeks monitoring sleep outcomes, including 2 week residential respite intervention for people with dementia.	2 weeks prior to respite, caregivers completed baseline assessment, and actigraphic monitoring of caregivers and care recipients commenced; 2 week residential respite, & 2 week follow-up Actigraph recording of sleep patterns both caregivers and care recipients; Pittsburgh Sleep Quality Index, SF-36, Epworth Sleepiness Scale (repeated weekly), daily sleep diaries.	"the benefits of respite were most evident for caregivers who did not share a bedroom with the patient" (p.252), however "for caregivers, .. Improved sleep quality during respite may come at the cost of personally disturbed sleep quality during the immediate post respite period This pattern off gains and losses... has also been reported for measurements of mood and burden in dementia caregivers. With improvements during respite period quickly returning to baseline in the immediate post respite period" (p.257) ". Institutional respite offers the potential to improve quality of sleep and quality of life for dementia caregivers.." (p.257)
Hoare P, Harris M, et al. (1998) <i>A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care.</i> <u>Journal of Intellectual Disability Research</u> Vol.42, No.3, pp.218-27.	8 - Carers' views (surveys, interviews)	Disabilities	Children with severe intellectual disability and their parents/caregivers. 143 surveys/interviews conducted.	Respite placement, ranging from simply attendance at a children's centre, to year-round residential placement at the other extreme. Stress, depression and coping. The Developmental Behaviour Checklist. General Health Questionnaire-28 (with 4 sub-scales: Somatic, Anxiety and Insomnia, Social Dysfunction, and Severe Depression). Self-esteem (30 item Robson Self-Esteem Questionnaire). Questionnaire on Resources and Stress. The Coping Inventory for Stressful Situations.	Aim of study was to investigate the relationship between the characteristics of the disabled child, and the psychological adjustment and current stress levels among their carers, particularly with regard to respite usage... Significant psychological morbidity among children with severe disability was shown. Overall stress levels in carers were not that different from probable community prevalence figures. Nevertheless, distress among carers was consistently associated with increased disability in the child. Finally, although respite use is a valuable resource for many carers, its use is indicative of underlying distress in the carer. Respite use is a valuable resource for many carers, and its use is indicative of underlying distress in the carer, so better methods of early detection of the need for respite in assessment systems would be helpful. Studies that use standardised methods to assess the need for respite at an early stage would be helpful to designing a local system of targeted services, rather than waiting for crises to generate the need for respite.
Treneman M, Corkery A, et al. (1997) <i>Respite-care needs--met and unmet: assessment of needs for children with disability.</i> <u>Developmental Medicine and Child Neurology</u> Vol.39,	8 - Carers' views (surveys, interviews)	Disabilities	Children with disability and their families. 1200 families sent an 11-page questionnaire. In a South London health authority.	Respite placement Carer stress	The results indicated that the child's level of dependency and the presence of behaviour and communication problems led to significantly higher levels of experienced stress among carers. This was also associated with a significantly greater use of respite care except by families of children with behavioural problems. The results showed that respite care was generally perceived as an inadequate service, though 88% of respondents had no knowledge of the existence of respite care services. Poor access to respite implies an important role for information services to carers

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
No.8, pp.548-53.					Research with a focus on difficult behaviours and the effectiveness of respite would be useful

## Family support, including home care

**Table A31 Summary of studies of family support interventions**

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Mahoney, EK et al. (2006) <i>Challenges to intervention implementation: Lessons learned in the Bathing Persons with Alzheimer's Disease at Home study</i> <u>Nursing Research</u> Vol.55 , No.2, pp.S10-S16	1 - Well supported practice	Dementia	US RCT of 42 care-recipient and caregiver dyads analysing interventions implementation issues in the personal care of people with dementia in the home	Nurse interventionist, who role-modelled and coached caregivers, problem-solved and helped them make connections between context and behaviour. In-home visits assistance with personal care e.g. hygiene. Qualitative descriptive study - data from direct observation, field notes, caregiver journals and transcribed notes from calls and team meetings.	5 key lessons: "(a) identification of caring dyads before crisis must be improved; (b) real-time observation is essential to develop individualized interventions targeting behavioural aetiology and developing caregiver skills and efficacy; © intervention delivery depends on the NIOs skills and a flexible, trusting researcher-dyad relationship.; (d) complex caregiver situations, such as competing demands, stress, health, and past experiences or family relationships, affect treatment receipt and enactment; and (e) intervention enactment requires coaching practice and support over time" (p.S14)
Vernooij-Dassen, M.; Felling, A.; Persoon, J. (1997) <i>Predictors of change and continuity in home care for dementia patients</i> <u>International Journal of Geriatric Psychiatry</u> , Vol.12, No.6 pp.671-677	1 - Well supported practice	Dementia	Dutch RCT of 122 people with dementia with 58 pairs receiving intervention of emotional and practical support - aim to investigate predictors of change in sense of competence and admission to residential care	Home help staff who were trained to deal with caregiver problems according to the family support model, 4 hrs per week for 10 months Brief cognitive rating Scale (Reisberg et al. 1983); duration of dementia (in months); behavioural problems (Green et al. 1982; Gurel et al. 1972); ADL (Cobussen et al. 1984)sense of competence (Zarit 1980) etc.	"It is striking that while caregiver characteristics influence the change in sense of competence, they do not influence the risk for institutionalization. This may indicate that other characteristics are more important than the primary caregiver's own strengths and limitations to continue home care" pp674-5. "Attention can be given to the negative consequences of agitated behaviour by giving the primary caregiver the opportunity to express feelings caused by the agitated behaviour and by explaining its nature. Attention should be given to the most vulnerable group, females living with the demented patient. These females were found to be sensitive to our intervention. The supportive predictors indicate the importance of both emotional and practical support and of supportive skills" (pp.675-6) Positive aspects of caring might explain why people continue caring.
Smith GC (1997) <i>Aging families of adults with mental retardation: Patterns and correlates of service use, need,</i>	10 - Economic evaluation (incl.service use)	Disabilities	Directly - older mothers of adults with mental disabilities. More generally - families of adults with mental disability. Study	17 family support services. Outcome measures - service utilisation and carer burden	Patterns and correlates are identified regarding families' service use, need, and knowledge of 17 family support services. Overall level of service use was low despite high knowledge. Also, the number of services needed exceeded number of services actually used. Greater service use occurred when offspring were younger, female, from lower income households, and were receiving high levels of care from mothers

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<i>and knowledge.</i> <u>American Journal on Mental Retardation</u> Vol.102, No.1, pp.13-26.			conducted in United States.		who reported higher subjective burden and self-reported health. Families had larger unmet service needs when mothers were married, received less assistance from their children without mental retardation, and reported higher levels of subjective burden. Services should more effectively and routinely explore the needs of informal carers and the differences between carers in terms of their family situation. Future studies might look for impact of consistently describing carer views in assessment systems
Fulford M and Farhall J (2001) <i>Hospital versus home care for the acutely mentally ill? Preferences of caregivers who have experienced both forms of service.</i> <u>Australian and New Zealand Journal of Psychiatry</u> Vol.35, No.5, pp.619-25.	8 - Carers' views (surveys, interviews)	Mental illness	Family carers of people with acute mental illness. 77 family carers from Victoria, Australia, with the patient in the public health system (hospital care), but had had contact with a Crisis Assessment and Treatment service (home care) within the previous 5 years.	Crisis Assessment and Treatment team to help with caring, as opposed to hospital care. CAT team care lasts for 8 weeks. Carer Questionnaire with 4 sections. A) Demographic information. B) Attitudes to Psychiatric Hospitals Questionnaire. C) 5 scales devised to measure psychological variables. D) Three 7-point Likert scale items sought preference for hospital versus CAT team care	Only half the carers preferred a CAT service to treat their relative for acute psychosis in the event of a future relapse (may be smaller than previously thought). Psychological variables were better predictors of preference/choice than were demographic variables. The lower carer satisfaction found here may be associated with the short-term interventions of Victoria's CAT teams, the severity of acute relapses and the duration of the patient's mental health problem. Low impact may be due to 8 week limitation of CAT intervention Recommend comparison studies to explore effects of different duration of contacts by CAT or to regular care (eg 8 weeks vs 16 weeks vs regular care by GP or by MH case manager)
Hastings RP and Johnson E (2001) <i>Stress in UK families conducting intensive home-based behavioural intervention for their young child with autism.</i> <u>Journal of Autism and Developmental Disorders</u> Vol.31, No.3, pp.327-336.	8 - Carers' views (surveys, interviews)	Disabilities	Parents (and families) caring for their young autistic child. Study conducted in UK. 141 UK parents conducting home-based behavioural intervention for their autistic child completed the questionnaire.	Intensive home-based behavioural intervention for children with autism. Stress levels and depression... Autism Behaviour Checklist, Questionnaire on Resources and Stress, Family Support Scale, Family Crisis Orientated Personal Evaluation Scales, Lovaas Efficacy Beliefs score.	Adaptive coping strategies, informal social support sources, and beliefs about the efficacy of the intervention were associated with lower reported stress and higher levels of autism symptomatology were associated with higher reported stress. There was also evidence that the use of Passive Appraisal coping and beliefs about the efficacy of the interventions moderated the effects of autism symptomatology on parents' pessimism. Positive benefits of in-home training of parents can be realised but this is resource-intensive in most systems of community support for families of children autism. May not be practical in routine practice. Details on the intervention itself, "intensive home-based behavioural intervention for children with autism", are not provided. Research in future should specify levels of intervention, program details and duration of the intervention
Kumamoto K, Arai Y, et al. (2006) <i>Use of home care services effectively reduces feelings of burden among family</i>	8 - Carers' views (surveys, interviews)	Disabilities	Disabled elderly and their carers. 88 elderly people with disability residing with carers, and their respective carers, participated (in	Aim of study was to examine whether the use of home care services (multi component - housekeeping, nursing, respite, bathing, adult day care and services) reduces the feeling of burden among family carers (under the LTC insurance system in Japan). Carer burden (using Japanese version of Zarit Burden	Results revealed that use of home care services is associated with lower feelings of burden among family carers. Also indicated that ADL deficits and severity of dementia of disabled elderly are related to higher burden. Availability of instrumental support from other family members associated with lower burden. Results also suggest that service use affects the relation of severity to burden and may mediate the impact. Indicated that

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<p><i>caregivers of disabled elderly in Japan: preliminary results.</i>  <u>International Journal of Geriatric Psychiatry</u>            Vol.21, No.2, pp.163-70.</p>			Japan).	interview), demographics, disabilities assessed using 10 item-ADL scale and Barthel Index, cognitive impairment assessed with Short Memory Questionnaire, behavioural disturbances assessed with Troublesome Behaviour Scale, service utilisation also measured.	<p>severity of ADL deficits and severity of dementia are associated with greater use of care services.</p> <p>Taken together, these findings suggest that caregivers of people with more severe impairment used more services which resulted in lower burden. Shows LTC has been fulfilling its objectives (care services provided successfully reduces burden). Suggested that when carers receive more family help, they also receive less formal help and get less benefit from it. Study shows that services use can be effective in helping carers with the demands placed on them.</p> <p>Small sample size precluded the use of variables that had been previously reported to be related to carer burden (e.g. the kinship of the carer). Interesting use of Zarit scale in a Japanese version. Unclear how much of the difference in burden were due to service use or pre-existing characteristics.</p>

## Educational and psycho-educational interventions

**Table A32 Summary of studies of educational or psycho-educational interventions**

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<p>Castro CM, Wilcox S, et al. (2002) <i>An exercise program for women who are caring for relatives with dementia.</i>  <u>Psychosomatic Medicine</u> Vol.64, No.3, pp.458-468.</p>	1 - Well supported practice	Dementia	Older women (aged 50 or older) caring for relatives with dementia. 100 sedentary women participated (51 to an exercise program and 49 to a nutrition education program). In San Francisco, United States.	<p>Purpose of the study was to evaluate the feasibility and success of a long-term health promotion program focused on increasing physical activity in older women caregivers. Participants were assigned to one of two conditions: 1) a 12-month moderate-intensity home-based exercise training condition or 2) a 12-month attention control (nutrition education) condition. Those in the exercise condition were instructed to engage in four 30-40 minute exercise sessions per week in a home-based format throughout the 12 month period, such as brisk walking. Included introductory session, face-to-face session, information and activity logs provided, and regular telephone contacts to monitor progress and provide help. Those in the attention-control condition received a telephone-based nutrition education program that matched the exercise condition in terms of amount and type of staff contact.</p> <p>Outcomes: Caregiving characteristics; Exercise</p>	<p>RCT demonstrates that exercise &amp; counselling programs can successfully encourage a stressed and burdened population to engage in physical activity at levels sufficient to produce health benefits. There was an exercise adherence rate of 74% (i.e., 3 sessions per week, averaging 35 minutes each). At 12 months the exercise condition demonstrated increased knowledge of the benefits of exercise and increased motivational readiness for exercise compared with the nutrition education condition. Both groups significantly improved in perceived stress, burden, and depression from baseline to post-test. Women who were older, less depressed, and more anxious at baseline showed better retention, and lower baseline depression was associated with better exercise retention. No differentially greater psychological improvements between the two groups, possibly because involvement in some type of health promotion program that incorporates consistent contact with health professionals may have provided sufficient stress reduction and me</p> <p>"On the basis of these results, depression seems to be a strong barrier for caregivers. Therefore, future health promotion programs for caregivers should incorporate components to more directly address</p>

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
				knowledge; Motivational readiness for physical activity; Exercise adherence; Program retention; and Psychological measures (including Screen for Caregiver Burden, Taylor Manifest Anxiety Scale, Beck Depression Inventory, Cohen Perceived Stress Scale, and perceived social support measured with Interpersonal Social Evaluation List).	depression. Furthermore... a telephone-supervised, home-based program [should be encouraged] as a useful model, because it was successful for sustaining contact and encouraging health behaviour change in the current sample". (p.466) Studies reaching caregivers who are more isolated and less advantaged are needed to see if results can be replicate in a more heterogenous population. Also, the attention-control condition (the unique nutrition education program), as opposed to a wait-list condition, limited the ability to determine the extent to which the psychological changes were a product of health behaviour changes versus the beneficial effect of attention or support from program staff. (p.466)
Coon, D., L. Thompson, et al. (2003). <i>Anger and Depression Management: Psychoeducational Skill Training Interventions for Women Caregivers of a Relative With Dementia</i> . <i>Gerontologist</i> Vol 43, No. 5, pp 678-689.	1 - Well supported practice	Dementia	Female caregivers aged 50 and over who were caring for a relative with dementia - compares the relative effectiveness of (1) anger management and (2) depression small group-class interventions, and (3) wait list control condition.	Classes were psychoeducational and skill training in nature, teaching and helping carers practice self-management skills. Small groups (8-10 people) met for 2hour highly structured workshops for 8 weeks, followed by two additional 'reinforcement' sessions at 1 month intervals. Outcomes: demographics, including relationship to person with dementia; length of time caring; perceived health; self-efficacy (Revised Scale for Caregiving Self-Efficacy - Steffen et al. 2002); Anger (State-Trait Anger Expression Inventory State Anger Scale - Spielberger 1988, 1999); Depression ((Multiple Affect Adjective Checklist Hostility and Depression subscales - Zuckerman and Lubin 1965); coping (Ways of coping checklist - Revised - Vitaliano et al. 1985)	The current study adds to a growing body of literature that middle aged and older female dementia caregivers respond well to time-limited, group-based psychoeducational and skill training interventions grounded in cognitive behavioural principles. ... (S)kills training through either depression management or anger management training can lead to reductions in symptoms of anger, hostility, and depression as well as increases in self-efficacy for managing behavior problems and controlling upsetting thoughts.' p686 'These results indicate that changes in caregivers' perceived competence to handle their caregiving situations as a result of intervention had an impact on outcomes above and beyond skills introduced .. (i.e.) self-efficacy plays a significant role in people's determination of their ability to accomplish difficult tasks.' (p.686) (T)hese relatively brief and group-based programs may have social significance .. By contributing to the search for cost-effective interventions that reduce caregiver distress and enable people to remain in the caregiver role longer while being less negatively affected by it.' p687 This study .. offers continued support for the importance of the construct of self-efficacy in understanding how caregiver interventions work and suggests the need to continue to develop and evaluate interventions that increase caregiver self-efficacy.' (p. 686)
Gitlin, L et al. (2003) <i>Effects of the Home Environmental Skill-Building Program on the Caregiver-Care recipient dyad: 6 month outcomes from the Philadelphia</i>	1 - Well supported practice	Dementia	US RCT of 255 families, with 190 follow-up interviews, including discussion re impact of intervention on gender, race (white/non-white), and carer relationship.	intervention group received 5 home contacts and one telephone contact by OT who provided education, problem-solving training and adaptive equipment; 6month follow-up Stress - Objective burden: vigilance, total hours IADL help and help received for ADLs; Subjective burden: Upset with RMBPC memory-related behaviours, disruptive behaviours, and assistance with ADLs and IADLs;	"The findings from this study underscore that the difficulties caregivers confront are multi-faceted, and both intervention and measurement strategies should be multi-dimensional as well...ESP had multiple but selective benefits. it did not result in improvements uniformly across all hypothesized outcomes" (p.544) "Given the targeted stress reduction and enhancement benefits of the ESP for women and spouses found in this study, we believe there is preliminary evidence to suggest that this type of intervention should be integrated into home and community

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<p>REACH initiative  <i>Gerontologist</i> Vol.43, No.4 pp.532-546</p>			<p>Environmental Skill-building Program (ESP) - developed as part of REACH study - Resources for Enhancing Alzheimer's Caregiver Health.</p>	<p>Enhancement - caregiving mastery Index (Lawton et al. 1989); Task Management Index (Gitlin et al. 2002)&amp; Wellbeing - Perceived Change Index (Machemer et al. 2000).</p>	<p>based services for families"(pp.544-5)            Need for multi-dimensional interventions and measurement strategies.            Gains particularly found for women and spouses.</p>
<p>Huang HL, Shyu YIL, et al. (2003) <i>A pilot study on a home-based caregiver training program for improving caregiver self-efficacy and decreasing the behavioral problems of leaders with dementia in Taiwan.</i> <i>International Journal of Geriatric Psychiatry</i> Vol.18, No.4, pp.337-345.</p>	1 - Well supported practice	Dementia	<p>48 elderly patients with dementia (aged 65 or older) and their family caregivers. 24 in the experimental group and 24 in the control group. In Northern Taiwan.</p>	<p>Objective was to investigate the effectiveness of a home-based carer training program for carers of elderly with dementia and behavioural problems. Experimental group received a two-session in-home training program (separated by 1 week, with visits lasting 2-3 hours) with follow-up telephone calls, and the control group received only written educational materials with general information about dementia. The program emphasised the helping of cares, to identify behavioural problems and their causes, and to plan for the individual care of the patient (ie. plan environmental and daily schedule modifications). Program focused on nurse-carer collaboration, with individualised training. Both groups received baseline assessment of behavioural problems and carer's self-efficacy in behavioural problem management, and 2nd assessment three weeks after the training program, and 3rd assessment three month after.            Chinese version of Cohen-Mansfield Agitation Inventory (CMAI) was used to measure behavioural problems of the patients with dementia. Carers' self-efficacy for managing the agitation of the demented person was measured by the Agitation Management Self-efficacy Scale (developed by this research team).</p>	<p>The experimental group displayed significantly decreased behavioural problems of person with dementia (except for physically aggressive behavioural problems), and also increased self-efficacy of the family carers. The home-based carer training program was shown to be effective, not only in improving conditions of the carers, but also in decreasing behavioural problems of the dementia patients. Shows how an individualised has an impact but is expensive to deliver, and did not benefit the carers of physically aggressive persons. Studies with larger sample sizes would be useful, and with more follow-up of the effects of the intervention (beyond 3 months). The program's content on helping carers with physically aggressive behaviour should be revised or emphasised. Also, studies are needed to see if this intervention would be effective in Australia, as presently relevance is only reported for Chinese populations.</p>
<p>Hudson PL, Aranda S, Hayman-White K (2005) <i>A psycho-educational intervention for family caregivers of patients receiving palliative care: A randomized controlled trial.</i></p>	1 - Well supported practice	Cancer/palliative	<p>RCT - participants (n=106) received standardised home-based palliative care services (n=52) or these services plus the new intervention (n=54). Data collected over 3 time points -</p>	<p>Six aims of the psycho-educational intervention pp332. It was a nurse-delivered intervention consisting of 2 home visits supplemented by a follow-up phone call between the 2 visits. A caregiver guidebook (written information related to typical aspects of caring for a dying person) and audiotape (featuring reflections from carers and incorporating self-help strategies and relaxation exercise) were used to complement the nurse interactions. The intervention was carefully developed to ensure that it was</p>	<p>No intervention effects were identified with respect to preparedness to care, self-efficacy, competence, and anxiety. However, participants who received the intervention reported a significantly more positive caregiver experience than those who received standard care at both times 2 and 3. The findings indicate that it is possible to increase caregiver rewards despite being immersed in challenging circumstances that often yield considerable negative psychosocial sequelae. Furthermore, it is feasible for health professionals to discuss emotive topics, such as impending death, with caregivers without adverse effects.</p>

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<u>Journal of Pain and Symptom Management</u> , Vol.30, No.4, pp.329-341.			upon commencement of home-based palliative care (time 1); 5 weeks later (time 2); and then 8 weeks following patient death (time 3). All data were collected as self-report questionnaires. Recruited from two palliative care services in Melbourne Australia. Entry criteria for the caregiver including an ECOG (Eastern Cooperative Oncology Group) status of 0-3.	uncomplicated to administer and could readily be incorporated or adapted into community palliative care service (CPCS) at relatively low cost. Data collected over 3 time points - upon commencement of home-based palliative care (time 1); 5 weeks later (time 2); and then 8 weeks following patient death (time 3). All data were collected as self-report questionnaires. The Preparedness for Caregiving scale, Caregiver Competence Scale, Rewards of Caregiving Scale, Hospital Anxiety and Depression Scale, one scale of the Caregiving Appraisal Instrument, self-efficacy instrument developed by Zeiss et al.	Paper suggests that ongoing evaluation of the intervention with larger samples and refinement of outcome variables.
Ducharme F, Lebel P, Lachance L, Trudeau D (2006) <i>Implementation and effects of an individual stress management intervention for family caregivers of an elderly relative living at home: a mixed research design.</i> <u>Research in Nursing &amp; Health</u> , Vol.29, No.5,	2 - Supported practice	Frail aged	Canada. 81 family carers of relative over 65 years old. Considered at-risk by case manager: high perceived burden on 2 scales and not attending support group or psychotherapy treatment. Mean age: 68.7 years; Relationship to care recipient: 48% spouse, 25% child, 4% sibling, 4% other. French-speaking.	Mixed: qualitative: Action Research, and quasi-experimental design: control group. To evaluate process and outcomes of an individual home-based program based on the stress-coping model of Folkman et al. 5 weekly visits by case-manager and 1 follow-up meeting. Set program with individual learning objectives, goal-setting and support activities re: steps in the stress management process. Carer outcomes: 6 standardised tests (French versions): Burden Inventory; Stress Appraisal Measure); Carers' Assessment of Managing Index: problem-solving, reframing, stress management subscales; Psychological Distress Index; Self-Assessed Health; Goal Attainment Scale. End of project semi-structured interview with case manager: behaviour and attitude changes, personal objectives achievement, coping strategies, most/least helpful aspects.	Significant positive effects on perceived challenge associated with caregiver role, control by self, use of social support, use of problem-solving, seeking and accepting help, managing own emotions and perceptions, improved relationships, increased self-care activities, more positive life outlook; caregiver empowerment re: caring role. No significant effects on burden, perceived distress and health. Transfer of knowledge/skills related to practicing strategies in a variety of related contexts. Health care professionals: importance of motivation and training/skill levels in delivering interventions; recognition of the caregiver as client, transferability and adaptation of effective problem-solving and coping strategies. Timing of skill development interventions: needs to be individualised re: needs and capabilities of the caregiver. Psychological distress, burden and health similar to previous studies. Authors suggest indicators might not be sensitive enough to change, instead target intermediate variables: specific coping strategies, learning abilities, or personal resources; use positive measures of mental health rather than measures of psychological distress. Program content and duration too short to reduce high levels of psychological distress and perceived health problems.
Cullen LA and Barlow JH (2004) <i>A training</i>	4 - Acceptable	Disabilities	Children with disabilities and their	Study of a training and support programme. Intervention aimed to equip caregivers with simple massage skills that	Results revealed statistically significant improvements in caregivers' self-efficacy in their ability to conduct massage, in managing children's

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<i>and support programme for caregivers of children with disabilities: an exploratory study.</i> <u>Patient Education and Counseling</u> Vol.55, No2, pp.203-9.	practice		caregivers (mainly parents). 82 parents and 82 children. UK.	they could use with their children at home. Data collected by self-administered questionnaires at 2 points in time: immediately before TSP and immediately after TSP (after 8 weeks). Caregiver and child demographics collected. Visual Analogue Scale measured caregivers' perceived Health Status. Hospital Anxiety and Depression Scale measured parents' psychological well-being. Psychosocial Subscale of Parents' Self-Efficacy Scale assessed caregiver's confidence in ability to manage their children's psychosocial well-being	psychosocial wellbeing and in levels of anxious mood. Caregiver reports of children's sleeping patterns and eating showed significant improvements. Qualitative data confirmed that caregivers believed that children's sleep patterns improved and also suggested improvements in children's bowel movements, awareness of their bodies, movement, and communication. A training and support programme that equips carers with the skill of massage is a relatively simple intervention that has positive effects for carer and care recipient. Requires further investigation as part of multi-component strategy, and changes in children need to be assessed in a more systematic way.
Dicker BS, Chawla S and Preston N (2005) <i>Carer training project for the management of behaviour and psychological symptoms of dementia (BPSD) by home-based carers: Phase 2.</i> <u>Geriatrication</u> Vol.23, No.2, pp.5-11.	4 - Acceptable practice	Dementia	50 family caregivers of people with dementia, 39 were women, 29 were spouses, mean age 63 years, mean length of caring 2.7 years. Carers were recruited via the Fremantle Seniors Mental Health Service (56% of participants), GP referrals, a dementia-specific respite and day centre and the hospital's department of geriatric medicine. Trial took place in Fremantle, WA. Of the original 50 participants, 37 completed the training (74%).	Evidence-based package of education modules, designed for delivery one-to-one in the carers' homes by community-based mental health professionals. Training times ranged from four to ten weekly or fortnightly sessions lasting 30-60 minutes. The package contains nine modules, providing practical strategies for managing 25 of the most common behavioural and psychological symptoms of dementia. On-going support is provided following completion of the education package. Pre- and post-testing of self-perceived carer competence, stress levels and learning (questionnaire data); qualitative data collected anonymously from carers by postal questionnaire immediately after they completed the training; follow-up telephone calls by an external interviewer at 6 and 12 months after training; rate of care recipient admission to RACF at 12 months after completion of training.	Carers made statistically significant learning gains in all nine modules of the training course. They also gained in self-perceived knowledge of dementia and its behavioural and psychological symptoms, management of these symptoms, care-giving ability and confidence, and stress reduction. These gains were maintained six months and 12 months after training, with the exception of stress, which had returned to near pre-intervention levels by 12 months. Qualitative feedback indicated that carers liked the one-to-one instruction format, convenience of home visits, the trainer's patience, emotional support and ability to explain things well; and the immediate feedback provided on issues as they arose. At 6 months after training, 22 care recipients were still living at home and 9 had been admitted to RACF; at 12 months, 11 remained at home and a further 6 had been admitted to RACF. The fact that reductions in stress were not maintained may reflect the way in which it was measured. The measure did not discriminate between stress due to behavioural and psychological symptoms of dementia and stress due to other factors, some of which (grief, physical burden) would be expected to increase over time as the illness progresses. The increase in stress may also be attributable to loss of contact with the trainer - although follow-up support was available, this tended to consist of a telephone call every six weeks (compared with weekly or fortnightly visits during the training).
Fortinsky, R. H., C. G. Unson, et al. (2002). <i>Helping family caregivers by linking primary care physicians with</i>	5 - Emerging practice	Dementia	US study looking at care partnership arrangements linking physicians and community education and support services.	Service coordinator (SC) establishes individualised plan for caregivers regarding all non-medical aspects of dementia care and available resources in the community, with monthly follow-ups for 6 months to see what actions had been accomplished and what barriers there were, if any. Plan also forwarded to family physician so they can	Despite the relatively small sample size (44 caregivers), we found statistically significant increases in reported levels of dementia symptom management self-efficacy, and in community support service self-efficacy.' p237 '74% were either satisfied or very satisfied with the Service Coordinator'. (p 237) "(these) results suggests that the ASCP successfully encouraged many physicians to refer family caregivers early

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<i>community-based dementia care services: The Alzheimer's Service Coordination Program</i> <u>Dementia: The International Journal of Social Research and Practice</u> Vol 2, No2, pp227-240.			29 physicians and 62 family caregivers participated over a 6 month period. Total of 44 carers completed pre- & post-intervention interviews.	participate in/monitor action plan. Self-efficacy 'the belief that one can perform a specific behavior or task' p231 re managing dementia symptoms and accessing community support services. Satisfaction with SC	enough in the dementia disease process so that the intervention was able to help family members to learn how to become more effective caregivers.' (p.238) As a service coordination model at the local community level, the ASCP holds promise as one potential solution to the growing challenge faced by primary care physicians of adequately caring for patients with dementia and their family members.' (p.238)
Levesque, L et al. <i>The process of a group intervention for caregivers of demented persons living at home: Conceptual framework, components, and characteristics.</i> <u>Aging and Mental Health</u> Vol.6, No.3 pp.239-247	5 - Emerging practice	Dementia	Canadian study - development of a group intervention model to improve carers' ability to cope with stress.	Group intervention -active modelling strategies, role-playing, homework, exercises during meetings, "The group leader must strive to maximize the therapeutic value of bringing together people living with similar experiences .." p244 descriptive study of intervention - currently the object of a multi-site RCT	" .. caregivers were exposed to various notions: how to break down a global stressor into specific ones, how to distinguish between changeable and unchangeable stressors, and how to establish a good fit between changeability of a stressor and choice of coping strategy (p.245); "our intervention prompts caregivers to examine the meaning that they give to their caring experience, to question themselves, and to examine their values, beliefs, and thoughts, which may hinder their efforts to cope with the difficult aspects of their role"(p.245) ; "A complementary approach where informal and formal help go hand in hand appears most relevant to facilitate the caring experience by not only fulfilling the sick person's needs but also by providing a supportive structure to caregivers" (p.246)
Tait C, Cutler D (2005) <i>Support for carers of people with communication impairments: The role of group therapy.</i> <u>ACQ: ACQuiring Knowledge in Speech, Language and Hearing</u> , Vol.7, No.3, pp.110-113.	5 - Emerging practice	Disabilities	Australian. 8 family carers of people with acquired neurological communication disorders.	Therapy (education) group for carers of patients with severe communication impairments. <i>Aim:</i> to evaluate a group designed to provide education and support for carers identified by hospital speech pathologists: patients had not responded to traditional speech therapy; and/or carers perceived as isolated, stressed, or overloaded. <i>Design:</i> exploratory, qualitative. Dose: one-hour sessions, once a week, for 4 weeks. Delivered by speech pathologists. <i>5 themes</i> discussed: communication with your family member, emotional issues, lifestyle, role change and identity, information and access to services. Pre- and post-group surveys and qualitative data collected in the sessions. Pre-group questionnaire to identify: carers' understanding of communication impairment and	Pre-group questionnaire: lack of knowledge about communication strategies to prevent communication breakdown. Carers successfully identified what patient could not do, but had difficulty identifying residual language skills and strengths. Changes in family dynamics as carer took on roles previously performed by patient: source of anxiety and burden. Carers' emotional states (feelings of tiredness, impatience and frustration affected their caring effectiveness. Lifestyle changes: social isolation, going out alone due to communication problems, reluctance to request respite/assistance from others. Information/access to services: reported minimal use in spite of knowledge and overload. Group format: helpful; most beneficial aspect was talking and sharing difficulties [and solutions] with others. Group provided opportunity for therapists to suggest practical speech therapy solutions, support, education and training; change in focus from communication deficits to positive capabilities of the patient in communication and broader contexts. Importance of wider

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
				strategies, and emotional and lifestyle changes. Post-group questionnaire: rating of group format, structure, and benefits. Informal process evaluation of each group session. Communication diaries.	multidisciplinary involvement, e.g. social worker. Collect more quantifiable data using standardised surveys; refine methodology.
Van Ast, P. and A. Larson (2007). <i>Supporting rural carers through telehealth</i> . <u>Rural and Remote Health</u> Vol 7, No. 1, pp33-7KB.	5 - Emerging practice	All recipients	Australian study of 8 rural carers, six service providers and videoconference program facilitator	Program of education and support delivered to rural carers via teleconferencing Outcomes: Semi-structured interviews of those who participated in the videoconferencing program, and attendance and financial records.	Carers reported having a positive interaction with the facilitator and other participants despite being at a distance, and the facilitator found the technology offered her more ways to observe non-verbal cues discretely. Carers retained the information provided and that they had made small behaviour changes. ... Videoconferenced sessions were 16% and 47% of the cost of a face-to-face session... The critical element of this program was that local services were augmented and enhanced through the use of a facilitator who brought skills that were not available locally.'
Bloomberg K, West D, et al. (2003) <i>PICTURE IT: an evaluation of a training program for carers of adults with severe and multiple disabilities</i> . <u>Journal of Intellectual and Developmental Disability</u> Vol.28, No.3, pp.260-82.	8 - Carers' views (surveys, interviews)	Disabilities	Carers of adults with severe and multiple disabilities. Project involved 16 carers of 8 individuals, with carers working in pairs comprising a carer from the individual's day setting and the other from the individual's home. In Victoria, Australia.	The PICTURE IT program. Project spanned six training modules over 8 months; these modules (or training days) were held once a month. Between monthly training sessions, carers completed work assignments and had 1 or 2 supervisory visits from course leaders. Within this model, the current communication skill of the individual was the focus and the aim was to increase the frequency of existing communication skills (rather than teaching new ones). Overall aim of project was to develop a course that would enhance the skills and knowledge of carers working with individuals with severe communication impairment, associated with severe ID. Long-term aim was to empower carers to create communication opportunities for these individuals in their day and home settings. Objectives of intervention were listed as: (1) improve ability of direct care staff to interact with individuals with disability. Tools used included questionnaires, rating scales (e.g. Goal Attainment Scale), video analyses, multiple choice tests, written descriptions, and question and answer formats. Functional outcome was improvement in the communication behaviours across varied contexts.	In general, the project led to positive outcomes in terms of carers' knowledge of communication and that of the individuals, ability to be involved in goal-setting and intervention and to structure the social environment to increase communication opportunities. Poor outcomes seen in failure of carer to complete tasks (mainly evaluative tasks) and to significantly impact on individuals' physical environment. "Results support an approach focusing on recognition of emerging communication skills by direct care workers as a means of enhancing development". However, significant costs involved in this type of intervention. "Further development of project is warranted in terms of the use of assessment protocols relevant to individuals' level of communication ... Recommended that future training be directed towards whole teams, rather than carers from different facilities or organisations. Such an approach would allow for sharing of expertise, evaluation of skills gained and group problem-solving".
Graff, M. J., M. J. Vernooij-Dassen, et al. (2006). "How can occupational therapy improve the daily performance and	8 - Carers' views (surveys, interviews)	Dementia	Carers of people with dementia living in the community	Occupational Therapy intervention - series of 10 sessions over 5 weeks; using system-based OT guideline, which has a focus on client empowerment rather than professional control. Retrospective case study of person with mild dementia and their carer living in the community. Content analysis	One important result of this case study was the conclusion that, despite the limited learning conditions and cognitive decline of the older patient with dementia, the daily performance and quality of life of this patient improved after OT intervention. Another important result was the improvement in sense of competence and quality of life of the primary caregiver of this patient with dementia after OT intervention.' p527

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
communication of an older patient with dementia and his primary caregiver?" Dementia: The International Journal of Social Research and Practice 5(4): 503-532.				based on patient record containing detailed descriptions of the context, treatment process and its outcomes on the patient and caregiver, written by OT. Quantitative data using validated instruments include: <i>Care recipient</i> : cognitive function, level of dementia, ADL/IADL, QOL & depression. <i>Carer</i> : sense of competency, mastery, QOL & depression.	The outcomes of this case study were... quite remarkable, because it was usually supposed that learning ability was a condition for the patient to participate successfully in an OT intervention.' p525 OT interventions 'might therefore prove to be of great value, because of the enormous problems in daily performance and the decrease in the quality of life that dementia causes for patients suffering from this disease and for their caregivers'.p527 Study has number of limitations – the main one being there was only one case study of a carer/care recipient. Need further research into whether this approach is useful for other clients - especially those with behavioural problems.
Green CA, Vuckovic NH, et al. (2002) <i>Adapting to psychiatric disability and needs for home- and community-based care. Mental Health Services Research</i> Vol.4, No.1, pp.29-41.	8 - Carers' views (surveys, interviews)	Mental illness	People with severe mental illness, and their carers. 33 people with severe mental illness interviewed, NOT THEIR CARERS. In Oregon and Washington, United States.	In-depth interviews and structured questionnaires to examine community function. Explored interventions to increase informal support networks and practical help plus informal caring. Functional status, adaptation, and needs for home- and community-based care. Used SF-36 version 2.0	Despite success in community living, Ss had significant functional deficits (physical & emotional), relied heavily on only 1 or 2 key informal carers, and often needed significant support from mental health professionals. Limited numbers of carers & social isolation placed Ss at risk of negative outcomes if informal support resources were to be lost. Home- & community-based care interventions attempting to increase informal support networks & provide instrumental help (cooking, cleaning, transport) on short notice during flare-ups could augment existing (but limited) informal care, help severely mentally ill individuals remain independent, & reduce likelihood that loss of informal carer would result in unwanted outcomes Interventions aimed at expanding informal support networks are important, due to the limited number of carers and consequences of loss of a carer. Better functioning individuals were more likely to participate in the study, biasing the small sample. However, the fact that severely mentally ill individuals who are coping well in the community still have significant met and unmet needs is important information anyway. Further research could examine severely mentally ill individuals with and without primary carers, in terms of their wider social networks.
Hayman F (2005) <i>Helping carers care: an education programme for rural carers of people with a mental illness. Australasian Psychiatry</i> Vol.13,	8 - Carers' views (surveys, interviews)	Mental illness	Program is open to carers of people with a mental illness living in the LCSM region (rural area) of Victoria, Australia. Program has been run in 3 locations. Number of participants	The Carers Education Exchange Program is a flexible, needs based model that can be modified to cater for individual groups. Program has an educational format, conducted in a supportive setting that encourages development of mutual support among carers. Consists of a number of sessions on topics relevant to caring for someone with mental illness, held over a period of several weeks (1st session is called 'Understanding mental	Feedback from carers who have participated indicates that the program has substantial (short-term) benefits for carers, particularly in increasing their knowledge and understanding, and reducing some of the negative emotions associated with mental illness and the stigma surrounding it. Also serves to reduce the isolation experienced by many rural carers. Some benefits of an educational, skills based program are apparent. Despite literature that reports that no positive effects can be achieved by a program that lasts less than 10 weeks, this program had a small

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
No.2, pp.148-53.			is not specified.	illness', and 3 other sessions are offered from a range of topics [topic titles are available in full text], and most commonly requested are then conducted. Follow-up sessions held at 12 monthly intervals). Involvement of local carer support groups/services and mental health agencies are encouraged. Information is shared/provided. Program is offered at locations throughout the region, making it accessible to carers in isolated, rural areas. Questionnaire evaluates the group's level of satisfaction with the venue, time and content of sessions using a series of questions on a Likert scale.	number of sessions in order to make it more accessible for isolated, rural carers. They claim a similar program with more sessions was trialled several years ago, but carers were disinclined to commit and those who did were less likely to complete all sessions. Both the short- and long-term benefits of attending this program have not yet been evaluated in a systematic way. Formal evaluation (using more formal evaluation measures) of the program is necessary in order to gain clear understanding of the benefits derived from it.

## Support groups

**Table A33 Summary of studies of support groups**

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
Chien WT, Chan S, et al. (2005) <i>Effectiveness of a mutual support group for families of patients with schizophrenia.</i> <u>Journal of Advanced Nursing</u> Vol.51, No.6, pp.595-608.	1 - Well supported practice	Mental illness	Families caring for a relative with schizophrenia. 96 Chinese families in RCT. Hong Kong	12-session mutual support groups for Chinese families (n = 32) caring for relative with schizophrenia, comparing mutual support group with a psycho-educational group (n = 33) & standard care only group (aka routine family support service group, n = 31). Interventions delivered in outpatient clinics over 6-month period. Pre & post testing took place (1 week prior, and also 1 week & 6 months following intervention) & families' functioning, mental health service utilisation, patients' level of functioning & duration of re-hospitalisation were measured. Mutual support group & psycho-education group consisted of 12 bi-weekly sessions lasting 2 hours each, as well as routine psychiatric outpatient care. Mutual support intervention had of 5 stages: engagement (intro); recognition of psychological needs; dealing with psychosocial needs of self & family; adopting new roles and challenges; & ending. Psycho-ed group focused on family environment & involvement in care provision, presentation of info about schizophrenia & its management and different aspects of patient care. Carers completed Chinese versions of 3 scales for pre and post testing to assess effects of the	At both post-test periods, family caregivers and patients in the mutual support group reported statistically significant improvements on family and patients' level of functioning, when compared with their counterparts in the psycho-education and standard care groups. The findings support the use of mutual support groups as an effective modality of family intervention in a Chinese population caring for a family member with schizophrenia to improve both family and patient functioning. RCT shows mutual family groups to be a more effective caring intervention than psycho-education or standard care. Sample may not have been representative of those seeking and receiving mental health services (highly motivated to participate, had secondary school education, satisfactory income and experienced no more than 3 years illness). Also, researcher delivered intervention, therefore may be biased. Important for future research not to involve researcher delivering the interventions.

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
				intervention. Family Assessment Device, which includes Family Support Services Index, Specific Level of Functioning Scale, and Demographic data.	
Harding R, Higginson I, Leam C, Donaldson N, Pearce A, George R, Robinson V and Taylor L (2004) <i>Evaluation of a short-term group intervention for informal carers of patients attending a home palliative care service.</i> <u>Journal of Pain and Symptom Management</u> , Vol.27, No.5, pp.396-408.	2 - Supported practice	Cancer/palliative	73 family caregivers of patients attending one of two home palliative care services in London, UK. 69% were women, 80% were white, 63% were spouse/partner, and average age was 59 years. Intervention n=36, comparison n=37. Analyses included examination of employed vs. not employed carers.	Short-term, multi-professional closed group ("The 90 Minute Group" or 9MG) which aimed to promote self care by combining informal teaching with group support. Maximum of 12 participants. One facilitator introducing a new guest speaker each week for six weeks. Group initially focused on patient issues. To enable attendance, transport for carers and a patient-sitting service was provided. Uptake was 25% of eligible carers. Pre-post design with comparison group. Psychological measures obtained from intervention and comparison groups at baseline, 8 weeks from baseline and 5 months from baseline. Semi-structured interviews with intervention participants 8 weeks from baseline. Palliative Outcome Scale, patient performance, Zarit Burden Inventory, Coping Responses Inventory, General Health Questionnaire-12, State Anxiety Scale shortened version.	Participation in the group sessions had no significant effect on any of the psychological variables at post-intervention or follow-up. Employment of carers was significantly associated with worsening patient psychological score from baseline to post-intervention. Higher daily output of care was associated with increasing strain on the carer, while longer duration of care was associated with less role strain. Older carers tended to have greater state anxiety and more problem-focused coping responses but less burden overall. The qualitative data showed that the intervention was acceptable to carers, who valued being able to talk with others who shared their experiences. Having a focus on the needs and care of the carer rather than the patient was also valued. Preparation and recruitment took longer than delivery (11 hours of group sessions of 29 hours of preparation). Analysis of the uptake data showed that carers with the greatest perceived burden were least willing or able to attend the sessions. Those in employment were also less likely to attend as the sessions took place during the afternoons. While the quantitative data showed no psychological benefits, the qualitative data indicated that carers had derived some benefits from the sessions. One explanation for this contradiction could be the timing of the post-intervention measure. At this time, carers have to adapt to the loss of group support. If psychological measures were taken during the life of the group instead of after it ceases, they may demonstrate a benefit.
Kaasalainen S, Craig D and Wells D (2000) <i>Impact of the Caring for Aging Relatives program: an evaluation.</i> <u>Public Health Nursing</u> , Vol.17, No.3, pp.169-177.	3 - Promising practice	Frail aged	Convenience sample of 23 female caregivers for an elderly relative, registered to attend the Caring for Aging Relatives (CARG) program. These were matched with a comparison group of 23 female caregivers in the same community, not attending CARG, on age, length of caring	Information and support was provided to caregivers in small groups in a community setting. Groups ran for one 2-hour session per week over 8 weeks and were delivered by public health nurses. Education included information about the ageing process, communication and problem-solving skills, stress management, information about community resources, issues relating to relocation (presumably RACF admission) and was imparted using 'creative exercises'. Social support was provided by group leaders and peers, as participants were encouraged to vent feelings, share experiences and take greater control over their situations. Morale (profile of mood states), social support (personal	Proportion of the group who had been providing care for longer than a year was 73% and 96% in the intervention and comparison groups respectively. (Note: the groups were not well matched and these are convenience samples) T tests were used to examine differences between groups and between pre- and post-intervention scores. In the intervention group there were no significant differences between pre- and post-test levels of morale or information, while social support increased slightly (significant to p=0.02). However, the comparison group also reported a significant increase in social support over the same period of time (significant to p=0.03). Morale and social support were positive correlated for both groups at pre- and post-tests. For the comparison group only, morale was correlated with information at both time points.

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
			and relationship to care recipient. Mean age for intervention participants was 50 years (range 30-72), for control participants 52 years (range 30-78 years). One intervention participant and four comparison participants were spouses. Study took place in Canada.	resource questionnaire, visual analogue scale for intervention participants only), knowledge (20 multiple choice questions developed by the investigator and validated with CARG program staff). Quasi-experimental pre-test post-test design with matched comparison group.	This study is flawed because of poor matching of groups. Perceived social support and information was higher at both time points for the comparison group than the intervention group. The slight increase in social support for the intervention group following the CARG program offers some support for a positive impact. Those who took part in CARG had high scores for morale, social support and information at the outset, raising the question of why they chose to attend in the first place.
Harding R, Leam C, Pearce A, Taylor E and Higginson I (2002) <i>A multi-professional short-term group intervention for informal caregivers of patients using a home palliative care service</i> . <u>Journal of Palliative Care</u> , Vol.18, No.4, pp.275-281.	5 - Emerging practice	Cancer/palliative	40 family caregivers of patients attending two home palliative care services in London, UK (uptake rate 25%). Carers who were bereaved during their participation in the study were not approached during data collection; therefore of the 36 who attended at least one session, 21 were interviewed. Analysis of attrition showed that these 21 did not differ from the whole group in terms of gender, age, employment status, daily hours of caring or months of caring.	Intervention design was based on previous qualitative study and aimed to overcome the ambivalence of people who were unwilling to identify themselves as carers or discuss their needs. The overall theme of the '90-Minute Group' was 'Caring for ourselves'. A maximum of 12 carers attended six weekly closed sessions of 90 minutes duration. Transport and a patient sitting service were provided to maximise participation. A facilitator introduced guest speakers (aromatherapist, clinical nurse specialist, dietician, occupational therapist, welfare rights specialist). Talks were followed by group discussion. Semi-structured interviews - topics addressed motivations for attending, format, participation, content, information and benefits gained. Transcripts were coded using NVIVO 1.2 software. Facilitators completed weekly monitoring forms to record issues raised by carers, problems, recommendations for change and general comments. Attendance records were kept.	"Qualitative data from attendees showed that identifying with other carers and validating feelings, asking questions of professionals, and providing each other with support and encouragement were valuable outcomes from the group." p 275 Raises issues of uptake and access - only 25% of those offered the intervention agreed to take part - provision of alternative (evening) times may increase participation by employed carers - although infrequently used, the offer of the sitting service and transport was seen by carers as encouraging participation. This intervention carried high costs in the preparation stage (telephoning participants, organising transport and sitting services) although it was relatively low cost in delivery. Experienced and skilled facilitators are needed.
Jansson, W. et al. (1998) <i>The Circle Model - support for relatives of people with dementia</i>	5 - Emerging practice	Dementia	Swedish study of 27 family caregivers, community dwelling	study circles of 8-10 caregivers and volunteers, 5 weekly sessions for 3 hours each, after which time volunteers provided in-home respite for those caregivers Questionnaires using open-ended questions - taped and transcribed for analysis	Satisfaction among Circle model participants - both caregivers and volunteers p680; 'The circle model brings new dimensions to the home care services...(and) should serve as a complement to social services support" p681

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
<u>International Journal of Geriatric Psychiatry</u> Vol.13, No.10 pp.674-81					
Shanley C, Roddy M, Cruysmans B and Eisenberg M (2004) <i>The humble telephone: a medium for running carer support groups.</i> <u>Australasian Journal on Ageing</u> , Vol. 23, No. 2, pp. 82-85.	5 - Emerging practice	Dementia	Family caregivers of people with dementia. Program focused on people from CALD or Indigenous backgrounds and people in rural areas. 10 groups were conducted: 2 in Greek, 2 in Cantonese, 1 in Korean and 1 in Italian, 1 for Aboriginal carers and 3 for English-speaking carers in rural areas. Each group consisted of 4-6 carers (total number not stated). Training of 22 health and community workers as group facilitators was also evaluated in this study.	Groups were run by trainee facilitators working in pairs, with supervision provided before and after group sessions (in many cases the supervisor listened in to the sessions). Trainees were recruited via ACAT and CALD health and community agencies and required knowledge of dementia, experience with carers and experience in running groups. They attended a 2-day training workshop and used the draft of an introductory manual (which they translated as needed) plus the 8-week Homereach program that includes manuals for the facilitator and participants (this program was evaluated in an earlier project by the same authors). Groups ran once a week for 60-90 minutes. Eight groups ran for 8 weeks, the other two ran for 5 weeks. Telephone interviews were conducted with all group participants in their first languages, by researchers independent of the project. Trainee facilitators completed questionnaires on the training days, experiential teleconference, supervision, manuals and overall evaluation.	Participants felt very strongly that their involvement was worthwhile. The main benefit was being able to obtain support and information from each other. The anonymity of the teleconference format appealed to a number of participants. Recruitment, especially in smaller CALD communities, and translation of materials was time consuming. CALD participants gained similar benefits to English-speaking participants. They were less able to deal with technical difficulties; however, underlining the importance of providing clear instructions about what might occur during sessions and what should be done. There was much difficulty in recruiting Aboriginal carers in spite of a concerted effort. It became clear that the content and format was not always culturally appropriate for Aboriginal people and there was a definite preference for face-to-face contact. Telephone support groups can be useful for carers who are isolated or housebound and appear acceptable to people from CALD backgrounds, although possibly not for Aboriginal people. There are more constraints on the size of the group compared with face-to-face groups, and use of the technology can be costly unless a subsidised service (e.g. Telstra Telelink) is available. Staff require dedicated time to plan and conduct groups and regular access to a clinical supervisor.
McGuire BK, Crowe TK, et al. (2004) <i>Mothers of children with disabilities: Occupational concerns and solutions.</i> <u>OTJR: Occupation Participation and Health</u> Vol.24, No.2, pp.54-63.	8 - Carers' views (surveys, interviews)	Disabilities	Mothers of children with disability (and their disabled children). 23 women with preschool or school-aged children participated. In a city in a south-western state of the United States.	A psychosocial occupational therapy intervention program designed to increase the satisfaction, time use, and occupational performance (and well-being generally) of mothers with school-aged children with disabilities. Involved 6 weekly group sessions and an individual session at beginning and end. Data came from statements made by women in the sessions, and one questionnaire, focusing on "concerns/obstacles" and "solutions". Time Perception Inventory, Time Use Analyser, and the Canadian Occupational Performance Measurement	Concerns/obstacles for mothers caring for disabled children are identified: such as burden of responsibility, feeling disorganised and physically drained, coping with feelings of isolation. Also identified factors related to occupation that hindered mothers' well-being, such as achieving occupational balance. Solutions, things learned, and changes made were also identified, such as importance of rebalancing lifestyle and establishing priorities. Such support groups can importantly contribute to mothers' well-being. OT's attending to needs of a parent can play a valuable role in helping individuals increase their self-awareness, adopt efficient time use strategies, and prioritise effectively so they can achieve occupational balance. Future studies might look for impact of consistently describing carer

Reference	Evidence rating	Reason for care	Carer population	Intervention description and outcome measures	Results, Service implications and Research implications
					views in assessment systems
Smith D (2006) <i>CADS: Carer and depression support group</i> . <u>Australian Journal of Primary Health</u> , Vol.12, No.3, pp.9-11.	8 - Carers' views (surveys, interviews)	Mental illness	Australia. Rural town. Carers attending an informal community, consumer developed mixed support group for depression. (Mixed = people with depression, carers/parents and professionals.)	Consumer driven community support group operating in partnership between consumers and services. Interactive sessions, led by volunteer professionals with assistance by consumer participants. Meetings twice a month, timing: alternating mornings and evenings for maximum accessibility. No formal evaluation – anecdotal feedback, observation.	Established a steering committee including consumers and professionals. Positively valued by participants, organised a community forum on depression, provided model for a similar consumer group in a neighbouring town. Sharing information and problem solving, informal education by professionals, increased knowledge about depression and support services. Partnership between consumers and professionals, responsiveness of professionals to consumers' needs. Formal evaluation, compare with support groups provided by health care system.