
SUPPORTING CARERS OF PEOPLE WITH DEMENTIA

CONTENTS

| | |
|---|-----------|
| 1. Key Messages..... | 2 |
| 2. Carer support flowchart..... | 4 |
| 3. Practice Points – What Can I Do? | 5 |
| a) Assessment of the carer’s health needs | 5 |
| b) Provide carer support | 7 |
| c) Provide information and education | 9 |
| d) Facilitate carer access to resources and support services..... | 10 |
| 4. Literature Review | 14 |
| a) Assessment of carer needs | 14 |
| b) Supporting the carer | 16 |
| c) Information and education | 18 |
| d) Carer resources and support organisations | 19 |
| 5. References..... | 20 |
| Appendix 1 – Extract from NHMRC guidelines | 22 |
| Appendix 2 – Evidence summary for chapter | 24 |

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Disclaimer: This document is a general guide, to be followed subject to the clinician’s judgment and person’s preference, choices and decisions in each individual case. The guideline is designed to provide information to assist decision making and is based on the best evidence available at the time of development of this publication.

1. Key Messages

- Carers play a key role in supporting people with dementia to live in the community and residential aged care services.
- Though caring offers rewards, carers often experience carer burden/strain and are at risk of poor health. Addressing carer well-being enables the carer to better provide for the well-being of the person with dementia and potentially enables longer care in the community. GPs should regularly assess, manage and review the carer's relationship with the person with dementia and their emotional and physical health, or encourage the carer to seek regular health assessment and advice from their treating GP.
- GP assessment, management and review of carer health should be person centred. Care should include screening and preventative health strategies. The health effects of the caring role should be monitored until after the death of the person with dementia.
- Carer experiences of caring should be elicited, listened to, respected and included when assessing, managing and reviewing care of the person with dementia and making decisions. Consideration should be given to the potential considerable short and long-term impact of BPSD on carer well-being (See BPSD Chapter).
- Carer access and involvement with dementia support programs optimises care for the person with dementia and carer well-being. Referral to support programs/resources should be based on assessed needs and tailored to the carer and person with dementia and should include:
 - information on dementia as a disease process and consequences, tailored to stage of the person's disease and the carer's situation;
 - practical strategies and skills to support the carer in communication with and meeting the care needs of the person with dementia, including engaging with the person through use of pleasant and meaningful activities and problem-solving changed behaviour;
 - accessing support organisations specific to dementia and caring (e.g. Carers Australia);

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- accessing volunteer organisations which provide unpaid assistance or support. People with a culturally and linguistically diverse (CALD) background may benefit from contacting CALD specific organisations (e.g. CALD Clubs and Migrant Resource Centres); and
 - maintaining physical and emotional carer well-being and fitness. As depression, stress-related psychiatric disorders, and a reduced quality of life are often experienced by carers, specialist psychological support may be appropriate.
 - Respite can enhance carer well-being and assist carers to continue caring in the community. Respite appropriate to the needs/situation of the carer and person with dementia should be offered and encouraged where available (e.g. culturally specific services, activity groups and in-home, day or residential respite services).

2. Carer support flowchart



3. Practice Points – What Can I Do?

a) Assessment of the carer's health needs

- Recognise the potential for changes in carer well-being and that the carer may have difficulty in addressing on their own well-being.
- Aim to regularly assess the health needs of the carer. Regular consultation intervals and ensuring adequate consultation time can assist in assessing carer health over time and as the demands of caring change. Alternatively encourage/facilitate regular health assessment and advice by the carer's treating GP.

The GP really has two patients – the person with dementia and the carer **(Quote from carer forum)**.

- Use a person-centred approach to assess and review the carer's relationship with the person with dementia and the carer's emotional and physical health. Regularly check-in with the carer by asking general health questions to ascertain how they are coping e.g. ask about their sleep and appetite.¹ Elicit, respect and consider carer experiences of caring as part of this assessment.

Validate the carers view (of caring) without alienating the person with dementia. Listen to carer information about activities of daily living and ensure that carer confidentiality isn't broken in conversations with the person with dementia. **(Quotes from carer forum)**.

- A carer burden self-report measure (e.g. Zarit Burden Interview²) can be used to inform interviews directed at identifying high levels of carer burden.
- To assess carer emotional well-being consider/explore:
 - feelings of being trapped by the carer role and/or lacking in time for themselves;
 - feelings of being under a lot of stress or feeling overwhelmed;

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- carer perceptions of coping (e.g. How does the carer perceive they are managing? What helps them to cope/coping skills used? How do they relieve stress? How do they perceive their own health?)³;
 - the adequacy of existing social support (e.g. What are the carer's commitments? What help does the carer have? Do they keep in touch with friends and family?)³;
 - whether the carer feels able to manage changed behaviours exhibited by the person with dementia³;
 - carer ability to maintain religious/spiritual activities³;
 - symptoms of depression and anxiety (e.g. loss of interest or enjoyment in usual activities, feelings of hopelessness, feeling irritable or feeling edgy; sleep disturbance);
 - possible fears about the future and what it will entail for the carer/person with dementia; and
 - presence of financial strain/hardship.
- To assess carer physical well-being consider:
 - how the carer perceives their own health and whether caring is impacting on their physical health³;
 - the effects of fatigue, sleep disruption and physical demands of caring activities,
 - presence and change in chronic health conditions;
 - maintenance of routine screening (e.g. cardiac risk; cervical/breast screening) and preventative health programs (e.g. flu vaccination);
 - engagement in routine physical health maintenance activities (e.g. medication use, physical activity, weight management, healthy diet); and
 - impacts of caring during home based care, residential care and after the person with dementia has died.
 - When assessing the carer's relationship with the person with dementia consider:

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- the impact of caregiving on their relationship with the person with dementia³;
 - impacts of loss and grief whilst caring, during residential care and after the person with dementia has died; and
 - whether decision-making processes for health and financial affairs are in place and functioning.³

b) Provide carer support

- Schedule regular appointments with the person with dementia and their carer following diagnosis. This can assist in alleviating carer stress by facilitating discussion of care issues and planning for future challenges.⁴
- Involve carers in planning, decision making and care/management of the person with dementia.
- Encourage a positive attitude toward caring and self-management. Suggest carers:
 - be proactive, and learn about dementia;
 - use problem-based coping approaches – seek information, name and confront and problem solve issues;
 - keep up leisure activities and self-care;
 - seek assistance from others including family and friends and those in the broader community;
 - accept that they and family members cannot be perfect carers;
 - be open in their communication with health professionals;
 - anticipate that as dementia progresses, they will have to adjust expectations; and
 - ask for respite if required.³
- Acknowledge the carer's experience of caring, competence and contribution by caring for the person with dementia. Help the carer feel valued (e.g. "You are doing a great job").⁴

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- Explain that the well-being of the carer is necessary and important to the well-being of the person with dementia.⁴ Where carers are reluctant to seek or accept support, GPs could indicate to the carer that they are “under doctor’s orders” to utilise the help that is available.¹
 - Help to normalise carer feelings/reactions to caring and ease their sense of isolation by encouraging access to resources such as Dementia Australia and associated local support groups^{1 3} (see [Facilitate access to carer resources and support services](#)).
 - Optimise care for the person with dementia and carer well-being by encouraging carer access and involvement with dementia support programs. Refer to support programs/resources based on assessed needs and individual circumstance/preferences of the carer and person with dementia, including resources/services which provide:
 - information on dementia as a disease process and consequences, tailored to stage of the person’s disease;
 - practical strategies and skills to support the carer in communicating with and meeting the care needs of the person with dementia, including engaging with the person through use of pleasant and meaningful activities, environmental adjustment and problem-solving changed behaviours;
 - interaction with other carers, particularly those caring for a person with dementia (e.g. Carers Australia); and
 - unpaid volunteer assistance or support. People with a culturally and linguistically diverse (CALD) background may benefit from contacting CALD specific organisations (e.g. CALD Clubs and Migrant Resource Centres).
 - Offer and encourage respite to enhance carer well-being and assist carers to continue caring in the community. Respite should be appropriate to the needs/situation of the carer and person with dementia (e.g. culturally specific services, activity groups and in-home, day or residential respite services).⁵

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- Refer to professional support services as appropriate for the carer. As depression, stress-related psychiatric disorders, and a reduced quality of life are often experienced by carers, specialist psychological support may be appropriate. Psychological group interventions for carers of people with dementia may improve carers' mental health conditions.⁶ Strategies that blend support, education, practical counselling about common carer stresses and community resources appear to mitigate carer burden and depression.^{3, 7}
 - Provide GP recommendations, support and guidance to assist in reducing carer remorse and indecision over inevitable decisions. Recommendations, support and guidance should be in the context of an understanding of the person with dementia and carer's beliefs, preferences, family tensions, racial and ethnic differences.³

c) Provide information and education

Providing carers with information and education is critical for carers to provide optimal care.³

Sometimes GPs won't talk to the carer because of a problem with privacy for the person living with dementia.
(Quotes from carer forum).

GPs should first ascertain what experience and understanding the carer has about dementia, and then provide education and information (written information, brochures and websites) on:

- dementia and its consequences, appropriate to the stage of the disease;
- realistic expectations for treatment ¹ (see Clinical Practice Guidelines and Principles of Care for People with Dementia ⁸);
- advance care planning (see Advance Care Planning chapter for further information) ³;
- available dementia specific and support services, including encouragement in their use;
- the importance of carer well-being - attending to their own emotional and other health needs¹;

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- being a carer, how their role will change as the dementia progresses, and the strategies they could use to cope. Support groups can offer a safe environment for carers to discuss issues with others experiencing similar challenges and life-changing events;
 - managing changed behaviours and providing coping strategies, because the carer's knowledge of dementia-related behaviour directly correlates to quality of care³; and
 - common issues (e.g. safety concerns) and how to address these proactively.

d) Facilitate carer access to resources and support services

Explicit recommendation of support services by the GP may provide additional motivation for carers to seek out the educational, emotional and social support they need. Overleaf is a range of support services that may assist carers.

Carer resources and support services

| Service | Contact information | Services offered |
|-----------------------------------|--|---|
| Dementia Australia | <p>https://www.dementia.org.au/</p> <p><u>National Dementia Helpline</u> 1800 100 500 during business hours</p> <p>13 36 77 for those with a hearing or speech impairment.</p> | <ul style="list-style-type: none"> • Free specialist counselling service for people with dementia, their families and friends. • Carer support groups. • Family carer education and help sheets on a range of topics. • Living with Dementia Series (LWDS). • National Younger Onset Dementia Key Worker Program. • State and territory specific information. |
| At home with dementia | <p>A manual for people with dementia and their carers © State of New South Wales through Department of Family and Community Services</p> <p>https://www.adhc.nsw.gov.au/_data/assets/file/0011/228746/at_home_with_dementia_web.pdf</p> | <ul style="list-style-type: none"> • To help locate resources and products to support the person living with dementia to remain living at home for as long as possible. |
| Carers Australia | <p><u>National Programs</u> http://www.carersaustralia.com.au/how-we-work/national-programs/</p> <p><u>CALD Resources</u> http://www.carersaustralia.com.au/about-carers/culturally-and-linguistically-diverse-carers/</p> | <ul style="list-style-type: none"> • Services include a national counselling program and advisory service for carers. • State/territory based, culturally-specific services and may arrange for some translation and interpretation services |
| Dementia Support Australia | <p>http://dementia.com.au/</p> <p><u>24-hour helpline</u> 1800 699 799</p> | <ul style="list-style-type: none"> • Incorporates the Dementia Behaviour Management Advisory Service (DBMAS) and the Severe Behaviour Response Teams • Provides individualised, clinical support for people caring for someone expressing behavioural and psychological symptoms of dementia (BPSD). |
| My Aged Care | <p><u>Telephone</u> 1800 200 422</p> <p>(Extra assistance is available for those with a hearing or speech impairment, or for those who do not speak English)</p> <p>https://www.myagedcare.gov.au/ click 'Getting Started' or on the 'Start here' button</p> | <ul style="list-style-type: none"> • Information on sources of support, services, aged care facilities, and information for carers (e.g. independent aged care advocacy information, counselling, and respite). |

| Service | Contact information | Services offered |
|---|---|--|
| Carer Gateway | <p><u>Telephone</u> 1800 422 737</p> <p>Monday to Friday. 8am to 6pm (A call back can be requested)</p> <p>https://www.carergateway.gov.au/caring-for-someone</p> | <ul style="list-style-type: none"> • A national online and phone service that offers practical information and resources to support carers (e.g. respite care, legal information, services) |
| healthdirect Australia | <p>Counselling Health information and advice online and over the phone (1800 022 222), available 24 hours a day, 7 days a week. Funded by the governments of Australia.</p> <p>https://www.healthdirect.gov.au/dementia</p> <p>Do not enter keywords, just enter the location to search for resources.</p> | <ul style="list-style-type: none"> • A government-funded service which may provide local information on dementia and dementia related services (e.g. aged care, respite/carer support, allied health, community health care). |
| Department of Human Services - Financial Assistance | <p>https://www.humanservices.gov.au/customer/subjects/payments-carers</p> <p>© Commonwealth of Australia</p> | <ul style="list-style-type: none"> • Carers may be eligible to receive financial assistance from the government for their care of a person with dementia. • Forms of support may include carer payment, allowance or supplement, and payments to meet the costs of incontinence. |
| Online Training Resource – University of Tasmania (UTAS) | <p>http://www.utas.edu.au/wicking/understanding-dementia</p> | <ul style="list-style-type: none"> • UTAS provides an online course on Understanding Dementia. • The Massive Open Online Course (MOOC) draws on the expertise of neuroscientists, clinicians and dementia care professionals, is free, runs for nine weeks and is available to all. |
| Interpreter Services - Department of Home Affairs | <p><u>Telephone</u> 131 450 (Cost of a local call)</p> <p>24 hours a day, 7 days a week</p> <p>https://www.tisnational.gov.au/</p> | <ul style="list-style-type: none"> • Interpreter services are available through the Translating and Interpreting Services (TIS). This service covers more than 100 languages. • GPs and medical specialists are eligible for free interpreting services and access to the Doctors Priority Line (DPL) when providing services that attract Medicare rebates, delivered in private practice, and provided to non-English speakers who are Australian citizens or permanent residents. |

| Service | Contact information | Services offered |
|--|--|--|
| Volunteer and other organisations | Further information about working with vulnerable people and appropriate person checks can be found at the Department of Social Services website https://www.dss.gov.au/about-the-department/doing-business-with-dss/vulnerable-persons-police-checks-and-criminal-offences or www.dss.gov.au | <ul style="list-style-type: none"> • People with a culturally and linguistically diverse (CALD) background may benefit from contacting CALD Clubs and Migrant Resource Centres for appropriate information/support. • Recognised volunteer organisations (with appropriately vetted members, e.g. criminal record checked) may provide unpaid assistance. • Note: When using voluntary assistance, the carer has the responsibility to check with the voluntary organisation to ensure the volunteers they use have been appropriately vetted. |

4. Literature Review

A carer is generally defined as a family member or friend who provides unpaid assistance to someone with a chronic illness or a disability⁹, including for someone living with dementia. A person with dementia may have more than one carer, though primary carers are most likely to reside with the person with dementia.¹⁰ Carers may be eligible to receive financial assistance from the government for their care of a person with dementia.¹¹ Although the terms ‘carer’ and ‘carers’ have been used interchangeably in this document, they can be assumed to mean one or more carer, dependent upon the circumstances.

a) Assessment of carer needs

GPs need to be cognisant of carer needs when they suspect a patient of having dementia/has been diagnosed with dementia, or when they have a patient who is a carer.⁸

Caring for a person with dementia is associated with benefits, including personal fulfilment, life enrichment, and enhanced confidence in own ability to care, and in the quality of relationships.^{3, 9} However, caring can be stressful and challenging for those providing care, and accepting the responsibility for caring can place a huge physical, emotional and financial toll on carers.^{3, 9} The carer role can become more stressful as the dementia worsens over time and reduces the person’s autonomy, including behavioural disturbances, dependency in activities of daily living, incontinence, need for constant vigilance, and personality changes.^{3, 9} Neuropsychiatric symptoms consequent to dementia have been associated with resource utilisation and distress in carers, with carer-centred interventions (e.g. carer education and support) advocated and deemed essential components of dementia care.¹² The toll commonly experienced by carers is often referred to as carer burden or strain.⁹

Depression, stress-related psychiatric disorders, and a reduced quality of life are often experienced by carers.¹ In a study by Bridges-Webb and colleagues, carers reported that they lacked time for themselves and their own social life, felt stressed and feared for the future, with some informants indicating that they felt they had lost control of their lives.¹³ However, the emotional strain of caring and seeing a loved one lose abilities can be especially difficult and may outweigh other hardships being experienced e.g. financial or personal time constraints.¹

Carers may be frail, older adults with chronic health conditions. As Grossberg and colleagues¹ note, it is important to regularly check-in with the carer by asking general health questions to ascertain how they are coping e.g. ask about sleep and appetite. Carer stress or other health issues might then be identified, leading to appropriate referral for the carer.

Bass and colleagues used three established measures of strain or negative caregiving effects to explore carer strain: physical health strain, relationship strain, and role captivity.⁵ Whilst these researchers utilised Likert scales (0 – strongly disagree, to 3 – strongly agree) to measure these components, GPs could assess these areas in consultation with carers by exploring the following areas:

- whether the carer's physical health is worse because of caregiving (e.g. unwell more often; bothered by more aches or pains);
- the impact of caregiving on their relationship with the person with dementia (e.g. does the carer feel closer to person with dementia, feel appreciated, gets pleasure from helping; or feels that the relationship is strained, feels angry or that person with dementia is manipulative?); and
- whether carers have feelings of wanting to escape their situation, feel trapped or want to live their life free of care responsibilities.⁵

Other areas to explore include:

- burden (e.g. Do they feel under a lot of stress/ feel overwhelmed?);
- depression and anxiety (e.g. loss of interest or enjoyment in usual activities, feelings of hopelessness, feeling irritable or edgy, sleep disturbance);
- behavioural issues (e.g. What is the person with dementia's needs? Are changed behaviours being exhibited? Does the carer feel able to manage these behaviours?);
- social support (e.g. What are the carer's commitments? What help does the carer have? Do they keep in touch with friends and family?);
- coping (e.g. How does the carer perceive they are managing? What helps them to cope/coping skills used? How do they relieve stress? How do they perceive their own health?);

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- religious (e.g. Is the carer able to maintain usual spiritual activities?); and
 - legal (e.g. Are decision-making processes for health and financial affairs in place and working well?).³

GPs may also utilise a self-report measure (e.g. Zarit Care Burden Interview²) to inform interviews directed at identifying high levels of carer burden.⁹

b) Supporting the carer

It is important to schedule regular appointments with the person with dementia and their carer following diagnosis. This can assist in alleviating carer stress by facilitating discussion of care issues and planning for future challenges.⁴

Acknowledgement by the GP that the well-being of the carer is necessary to the well-being of the person with dementia is important.⁴ Those carers who give priority to self-care are more likely to provide enhanced care and maximise the time that the person with dementia lives within the community.^{1, 3, 4} Where carers are reluctant to seek or accept support, GPs could indicate to the carer that they are “under doctor’s orders” to utilise the help that is available.¹

A small, effective intervention the GP may use is to acknowledge the carer’s competence and help the carer feel valued (e.g. “you are doing a great job”). It is also important to ask about the carer’s specific needs (e.g. if any support or information is required).⁴

Resources such as Dementia Australia and associated local support groups may show carers that they are not alone. Therefore, it is important for the GP to emphasise to carers is that there are other people in similar situations to their own and that other carers have similar feelings.³ Dang and colleagues suggest carers:

- be proactive, learn about on dementia;
- use problem-based coping approaches – seek information, confront issues;
- keep up their leisure activities and self-care (e.g. healthy diet, exercise and preventative health care);
- seek assistance from others including family and friends and those in the broader community;
- accept that they and family members cannot be perfect carers;

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- be open in their communication with health professionals;
 - anticipate that as dementia progresses, they will have to adjust expectations; and
 - ask for respite if required.^{3,9}

Referral of the carer to professional support services may be appropriate in some instances. Research suggests psychological group intervention for carers of people with dementia (i.e. cognitive behaviour therapy to help manage dysfunctional thoughts about caregiving, scheduling pleasant activities between sessions; training in self-help techniques) may improve carers' mental health.⁶ Strategies that blend support, education, practical counselling about common carer stresses and community resources appear to mitigate carer burden and depression.^{3,7}

Carer support may also enable the person with dementia to remain living in the community longer. A uniquely long (9.5 year) randomised controlled trial by Mittelman and colleagues found spouses of community dwelling patients with Alzheimer's disease who received an enhanced counselling and support intervention, as compared to usual care, reported improvements in carers' satisfaction with social support, response to patient behavioural issues, and symptoms of depression; this collectively accounted for 61.2% of the intervention's beneficial impact on placement.¹⁴ That is, when spouses were involved in the counselling and support intervention, there was a reduction of 28.3% in residential aged care placement for the people with dementia compared to the control group. The intervention consisted of six sessions of individual and family counselling, continuous availability of ad hoc telephone counselling, and support group participation.¹⁴

In community settings, patients commonly have multiple aetiologies underlying their dementia and carers frequently have a great need for resources.¹⁴ A systematic review by Parker and colleagues assessed the effectiveness of interventions (e.g. skills training, education, and support group programs) for carers of people living with dementia who were still residing in the community, finding that psychoeducational or multi-component interventions to be beneficial.¹⁵ Factors that appeared to positively contribute to intervention effectiveness included: opportunity for both the carer and person with dementia to be involved; active participation of the

carer in educational interventions; individualised rather than group supports; ongoing provision of information with specific information for carers about services and how to manage their new carer role; and interventions that focussed on reducing challenging behaviours in the person with dementia. Simply referring the carer to support groups, only providing self-help material, or only offering peer support did not appear to be beneficial.¹⁵

c) Information and education

Carer education is critical for carers to provide optimal care.³ However, GPs should first ascertain carer experience and understanding about dementia.

Usually people with dementia and carers are very concerned about what to expect with disease progression,¹ although communication should to be tailored to the particular person and carers as people's information preferences will vary. At a minimum, the GP needs to focus on positive aspects of care, while discussing with carers the stage the person with dementia is currently at and how care needs may change in the future, and what resources may assist. The likely shift to managing behaviours and accommodating functional decline should be noted.¹ As such, GPs need to educate carers and provide information on:

- dementia in a stage-of-disease-appropriate manner making the most use of available educational resources;
- realistic expectations for treatment ¹(see Clinical Practice Guidelines and Principles of Care for People with Dementia ⁸);
- advance care planning – initiating discussions early can enable people with dementia to be involved in the decision-making process ³ (see Advance Care Planning chapter);
- available services, and encourage the use of these;
- written information, brochures and websites (see [Carer resources and support organisations](#));
- common issues, such as safety, and addressing these proactively;
- the importance of self-care, both in terms of psychological and physical health (and enable access to resources) ¹;

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- how the carer's role will change as the dementia progresses; and
 - managing changed behaviours and providing coping strategies because the carer's knowledge of dementia-related behaviour directly correlates to quality of care.³

GP recommendations, support and guidance may assist in reducing carers' remorse and agony over inevitable decisions.³ However, as Dang and colleagues note, support and guidance should be in the context of an understanding of the person with dementia and carer's beliefs, preferences, family tensions, racial and ethnic differences.³

It may be prudent for the GP to explore carer's perceptions about their carer role and possibly provide the carer with information regarding common caregiving experiences. Carers of someone who has been diagnosed with dementia often have their own feelings to come to terms with and, as reliance on them increases, previous roles and relationships can become harder for the carer to maintain.³ Research suggests carers commonly felt the person with dementia was dependent on them and expected the carer's care; and most carers reported the carer role adversely affected their health.¹³ Nichols and colleagues found that compared to carers who were not depressed, those carers who were depressed were significantly more likely to enquire about adult day care and to ask for information about carers' emotions, and were more likely to be stressed and have difficulties in coping.¹⁶ Carers may also be juggling caregiving responsibilities for both their elderly parents and their own children.³

d) Carer resources and support organisations

GPs need to be aware of available resources, as they are pivotal in raising awareness, and facilitating acceptance of services by people with dementia and their carers.¹⁷ Explicit recommendation of support services by the GP may provide additional motivation for carers to seek out the educational, emotional and social support they need.

Bridges-Webb and colleagues found the most commonly used community services were the aged care assessment teams (ACAT), Dementia Australia, respite care, day care and carer support groups.¹³ The person with dementia and their carers should be referred to respite appropriate to their needs (e.g. in-home respite, day

respite and residential respite), as well as referred to resources and programs tailored to the needs of the individual and delivered in the home or at another accessible location.⁸ GPs could also inform carers about advocacy services and voluntary support and encourage their use, keeping in mind that both the person with dementia and their carers can access the services independently, if required.⁸

People with a culturally and linguistically diverse (CALD) background may benefit from contacting CALD Clubs and Migrant Resource Centres for appropriate information/support. Recognised volunteer organisations (with appropriately vetted members, e.g. criminal record checked) may provide unpaid assistance. Please note that when using voluntary assistance, the carer has the responsibility to check with the voluntary organisation to ensure the volunteers they use have been appropriately vetted. Further information about working with vulnerable people and appropriate person checks can be found at the Department of Social Services website <https://www.dss.gov.au/about-the-department/doing-business-with-dss/vulnerable-persons-police-checks-and-criminal-offences> or www.dss.gov.au.

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 13. Bridges-Webb C, Giles B, Speechly C, Zurynski Y, Hiramaneek N. Patients with dementia and their carers. *Ann N Y Acad Sci*. 2007;1114:130-6.
 14. Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*. 2006;67:1592-9.
 15. Parker D, Mills S, Abbey J. Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *Int J Evid Based Healthc*. 2008;6(2):137-72.
 16. Nichols LO, Martindale-Adams J, Greene WA, Burns R, Graney MJ, Lummus A. Dementia caregivers' most pressing concerns. *Clinical Gerontologist: The Journal of Aging and Mental Health*. 2009;32(1):1-14.
 17. Jaglal S, Cockerill R, Lemieux-Charles L, Chambers LW, Brazil K, Cohen C. Perceptions of the process of care among caregivers and care recipients in dementia care networks. *Am J Alzheimers Dis Other Dement*. 2007;22(2):103-11.

Appendix 1 – Extract from NHMRC guidelines

The following recommendations for support of carers and evidence strength/quality definitions have been extracted from [Clinical Practice Guidelines and Principles of Care for People with Dementia](#).^{8(pp.IV,XIV-XV)}

Recommendations

| Number | Detailed Recommendation |
|-------------------|--|
| 99 PP | Carers and families should be respected, listened to and included in the planning, decision making and care and management of people with dementia. |
| 100 PP | Carers are at an increased risk of poor health and their needs should be assessed and reviewed regularly by their own health practitioner. Carer and family needs should be addressed regularly, including if the person with dementia has entered residential care, and after their death. |
| 101 CBR | The person with dementia, their carer(s) and family should be offered respite appropriate to their needs. This may include in-home respite, day respite, planned activity groups and residential respite. |
| 102 EBR Low | <p>Carer(s) and family should have access to programs designed to provide support and optimise their ability to provide care for the person with dementia. Programs should be tailored to the needs of the individual and delivered in the home or at another accessible location. Programs should be delivered over multiple sessions and include:</p> <ul style="list-style-type: none"> • education regarding dementia and its consequences • information regarding relevant services including respite • referral to support organisations such as Alzheimer’s Australia or Carers Australia • development of individualised strategies and building carer skills to overcome specific problems experienced by the person with dementia as reported by the carer • training in providing care and communicating most effectively with the person with dementia • support and information regarding coping strategies to maintain their own wellbeing including stress management • training in the use of pleasant and meaningful activities as a strategy to engage the person with dementia |
| 103 PP | Consideration should be given to involving the person with dementia, as well as their carer(s) and family, in support programs. |
| 104 EBR Low | Health and aged care professionals should provide carers and families with information regarding how to join a mutual support group. Individual preferences for group composition may vary and groups of the preferred composition should be available. |
| 105 PP | Carers and families of people with dementia should be supported to build resilience and maintain overall health and fitness. Where necessary, they should be offered psychological therapy, conducted by a specialist practitioner. |

Definitions of types of recommendations

Evidence-based recommendation (EBR) - Recommendation formulated after a systematic review of the evidence, with supporting references provided.

Consensus based recommendation (CBR) - Recommendation formulated in the absence of quality evidence, when a systematic review of the evidence has failed to identify any quality studies meeting the inclusion criteria for that clinical question.

Practice point (PP) - A recommendation that is outside the scope of the search strategy for the systematic evidence review and is based on expert opinion.

Definitions of GRADE ratings of the quality of the evidence

High - Further research is very unlikely to change our confidence in the estimate of effect.

Moderate - Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.

Low - Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.

Very Low - Any estimate of effect is very uncertain. ^{8(pp.IV)}

Appendix 2 – Evidence summary for chapter

Evidence summary for literature reviews

| Reference Country | Study design/ Level of evidence | Sample characteristics (n=) | Intervention | Comparison | Results/findings | Quality appraisal*^ |
|--|--|-----------------------------|--------------|------------|--|---|
| Collins & Swartz (2011) USA | Non-systematic review about care of the caregiver in primary care | NA | NA | NA | Physicians need to identify carers of persons with cognitive impairment early and provide appropriate support (article included some other particular caregiving scenarios, e.g. cancer, stroke). Carers should: be assessed when there is a change in status of the carer or care-recipient; directed to appropriate resources including national and local agencies, websites and respite care. Interventions for carer (psychoeducational, skills-training and therapeutic counselling) have shown small to moderate success in decreasing carer burden and increasing carer quality of life. During care transitions and at end-of-life, additional support and anticipatory guidance for the carer and care-recipient are particularly helpful. | 1. NA 2. NA 3.CA 4.NA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11. Y (no conflict) |

| Reference Country | Study design/ Level of evidence | Sample characteristics (n=) | Intervention | Comparison | Results/findings | Quality appraisal*^ |
|--|--|---|--|------------|---|---|
| Dang et al. (2008) USA | Non-systematic review about caregiver care | NA | NA | NA | The carer role can be challenging and stressful; accepting carer responsibilities can place physical, emotional, and financial burdens on carers; strategies to mitigate care burden and depression include: education, support and counselling (practical counselling about common carer stresses), referral to community resources; provides play an integral role in supporting the carer; care of both the patient and carer is enhanced by collaboration across disciplines and a team approach (nurses, social workers, therapists, psychologists, specialists and other office staff can serve as valuable resources). | 1. N 2. NA 3.CA 4.NA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.Y (no conflict) |
| Grossberg et al. (2010) USA | Non-systematic review and expert opinion to develop a set of recommendations for GPs on how best to communicate with patients and carers about the diagnosis and management of AD. | NA. Expert opinion (n=6) supported by academic literature from PubMed database. | Expert opinion (moderated dialogue aimed at generating consensus opinion; only statements endorsed by all authors included). Search limits English language, 1996–2008; search terms: Alzheimer's disease, primary care, diagnosis, management, caregiver, family, patient-physician relationship. | NA | Recommended: timely diagnosis and initiation of therapy for AD to optimise treatment response and opportunity for future planning; tailor how a diagnosis of AD is disclosed to the individual and their family; communicate a specific diagnosis and include carers as possible; focus on the positive aspects of the patient's current capabilities and the value of maintaining function. With progression of the dementia, focus toward managing behaviours and accommodating functional decline; communicate with carers about these issues and to recommend resources for management. | 1.NA 2.NA 3.CA 4.CA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.Y (no conflict) |

| Reference Country | Study design/ Level of evidence | Sample characteristics (n=) | Intervention | Comparison | Results/findings | Quality appraisal*^ |
|---|---|---|---|------------|---|--|
| Parker et al. (2008) Australia | Systematic review which assessed the effectiveness of interventions that assisted carers to provide support for people living with dementia in the community. | Studies from 2000 – 2005 (N=40) included meta-analyses (n=3), systematic reviews (n=3), randomised control trials (n=34), quasi-experimental studies, cohort studies, case control studies and observational studies without control groups that addressed the effectiveness of interventions that assisted carers to provide support for people living with dementia in the community. | Methodological quality of each article was assessed by two independent reviewers; standardised mean differences or weighted mean differences and their 95% CI were calculated for each included study reported in the meta-analysis. Results from comparable groups of studies pooled in statistical meta-analysis using Review Manager Software. Heterogeneity between combined studies was tested using standard chi-square test. The findings were summarised in narrative form where statistical pooling was not appropriate/ possible. | NA | Evidence supported the use of well-designed psychoeducational or multi-component interventions for carers. Factors that appeared to positively contribute to effective interventions were those which: provided opportunities within the intervention for the involvement of the person with dementia as well as the carer; encouraged active participation in educational interventions for carers; offered individualised programs rather than group sessions; provided information on an ongoing basis, with specific information about services and coaching regarding their new role; targeted the care recipient particularly by reduction in behaviours. Factors which did not appear to have benefit in interventions were those which: simply referred carers to support groups; only provided self-help materials; only offered peer support. | 1.Y 2.Y 3.Y 4.Y 5.Y 6.Y 7.Y 8.Y 9.Y 10.Y 11.N. |

| Reference Country | Study design/ Level of evidence | Sample characteristics (n=) | Intervention | Comparison | Results/findings | Quality appraisal*^ |
|-------------------------------|--|--|--------------|------------|--|--|
| Robinson et al. (2010) | Narrative review about the role of GPs in the long-term care of people with dementia living at home (Updated the systematic review conducted for the NICE/SCIE Guides from 2006) | Literature from Jan 2006 using the NICE/SCIE criteria; Cochrane Reviews were identified and other publications by consultations with experts; articles included when consensus about their implications for the review themes was reached. | NA | NA | Caring for people with dementia in primary care requires the same systematic approach as the management of other long-term conditions; integrate systematic follow-up of people with dementia and their carers into primary care; reframe dementia, with an emphasis on abilities retained; active use of information sources; support carers. An increase in skill mix may be required within primary care, which may also improve the management of behavioural problems. Further evaluation required on the ability of interventions and alternative models of service delivery to deliver more integrated person-centred care. | 1.NA 2.NA 3.CA 4.NA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.Y (no conflict) |

| Reference Country | Study design/ Level of evidence | Sample characteristics (n=) | Intervention | Comparison | Results/findings | Quality appraisal*^ |
|---|--|------------------------------|--------------|------------|---|---|
| Siemens & Hazelton (2011) Canada | Non-systematic review about communicating with families of persons with dementia providing a practical guide to relieving carer stress | NA | NA | NA | Essential for family physicians to work with families of dementia patients on a continuing bases; resources such as the Alzheimer's society can provide valuable information; diagnosis is a key moment – and evolving progressive disclosure beginning when cognitive impairment is first suspected can counterbalance communication difficulties around uncertainty surrounding diagnosis; the susceptibility of the carer to stress-related health issues should be assessed and the carer supported; involve the carer in the decision-making process whenever possible; make families aware of respite options; physician acknowledgement of the health of the carer is necessary to the health of the care-recipient important. | 1.NA 2.NA 3.CA 4.NA 5.NA 6.NA 7.N 8.CA 9.NA 10.NA 11.Y (no conflict declared) |

Notes: * Appraisal criteria from the AMSTAR measurement tool Shea BJ, Grimshaw JM, Wells GA, Boers M, Andersson N, Hamel C, et al. Development of AMSTAR: a measurement tool to assess the methodological quality of systematic reviews. BMC Med Res Methodol. 2007;7(1):10.

^ Where the above evidence summaries are not systematic literature reviews, the appraisals of these using this instrument were done to give some indication of the evidence reviewed. Later, the JBI Critical Appraisal Checklist for Text and Opinion Papers became available and replaced using the AMSTAR tool this way.

Appraisal items:

1, 'A priori' design provided; 2, duplicate study selection and data extraction; 3, comprehensive literature search performed; 4, the status of publication (i.e. grey literature) used as an inclusion criterion; 5, a list of studies (included and excluded) provided; 6, characteristics of the included studies provided; 7, scientific quality of the included studies assessed and documented; 8, scientific quality of the included studies used appropriately in formulating conclusions; 9, methods used to combine the findings of studies appropriate; 10, likelihood of publication bias assessed; 11, conflict of interest stated.

Ratings:

Yes (Y); No (N); Can't answer (CA); Not applicable (NA)

Evidence summary for qualitative studies

| Reference Country | Objective | Participants (n=) | Method | Findings | QATSDD* | Paper No.* |
|---|--|---------------------------------------|---|---|---------|------------|
| Reuben et al. (2009) USA | Part of a practice redesign study, which aimed at improving the quality of dementia care by primary-care physicians. | Physicians (n=22) from two practices. | Explored unmet management needs facing patients with cognitive impairment or dementia and their families, and how physicians preferred to communicate with Alzheimer's Association (AA) chapters, via four focus groups of 4 to 7 participants (60-75 minutes). Focus groups were audio-recorded and transcribed for content analysis for major themes. | Physicians estimated about 40% of patients were above 65 years and about 10% had cognitive impairment, Alzheimer's disease or other form of dementia. Three of 22 physicians made five or more referrals the AA in the preceding 6 months; over half made no referrals, though about half rated such referrals as potentially beneficial to the patient and the physician. All participants acknowledged a lack of understanding about the services available and identified the need for more support of families and patients. Most physicians preferred to communicate with AA via mail or fax. Practice redesign may facilitate linkages between practices and AA chapters. | 55% | 1 |

Note: * Appraisal criteria from - Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52.
See QATSDD scoring of qualitative articles for details

Quality Assessment Tool for Studies with Diverse Designs (QATSD) scoring of qualitative studies

| | | Paper no: | 1 |
|------------------------------|---|-----------|-----|
| No. | Criteria (Scored 0-3) | | |
| 1 | Explicit theoretical framework | | 2 |
| 2 | Statement of aims/objectives in main body of report | | 3 |
| 3 | Clear description of research setting | | 3 |
| 4 | Evidence of sample size considered in terms of analysis | | 0 |
| 5 | Representative sample of target group of a reasonable size | | 2 |
| 6 | Description of procedure for data collection | | 3 |
| 7 | Rationale for choice of data collection tool(s) | | 2 |
| 8 | Detailed recruitment data | | 2 |
| 9 | Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative only) | | 2 |
| 10 | Fit between research question and method of analysis | | 3 |
| 11 | Good justification for analytic method selected | | 1 |
| 12 | Assessment of reliability of analytic process (Qualitative only) | | 0 |
| 13 | Evidence of user involvement in design | | 0 |
| 14 | Strengths and limitations critically discussed | | 0 |
| Total score (max 42): | | | 23 |
| Percentage: | | | 55% |

Appraisal criteria from - Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. *J Eval Clin Pract.* 2012;18(4):746-52.

Key to paper:

1. Reuben D, Levin J, Frank J, Hirsch S, McCreath H, Roth C, et al. Closing the dementia care gap: Can referral to Alzheimer's Association chapters help? *Alzheimer's & dementia: the journal of the Alzheimer's Association.* 2009;5(6):498-502.

Evidence summary for quantitative studies

| Reference Country | Objective | Participants (n=) | Method | Results/findings | QATSDD* | Paper No.* |
|---|--|--|--|--|---------|------------|
| Bass et al. (2013) USA | To test the effectiveness of Partners in Dementia Care (PDC) while strengthening the informal care network and providing information, coaching, and emotional support. | Initially: carers (n= 486) of veterans with diagnosed dementia (n=508; ≥ 50yrs; no restrictions based on severity of dementia or symptoms); outcomes evaluated for carers at 6 months (n=394) and 12 months (n=324). Carers recruited from Veteran Affairs (VA) facilities in five communities, four VA medical centres, and one VA outpatient clinic. | Selected communities paired by geographic region; two communities randomly selected from five to implement PDC program which was delivered by telephone and e-mail. Matched intervention and comparison sites enabled PDC to be implemented through partner organisations at intervention sites without exposing comparison subject to the intervention – they received the same educational materials and had access to usual care from the VA and Alzheimer’s Association chapter. Carers participated for 12 months completed three research telephone interviews conducted by trained blinded interviewers. A variety of carer outcomes measured after 6 and 12 months by 14 regression equations – 7 for 6 months and 7 for 12 months. Four product/ interaction terms tested the conditional-effects hypothesis that benefits of PDC would be greater for carers experiencing more negative caregiving effects or carers of more severely impaired veterans. | Carers in the intervention group had significant improvements in outcomes representing unmet needs, three types of carer strains, depression, and two support resources. Most improvements evident after 6 months; more-limited improvements from 6 to 12 months. Some outcomes improved for all carers whereas some improved for carers experiencing more difficulties initially or caring for veterans with more severe impairments. | 86% | 1 |

| Reference Country | Objective | Participants (n=) | Method | Results/findings | QATSDD* | Paper No.* |
|--|---|---|--|--|---------|------------|
| Bridges-Webb et al (2007) Australia | To collect information about the GP's role in dementia care (e.g. recognition of early dementia; confirmation of diagnosis; management; health promotion and prevention for patient and carers; and follow-up). | Patients diagnosed with dementia living in the community (n=25); primary carers of the patients (n=107); GPs attending workshop (n=24); GPs undertook audit prior to workshop (n=8) | Trial of an educational module – included a clinical audit of 5 patients and an educational workshop for each GP. GPs and Alzheimer' Australia NSW distributed a modification of the Zarit Burden Questionnaire to carers by reply-paid post. Descriptive statistical analysis. | Of the patients: diagnosis not fully established for 20%; the MMSE score not known by the GP for 56%; home safety not assessed for 44%; over half had not considered legal matters (e.g. guardianship). Most carers: felt supported by their GP in their role as carer; felt being a carer affected their own health; useful services were found not available to 23%. The small numbers for audit meant results could not be reliably representative, though provided an indication of priority areas for improved care. An educational module on dementia for GPs was developed. | 57% | 2 |
| Jaglal et al. (2007) Canada | To investigate 4 community-based, not-for-profit dementia care networks re network effectiveness from the care recipients and carers' (dyad) perspective. Explored: the links between dyad's perceptions of their experiences with care processes for dementia services and their sociodemographic and health characteristics, support networks, and amount of service use. | A non-random convenience sample consumers of network services. Care recipient /carer dyads (n=267). Care recipients had a diagnosis of dementia and lived in the community (in independent living residence or retirement home); carers were those who coordinated or organized care for the care recipient. When a care-recipient did not have an informal carer but lived alone, or when a primary carer lived in another community, the person who identified him/herself as coordinating the care for the care-recipient was eligible to participate. | A multiple comparative case study design. Consenting dyads sent a survey package including surveys for the care recipient and the caregiver. Descriptive statistics were used to characterize the results. Bivariate relationships between the process of care variables and hypothesized correlates were explored using Pearson correlation coefficients, Spearman rank correlation coefficients, and chi-square tests prior to multivariate regressions. Regression models were developed for care process factors (family physician, health care worker, assessment, and placement) and included network site as a covariate. | GPs' understanding of dementia and their ability to work with the dyad to become aware of and accept services appeared an important component in the dyad's satisfaction. Those more likely to be satisfied with their experiences with health care workers were for carers, those that received home support, and the care recipients received emotional support from their social support network. Increased awareness and provision of services were found associated with more positive perceptions of network effectiveness. | 55% | 3 |

| Reference Country | Objective | Participants (n=) | Method | Results/findings | QATSDD* | Paper No.* |
|--|---|--|--|---|---------|------------|
| Nichols et al. (2009) USA | To determine the needs as identified by the informal carer. | Carers (n=165: 77 received the Behaviour Care intervention with behavioural material only, and 88 received the Enhanced Care intervention with behavioural as well as stress/coping material.). Carers: ≥ 21 yrs; lived with the care recipient (diagnosed with probable ADRD/scored < 24 on MMSE; at least one limitation in basic activities of daily living/ two dependencies in instrumental activities of daily living); provided ≥ 4 hours of supervision or direct care per day for at least the past 6 months. Care recipients (n=165); those with more advanced dementia (n=122); and mild dementia (n=38). | Secondary analysis of baseline data from the Memphis site of the Resources for Enhancing Alzheimer Caregiver's Health (REACH) study. Descriptive statistics of carers and care recipients (compared between different demographic and clinical groups using chi-square tests, or independent-samples t-tests) and data analysis designed to examine topics selected by carers – measures of the frequency of topic selection reflected the number of carers who selected a topic at least once (repeated requests for same topic were not reflected in measures of frequency). | Depressed carers requested more information about depression, adult day care, grief, carer feelings, and relaxation. Carers of persons with mild dementia requested more information on confusion, driving, patient depression, shadowing, telling the patient and others, grief, and depression. Behavioural (activities, combativeness, communication, confusion) and stress (healthy lifestyle, grief, relaxation, depression) needs were similar across race, gender, and relationship. Clinical characteristics of carers (depression) and care recipients (cognitive impairment severity) affected behavioural and stress and coping needs. | 60% | 4 |

| Reference Country | Objective | Participants (n=) | Method | Results/findings | QATSDD* | Paper No.* |
|---|--|--|--|--|---------|------------|
| Teipel et al. (2015) Germany | Investigated the prevalence of neuropsychiatric symptoms and their association with use of medication, carer distress, and resource use in primary care. | Patients who screened positive for dementia in primary care during home visits (n=176). Sample included males with no formal diagnosis of dementia prior to screening (n=37) and fem. (n=58); and those with formal diagnosis of dementia prior to screening: males (n=35), fem. (n=46). | Neuropsychiatric symptoms were assessed using the neuropsychiatric inventory (NPI) through face to- face interviews by proxy during home visits. Data collection included; global cognition (MMSE), quality of life (QoL-AD), resource utilization in dementia (RUD), caregiver distress (BIS), and patients' use of psychotropic medication. A linear mixed effect models took into account the clustering of patients within general physician practices. NPI scores were binarized according to clinical relevance and analyses conducted in three steps to determine (i) potential predictors of higher NPI scores; (ii) the effect of NPI score increase on patient or carer-related outcomes; (iii) associations between medication use and binarized NPI scores (NPI score < 3 was considered clinically non-relevant and NPI score > 4 considered clinically relevant) | Clinically relevant neuropsychiatric symptoms occurred in about 53% of the patients. Higher NPI scores were significantly associated with more severe cognitive impairment, higher carer distress, and higher utilisation of carer resources by patients, but not with a formal diagnosis of dementia from the GP. Antipsychotics use was associated with higher NPI scores, particularly in non-psychotic domains. In contrast to guideline recommendations, the use of antipsychotics was associated with non-psychotic domains of behavioural symptoms. | 62% | 6 |

Note: * Appraisal criteria from Sirriyeh R, Lawton R, Gardner P, Armitage G. Reviewing studies with diverse designs: the development and evaluation of a new tool. J Eval Clin Pract. 2012;18(4):746-52. See QATSDD scoring of quantitative studies_for details below.

QATSDD scoring of quantitative studies

| | | Paper No: | | | | | |
|------------------------------|---|-----------|-----|-----|-----|-----|-----|
| | | 1 | 2 | 3 | 4 | 5 | 6 |
| No. | Criteria (Scored 0-3) | | | | | | |
| 1 | Explicit theoretical framework | 3 | 2 | 2 | 3 | 2 | 2 |
| 2 | Statement of aims/objectives in main body of report | 3 | 3 | 2 | 3 | 3 | 3 |
| 3 | Clear description of research setting | 3 | 3 | 3 | 3 | 3 | 3 |
| 4 | Evidence of sample size considered in terms of analysis | 1 | 3 | 0 | 0 | 0 | 1 |
| 5 | Representative sample of target group of a reasonable size | 3 | 1 | 2 | 2 | 2 | 2 |
| 6 | Description of procedure for data collection | 2 | 2 | 1 | 2 | 2 | 2 |
| 7 | Rationale for choice of data collection tool(s) | 3 | 2 | 2 | 2 | 1 | 2 |
| 8 | Detailed recruitment data | 3 | 2 | 2 | 2 | 3 | 2 |
| 9 | Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only) | 3 | 0 | 1 | 1 | 0 | 0 |
| 10 | Fit between stated research question and method of data collection (Quantitative only) | 3 | 2 | 2 | 2 | 3 | 2 |
| 11 | Fit between research question and method of analysis | 3 | 1 | 2 | 1 | 2 | 3 |
| 12 | Good justification for analytic method selected | 3 | 1 | 1 | 1 | 2 | 1 |
| 13 | Evidence of user involvement in design | 0 | 0 | 0 | 0 | 0 | 0 |
| 14 | Strengths and limitations critically discussed | 3 | 2 | 3 | 3 | 2 | 3 |
| Total score (max 42): | | 36 | 24 | 23 | 25 | 25 | 26 |
| Percentage: | | 86% | 57% | 55% | 60% | 60% | 62% |

Key to papers:

1. Bass DM, Judge KS, Snow A, Wilson NL, Morgan R, Looman WJ, et al. Caregiver outcomes of partners in dementia care: Effect of a care coordination program for veterans with dementia and their family members and friends. *J Am Geriatr Soc.* 2013;61(8):1377-86.
2. Bridges-Webb C, Giles B, Speechly C, Zurynski Y, Hiramaneek N. Patients with dementia and their carers. *Ann N Y Acad Sci.* 2007;1114:130-6.
3. Jaglal S, Cockerill R, Lemieux-Charles L, Chambers LW, Brazil K, Cohen C. Perceptions of the process of care among caregivers and care recipients in dementia care networks. *Am J Alzheimers Dis Other Demen.* 2007;22(2):103-11.
4. Nichols LO, Martindale-Adams J, Greene WA, Burns R, Graney MJ, Lummus A. Dementia caregivers' most pressing concerns. *Clinical Gerontologist: The Journal of Aging and Mental Health.* 2009;32(1):1-14.
5. Teipel SJ, Thyrian JR, Hertel J, Eichler T, Wucherer D, Michalowsky B, et al. Neuropsychiatric symptoms in people screened positive for dementia in primary care. *Int Psychogeriatr.* 2015;27(1):39-48.

Evidence summary for randomised controlled trials[^]:

| Reference Country | Study design/Level of evidence | N(n) | Participants | Intervention | Comparison | Main outcomes | Measure/s | Length of follow-up | Results/ Effect size |
|--|---|----------------------------------|---|---|--|---|--|---|--|
| Mittelman et al. (2006) USA | RCT enrolment over 9.5 yrs; data collected over 18 yrs. 1987 -1991 1991 - 1997 | N= 406 (n=206) (n=200) | Spouse carers of community dwelling patients with Alzheimer's disease (AD) | Six sessions of individual and family counselling, support group participation, and continuous availability of ad hoc telephone counselling. | Usual care group received services routinely provided to patients and their families (e.g. resource information and help upon request; they did not participate in formal counselling sessions, and did not generally have any contact with the counsellors. | Reduction in the rate of nursing home placement. Improvements in carers' satisfaction with social support, response to patient behaviour problems, and symptoms of depression. | Structured questionnaires were administered at baseline and at every 4 months for the first year and every 6 months thereafter. | Participation continued until the carer became too ill to participate, died, or refused to continue in the study, or until 2 years after the death of the patient with AD. | Patients whose spouses received the intervention experienced a 28.3% reduction in the rate of nursing home placement (hazard ratio = 0.717 after covariate adjustment, p = 0.025); difference in model- predicted median time to placement was 557 days (approx. 1.5 yrs). Improvements in carers' satisfaction with social support, response to patient behaviour problems, and symptoms of depression collectively accounted for 61.2% of the intervention's beneficial impact on placement. |

| Reference Country | Study design/Level of evidence | N(n) | Participants | Intervention | Comparison | Main outcomes | Measure/s | Length of follow-up | Results/ Effect size |
|--|---------------------------------|-------|---|---|--|---|---|---|---|
| Rodriguez-Sanchez et al. (2013) Spain | RCT July 2008 – Nov. 2009 | N=125 | Primary carers of a dependent relative with dementia or any other disability, and having been a carer to them for at least 6 months | Cognitive-behavioural therapy to for manage dysfunctional thoughts about caregiving and to train in self-help techniques (8 ninety-minute sessions over 8 weeks at health care centres) | Usual care – coordinated by Health and Social Services centres; the quantity and type of support provided by the institutions depended on the level of functional status of the care recipient and was managed by their relatives. | Carer self-perceived improvement in mental health and managing dysfunctional thoughts about caregiving. | General Health Questionnaire [GHQ-12], dysfunctional thoughts about caregiving questionnaire, quality of life (Ruiz and Baca's Questionnaire), and burden (Short Zarit Burden Interview). | All participants assessed through face-to-face interviews by a psychologist not participating in the intervention between 2 and 6 weeks pre-intervention and 1 and 3 weeks post-intervention. | The intervention group showed improvement in mental health: A mean reduction in GHQ-12 score of -3.33 points was recorded in the intervention group vs. the control group (95% CI: -5.95 to -0.70; p = .01; Cohen d = 0.55); improvement in dysfunctional thoughts about caregiving: (-5.84; 95% CI: -10.60 to -1.09; p = .01; Cohen d = 0.62). |

Note: ^ See [Evidence appraisal for randomised controlled trials](#) for appraisal criteria

Evidence appraisal for randomised controlled trials

| RCT: Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. <i>Neurology</i> . 2006;67:1592-9. | | |
|--|--|-------------------------------|
| 1 | eligibility criteria were specified | yes, where: p.1593 |
| 2 | subjects were randomly allocated to groups (in a crossover study, subjects were randomly allocated an order in which treatments were received) | yes, where: p. 1592 |
| 3 | allocation was concealed | yes (initially; p.1592) |
| 4 | the groups were similar at baseline regarding the most important prognostic indicators | yes, where: p.1595 |
| 5 | there was blinding of all subjects | yes (initially; p.1592) |
| 6 | there was blinding of all therapists who administered the therapy | yes (initially; p.1592) |
| 7 | there was blinding of all assessors who measured at least one key outcome | no |
| 8 | measures of at least one key outcome were obtained from more than 85% of the subjects initially allocated to groups | yes, where: p.1594 |
| 9 | all subjects for whom outcome measures were available received the treatment or control condition as allocated or, where this was not the case, data for at least one key outcome was analysed by "intention to treat" | yes, where: p.1595 |
| 10 | the results of between-group statistical comparisons are reported for at least one key outcome | yes, where: pp.1596-97 |
| 11 | the study provides both point measures and measures of variability for at least one key outcome | yes, where: pp.1596-98 |

Reference: Maher CG, Sherrington C, Herbert RD, Moseley AM, Elkins M. Reliability of the PEDro Scale for Rating Quality of Randomized Controlled Trials. *Phys Ther*. 2003;83(8):713-21.

Appraisal instrument: PEDro Partnership. PEDro Scale 1999 [updated 21 June. Available from: https://www.pedro.org.au/wp-content/uploads/PEDro_scale.pdf.

Evidence appraisal for randomised controlled trials

RCT: Rodriguez-Sanchez E, Patino-Alonso MC, Mora-Simon S, Gomez-Marcos MA, Perez-Penaranda A, Losada-Baltar A, et al. Effects of a psychological intervention in a primary health care center for caregivers of dependent relatives: a randomized trial. *Gerontologist*. 2013;53(3):397-406.

| | | |
|----|--|--------------------------|
| 1 | eligibility criteria were specified | yes where: p.398 |
| 2 | subjects were randomly allocated to groups (in a crossover study, subjects were randomly allocated an order in which treatments were received) | yes where: p.398 |
| 3 | allocation was concealed | no |
| 4 | the groups were similar at baseline regarding the most important prognostic indicators | yes where: p.402 |
| 5 | there was blinding of all subjects | no |
| 6 | there was blinding of all therapists who administered the therapy | no |
| 7 | there was blinding of all assessors who measured at least one key outcome | no |
| 8 | measures of at least one key outcome were obtained from more than 85% of the subjects initially allocated to groups | yes where: p.399 |
| 9 | all subjects for whom outcome measures were available received the treatment or control condition as allocated or, where this was not the case, data for at least one key outcome was analysed by "intention to treat" | yes where: p.402 |
| 10 | the results of between-group statistical comparisons are reported for at least one key outcome | yes where: p.402 |
| 11 | the study provides both point measures and measures of variability for at least one key outcome | yes where: p.p.401-03 |

Reference: Maher CG, Sherrington C, Herbert RD, Moseley AM, Elkins M. Reliability of the PEDro Scale for Rating Quality of Randomized Controlled Trials. *Phys Ther*. 2003;83(8):713-21.

Appraisal instrument: PEDro Partnership. PEDro Scale 1999 [updated 21 June. Available from: https://www.pedro.org.au/wp-content/uploads/PEDro_scale.pdf.

Grey literature appraisal

| Instrument: AACODS | | Reference: Guideline Adaptation Committee. (2016). Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney | YES | NO | ? |
|---|---|---|-----|----|---|
| Authority | <i>Identifying who is responsible for the intellectual content.</i> | | | | |
| | Individual author: | | | | |
| | • Associated with a reputable organisation? | | | | |
| | • Professional qualifications or considerable experience? | | | | |
| | • Produced/published other work (grey/black) in the field? | | | | |
| | • Recognised expert, identified in other sources? | | | | |
| | • Cited by others? (use Google Scholar as a quick check) | | | | |
| | • Higher degree student under “expert” supervision? | | | | |
| | Organisation or group: | | | | |
| | • Is the organisation reputable? (e.g. W.H.O) | x | | | |
| | • Is the organisation an authority in the field? | x | | | |
| In all cases: | | | | | |
| • Does the item have a detailed reference list or bibliography? | x | | | | |
| Accuracy | • Does the item have a clearly stated aim or brief? | X | | | |
| | • Is so, is this met? | X | | | |
| | • Does it have a stated methodology? | X | | | |
| | • If so, is it adhered to? | X | | | |
| | • Has it been peer-reviewed? | X | | | |
| | • Has it been edited by a reputable authority? | X | | | |
| | • Supported by authoritative, documented references or credible sources? | X | | | |
| | • Is it representative of work in the field? | x | | | |
| | • If No, is it a valid counterbalance? | | | | |
| | • Is any data collection explicit and appropriate for the research? | x | | | |
| | • If item is secondary material (e.g. a policy brief of a technical report) refer to the original. Is it an accurate, unbiased interpretation or analysis? | | | | |
| Coverage | <i>All items have parameters which define their content coverage. These limits might mean that a work refers to a particular population group, or that it excluded certain types of publication. A report could be designed to answer a particular question or be based on statistics from a particular survey.</i> | | | | |
| | • Are any limits clearly stated? | x | | | |
| Objectivity | It is important to identify bias, particularly if it is unstated or unacknowledged. | | | | |
| | • Opinion, expert or otherwise, is still opinion: is the author’s standpoint clear? | x | | | |
| | • Does the work seem to be balanced in presentation? | x | | | |
| Date | <i>For the item to inform your research, it needs to have a date that confirms relevance</i> | | | | |
| | • Does the item have a clearly stated date related to content? No easily discernible date is a strong concern. | x | | | |
| | • If no date is given, but can be closely ascertained, is there a valid reason for its absence? | x | | | |
| | • Check the bibliography: have key contemporary material been included? | x | | | |
| Significance | <i>This is a value judgment of the item, in the context of the relevant research area</i> | | | | |
| | • Is the item meaningful? (this incorporates feasibility, utility and relevance)? | x | | | |
| | • Does it add context? | x | | | |
| | • Does it enrich or add something unique to the research? | x | | | |
| | • Does it strengthen or refute a current position? | x | | | |
| | • Would the research area be lesser without it? | x | | | |
| | • Is it integral, representative, typical? | x | | | |
| | • Does it have impact? (in the sense of influencing the work or behaviour of others) | x | | | |

Appraisal instrument: Tyndall J. Authority, accuracy, coverage, objectivity, date and significance scale (AACODS) 2010 [Available from: https://dspace.flinders.edu.au/xmlui/bitstream/handle/2328/3326/AACODS_Checklist.pdf;jsessionid=2EB4A7A580B36D6D06FFD6428FB02920?sequence=4].

Search strategy summary

| Medline | PsycINFO | EMBASE |
|---|--|--|
| <p>1. (general practitioner or primary care physician or family physician).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>2. (primary health care or general practice of family medicine or family practice).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>3. 1 or 2</p> <p>4. dementia.mp. or Dementia/ or Delirium, Dementia, Amnestic, Cognitive Disorders/ or AIDS Dementia Complex/ or Frontotemporal Dementia/ or Dementia, Vascular/ or Dementia, Multi-Infarct/</p> <p>5. Alzheimer Disease/ or alzheimer\$.mp.</p> <p>6. 4 or 5</p> <p>7. 3 and 6</p> <p>8. aged care.mp. or Aged/ or Health Services for the Aged/ or support service.mp. or community aged care.mp. or Community Health Services/</p> <p>9. 7 and 8</p> <p>10. patient care/ or patient-centered care/ or patient care management/ or patient care planning/ or uncompensated care/ or patient care team/ or patient care management.mp. or patient care.mp.</p> <p>11. 7 and 10</p> <p>12. caregivers/ or caregiver\$.mp. or carer.mp. or spouse.mp. or relati\$.mp. or family member of support person.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>13. 9 and 12</p> <p>14. 11 and 12</p> | <p>1. (general practitioner or primary care physician or family physician).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>2. (primary health care or general practice of family medicine or family practice).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>3. 1 or 2</p> <p>4. exp Vascular Dementia/ or exp Dementia/ or exp Semantic Dementia/ or exp AIDS Dementia Complex/ or exp Presenile Dementia/ or dementia.mp. or exp Dementia with Lewy Bodies/ or exp Senile Dementia/</p> <p>5. Alzheimer's Disease/ or alzheimer\$.mp.</p> <p>6. 4 or 5</p> <p>7. 3 and 6</p> <p>8. aged care.mp. or Elder Care/ or support service.mp. or community aged care.mp. or Health Care Services/</p> <p>9. 7 and 8</p> <p>10. (patient care or patient-centered care or patient care management or patient care planning or uncompensated care or patient care team).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>11. 7 and 10</p> <p>12. caregivers/ or caregiver\$.mp. or carer.mp. or spouse.mp. or relati\$.mp. or family member.mp. or support person.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>13. 9 and 12</p> <p>14. 11 and 12</p> <p>15. 7 and 12</p> <p>16. Education/ or education.mp.</p> <p>17. 15 and 16</p> <p>18. (burden or stress or distress or anxiety or depressi\$.mp. or caregiver burden/ [mp=title, abstract,</p> | <p>1. (general practitioner or primary care physician or family physician).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>2. (primary health care or general practice of family medicine or family practice).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>3. 1 or 2</p> <p>4. HIV associated dementia/ or Pick presenile dementia/ or dementia assessment/ or multiinfarct dementia/ or semantic dementia/ or dementia/ or "mixed depression and dementia"/ or presenile dementia/ or frontal variant frontotemporal dementia/ or Cornell Scale for Depression in Dementia/ or Clinical Dementia Rating/ or dementia.mp. or senile dementia/ or frontotemporal dementia/</p> <p>5. Alzheimer disease/ or alzheimer\$.mp.</p> <p>6. 4 or 5</p> <p>7. 3 and 6</p> <p>8. (aged care or support service or community aged care).mp. or elderly care/ or community health services.mp.</p> <p>9. 7 and 8</p> <p>10. patient care planning/ or patient care/ or patient care management.mp.</p> <p>11. 7 and 10</p> <p>12. caregiver/ or caregiver\$.mp. or carer.mp. or spouse.mp. or relati\$.mp. or family member of support person.mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>13. 9 and 12</p> <p>14. 11 and 12</p> <p>15. 7 and 12</p> <p>16. education/ or education.mp. or patient education/</p> |

| | | |
|---|--|---|
| <p>15. 7 and 12</p> <p>Medline</p> <p>16. Education/ or Patient Education Handout/ or Education.mp. or Patient Education as Topic/</p> <p>17. 15 and 16</p> <p>18. (burden or stress or distress or anxiety or depressi\$).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>19. 15 and 18</p> <p>20. (assess\$ or evaluat\$ or monitor\$ or measur\$).mp. or questionnaires/ [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>21. 19 and 20</p> <p>22. (organization or organisation).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]</p> <p>23. 17 and 22</p> <p>24. counsel\$.mp.</p> <p>25. 15 and 24</p> <p>26. 13 or 14 or 17 or 19 or 21 or 23 or 25</p> <p>27. limit 26 to (english language and humans and yr="2008 -Current")</p> | <p>heading word, table of contents, key concepts, original title, tests & measures]</p> <p>19. 15 and 18</p> <p>PsycINFO</p> <p>20. (assess\$ or evaluat\$ or monitor\$ or measur\$).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>21. 19 and 20</p> <p>22. (organization or organisation).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>23. 17 and 22</p> <p>24. counsel\$.mp.</p> <p>25. 15 and 24</p> <p>26. 13 or 14 or 17 or 19 or 21 or 23 or 25</p> <p>27. limit 26 to (human and english language and yr="2008 -Current")</p> | <p>17. 15 and 16</p> <p>18. (burden or stress or distress or anxiety or depressi\$).mp. or caregiver burden/ [mp=title, abstract, subject headings, heading</p> <p>EMBASE</p> <p>word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>19. 15 and 18</p> <p>20. (assess\$ or evaluat\$ or monitor\$ or measur\$).mp. or questionnaires/ [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>21. 19 and 20</p> <p>22. (organization or organisation).mp. [mp=title, abstract, subject headings, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword]</p> <p>23. 17 and 22</p> <p>24. counsel\$.mp.</p> <p>25. 15 and 24</p> <p>26. 13 or 14 or 17 or 19 or 21 or 23 or 25</p> <p>27. limit 26 to (human and english language and yr="2008 -Current")</p> |
| <p>PHCRIS search strategy Carer Support: Topic: General Practitioners; Keywords: carer* or caregiv* and support and dementia or Alzheimer*; Published date: last 10 years</p> | | |