Interventions to support carers of people with dementia

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What are *What Works* reviews?

What Works reviews complement the performance reporting in the Report on Government Services (RoGS) by reviewing current global evidence on what works (or does not) to achieve particular outcomes for government services. The aim is to improve the wellbeing of all Australians through providing decision makers with high quality information on what works to address existing social policy needs.

The reviews are intended to be targeted at policy issues, be rigorous yet timely and balance the overall evidence with practical advice and theory. The *What Works* approach will also include follow-up with governments on the use of the reviews, and the monitoring of relevant outcomes in the RoGS to ensure a feedback loop between evidence production and implementation.

Contents

Steering Committee

The Commission undertook the development and production of this review under the auspice of the Steering Committee for the Review of Government Service Provision (SCRGSP). The Steering Committee comprises the following current members:

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Abbreviations

ADAT	Adult Disability Assessment Tool
CALD	Culturally and linguistically diverse
GP	General Practitioner
PC	Productivity Commission
RCT	Randomised controlled trials
REA	Rapid evidence approach
UK	United Kingdom
USA	United States of America

Glossary

Carer	Informal carer.
Care coordination	The coordination of services, provided with the aim of enhancing care delivery and transitions, and including preliminary care plans and identification of the need for more intensive case management.
Care recipient	A person who is receiving care and support, either in the community, in their own home or in a residential care facility.
Case management	Focus is on planning and co-ordinating care to meet the individual needs of the person with dementia and their carer (including taking on the carer’s role of coordinating the care for the person with dementia). Usually involves a case manager conducting an individual needs assessment and developing a support plan, and providing education, problem solving, referral to services and/or purchasing services to meet the needs identified in the plan.
Counselling	Emotion-orientated or education-based counselling, including individual, family and group therapy.
Dementia	A chronic, progressive and irreversible condition that involves loss of cognitive function affecting behaviour and the ability to perform everyday activities.
Education and skills building	Building knowledge about dementia and available resources and help to develop skills to address identified problems, particularly concerning the management of behavioural and psychological symptoms of dementia.
Informal carer	Individuals providing care and support to a care recipient on a regular basis (on an unpaid basis and without contract). Usually a family member such as a spouse, child or relative, but can also be a friend or neighbour.
Hazard ratio	Compares the probability that a care recipient (across intervention and control groups) who is not already in residential care, will enter in the next time period.

Odds ratio	Indicates how much more (or less) likely a care recipient in the intervention group will be in residential care at a point in time (for example, 12 months after the intervention) compared with a care recipient in the control group.
Residential aged care	A special-purpose facility which provides accommodation and other types of support, including assistance with day-to-day living, intensive forms of care, and assistance towards independent living, to frail and aged residents.
Respite care	Temporary care services provided to the person with dementia to provide a break for the carer.

Key Messages

- Australia’s population is ageing, and as it does the prevalence of dementia will increase. By 2056 over a million people are anticipated to be living with dementia.
- Dementia leads to significant disability in later life. Due to its disabling effects, people with dementia are at greater risk of placement in residential care. Over half of those in residential care in Australia have dementia.
- Most Australians prefer to age in place rather than in residential care and supporting them at home could also reduce governments’ aged care costs.
- The role of carers is crucial if older people with dementia are to stay at home, but caring for a person with dementia at home can be demanding. Governments fund a range of supports to assist them in this role. Keeping older people with dementia at home is only one of a range of objectives in providing these supports.
- This review considers *what works* to support carers of older people with dementia to prevent or delay entry into residential aged care. It identified 44 interventions (most from overseas) that supported carers of people with dementia, of which 26 were from studies assessed as high quality and so were the focus of the analysis.
- Interventions that support carers of older people with dementia show limited effectiveness in achieving the outcome of preventing or delaying entry into residential care. Of the 26 interventions in high-quality studies, only three were found to be effective. Two involved counselling and the other involved case management.
- None of the effective interventions are considered appropriate for adoption at this stage for the purpose of preventing or delaying entry into residential aged care. The overall evidence of effectiveness for the counselling interventions was inconclusive as some adaptations were ineffective. But there may be value in further testing. One adaptation had success in the Australian context albeit with important caveats. The case management intervention had several context-specific aspects that limit its transferability to Australia.
- Overall, why some interventions were effective in delaying or preventing entry to residential care and others were not is unclear. The interventions often have multiple components, making it hard to isolate the characteristics that influence residential care placement. In addition, many of the components in effective interventions also existed in those that were not. And context — in relation to place and time — matters.
- Reducing the risk and delaying the progression of dementia may be a more fruitful avenue to prevent or delay entry into residential care than interventions to support carers.
- But the finding of limited effectiveness of interventions to support carers does not suggest that dementia-related funding for carer services, resources and research should be reduced. There are gaps in the research (in particular, studies for respite services). And supporting carers of people with dementia may have important benefits beyond keeping the person with dementia at home.

Executive Summary

This review considers *what works* to support carers of older people with dementia to prevent or delay entry into residential aged care. It adopts a rigorous and systematic approach to identify and appraise the evidence, aiming to inform dementia policy.

Why is this review important?

Australia's population is ageing, and as it does the prevalence of dementia will increase. Around 425 400 Australians are currently living with dementia, and this is projected to increase to over a million by 2056.

Dementia is a progressive and irreversible condition leading to significant disability in later life. Due to its disabling effects, people with dementia are more likely than those without it to be placed in residential care. More than half of those in permanent residential care in Australia have dementia.

Preventing or delaying the entry of people with dementia into residential care could be beneficial:

- as it is consistent with the preference of the majority of older Australians to 'age in place'
- in reducing Australian governments' aged care costs into the future — residential care accounts for about 70 per cent of these costs.

The role of carers is crucial if older people with dementia are to stay at home for longer. Caring for a person with dementia at home can be demanding, particularly as the condition progresses and care needs increase. The risk that the person they care for will enter residential care can be influenced by their feelings of stress and burden, and ability to cope.

What were the carer support interventions included?

The review identified 44 randomised controlled trials (RCTs) of interventions (from 48 research studies). Most of these studies (80 per cent) were published since 2000.

Very few studies had been conducted in Australia. There were only two, one of which was conducted in the late 1980s. The majority of studies were from the United States or Europe.

There was considerable variation across the interventions, but they were grouped according to their key components into four broad categories:

- case management — involves identifying the needs of the person with dementia and their carer, and planning and co-ordinating the care required, including the purchasing of services
- education and skills building — involves building carers' knowledge about dementia and available resources, and helping them to develop skills to address identified problems, such as managing difficult behaviours
- counselling — involves emotion-orientated or education-based counselling, including individual, family and group therapy
- respite care — involves temporary care services (day or overnight) provided to the person with dementia to provide a break for the carer.

While some interventions were relatively easy to categorise, many were difficult as they were multicomponent and could have been included under multiple categories.

Despite variation across interventions, there were some key common features:

- the majority were of 12 months or less duration
- most started with an initial short period of intense contact that decreased over time
- all but one were delivered by skilled people such as nurses and occupational therapists
- over half the studies had less than 200 participants.

Of the 48 studies, 28 (covering 26 interventions) were assessed at relatively low risk of bias (high quality). The review primarily focused on these studies in order to ensure that the results presented reflected the effectiveness of interventions, and not potential problems with study design and evaluation.

Are carer support interventions effective in delaying or preventing entry into residential care?

Interventions that support carers of older people with dementia show limited effectiveness in achieving the outcome of preventing or delaying entry into residential care. Of the 26 high-quality interventions, nine were found to have a positive effect on this outcome. However, only three had a positive effect that was also statistically significant.

Of the three effective interventions, none are considered appropriate for adoption at this stage. One was conducted in a context that is substantively different to Australia, so the results are unlikely to be transferable. The other two interventions were very similar, with one an adaptation of the other. However, other adaptations of this intervention were not effective and therefore the overall evidence for the effectiveness of this approach is inconclusive.

What are the implications?

The limited evidence of effectiveness of these carer support interventions in preventing or delaying the placement of older people with dementia in residential care has a number of implications. It suggests that other options aimed at preventing or delaying entry into residential aged care for older people with dementia should be explored (or continued). Interventions that seek to reduce risk and delay the progression of dementia, as well as research to improve prevention and find effective treatments and cures, for example, may be more fruitful avenues.

While the evidence of effectiveness is limited, interventions should be considered using a broader framework. First, this review uses a high threshold (95 per cent confidence level) that provides a substantial degree of certainty regarding whether or not interventions prevented or delayed residential care placement. If policy makers are willing to accept a lower level of certainty (for example, an 80 per cent confidence level) then additional interventions might be considered (especially if the effect sizes are large). Second, in assessing the merits of any intervention, costs should be considered (costs of interventions were not included in this review).

The finding of limited effectiveness of carer support interventions does not suggest that dementia-related funding for carer services, resources and research should be reduced. There are gaps in the research, and — perhaps more significantly — supporting carers of people with dementia may have important benefits beyond keeping the person with dementia at home.

- Reliable evidence for some common carer support services was not available (for example, studies of respite services). Moreover, the methodological and reporting weaknesses of many studies limited the number and range of intervention evidence available for this review. Further, more experimentation may be required to better understand and target the factors leading to residential care placement.
- Caring itself can have a negative impact on carer physical and mental health, especially for those who provide a high intensity of care. Recognising this, governments fund a range of services and resources to support for carers. These services and resources can offset some of the negative effects of caring, improve carer quality of life and perhaps reduce carers’ own health risks.

1 What is this report about?

1.1 Why is this review important?

Australia's population is ageing, and this trend will continue over coming decades. The proportion of Australians aged 65 years or over will increase from about 15 per cent today to 21 per cent by 2050. Over the same period the proportion of very elderly (aged 85 years or over) is also predicted to increase from 2 per cent to 5 per cent (ABS 2013).

As the Australian population ages, there will be an increasing prevalence of dementia — characterised by the gradual impairment of brain function, and associated with reduced cognitive capacity and impacts on personality and mental health. One in 10 people aged 65 years or over has dementia, and this increases to one in three for those aged 85 years or over. In 2018, about 425 400 Australians are living with dementia, with the number expected to increase to an estimated 536 200 by 2025 and 1 100 900 by 2056 (Dementia Australia 2018l; NATSEM 2017).

Dementia is a progressive and irreversible condition (AIHW 2016). In the early stages of dementia, people may have difficulty managing household duties such as shopping, preparing meals and managing finances (Brooks, Ross and Beattie 2015). As the condition progresses, they can begin to exhibit problem behaviours such as wandering, hallucinations, aggression, depression and loss of inhibition (Donaldson, Tarrier and Burns 1997; Haro et al. 2014). In the final stages, the person living with dementia may be unable to dress or feed themselves or undertake other basic activities (Dementia Australia 2018p).

The most common form of dementia is Alzheimer's disease, accounting for over half of dementia cases worldwide. Other types include vascular dementia, frontotemporal dementia and Lewy body disease (AIHW 2012).

Dementia leads to significant disability in later life (Alzheimer's Disease International 2009). People with dementia are more likely to experience profound disabilities than people with other age-related conditions (ABS 2015). Over 75 per cent of those aged 65 years or over with dementia are profoundly limited in core everyday activities (that is, communication, mobility and self-care), the proportion is 90 per cent for those aged 85 years or over (AIHW 2012).

Due to its disabling effects, people with dementia are more likely to be placed in residential aged care than those without dementia. Dementia increases the chance of placement among older people more than fivefold (Eaker, Vierkant and Mickel 2002; Hajek et al. 2015). In Australia in 2015, more than half of those in permanent residential aged care (52 per cent, or about 90 000 people) had dementia, and were more likely to require high levels of care than people without dementia (AIHW 2016).

Preventing or delaying the entry of people with dementia into residential aged care could be beneficial:

- as it is consistent with the preferences of many older Australians (including those with care needs) to 'age in place' at home, where they are able to maintain their family and social networks and enjoy a higher quality of life (Luppa et al. 2009; PC 2015)
- to reduce Australian governments' aged care costs into the future — residential aged care is more costly than home care and support, accounting for approximately 70 per cent, or $12.1 billion of governments' aged care expenditure, but only about a quarter of people receiving aged care services in 2016-17 (SCRGSP 2018).

The majority of people with dementia do live in the community where they rely on informal carers to support them (Brooks, Ross and Beattie 2015). Informal carers (generally referred to as carers in this review) are usually a family member such as a spouse, child or relative, but can also be a friend or neighbour. Of Australians with dementia living in the community, 92 per cent have one or more carers, and about 20 per cent receive no other care services (AIHW 2012).

Dementia carers are often living with the person with dementia, providing intensive support (AIHW 2012). Caring for a person with dementia at home can be demanding, particularly as the condition progresses and dementia care needs increase (Spijker et al. 2008a). In Australia, co-resident primary carers of people with dementia are more likely than other co-resident primary carers to provide 40 or more hours of care per week, have their sleep interrupted and report at least one of four negative consequences (such as feeling weary or frequently feeling worried) due to their role as carer (AIHW 2012).

In addition, compared with non-carers and carers of people with other health conditions, dementia carers tend to experience considerable strain, and have high levels of stress and depression (Burns and Rabins 2000; Pinquart and Sörensen 2003). Dementia carers can also feel isolated from their own family and social networks (Haley et al. 1987; Robison et al. 2009).

If older people with dementia are to stay in the community for longer, the role of carers is crucial (Gaugler et al. 2000; Mittelman et al. 2006a). Carers' feelings of stress and burden, and lack of ability to cope (low self-efficacy), are factors that increase the likelihood of a person with dementia being admitted to residential aged care (Dunkin and Anderson-Hanley 1998; Gallagher et al. 2011; Gaugler et al. 2003, 2009). Interventions that aim to support carers by helping them to manage stress, cope with problem behaviours, link them with support services, and increase their feelings of self-efficacy, may be effective in delaying or preventing this entry (Reilly et al. 2015; Spijker et al. 2008a).

The significance of dementia and the vital role performed by carers is reflected in the priority given to it by Australian governments (appendix A). The Australian Government funds numerous programs that support people living with dementia as well as their carers, and also funds dementia-related research. While government objectives in supporting carers of people with dementia are multifaceted, facilitating the independence of older people and enabling them to stay in the community for longer is one of them (SCRGSP 2018).

1.2 Objectives of this review

The objective of this review is to identify what interventions to support carers of older people living with dementia are effective in preventing or delaying entry into residential aged care. The focus is on informal carers as distinct from formal or paid carers. Interventions are those that support carers in their role or in coping with the challenges they face (such as through counselling or respite). Those directed solely at the care recipient, even if the carer benefits indirectly, are out of scope. The focus is long-term entry into residential aged care, rather than short-term stays.

While this review measures effectiveness in terms of preventing or delaying entry into residential aged care, this outcome may not be appropriate in all cases (for example, where a person's condition has advanced to a point where they cannot receive the care they need at home, or, where due to the impact of caring, delaying or preventing residential care placement places a substantial toll on carer health and wellbeing). In addition, other valid measures of the effectiveness of these interventions, such as increasing the quality of life of the carer and the person with dementia, are not considered.

1.3 Review type

This review is conducted using a Rapid Evidence Assessment (REA) approach. Rigorous and tested evidence is central to informed decision making (PC 2010). REAs are a synthesis of evidence, and adopt a timely but rigorous standard and method to search and appraise evidence. This approach reduces the risk of bias in the findings that can occur from less systematic approaches; for example, if researchers focus on studies that are easily accessible or that have results conforming to their hypothesis.

The Steering Committee for the Review of Government Service Provision (Steering Committee) is undertaking this review to complement the performance reporting in the Report on Government Services. It is the Steering Committee's first review of this type and it has drawn on advice from two independent consultants who have expertise in the subject area and/or in conducting this type of review.

1.4 Review structure

The remainder of this report is structured as follows:

- chapter 2 outlines the methods employed in this review to select, extract data from and assess the quality of, studies included, and to undertake the evidence synthesis
- chapter 3 presents an overview of the included studies, describing the results of the study selection process, the characteristics of the participants and interventions, and the outcomes of the evidence quality assessment
- chapter 4 presents the results, outlining interventions that work and do not work
- chapter 5 outlines the implications for policy makers. It also presents implications for researchers in this field, and the strengths and limitations of this review.

2 Review methods

This chapter provides information on the methods used in this review to:

- select studies — including the criteria for study inclusion, the search strategy and process for literature screening
- extract data from included studies
- assess the quality of the evidence collected
- synthesise the evidence and report on the findings.

The methods were pre-defined in the What Works review protocol and is available at www.pc.gov.au/research/ongoing/report-on-government-services/what-works. The What Works review protocol sets out the high-level framework for undertaking What Works reviews and includes general guidance, which is not specific to this review. It was informed by existing handbooks and guides on conducting systematic reviews including the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins and Green 2011).

2.1 Study selection

Search strategy

To find potentially relevant studies, three databases were searched — Medline, Ageline and PsycINFO — using a search string that referenced the main components of the inclusion criteria. To identify key words for the search string, common words were identified in similar studies and systematic reviews and tested extensively.

The search was undertaken on 18 December 2017 using the following search string:

> (Older or Elder* or Dementia or Alzheimer*) AND (Caregiver* or Carer*) AND (Home* or Communit*) AND (Intervention* or Support* or Program*) AND (Control* or Random* or Trial*).

Additional studies were identified by hand-searching the reference lists of studies included after the literature screening process and through checking the studies in related systematic reviews.

Criteria for study inclusion

Studies were selected for the review if they met all the following criteria.

- The sample comprised carers of older people living in the community with care needs arising from dementia. Studies were excluded if the carers were employed as carers (including volunteers in formal care programs).
- The intervention had components that were clearly aimed at assisting the carer in their role (for example, counselling for carers), providing relief to carers by giving them a short-term break (such as respite), or reducing the number of tasks they did for the care recipient (for example, case management). Interventions that provided assistance to the person with dementia were included as long as they were accompanied by measures aimed at supporting the carer.
- The study's outcome measures included the prevention of, or delay in entry to, residential aged care or other long-term care placement. For example, outcome measures included the difference between the treatment and control group in the proportion who were placed in residential care, or in the time they remained in the community before entering residential care.
- The study was a randomised controlled trial (RCT) or cluster RCT[1] that included a control group who did not receive the intervention, and instead received usual care, augmented usual care, or an alternative intervention.

The review's scope was restricted to RCTs, as they are more likely than non-randomised studies to measure the effectiveness of the intervention accurately and, therefore, are considered to provide a higher quality of evidence. Moreover, a sufficient number and diversity of RCTs was identified to justify the exclusion of non-randomised studies. Systematic reviews were not included, as those identified did not adequately address this review's scope or objective.

To reduce the time taken for the review, it was restricted to studies published in peer-reviewed journals (grey literature was excluded) and in English. No limit was placed on the publication date.

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[1] In cluster RCTs, randomisation occurs at the group rather than participant level. For example, where an intervention is to be delivered to patients through general practices, the general practices might be randomised rather than the patients attending those practices. In this case, all the participants attending a general practice that has been randomised to the treatment group will receive the treatment. If this clustering is not accounted for when analysing results, the resulting p-values will be artificially small, making the results appear more precise than they actually are (Higgins and Green 2011).

Literature screening process

The literature screening was undertaken in two stages:

- first, by reading the title and abstract of each article
- second, by assessing the full text of each article that remained after title and abstract screening.

Two reviewers screened the titles and abstracts independently. Full texts were assessed by one reviewer first, and then a second reviewer screened the study to confirm the result. Where the assessment of the two reviewers conflicted for the title and abstract or full text screening, differences were resolved by discussion or in consultation with a third reviewer.

2.2 Data extraction

Once the screening process was completed and the included studies finalised, the relevant data were extracted from each study. A data extraction form was developed to collect consistent information. The form was based on data extraction approaches used in other reviews, and had fields on:

- author and date
- country of study
- study design and methods
- participant characteristics for the total sample, and across the intervention and control groups
- intervention characteristics and control group conditions (usual care or other)
- outcomes related to residential care placement.

One reviewer extracted the data and a second reviewer then checked the data extracted, adding to or revising the information as required.

2.3 Quality assessment

Once the data had been extracted from each study, the quality of the studies was assessed to determine studies that included evidence of relatively:

- high quality and, therefore, should be the focus of the analysis and presentation of results
- low quality and should not be focused on in detail.

To assess the quality of each study, the Risk of Bias tool, outlined in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins and Green 2011), was used. This tool is used to assess whether a study's results are subject to bias — in other words, whether the results should be believed — and covers selection, performance, detection, attrition, reporting and other biases.

These six biases are covered by seven domains in the risk of bias tool (table 2.1). For this review, only five of the seven domains were considered when assessing studies for overall risk of bias — random sequence generation, allocation concealment, incomplete outcome data, selective reporting, and other sources of bias. While information for the two blinding domains was collected, these domains did not contribute to the overall assessment as the results were consistent across the studies.

- All studies were assessed at high risk of bias on the blinding of participants and personnel domain as no studies blinded participants *and* personnel.
- All studies were assessed at low risk of bias on the blinding of outcome assessments domain as preventing or delaying entry to residential care is an objective outcome. Unlike a subjective outcome such as self-reported anxiety, where the outcomes assessor is reliant on the carer's assessment and might be influenced by knowledge of treatment allocation, an objective outcome such as residential care placement or mortality is observable by others and unlikely to be influenced by knowledge of treatment allocation.

Table 2.1 **Cochrane risk of bias tool domains**

Biases	*Corresponding risk of bias domains*
Selection bias — Systematic differences in the baseline characteristics of the intervention and control groups.	**Random sequence generation** — Whether the method used to generate the random sequence should produce comparable groups. **Allocation concealment** — Whether the allocation sequence was concealed or could have been foreseen.
Performance bias — Systematic differences in the care received or in exposure to factors other than the intervention.	**Blinding of participants and personnel** — Whether participants or personnel were blinded or knew to which group a participant was allocated.
Detection bias — Systematic differences in how each group's outcomes are determined.	**Blinding of outcome assessment** — Whether people reporting outcomes were blinded or knew to which group a participant was allocated.
Attrition bias — Systematic differences in withdrawals from the study between groups.	**Incomplete outcome data** — Whether the outcome data are complete or, if incomplete, whether attrition was reported on and any methods used to impute data.
Reporting bias — Systematic differences between reported and unreported findings.	**Selective reporting** — Whether outcomes were reported selectively.
All biases	**Other sources of bias** — Any other potential sources of bias.

Source: Higgins and Green (2011).

To assess the risk of bias of studies, the five domains were given a rating of high, low or unclear risk of bias. A domain was assessed as unclear if there was insufficient information to determine if it was at a high or low risk of bias. For example, if a study stated that participants were allocated randomly to the intervention and control groups, but did not state how the random sequence was generated, then the random sequence generation domain was assessed as unclear. Where information was incomplete, other sources were also checked where available, including other journal articles on the same study, and trial registrations and protocols. Studies were judged as having a relatively high risk of bias if there was a high or unclear risk of bias for three or more of the five domains.

It should be noted that the risk of bias tool is not a complete measure of the quality of a study. For example, it captures many risks of bias related to the internal validity of a study — that is, whether the study was conducted well — but it does not cover the external validity of a study — whether the study was asking the right research question and the results can be generalised. A study might be conducted well, but be undertaken on a sample that is very different to the general population of interest. Therefore, the results might provide good evidence about how the intervention affects that sample, but are not generalisable to the actual population of interest.

Two reviewers assessed the risk of bias of each study separately, and then finalised the assessment together, resolving any differences. Once the initial assessments were completed, the assessments were checked to ensure the frameworks were applied consistently across each domain.

2.4 Evidence synthesis

The results of this review were synthesised and discussed using a narrative approach. A meta-analysis was not undertaken due to the heterogeneous nature of the included studies. To determine the effectiveness of studies in preventing or delaying entry to residential care, the different measures of residential care placement and the relevant data were collated, including the:

- proportion of participants in residential care
- time to entry into residential care
- odds of participants having entered residential care or ‘odds ratio’
- likelihood participants will enter residential care or ‘hazard ratio’ (box 2.1).

For each study, an overall assessment of effectiveness was generally made using the odds ratio or hazard ratio. Studies were classified as having a positive (prevented or delayed entry), neutral or negative (did not prevent or delay entry) effect on residential care placement depending on the size of the effect. An odds or hazard ratio of less than 0.9 was positive, between 0.9 and 1.1 was neutral, and greater than 1.1 was negative.

Studies were determined to have had a significant effect on residential care placement if the results were statistically significant at the 5 per cent level.[2] The 5 per cent level was chosen as this was the most consistently reported level across the studies.

Where a study included more than one measure and/or measurement point, the assessment was usually based on the measure that was the best quality and for the longest follow-up period. For example, where a study reported a hazard ratio and an odds ratio, the assessment was generally based on the hazard ratio. This is because a hazard ratio takes into account when a person entered residential care in the measurement period, whereas an odds ratio only takes into account whether they were in residential care at the end of the measurement period. If a study reported results for 12 and 24 months follow-up, the assessment was based on the outcome at 24 months (that is, if a hazard ratio was reported for 12 and 24 months, the 24-month follow-up ratio was used).

Box 2.1 **Measures of effect size — odds and hazard ratios**

Two of the most common measures of the effect sizes in the studies included in this review are odds and hazard ratios.

An odds ratio indicates how much more or less likely an intervention group participant is to be in residential care at a point in time (for example, 12 months after the intervention) compared with a control group participant. In contrast, a hazard ratio compares the probability across the intervention and control groups that a care recipient who is not already in residential care, will enter in the next time period.

In this review, a hazard or odds ratio of less than 0.9 indicates that the intervention was relatively effective in delaying and/or preventing residential care placement.

A key difference between odds and hazard ratios is, while an odds only takes into account whether a participant is in residential care at the end of the measurement period, a hazard ratio also takes into account *when* the person entered residential care.

In the studies in this review, hazard ratios were usually calculated using the Cox Proportional Hazard model. This model includes controls for confounding variables, such as the age and gender of the carer and care recipient, carer relationship, and dementia severity. Hazard ratios should, where possible, be considered in conjunction with other indicators such as average time to residential care placement.

Sources: Berry et al. (2010); Spruance et al. (2004).

In some cases, data included in the studies were incomplete. For example, data on the number of residential care placements were reported but no information on the statistical significance of the result was provided. In contrast, some other studies reported the statistical significance of the result, but underlying data were not provided. Where data were provided, but there was no information on statistical significance, the odds ratio was calculated to help compare the results of studies.

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[2] Statistical significance is a measure of how likely a result is due to the intervention or to chance. Statistically significant at the 5 per cent level means that there is a 95 per cent chance that the result is true and 5 per cent chance that the result is not true and due to chance.

The evidence synthesis focused on the studies rated at a relatively low risk of bias. This was done to reduce the chance that the results presented did not reflect the effectiveness of interventions, but were due to problems with the study design and evaluation of the intervention.

To simplify the presentation of the results, interventions were grouped into categories. As there is no consistent approach to classifying caregiver interventions in the literature (Gaugler et al. 2017), intervention categories were developed for this review. The categories were developed by analysing the information on interventions to identify their key elements. While some interventions were relatively easy to categorise, many were difficult. A lot of the interventions were multicomponent (chapter 3) and, therefore, could be included under multiple categories. Also, in some cases, the author's descriptions of the intervention type and the intervention's components appeared to be inconsistent. Where the category was not clear, or the study could have been included under multiple categories, the decision was based on the author's summary of the type of intervention, the description of the components, how similar interventions were categorised, and classifications used in similar systematic reviews. Further information on the intervention categories is provided in chapter 3.

3 Overview of included studies

This chapter provides an overview of all studies included in this review. Information is provided on the:

- process and results for study selection (section 3.1)
- characteristics of the included studies (section 3.2)
- assessment of the risk of bias of the included studies (section 3.3).

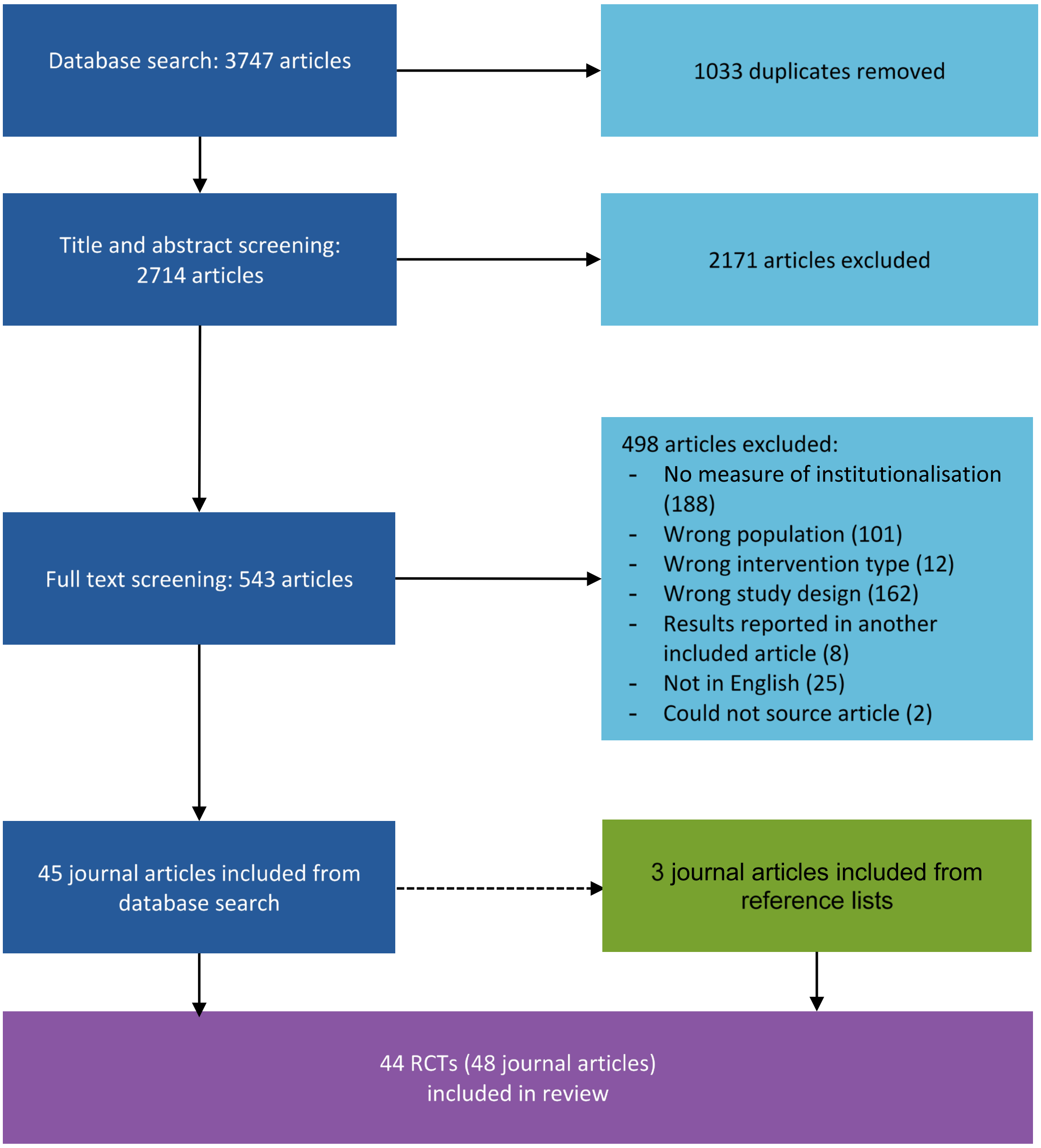
3.1 Study selection

The process for locating eligible studies is outlined in figure 3.1 and chapter 2. The database search of Medline, Ageline and PsycINFO identified 3747 studies. Once duplicates were removed, and titles and abstracts and full texts of studies were screened, 45 journal articles (covering 41 randomised controlled trials (RCTs)) remained. The main reasons studies were screened out at the full text stage included:

- the study did not measure preventing or delaying entry into residential aged care as an outcome
- the intervention was not focused on *carers* of people with *dementia* (for example, the intervention was aimed at the care recipient or the care recipients did not have dementia)
- the study was not a RCT
- the results reported were in another study already included in the review.

Hand searching the reference lists of included studies and checking relevant systematic reviews identified another 3 RCTs. In total, 44 RCTs (48 journal articles) were included in the review (figure 3.1).

Figure 3.1 **Study selection process**



3.2 Characteristics of studies

There is considerable variation in the characteristics of the 44 RCTs.[3] Studies differ by publication date, country of study, intervention type, the duration and intensity of the intervention, and the number and type of participants (appendix B, table B.1).

The publication dates spanned 28 years, from 1989 to 2017. However, most of the studies were published more recently — 80 per cent were published since 2000 and about forty per cent were published since 2010.

Only two studies were conducted in Australia, and one of these was part of a study that spanned three countries (Australia, United Kingdom and the United States). Most other studies were conducted in the United States (18) or Europe/United Kingdom (19), with Canada (3) and Hong Kong (2) accounting for the rest.

A number of RCTs replicated an intervention or part of an intervention in a different country or for a different carer cohort, or with an expanded cohort (appendix B).

Intervention types

As discussed in chapter 2, intervention categories were developed to group studies according to their key components. Studies were grouped into four broad intervention categories: case management (13); education and skills building (18); counselling (11); and respite care (2) (table 3.1). However, many interventions were multicomponent, containing features or activities of more than one of the four intervention types (appendix B, table B.1).

Table 3.1 **Carer interventions**

Intervention type	*Essential characteristics*	*Number*
Case management	Focus is on planning and co-ordinating care to meet the individual needs of the person with dementia and their carer (including taking on the carer's role of coordinating the care for the person with dementia). Usually involves a case manager conducting an individual needs assessment and developing a support plan, and providing education, problem solving, referral to services and/or purchasing services to meet the needs identified in the plan.	13
Education and skills building	Building knowledge about dementia and available resources and help to develop skills to address identified problems, particularly concerning the management of behavioural and psychological symptoms of dementia.	18
Counselling	Emotion-orientated or education-based counselling, including individual, family and group therapy.	11
Respite care	Temporary care services provided to the person with dementia to provide a break for the carer.	2

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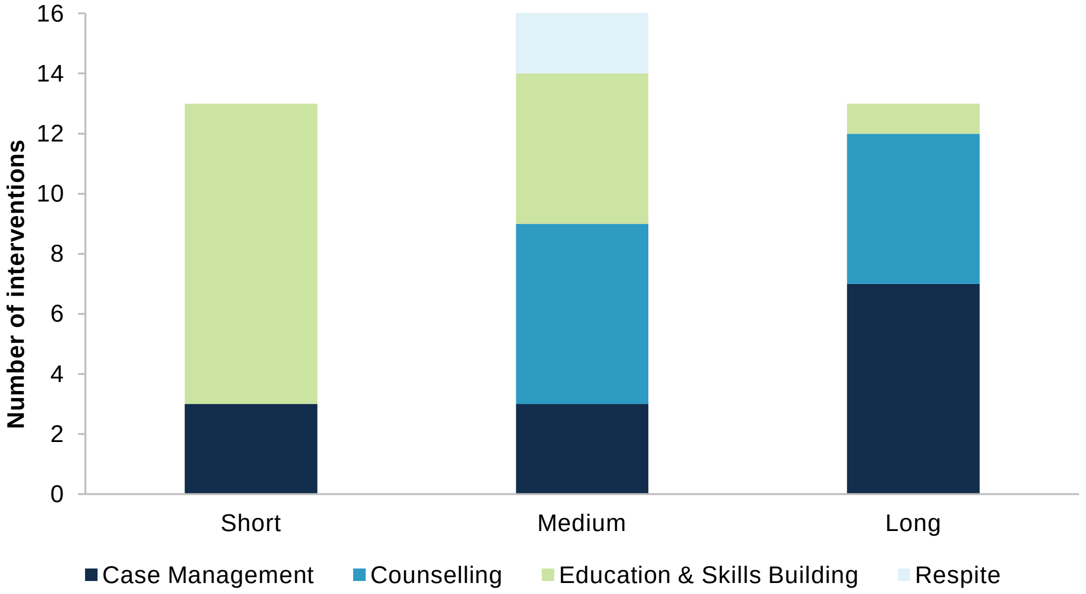
[3] Eight of the RCTs are cluster RCTs (chapter 2).

Other intervention characteristics

About half of the interventions included support for care recipients, as well as carers. Counselling, and education and skills building interventions were more likely to be directed at the carer only. Counselling interventions also often involved other family members. In contrast, case management interventions tended to be directed at both carer and care recipient.

The interventions varied in duration. Thirteen studies were of short duration (up to six months), 16 studies were medium duration (longer than six months and up to 12 months) and the remaining 13 were long (longer than 12 months). Duration also varied by intervention type. Case management and counselling interventions were more likely to be of medium or long duration, whereas education and skills building interventions were more likely to be short. The two respite interventions ran for 12 months (figure 3.2).

Figure 3.2 **Intervention duration**[a]



[a] Two studies did not report the intervention duration.

Source: Appendix B, table B.1.

The intensity of support varied across the studies. However, the most common approach was to start with an initial short period of intense contact, followed by varying amounts that often decreased over time.

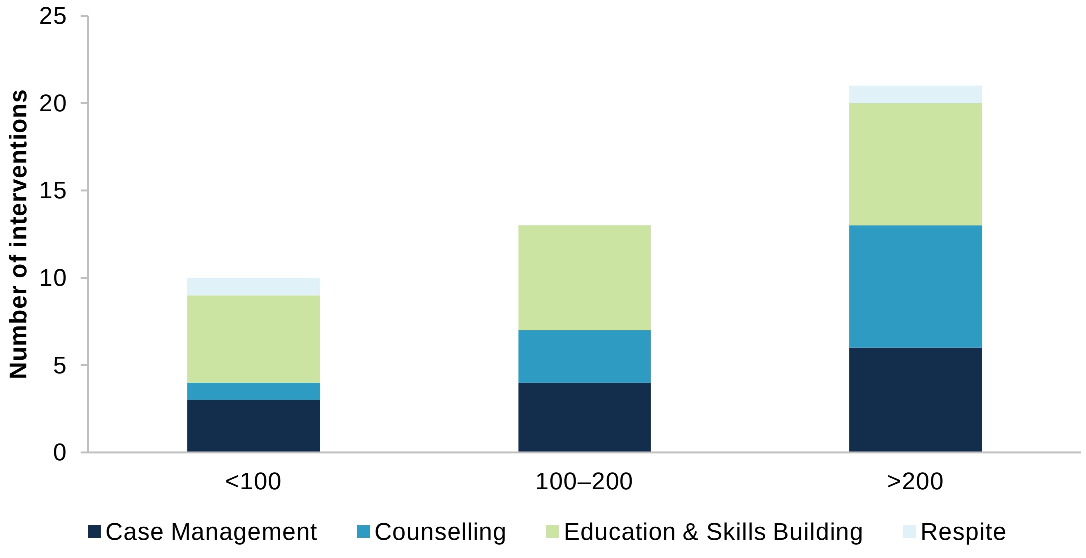
All interventions were delivered by skilled people such as nurses, social workers or occupational therapists or students with training at masters' level or above. The exception was an education and skills building intervention that used trained volunteers (Charlesworth 2008). In three studies (all cluster RCTs) the intervention was the provision of training to skilled professionals to deliver the support (Specht 2009; Spijker 2011; Menn 2012).

Participants in the control groups generally received usual care (that is, the care usually provided to people with dementia in the country of the study) or augmented usual care (which included some additional activities to usual care such as information packages or access to limited respite care). Usual care could include supports to carers similar to those provided under the intervention such as respite care, making it difficult to clearly identify the intervention effect. In some cases, the control group received a similar intervention that differed in mode of delivery or intensity of support.

Participants

Across studies, the number of participants was 17 408 (9135 in the intervention and 8273 in the control groups). The smallest study had 45 participants and the largest had 8095. Over half of all studies (52 per cent) had fewer than 200 participants. Case management and counselling studies had relatively large numbers of participants (figure 3.3).

Figure 3.3 **Participants per study**



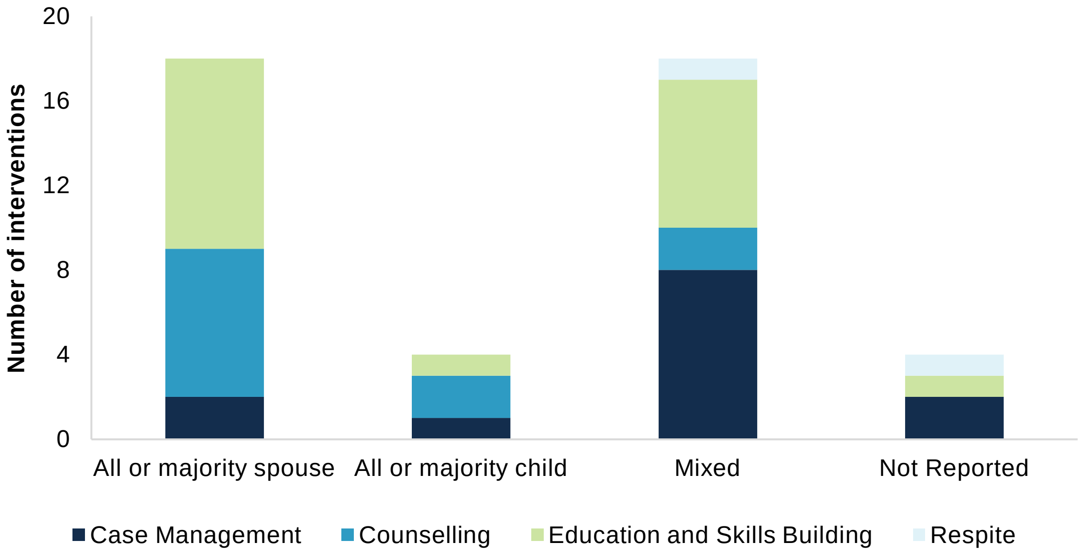
Source: Appendix B, table B.1.

The average age of carers ranged from 44 to 75 years. For studies where an average carer age was reported, over half had carers whose average age fell within the range of 60–70 years. There were no clear differences in the age profile of carers across intervention types.

Carers were more often female than male. For studies where the gender of carers was reported, all had greater female representation (up to 94 per cent).

Most carers in the studies were spouses of the care recipients. In 19 studies the majority of the carers were spouses, and six included only spouse carers. Adult children were the next most common category of carer. Five studies did not provide information on the care relationship (figure 3.4).

Figure 3.4 **Relationship between carer and care recipient**[a,b]



[a] The relationship category of ‘majority’ (spouse or child) was assigned if 60 per cent or more of carers were of that relationship type, or if the margin between the category and the next largest was greater than 20 percentage points. [b] The mixed category applied to studies where there was no dominant carer and care recipient relationship category.

Source: Appendix B, table B.1.

In the studies that measured average dementia severity, most had care recipients with moderate dementia (25 studies). Thirteen studies included care recipients with mild dementia. The remaining studies did not provide information about dementia severity.

3.3 Quality of studies

The risk of bias varied across the RCTs (table 3.2). Of the 48 journal articles (reporting on the 44 RCTs) included in the review, 20 were judged to have a relatively high overall risk of bias, as they had a high or unclear risk of bias for three or more domains (chapter 2). The other 28 studies were assessed as having a relatively low overall risk of bias, and are the studies focused on when analysing and discussing the results (chapter 4).

Risk of bias varied by domain (table 3.2). Studies were more likely to be rated at high or unclear risk of bias on allocation concealment, incomplete outcome data and other sources of bias.

- Allocation concealment — 19 studies were rated as unclear and 10 as high risk. While most studies discussed the randomisation process in some detail, many either did not adequately conceal the allocation process or provide sufficient information to determine whether allocation was concealed.
- Incomplete outcome data — 24 studies were rated as high risk and five as unclear risk. Incomplete outcome data for these studies resulted in high risk of bias because the number of people placed in residential care is small, and therefore, even a small number of missing outcomes can have a substantial effect on the results. For example, if five people in the intervention group were placed in residential care and data were missing for another five people, the actual number of people placed in residential care could have been as high as ten.
- Other sources of bias domains — 31 studies were rated as high risk and four as unclear risk. Most studies were rated at high risk of bias on this domain due to chance baseline imbalance between the treatment and control groups in characteristics that could affect residential care placement, such as dementia severity or carer relationship type. Other reasons studies were rated high risk included differences in timing of data collection for the intervention and control groups, low adherence to the intervention, and clustering not being considered when analysing the results of a cluster RCT.

The risk of bias of studies also varied by intervention type (table 3.2). Most studies in the counselling and education and skills-building categories had a relatively low risk of bias, whereas most of the studies in the case management category and both of the respite studies had a relatively high risk of bias. Risk of bias also differed by publication date, with older studies more likely to be at a relatively high risk of bias.

Table 3.2 **Risk of bias assessment by study**[a]

● indicates a low risk of bias, ■ indicates a high risk of bias and ▲ indicates an unclear risk of bias

Study	*Random sequence generation*	*Allocation concealment*	*Incomplete outcome data*	*Selective reporting*	*Other sources of bias*	***Overall***[b]
Case management						
Callahan 2006	●	●	■	●	■	●
Chien 2008	▲	▲	●	●	▲	■
Chien 2011	●	▲	●	●	●	●
Chodosh 2015	●	▲	■	●	■	■
Chu 2000	■	■	▲	■	■	■
Duru 2009	●	▲	■	●	■	■
Eloniemi-Sulkava 2001	■	●	●	●	■	●
Eloniemi-Sulkava 2009	●	●	●	●	■	●
Miller 1999	▲	▲	■	●	●	■
Samus 2014	●	■	●	●	■	●
Specht 2009	▲	■	■	●	■	■
Thyrian 2017	●	■	■	●	■	■
Weinberger 1993	▲	▲	■	●	■	■
Counselling						
Brodaty 2009	●	▲	●	●	●	●
Bruvik 2013	●	▲	■	●	■	■
Charlesworth 2008	●	●	■	●	●	●
Fortinsky 2009	▲	●	■	●	■	■
Gaugler 2013	●	●	●	●	■	●
Joling 2012	●	●	●	●	■	●
Koivisto 2016	●	●	■	●	●	●
Menn 2012	▲	■	■	●	■	■
Mittelman 1993	●	●	●	●	■	●
Mittelman 1996	●	●	●	●	■	●
Mittelman 2006	●	●	●	●	■	●
Phung 2013	●	●	■	●	●	●
Woods 2012	●	●	■	●	■	●
Education and skills building						
Belle 2006	●	●	■	▲	●	●
Brodaty 1991	■	■	▲	●	▲	■
Brodaty 1993	■	■	▲	●	▲	■
Brodaty 1997	■	■	▲	●	▲	■
Farran 2004	●	■	●	●	●	●
Graff 2008	●	●	■	●	●	●

(continued next page)

Table 3.2 (continued)

Study	*Random sequence generation*	*Allocation concealment*	*Incomplete outcome data*	*Selective reporting*	*Other sources of bias*	***Overall***[b]
Hébert 1995	▲	▲	●	●	●	●
Kunik 2017	●	▲	■	●	●	●
Kurz 2010	▲	▲	▲	●	■	■
Laakkonen 2016	●	●	●	●	■	●
Livingston 2014	●	●	■	●	■	●
Mohide 1990	●	▲	●	●	■	●
Nobili 2004	●	■	■	●	■	■
Spijker 2011	▲	●	●	●	■	●
Teri 2003	●	▲	●	●	■	●
Tremont 2017	●	▲	■	●	●	●
Ulstein 2007	▲	▲	■	●	■	■
Voigt-Radloff 2011	●	●	■	●	■	●
Wray 2010	▲	▲	●	●	●	●
Wright 2001	■	▲	■	●	■	■
Respite						
Engedal 1989	▲	▲	■	●	■	■
Lawton 1989	▲	▲	●	●	■	■

a The blinding of participants and personnel and blinding of outcomes assessor domains are not included given the consistent results across the studies (chapter 2). **b** Studies were judged as having an overall high risk of bias if there was a high or unclear risk of bias for three or more of the five domains.

Sources: Appendix B, table B.1 for included articles references. Additional sources used for risk of bias assessment: ANZCTR (2007, 2011); Bradford et al. (2012); Brodaty and Gresham (1989); Clinicaltrial.gov (2006, 2014, 2015a, 2015c, 2015b, 2016); GCTR (nd); Graff et al. (2006); Hébert (1994); Holle et al. (2009); ISRCTN registry (2011, 2013, 2017); Maayan, Soares-Weiser and Lee (2014); Pimouguet et al. (2010); Reilly et al. (2015); Schulz (nd); Spijker et al. (2009); Tam-Tham et al. (2013); Thyrian et al. (2012); Tremont et al. (2013); Vickrey et al. (2006); Waldemar et al. (2011).

4 Results

This chapter summarises the main results of the review including:

- key results of the studies and how they varied by the type of support they provided (section 4.1)
- what might be driving the results and important caveats (section 4.2).

4.1 What types of interventions were effective?

Of the 44 interventions included in this review, 19 had a positive effect on residential care placement. However, only 7 interventions had a positive and statistically significant effect (appendix B). The interventions that successfully prevented or delayed entry into residential care varied, with no one category of intervention clearly more effective than another.

As discussed in chapter 2, the focus of this chapter is on the 26 interventions in studies rated at a relatively low risk of bias, including:

- 3 interventions that had a positive, statistically significant effect
- 6 interventions that had a positive, but not statistically significant effect
- 8 interventions that had a neutral, but not statistically significant effect
- 1 intervention that had a negative, statistically significant effect
- 5 interventions that had a negative, but not statistically significant effect
- 2 interventions that did not have a statistically significant effect, but the direction of the effect was unclear
- 1 intervention that had a negative effect, but the statistical significance was not reported or able to be calculated (table 4.1).[4]

The results of the interventions in each category are discussed below.

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[4] Chapter 2 provides more information on these categories.

Table 4.1 Effectiveness of studies with a relatively low risk of bias[a,b]

Study	*Effect*	*Study*	*Effect*
Case management			
Chien 2011	✚	Eloniemi-Sulkava 2009	●
Samus 2014	●	Callahan 2006	■
Eloniemi-Sulkava 2001	◘		
Counselling			
Gaugler 2013	✚	Mittelman 1993, 1996, 2006	✚
Brodaty 2009	▲	Charlesworth 2008	▲
Phung 2013	▲	Woods 2012	▲
Joling 2012	■	Koivisto 2016	■
Education and skills building			
Belle 2006	●	Graff 2008	●
Hébert 1995	●	Livingston 2014	●
Kunik 2017	▲	Mohide 1990	▲
Spijker 2011	▲	Teri 2003	▲
Voigt-Radloff 2011	■	Wray 2010	■
Farran 2004	◆	Tremont 2017	◆
Laakkonen 2016	○		

[a] ✚ = positive, statistically significant; ● = positive, not statistically significant; ▲ = neutral effect, not statistically significant; ■ = negative, not statistically significant; ◘ = negative, statistically significant; ◆ = not statistically significant, direction of effect not reported; ○ = negative, statistical significance not reported and unable to be determined. [b] No respite studies were rated at relatively low risk of bias.

Source: Appendix B, table B.2.

Case management

The effectiveness of the case management studies rated at a relatively low risk of bias was mixed. Three interventions had a positive effect on residential care placement (one was statistically significant) and two had a negative effect (table 4.2).

The three interventions that had a positive effect were either primarily focused on delaying entry to residential care, or the study authors hypothesised that the intervention would delay residential care placement. They also had similar features, including a case manager who undertook a comprehensive needs assessment and identified the individually tailored support needed. However, the exact role of the case manager in meeting clients’ needs varied. In Chien and Lee (2011), the case manager worked directly with the families providing education and support services. Under the approach taken by Samus et al. (2014) and Eloniemi-Sulkava et al. (2009), the case manager had a coordinating role and referred participants to external services, rather than providing direct support.

Table 4.2 **Effectiveness of case management interventions**[a]

Study	*Measure*	*Follow-up period*	*Result*	*P-value or confidence interval*[b]	*Effect*
Chien 2011	Mean difference in institutionalisation	18 months	-3.4	P = 0.001	✚
Eloniemi-Sulkava 2009	Hazard ratio	Up to 24 months	0.53	(0.23, 1.19)	●
Samus 2014[c]	Odds ratio	18 months	0.78	(0.45, 1.35)	●
Callahan 2006[c]	Odds ratio	18 months	1.16	(0.35, 3.84)	■
Eloniemi-Sulkava 2001	Hazard ratio	Up to 24 months	1.18	(1.02, 1.4)	▣

[a] ✚ = positive, statistically significant; ● = positive, not statistically significant; ■ = negative, not statistically significant; ▣ = negative, statistically significant. [b] 95 per cent confidence interval. [c] Odds ratio calculated by review authors.

Source: Appendix B, table B.2.

The intervention with a statistically significant positive effect was implemented in Hong Kong (Chien and Lee 2011). This program extended the time intervention group participants spent in the community in the 18-month follow-up period. However, the measurement of ‘entry into residential care’ differed to that used in most other studies, with the results expressed as the average number and duration of residential placements or hospitalisations over the past six months. This limits the comparability of these results to those of other studies in this review.

Another study tested a case management intervention in Finland (Eloniemi-Sulkava et al. 2009). Over the 24-month follow-up period, care recipients in the intervention group were less likely to enter residential care than those in the control group (adjusted hazard ratio of 0.53); however, the difference was not significant. The results indicated that it took time for the intervention to take effect, with the gap between the intervention and control group in the proportion of care recipients admitted to residential care increasing over time and peaking at about 18 months. At that time, there was a 15 percentage point difference between the groups. By 24 months, the gap had narrowed to just 4 percentage points.

In contrast, Samus et al. (2014) found that a case management intervention implemented in the United States was most effective in the first 12 months. At nine months the gap between the intervention and control group in the proportion admitted to residential care was 7 percentage points, compared with about 5 percentage points at 18 months. However, the result was not statistically significant at either point in time. Samus et al. (2014) found that the intervention did have a statistically significant effect when residential care placements and deaths were combined. The intervention decreased the likelihood of leaving home over the 18-month period by about 40 per cent, extending the average time in the community by 51 days. No other studies reported results combining residential care placements and deaths.

That said, another case management intervention with the features described above had a negative effect. Eloniemi-Sulkava (2001) reported on a intervention similar to Eloniemi-Sulkava (2009), and found that, over the 24-month follow-up period, care recipients in the intervention group were significantly more likely to enter residential care than those in the control group (adjusted hazard ratio of 1.18). However, similar to Eloniemi-Sulkava (2009) and Samus et al. (2014), the authors found that the effectiveness of the intervention did vary over the 24 month period, as earlier in this period the effect was positive and significant.

The other intervention with a negative (but, in this case, not significant) effect on residential care placement also involved a case manager undertaking a needs assessment, but the nature of the intervention reflected its primary focus on improving the neuropsychiatric symptoms of dementia (Callahan et al. 2006). The needs assessment and support provided were directed at helping carers to manage the behavioural symptoms of the person with dementia, with little focus on the broader needs of the carer. At 18 months, care recipients in the control group were less likely to be in residential care than the intervention group (7.2 per cent compared to 8.3 per cent).

Counselling

Interventions that focused primarily on counselling also had mixed effects on residential care placement. Of the eight counselling interventions rated at a relatively low risk of bias, two had a positive effect, four had no effect and two had a negative effect (table 4.3).

Four of the counselling interventions were very similar — the New York University Caregiver Intervention (NYUCI) and three interventions that replicated this study. The NYUCI included individually tailored counselling and support for spouses of people with Alzheimer’s disease that aimed to improve carer wellbeing while preventing or delaying entry into residential care. It included:

- six counselling sessions — two with the carer, and four with the carer and at least one other family member — within four months of enrolment in the intervention
- ad hoc telephone counselling as needed on an ongoing basis
- a requirement to join a support group, which could also be used as needed on an ongoing basis.

Evaluations of the original NYUCI showed it significantly delayed entry into residential aged care.

- Mittelman et al. (1993) found that care recipients in the control group were 60 per cent less likely to be in residential care than care recipients in the control group after 12 months.

- Mittelman et al. (1996) found this effect had continued up to eight years after the intervention and that carers in the intervention group were significantly less likely than carers in the control group to place their relative in residential care. This translated into an increase in the time until entry into residential care of 329 days.
- Mittelman et al. (2006b) reported that the intervention continued to be effective for up to at least ten years after the initial intervention. The intervention increased the median time to residential care placement by 557 days.

Table 4.3 Effectiveness of counselling interventions[a]

Study	*Measure*	*Follow-up period*	*Result*	*P-value or confidence interval*[b]	*Effect*
Gaugler 2013	Hazard ratio	Up to 3.5 years	0.53	(0.28, 0.99)	✚
	Time to residential care	Up to 3.5 years	I=971.6 days C=743.24 days	P < 0.05	✚
Mittelman 1993, 1996, 2006	Odds ratio	At 12 months	0.4	P < 0.05	✚
	Hazard ratio	Up to 8 years[c]	0.65	(0.45, 0.94)	✚
	Difference in median time to residential care	Up to 8 years[c]	329 days	(47, 611)	✚
	Hazard ratio	Up to 10 years[c]	0.72	P = 0.025	✚
	Difference in median time to residential care	Up to 10 years[c]	557 days	**na**	**na**
Brodaty 2009	Hazard ratio	Up to 8.5 years	1.06	P = 0.835	▲
	Time to residential care	Up to 8.5 years	I=4.1 years C=4.3 years	P = 0.998	●
Charlesworth 2008	Odds ratio	Up to 24 months	1.05	P = 0.911	▲
Phung 2013	Hazard ratio	Up to 18 months	0.97	(0.64, 1.47)	▲
Woods 2012	Mean nights in residential care	At 10 months	I=0 nights C=0 nights	**na**	▲
Joling 2012	Hazard ratio	Up to 18 months	1.46	(0.78, 2.74)	■
Koivisto 2016	Hazard ratio	Up to 36 months	1.3	(0.69, 2.45)	■

[a] ✚ = positive, statistically significant; ● = positive, not statistically significant; ▲ = neutral effect, not statistically significant; ■ = negative, not statistically significant. [b] 95 per cent confidence interval. [c] Not all participants were in the study for the full 8 or 10 years. **na** Not available.

Source: Appendix B, table B.2.

However, the NYUCI has been replicated with mixed success, and no studies have matched the effectiveness of the original. The Three Country Study replicated the original study in Australia, the United Kingdom and the United States (Brodaty et al. 2009). The authors found that, after up to 8.5 years follow-up, there was no difference between the intervention and control groups in the time until residential care placement (adjusted hazard ratio of 1.06). While not effective when the results for the three countries are combined, in Australia there was a positive and statistically significant difference between the intervention and control groups in the proportion of care recipients placed in residential care (50 per cent versus 77 per cent). However, this result should be treated with caution, as the baseline characteristics between the treatment and control group in Australia were not reported and the result was not adjusted for any potential differences in characteristics between the treatment and control groups that could affect residential care placement. In addition, the sample size in Australia was relatively small.

There were some differences between the Three Country Study and the earlier NYUCI. The Three Country Study:

- included three family counselling sessions instead of four
- provided ad hoc telephone counselling for two years instead of on an ongoing basis, and some Australian participants had face-to-face ad hoc counselling instead of over the phone
- included participants whose dementia was less severe on average
- was conducted a decade later, and the context and policy settings might have changed in that time.

An adaption of the NYUCI with adult child carers instead of spouses was tested in Minnesota, United States with some success. After up to 3.5 years follow-up, Gaugler, Reese and Mittelman (2013) found that parents of carers in the intervention group were 47 per cent less likely to be in residential care, and stayed in the community for 228 days longer on average, than parents in the control group. Again, there were some differences compared to the original intervention, in addition to the focus on adult child carers. A much higher proportion of the carers were women (94 per cent compared with 66 per cent), and the split between individual and family counselling sessions varied depending on the preferences of the carer (Gaugler, Reese and Mittelman 2013; Mittelman et al. 2006b).

Another study partially replicated the NYUCI in the Netherlands, but it was not successful (Joling et al. 2012). This intervention included the six individual and family counselling sessions, but not the requirement to join a carer support group or ad hoc counselling support. After 18 months, a higher proportion of care recipients in the intervention group had entered residential care than in the control group (24.0 per cent versus 18.8 per cent). This resulted in an adjusted hazard ratio of 1.46, meaning that intervention group participants were more likely to enter residential care. However, this result was not statistically significant. In addition to the lack of support group participation and ad hoc support, Joling et al. (2012) also reported that adherence to the intervention was low. However, Mittelman et al. (1993, 1996, 2006b) did not report on adherence to the original intervention; therefore, whether and how adherence differed across the two interventions is unknown.

None of the other counselling interventions had a positive or significant effect on residential care placement. Two interventions have similarities to the NYUCI, and included education, counselling and support groups.

- The Kuopio ALSOVA study aimed to delay residential care placement (Koivisto et al. 2016). After 36 months, a higher proportion of care recipients in the intervention group were in residential care (21 per cent versus 16 per cent), but the hazard ratio did not differ significantly across the 36-month period.
- The Danish Alzheimer Intervention Study aimed to improve carers' and care recipients' quality of life, stabilise care recipients' cognitive function and delay residential care placement (Phung et al. 2013). After 36 months, there was no real difference between the intervention and control groups in the rate of, or time to, placement.

The remaining interventions categorised as counselling, were quite different from the others in the types of support provided.

- In the Befriending and Costs of Caring Intervention, volunteers were trained to 'befriend' carers to provide emotional and social support. This intervention had no significant effect on residential care placement at 24 months follow-up (Charlesworth et al. 2008).
- In the REMCARE intervention, carers and care recipients attended reminiscence groups. After ten months the intervention had no effect on the number of nights spent in nursing homes, as no participants in either group spent any nights in nursing homes (Woods et al. 2012).

Education and skills building

Most of the interventions classified as education and skills building had a positive or neutral effect on residential care placement, but no studies had a significant effect (table 4.4).

All four interventions with a positive (but not statistically significant) effect focused on improving the wellbeing of the carer (such as by building resilience) and interactions between the carer and care recipient (such as through behavioural management). One of these interventions provided ten sessions of occupational therapy in the Netherlands (Graff et al. 2008). After three months, a higher proportion of care recipients in the control group were in residential care.

Another intervention — the Resources for Enhancing Alzheimer's Caregiver Health II (REACH) intervention — provided education and support to build skills and manage stress. Belle et al. (2006) reported that, after six months, care recipients in the intervention group were 42 per cent less likely to be in residential care than care recipients in the control group.

Hébert et al. (1995) found that, in a support group program focused on information on dementia, dealing with behavioural and emotional problems, and relaxation techniques, 33 per cent of care recipients in the intervention group were in residential care compared with 45 per cent in the control group after 24 months. Finally, Livingston et al. (2014) found that an intervention aimed at improving carers' understanding of dementia, ability to cope and manage problem behaviours resulted in a 17 per cent reduction in the likelihood of the care recipient being in residential care at 24 months follow-up.

However, not all the education and skills-building interventions that focused on carer wellbeing and interactions between the carer and care recipient had a positive effect. For example, the occupational therapy intervention discussed above (Graff et al. 2008) was replicated in Germany (Voigt-Radloff et al. 2011). After 12 months, two care recipients in the intervention group were in residential care, compared with one participant in the control group. However, these results should be treated with caution, as the small number of residential care placements and the relatively small sample (141 participants) meant this study had insufficient power to determine the true effect.[5]

Table 4.4 **Effectiveness of education and skills-building interventions[a]**

Study	*Measure*	*Follow-up period*	*Result*	*P-value or confidence interval[b]*	*Effect*
Belle 2006[c]	Odds ratio	At 6 months	0.58	(0.29, 1.15)	●
Graff 2008[c]	Odds ratio	At 3 months	0.61	(0.21, 1.83)	●
Hébert 1995[c]	Odds ratio	At 24 months	0.55	(0.16, 1.84)	●
Livingston 2014	Hazard ratio	Up to 24 months	0.83	(0.44, 1.56)	●
Kunik 2017[c]	Odds ratio	At 12 months	0.98	(0.54, 1.79)	▲
Mohide 1990[c]	Odds ratio	At 12–18 months[d]	1.00	(0.35, 2.86)	▲
Spijker 2011	Hazard ratio	Up to 12 months	0.93	(0.57, 1.53)	▲
	Time to residential care	Up to 12 months	I=307 days C=300 days	P = 0.87	▲
Teri 2003[c]	Odds ratio	At 24 months	0.95	(0.47, 1.93)	▲
Voigt-Radloff 2011[c]	Odds ratio	At 12 months	2.00	(0.18, 22.57)	■
Wray 2010	Average number of residential care placements	At 12 months	I=0.2[e] C=0.1	P > 0.05	■
Farran 2004	Time to residential care	At 18 months	**na**	P > 0.75	◆
Tremont 2017	Proportion institutionalised	At 6 months	**na**	P = 0.7	◆
Laakkonen 2016	Days in residential care	At 24 months	I=626 days C=151 days	**na**	○

[a] ● = positive, not statistically significant; ▲ = neutral effect, not statistically significant; ■ = negative, not statistically significant; ◆ = not statistically significant, direction of effect not reported; ○ = negative, statistical significance not reported and unable to be determined. [b] 95 per cent confidence interval. [c] Odds ratio calculated by review authors. [d] The follow-up measurement period varied by participant. [e] Per person. **na** Not available.

Source: Appendix B, table B.2.

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[5] RCT power is its ability to detect a difference in effect between the treatment and control group. The power of a study is determined by several factors, including the frequency of the outcome, the magnitude of the effect, the study design, and the sample size (Akobeng 2005).

In addition, Mohide et al. (1990) found that a carer support intervention had no effect on the proportion of care recipients in residential care after 18 months. Laakkonen (2016) reported on a group self-management intervention that provided information and support with the aim of improving problem solving skills and self-efficacy. In the 24-month follow-up period, the intervention group had spent 626 days in nursing homes compared with 151 days for the control group. However, the statistical significance of this result was not reported. As well, the Systematic Care Program for Dementia intervention, which trained health care professionals to assess carers' sense of competence and depressive symptoms and organise support for the carer based on their needs, had no significant effect (hazard ratio of 0.93) (Spijker et al. 2011).

Delivering education and skills-building interventions solely over the phone was not a successful strategy for preventing or delaying entry to residential care. Neither telephone-only interventions — the Telehealth Education Program and the FITT-C — had a statistically significant on residential care placement after six months (Tremont et al. 2017; Wray et al. 2010).

In addition, the three education and skills-building interventions that focused primarily on behavioural management rather than carer wellbeing did not prevent residential care placement.

- Farran et al. (2004) reported on the results of an intervention that aimed to determine whether traditional psychoeducation with information support or more practical support designed to improve carers' skills in managing behavioural symptoms was more effective at reducing carer stress. There was no significant difference in the time to entry into residential care between the groups up to 18 months later.
- The Preventing Aggression in Veterans with Dementia intervention, which focused on aggressive behaviours due to pain, had no significant effect on residential care placement after 12 months (Kunik et al. 2017).
- The Reducing Disability in Alzheimer Disease intervention, which provided an exercise program for care recipients and training to carers in behavioural management techniques had no effect on residential care placement at 24 months (Teri et al. 2003).

4.2 What are the key findings?

Interventions that support carers of older people with dementia show limited effectiveness in preventing or delaying older people's entry into residential aged care. Of the 26 interventions rated at a relatively low risk of bias studies, only nine reported a positive effect and only three of these had a statistically significant effect.

Of the three interventions that had a significant effect, one was a case management intervention in Hong Kong that extended the time participants spent in the community by reducing the number and duration of stays in residential care or hospital (Chien and Lee 2011). However, the outcome in this study was different from the residential care outcomes measured in most of the other studies included in this review, where the focus was on permanent entry into residential care. Also, the residential aged care system in Hong Kong is quite different to the systems in Australia and other countries covered in this review, as there are relatively few residential care facilities in Hong Kong compared with Western countries such as Australia.

Two other case management interventions had a positive, but not significant effect. These interventions had a similar focus and objective, to prevent or delay entry to residential care, to the study by Chien et al. (2011). However, the role of the case manager was different. In Eloniemi-Sulkava et al. (2009) and Samus et al. (2014), the case manager played a coordination role and referred participants to services, whereas in Chien et al. (2011), the case manager provided education and support services directly.

The two other interventions that had a significant effect on residential care placement were counselling interventions — the original NYUCI and a replication of it implemented in Minnesota. The NYUCI was found to delay entry into residential aged care for at least ten years on average after enrolment in the study (Mittelman et al. 2006b). The adaptation resulted in an average delay in residential care placement of 228 days in the 3.5-year follow-up period (Gaugler, Reese and Mittelman 2013). However, other replications have not been successful, including the Three Country Study, which had no effect overall for the three countries combined on the rate of entry into residential care in the up to 8.5-year follow-up period (Brodaty et al. 2009).

There were differences between the NYUCI and the adaptations that could at least partially explain the results. For example, the adaptation implemented in Finland, which had the most unfavourable outcome, did not include ad hoc counselling or support group participation. In addition, the Three Country Study provided ad hoc telephone counselling for two years rather than on an ongoing basis.

Four of the education and skills-building interventions had a positive (but not significant) effect on residential care placement. These interventions focused on improving the wellbeing of the carer and the interactions between the carer and care recipient. However, other education and skills-building interventions that also focused on these elements did not have a positive effect.

Overall, why some interventions had a positive and significant effect on residential care placement and others did not is unclear. The multicomponent nature of the interventions makes it hard to isolate the characteristics of the interventions that influenced residential care placement. In addition, many of the components in effective interventions also existed in interventions that were not effective.

Context could be an important factor. For example, the NYUCI intervention might have been more effective than later replications in different places due to the policy settings and standard services provided in each place and point in time. This might also be the case for the Three Country Study, which was more effective in Australia (albeit with caveats) than in the United Kingdom and the United States.

In addition, factors other than the intervention type and the main intervention components could have influenced effectiveness, including:

- the quality of its implementation, for example, whether or not carers attended all of the counselling sessions or the staff delivered the intervention as intended (Boersma et al. 2015; Burgio et al. 2001)
- other factors related to the intervention such as the duration or intensity of the intervention, when the outcomes were measured, what the control group received (for example, usual care or another type of support), and the education and skills of the staff implementing the intervention
- the characteristics of the participants themselves, such as carer and care recipient age and gender, the severity of the care recipient's dementia, the health of the carer, and the relationship between the carer and care recipient, all of which can affect residential care placement (Gaugler et al. 2003, 2009; Smith et al. 2001; Yaffe et al. 2002)
- the quality of the study design and evaluation, as a poorly designed or implemented evaluation could bias the results of the study. While the review focused on studies rated at a relatively low risk of bias, some of these studies still had other issues, such as imprecise estimates due to relatively small sample sizes and low numbers of residential care placements.

This review briefly explored the relationships between the duration of the intervention, when the outcomes were measured, and a range of carer and care recipient characteristics by plotting these against the odds ratios. No clear patterns were identified (appendix B, figures B.1–3). More rigorous statistical analysis of these relationships was not possible given the timeframes for this rapid review.

All this said, it is important to recognise that even though most of the interventions included in this review were not found to be effective in preventing or delaying entry into residential care, they might have a positive effect on carers in other ways, such as decreasing burden. This idea, and its implications for policy and practice, are discussed in more detail in chapter 5.

How do these results compare to other reviews?

Other reviews that examined the effectiveness of interventions that support carers of people with dementia have generally found that these interventions have a small, positive effect on preventing or delaying residential care placement. However, similar to what this current review found, the evidence on whether this effect is statistically significant is mixed.

A number of reviews looked at the effectiveness of case management in particular. Reilly et al. (2015) undertook a Cochrane review and meta-analysis, pooling the results of 14 RCTs. The authors found that case management had a small, but statistically significant, effect on institutionalisation at 6 and 18 months, but no significant effect at 10–12 months or 24 months. However, they also noted that the quality of the evidence was low.

Another two meta-analyses (Backhouse et al. 2017; Tam-Tham et al. 2013), which had significant overlap in included studies with Reilly et al. (2015), found no overall significant effect. However, Tam-Tham (2013) did find a small, positive and significant effect when the follow-up duration was restricted to 18 months. Pimouguet et al. (2010) completed a systematic review of case management interventions and concluded that four of the six included high-quality RCTs had a positive effect on reducing the risk of residential care placement. However, this effect was not statistically significant in all cases.

Other systematic reviews looked at a broader range of interventions. Olazarán et al. (2010) reviewed non-pharmacological interventions. They undertook a meta-analysis of three interventions and found that these interventions prevented or delayed residential care placement (this result was statistically significant). However, this result should be interpreted with caution. It is based on three interventions with quite different characteristics (education and skills building, counselling and respite) and one of the studies (Lawton, Brody and Saperstein 1989) was rated in the current review as having a relatively high risk of bias.

In addition, Van’t Leven (2013) reviewed interventions that included support for both carers and care recipients and found that, out of seven studies that measured the effect of the intervention on residential care placement, five had a positive and significant effect. Another systematic review of interventions for carers found mixed evidence on effectiveness (Peacock and Forbes 2003).

Systematic reviews that included non-randomised studies (outside the scope of this review), as well as RCTs, also reported inconsistent findings. Brodaty et al. (2003) undertook a systematic review of psychosocial interventions for carers of people with dementia. They found that two of the seven included studies had a statistically significant effect. Spijker et al. (2008b) conducted a meta-analysis on the effect of non-pharmacological interventions. The authors found these interventions delayed residential care placement; however, the effect was not statistically significant when only high-quality studies were included in the analysis. Pinquart and Sörensen (2006) also completed a meta-analysis of carer interventions and found a small, positive but not significant effect on residential care placement. That said, the effect was statistically significant when the analysis was restricted to multicomponent interventions.

5 Implications and conclusion

Interventions that support carers of older people with dementia show limited effectiveness in preventing or delaying entry into residential aged care, though two counselling interventions showed promise (chapter 4). In light of these findings, this chapter includes:

- the implications of this review for
  - policy makers (section 5.1)
  - researchers in this field (section 5.2)
- the strengths and limitations of this review (section 5.3).

5.1 Implications for policy makers

Based on current evidence, interventions to support carers of older people with dementia show limited effectiveness in preventing or delaying entry into residential care (chapter 4).

This limited effectiveness might be explained by a number of factors. It may be due to the research studies themselves — including the features and characteristics of the interventions. Or, it may be due to the context in which the interventions were conducted. For example, ease of access to local residential care facilities would be a key factor influencing residential care entry or placement. On the other hand, limited effectiveness may be due to the characteristics of the study participants. An ineffective intervention involving participants with a particular set of characteristics may be effective with a different set of participants. For example, an intervention found to be ineffective for carers of people with severe dementia, may prove to be effective for carers of people with mild dementia.

In addition, the lack of evidence on effectiveness may be due to the complexities of the challenge at hand. The causes leading to an older person entering residential aged care are multifaceted, and isolating those causes amenable to change and intervening successfully is difficult.

The effective interventions identified in this review were in the categories of case management and counselling (chapter 4). However, context — in relation to place and time — is important when interpreting results. Understanding cultural ‘norms’ and policy settings, such as the ‘usual care’ available to carers, is necessary to determine if the results are transferable. The successful case management intervention was conducted in Hong Kong where the cultural context, and aged care system, are substantively different to those in Australia. Therefore, the results of the study are likely to have limited transferability to the Australian context.

The New York University Caregiver Intervention (NYUCI) and one of its adaptations, featuring individually tailored counselling and support, showed the most promise. However, other adaptations of this intervention were not effective and therefore the overall evidence of effectiveness for this approach is inconclusive.

Given that the evidence is inconclusive, adoption of this intervention in the current Australian context may not be warranted. But there may be value in further testing. An adaptation of the NYUCI (counselling) previously had some success in the Australian context, but there were important caveats related to this success (chapter 4). In addition, this trial was conducted in the late 1990s and since then the Australian aged care sector has experienced significant reforms, so these results may no longer apply (appendix A).

While the evidence of effectiveness is limited, all interventions still need to be considered using a broader cost–benefit framework, both when thinking about further research and policy options. An intervention that is found to be effective (statistically significant) may not be worthwhile if the effect size is small and the intervention costly. If multiple interventions generate the same possible benefits, all other things being equal, a low-cost intervention is preferred. Likewise, if interventions show equal likelihood of generating benefits and the cost is similar, the intervention with the largest effect size (benefit) is preferred (PC 2010).

Notably, though an intervention with a large positive effect that is statistically insignificant (at the 95 per cent confidence level) is assessed here as ineffective, it does not follow that it should be automatically disregarded. This review uses the 95 per cent confidence interval as its threshold to assess effectiveness[6] as it provides policy makers with a high degree of certainty that the intervention will or will not work. However, if the positive effect size of an 'ineffective' intervention is large, policy makers could be justified in accepting a lower degree of certainty (for example, at the 80 per cent confidence level). That is, policy makers may be willing to take a greater risk of the intervention having no effect for the potential larger benefit (this will particularly be the case if the cost of the intervention is low). One example from this review is Belle (2006) that had an large effect size (odds ratio of 0.53), and would be considered effective if the assessment was at the 80 per cent confidence level.

Where evidence is limited, and benefits are uncertain, a cautious approach to practice design and implementation is required. Where programs are developed and rolled out, this should be done gradually, based on thorough detailing of the practice, with a focus on continual evidence gathering, evaluation and adjustment (Banks 2009).

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[6] The 95 per cent confidence level was chosen as it is one of the more commonly used (SCRGSP 2018) and is also consistent with the approach in nearly all the academic literature from which the studies were accessed.

The limited evidence of effectiveness found in this review also suggests that other options to prevent or delay the entry of older people with dementia into residential aged care need to be explored or continued. Interventions that seek to reduce risk and delay the progression of dementia, as well as research to improve prevention and find effective treatments and cures, for example, may be more fruitful avenues.

However, the finding of limited effectiveness of these carer interventions to prevent or delay entry to residential aged care does not suggest that dementia-related funding for carer services, resources and research should be reduced.

The gaps in the research are various. For example, evidence for some of the carer support services commonly provided in Australia was not available. In particular, studies of respite services (any service that provides a break in the caring role) comprised only a small number of the included studies (both of which were relatively low quality) in this review. No studies were identified that tested the effectiveness of providing carers with financial support.

Moreover, the methodological and reporting weaknesses of many studies limited the number and range of intervention evidence available for this review (chapter 3 and section 5.2). This highlights the importance of continued funding for high-quality dementia research on carers.

Further, more experimentation may be required. If limited evidence of effectiveness reflects the complexity of factors leading to a person with dementia entering residential care, further research into more comprehensive or better targeted interventions is desirable.

Perhaps more significantly, supporting carers of people with dementia may have important benefits beyond keeping the person with dementia at home. This is reflected in the numerous government funded initiatives that seek to address the needs of carers (appendix A). Caring itself can have a negative impact on carer physical and mental health, and this can be especially so for those who provide a high intensity of care (OECD 2018; Zwart et al. 2017). These challenges are likely to become more complex as the carer demographic ages (section 3.2). Research also points to a link between modifiable risk factors, such as physical inactivity — which for carers might be compromised by their caring role, and ill health (AIHW 2018; DCRC 2010). Services and resources that support carers can offset some of these negative effects, improve carer quality of life and perhaps reduce carers' own health risks (Cooper et al. 2012; Kishita et al. 2018; Van't Leven et al. 2013).

5.2 Implications for researchers in this field

The quality of the research about the effectiveness of interventions that support carers of people with dementia has improved over time (chapter 3). Notwithstanding this, there are areas for further advancement that would enable more effective synthesis of evidence in this field in future, particularly in the area of reporting.

First, improved descriptions of interventions is required. In many studies the content and process of the intervention, and information on implementation, was not readily available or was difficult to understand. This may simply reflect poor-quality reporting practice, or it may reflect poor quality interventions (including intervention implementation). Poor descriptions can limit the synthesis of evidence, as well as the replicability of interventions for continued evidence gathering. Other similar reviews have highlighted this issue (Bourgeois and Schulz 1996; Cooke et al. 2001; Selwood et al. 2007).

Second, improved reporting about study conduct is desirable. For example, a number of studies fail to adequately detail how randomisation was achieved and the method employed for concealing the randomisation sequence. Other similar reviews have highlighted this issue, for example Thompson et al. (2007). Where such details were unclear, the overall risk of bias assessment might have been affected.

Third, reporting on outcome measures varied and, in general, reporting in this area could be improved. (For example, Dixon, Karagiannidou and Knapp (2018) found limited discussion about the choice of outcome measures.) While some studies reported high-quality measures such as adjusted hazard ratios that accounted for differences across the treatment and controls group in important characteristics such as severity of dementia and age of carers, other studies did not. For example, some studies noted the difference between the treatment and control was not statistically significant, but did not provide any further information such as the direction (negative or positive) or size of the effect.

The limitations of current reporting practices are further compounded by publication bias — a reluctance to publish or report results that are negative, introducing bias into meta-analyses of published studies (for example, Reilly et al. (2015)).

5.3 Strengths and limitations of this review

This review had a number of strengths and limitations that should be noted when considering the results.

A key strength of this review is its ‘rapid evidence assessment’ approach — a rapid evidence assessment is more rigorous than many other types of literature summaries, such as a standard literature review. This review used a systematic, transparent and therefore replicable approach to identify studies, extract data, assess quality and report on results.

Rapid evidence assessments aim to balance rigour and timeliness, and ‘shortcuts’ are implemented that can bias the results. For this review, the shortcuts taken included:

- searching only three databases — Medline, Ageline and PsycINFO — for relevant studies. As a result, articles in journals that are not indexed in these databases were not located in the initial search. To reduce the chance of studies being missed, reference lists of included studies and similar systematic reviews were also searched.
- applying restrictions to the type of study that would be included. Studies had to be published in peer-reviewed journals, and grey literature such as book chapters and government publications was excluded. Therefore, interventions not published because they had less promising results would have been missed. Moreover, only studies in English were included, therefore excluding otherwise relevant interventions published in another language.

In addition to the strengths and limitations of the rapid evidence assessment process, the review team did not have prior expertise in conducting rapid evidence assessments, or the subject area. To account for this, consultants with expertise in rapid evidence assessments, and the subject area provided advice and guidance. On the other hand, the lack of prior experience of the review team could also be a strength of this review, as the team members were not biased by any preconceived notions or past experiences.

Another limitation was the search string used to search the three databases. For many reviews, a librarian generally constructs the search string with input from the subject area experts working on the review. For this review, the search string was developed by the review team who did not have expertise in searching databases. To mitigate the risk that some relevant studies might have been missed and to provide quality assurance, the search string was tested extensively.

Originally, it was planned that this review would assess interventions aimed at carers of all older people. However, once the initial search was conducted it became clear that the studies that would be included were too numerous, given time constraints. The scope was limited to carers of people with dementia, to ensure the task was manageable and the question being answered remained policy relevant (chapter 1).

As the database search had already been conducted when this decision was made, this change could have biased the review, as the search string might have been different if the review was limited to dementia from the start. However, the search string already included two dementia-related terms. In addition, testing was undertaken using two of the databases to determine if including additional dementia-related terms would have resulted in more relevant studies being identified, and this was found not to be the case.

A Dementia policy, programs and services

This appendix provides information on:

- the development of the current policy focus on dementia (A.1)
- dementia programs and services funded by Australian governments (A2).

A.1 Policy focus on dementia

Dementia was formally added to Australia’s health priority areas in 2012, reflecting its importance and following a period of mounting policy focus. This increased focus on dementia emerged from a period of increasing awareness and advocacy (box A.1).

Signifying the nation’s continuing focus on dementia is the *National Framework for Action on Dementia 2015–2019*. It guides the development and implementation of actions, plans and policies to reduce the risk of dementia and improve the outcomes for people with dementia and their carers. Among its seven priority areas for action are awareness and risk reduction, timely diagnosis, and accessing care and support, both post-diagnosis and ongoing (AHMAC 2015).

The National Framework for Action on Dementia recognises the vital role performed by informal carers. It also recognises that living at home — when aligned with the preferences of people with dementia and their carers and family — can improve health outcomes and reduce healthcare costs. It has joint endorsement from state and territory health ministers, and some state and territories programs target dementia.

The current policy focus on dementia is reflected in the numerous Australian Government programs that fund initiatives specifically to support people living with dementia, and support for research. Research areas range from prevention to living with dementia and care (NNIDR 2017b; Treasury 2018).

Box A.1 A brief history — policy focus on dementia

- 1980s to 1990s
  - State-based groups for dementia carers emerge, founded in response to public concern.
  - Government funding is provided, and services include support groups for carers, community education, training for workers, and a national helpline.
  - Focus strengthens on care in the community.
  - A national approach to home and community care emerges that includes home nursing and domestic help, aiming to support frail older people remaining in the community, with support extending to carers.
- 2005 — National Dementia Initiative implemented, focusing on:
  - collaborative research centres, research and support grants
  - high care community packages
  - training for workers and behaviour management advisory services.
- 2008
  - Effective Caring report released, synthesising international evidence on carer needs and interventions (Eagar et al. 2007).
- 2009
  - Report on the *inquiry into Better Support for Carers Report (Who Cares … ?)* makes a number of recommendations.
- 2012, 2013, 2014
  - Dementia is formally added to Australia's list of health priorities.
  - Dementia in Australia report released, including prevalence statistics and estimates of the demands placed on informal carers.
  - *My Aged Care* website and contact centre introduced.
  - Report on the *inquiry into Dementia — Early Diagnosis and Intervention (Thinking Ahead)* makes a number of recommendations.
  - Report on the *Care and Management of Younger and Older Australians Living with Dementia and Behavioural and Psychiatric Symptoms of Dementia (BPSD)* makes a number of recommendations.
- 2015
  - *National Framework for Action on Dementia 2015 – 2019* released, guiding a strategic, collaborative and cost effective response to dementia.
  - *Carer Gateway* launched, providing a national online and telephone service for carers to find information, advice and services.
  - The National Institute for Dementia Research is established as part of a broader initiative to increase dementia research funding.

(continued next page)

Box A.1 (continued)

- 2016
  - Dementia Behaviour Management Advisory Services (DBMAS) and Dementia Training Programs commence, establishing national consistency.
- 2017
  - World Health Organisation adopts a global plan of action on dementia.
- 2018
  - New ‘digital’ services funded for carers (rolled out as part of the government Carer Gateway) including counselling services, peer support, networking, mentoring, coaching and educational resource (pending, from October).
  - The Australian Government announces new funding for technological solutions that help people living with dementia, their families and carers to understand dementia, and develop skills and strategies for caring.
- 2019
  - New Regional Delivery Partners network includes information and advice, coaching, counselling and peer support, and respite access (pending, from September).

Sources: AIHW (2012); Dementia Australia (2018q, 2018r, 2018g); DoH (2018a, 2018c, 2018g); DSS (2018b); Eagar et al. (2007); NNIDR (2017a); Parliament of the Commonwealth of Australia (2009, 2013, 2014); WHO (2017).

A.2 Dementia programs and services

Many dementia-specific programs that facilitate and address the needs of people living with dementia also seek to address the needs of dementia carers. The National Dementia Support Program is one such program, and includes early intervention, carer education and training, counselling, community education and public awareness raising initiatives. The program encompasses the national dementia helpline and referral service.

The Dementia Education and Training for Carers (DETC) program aims to improve the competence and confidence of carers and to ‘connect … carer[s] to information’. Several programs provide behaviour management support (below) (DoH 2017).

The Australian Government also funds several key organisations, including Dementia Australia and Dementia Training Australia (DTA 2018).

People with dementia and their carers have access to, and may benefit from, mainstream programs that meet many of their health, home care and other needs. For example, the Commonwealth Home Support Program aims to help older people remain independent and in their homes and communities, providing ‘entry-level’ home support. It provides streamlined access, with increased focus on wellness and ‘reablement’ services that target restoring function, and is available to people living with dementia (DoH 2018b). (It consolidates several formerly separate programs, including home and community care and respite for carers.)

Still further home support is provided under the Home Care Packages Program, tailored to the level of support required — ranging from relatively basic care to high care needs — and responding to more complex needs than those addressed under 'entry-level' home support (DoH 2018b).

Services and resources for people with dementia and their carers

Gateways to services and resources

The numerous services and resources funded by Australian Government programs are delivered through a range of government agencies and other entities. A number of 'gateways' provide — or link to — information resources and assistance. They also provide a gateway for information for people from diverse backgrounds.

- The National Dementia Helpline provides information about dementia, memory loss and reducing the risk of getting dementia, information about government support services and emotional support for people with dementia, their carers and families (Dementia Australia 2018o).
- *MyAgedCare* provides an online and telephone service to assist people finding relevant Australian Government funded aged care services. It is also a portal to information on health conditions including dementia and to information and support for carers (DoH 2018a; My Aged Care 2018a, 2018b).
- The *Carer Gateway*, an online and telephone service, provides information, support and resources targeting the needs of carers, including people caring for someone with dementia. The 'looking after yourself' webpage provides information on keeping healthy and active, mental health and wellbeing, taking a break (respite), advocacy, and advice on 'juggling' other commitments and goals (Australian Government 2018).

Services and resources aimed at risk reduction and prevention

Many of the numerous dementia services and resources focus on risk reduction and prevention, detection, and early stage intervention.

- Early detection of dementia resources and links — aimed at general practitioners and chemists, though including carers — are provided under the 'detect early' banner (Dementia Australia 2018n).
- Comprehensive assessments that determine the needs of elderly people including home help (eligibility for home care packages, below) are provided by Aged Care Assessment Teams (My Aged Care 2017).
- *Your Brain Matters* aims to reduce the risk of dementia by providing information and strategies to enable people to maximise their brain health (Dementia Australia 2018j).

- BrainyApp provides help with brain health, recognising that it can be improved and protected and in turn reduce the risk of developing dementia late in life (Dementia Australia 2018c).

Public education initiatives seek to improve awareness and reduce stigma, building dementia-friendly communities, and some sessions may extend to prevention strategies (Dementia Australia 2018k, 2018d).

Services and resources for carers

Recognising the central role of carers, many of the services and resources that facilitate and address the needs of people living with dementia also seek to address the needs of the carer, and some initiatives specifically target carers.

Those that benefit or target carers include: basic information; care coordination services; education and training that provide skills building and psychoeducation; counselling; and respite care that provides a temporary break for the carer.

- Information resources, including ‘help sheets’ that provide advice and ‘common sense approaches’, and a list of risk factors and how to reduce them (Dementia Australia 2018q, 2018e).
- Education for families and carers (Dementia Australia 2018f).
- Information and ‘skills building’ sessions under ‘Living with Dementia’, including for carers, focussing on maintaining and enhancing skills, practical strategies, and ‘managing now and in the future’ (Dementia Australia 2018b, 2018h).
- Counselling, including for carers, that provides support, advice and practical assistance (Dementia Australia 2018a).
- Carer support groups to learn coping mechanisms and techniques for stress management, receive support from other carers, and to receive other benefits including from social outings (Dementia Australia 2018i).
- *Home Care Packages*[7] provide coordinated services to older people — including those with dementia — with the aim of helping them to live independently, targeting the intensity of their needs. Home help that can be useful for carers includes clinical care such as nursing, support services including domestic help, personal care such as showering and dressing, and care coordination services. These packages are generally delivered on a consumer directed care basis (DoH 2018e).

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[7] Home care packages are delivered using a client directed care approach — where the choice of services, and their delivery is guided by client preference. It supports the active participation of the care recipient and their family and carers in service planning and delivery and enables the care recipient and their family/carers to make choices about the types of care and services they access, the delivery of those services, and who delivers them and when and how (DSS nd).

Many of these services and resources are delivered through subcontract arrangements. A range of further services are delivered through the Department of Social Services, including advocacy.

- Dementia education and training for carers (DETC) contribute to the 'support and maintenance of caring relationships', and is delivered through some Commonwealth respite and carelink centres (DoH 2018f, 2018d).
- Counselling, support, information and advocacy services (CSIA) provide assistance to carers to understand and manage situations, behaviours and their relationships. Services include emotional support and informal counselling, and peer support groups. Services are delivered over the phone or in drop-in centres, or through home visits to isolated carers (DSS 2018c, 2018a).

Some services focus on the kind of support required when behavioural changes emerge.

- Dementia Support Australia offers a nationwide behaviour management advisory service (DBMAS) providing support for people to better understand and respond to individual changes in behaviour and emotions, and enhance quality of life. The service is available to family carers of people living in the community (Dementia Support Australia 2018).

Policy focus on carers continues to evolve, incorporating changes to the type and mix of support services for carers, and delivery methods. 'Skill building supports' to improve carer wellbeing and to 'better long-term outcomes' will be available through the Carer Gateway from October 2018. These digital services will be available online and through automated processes. They will include: counselling services to help carers with day-to-day management and future planning; links to peers for emotional support and mentoring; carer coaching with strategies for goal-setting and future planning; and educational resources to increase skills, build confidence, and improve wellbeing (DSS 2018b).

A network of carer support will be available through regional delivery partners to help carers access new and improved local and targeted services. They will include information and advice, coaching (in-person and phone-based), counselling and peer support, respite access and transport (available from September 2019) (DSS 2018b).

Improving inclusiveness

Like the rest of the population, people with dementia are not a homogeneous group. Some initiatives aim to improve care and support for people with dementia and their carers who might have particular service needs and preferences. The National Framework for Action on Dementia recognises that particular population groups benefit from a more tailored approach. For example, different cultural perceptions of dementia are present in culturally and linguistically diverse (CALD) communities that might affect a person with dementia or their carer accessing services unless those services take these differences into account.

With this in mind, the Australian Government funds support for emerging priorities and challenges in aged care, and several projects to support people from a CALD background, Aboriginal and Torres Strait Islander people, and people who identify as lesbian, gay, bisexual, transgender and intersex (DoH 2018d). For example, among Dementia Australia provides a suite of ‘Looking out for Dementia’ resources tailored to inform Indigenous people in remote communities (Dementia Australia 2018m).

Financial help for carers

Financial support is also provided by the Australian Government to carers of people living with dementia. The Carer Payment provides income support for Australian residents who are unable to work in substantial paid employment because of the demands of their caring role for a person who has a severe disability, illness or is frail aged. For a carer to qualify, they must satisfy the income and assets tests that apply to carers. They must also provide constant in-home care to a person who — in turn — meets the prescribed care-receiver needs eligibility requirements.

Medical reports are used to check if the person being cared for have needs that meet the eligibility requirements. The Adult Disability Assessment Tool (ADAT) contains two questionnaires that together measure the amount of help the care receiver needs to undertake basic activities of daily living. Generally, the person receiving care must score high enough on the ADAT test, be likely to need care for at least 6 months (or have a terminal illness) and need care in their home, their carer’s home or in hospital to qualify (Australian Government 2015; DoHS 2018b).

The Carer Allowance is a fortnightly income supplement for individuals who give daily care to someone who has a disability, severe illness or are frail aged. Eligibility requirements are similar to those of the Carer Payment, except that the person receiving care must have care needs for at least 12 months or for the rest of their life. A family income threshold will apply from September 2018 (DoHS 2017, 2018a; DSS 2018d).

The Carer Supplement is an annual lump-sum payment to help carers with the costs of caring. Carers with more than one person in their care will receive more than one supplement, and part-time carers will receive a part supplement depending on the amount of care they provide (DoHS 2018c).

B Study characteristics and results

This appendix provides further information on:

- the characteristics of the interventions (table B.1)
- the results of the included studies (tables B.1–B.2)
- how the results of the studies varied by the carers' age and gender, the type of carer, dementia severity, the duration of the intervention and when the outcomes were measured (figures B.1–B.3).

Table B.1 **Characteristics of studies**[a]

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Case management									
Callahan 2006[e]	USA	Fortnightly initially, then monthly	12 months	Collaborative care management including education; coping skills; advice; and exercise guidelines. In addition, individualized recommendations were made regarding how to manage a patient’s behavioural symptoms. Care physicians and manager were also supported. As were caregivers who were invited to voluntary group sessions and support sessions with a psychologist.	Augmented usual care (primary care physicians could pursue any evaluation or treatment they deemed appropriate)	I=84 C=69	Age: 61 F=89%	S=44% AC=36%	Moderate
Chien 2008	Hong Kong	Fortnightly, 12 sessions	6 months	Orientation to dementia care, educational workshop about dementia care, family role and strength rebuilding, community support resources, review of program and evaluation	Routine dementia care	I=44 C=44	Age: 43.6 F=64%	AC=36% S=22%	Moderate
Chien 2011	Hong Kong	Fortnightly, 10 sessions	6 months	Intervention phased: • 1 month: weekly home visits, family health and educational needs assessment, education • 5 months: Education, sharing and discussion, psychological support and problem-solving	Routine dementia care	I=46 C=46	Age: 45.3 F=66%	AC=39% S=27%	Moderate

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Chodosh 2015	USA	Monthly for first 3 months then at least quarterly	12 months	Seven interactions including: Home visits, interactions at local community facilities and personal care management. Supplemented by telephone calls.	Telephone based care management	I=71 C=73	Age: 49.5 F=65%	AC=54% S=17%	Moderate
Chu 2000	Canada	Monthly	18 months	Case management, occupational therapy, physical therapy, social work, nursing, respiratory therapy, in home respite, and out-of-home respite, homemaking, personal care assistance, volunteer service, education, counselling and psychiatric consultation.	Information on community resources	I=33 C=36	Age: na F=73%	na	Mild
Duru 2009[e]	USA	As needed, plus 6 monthly assessment	18 months	Structured needs assessment, problem identification, care plan creation, initiation of care plan actions, referral of summary to physician, follow-ups when needed, home assessments.	Treatment as usual in a primary care clinic	I=170 C=126	Age: na F=69%	na	Mild–Moderate
Eloniemi-Sulkava 2001	Finland	Variable (once per month to five times a day)	24 months	Advocacy, support, counselling, training, follow-up calls, home visits, assistance with arrangements for social and healthcare services, 24-hour phone availability.	Usual services from private sector or municipal social and healthcare system	I=53 C=47	Age: 64 F=69%	S=55% AC=35%	Moderate

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Eloniemi-Sulkava 2009	Finland	Bimonthly support groups + 3 info sessions in total	24 months	Private sector or non-profit services from an intervention budget, geriatrician investigation and treatment, spouse support group meetings, peer-support groups, information sessions, care-recipient exercised training.	Usual services from private sector or municipal social and healthcare system.	I=63 C=62	Age: 75 F=62%	All spouse	Moderate
Miller 1999	USA	Variable (services as needed)	36 months	Subsidised community services for up to 3 years if care recipient is not institutionalised, including homemaking, personal care, companion services, social or dementia-specific adult day care.	Not reported	I=4151 C=3944	Age: 59% under 70 years F: not reported	S=47% AC=36%	Moderate
Samus 2014	USA	Monthly	18 months	Needs assessment; care coordination consisting of: identification and care planning to address unmet needs, dementia education and skill building, referral to services, and care monitoring.	Needs assessment and resource guide	I=110 C=193	Age: 66.5 F=75%	AC=48% S=43%	Moderate
Specht 2009[e]	USA	Weekly then decreasing to at least monthly	36 months	Coordinated care management with home visits by nurse manager (who had undergone intensive specialised training), who used traditional and non-traditional methods to meet needs including provision of care and resources to sustain living at home.	Traditional case management services	I=167 C=82	Age: 66.6 F=72%	AC=52% S=42%	Mild

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Thyrian 2017[e]	Germany	Monthly for first 6 months	12 months	Nurse assessment; GP individualised treatment plan; nurse home visits and monitoring in cooperation with GP, health care and social service professionals.	Treatment as usual	I=291 C=116	Not reported	Not reported	Mild
Weinberger 1993	USA	2 meetings and 1 phone call, follow up at 6 months	6 months	Social worker assessment, four week follow up meeting and phone call 1 month after. Carer completed diary of service use.	General written information packet	I=193 C=71	Age: 59.4 F=64%	S=65% AC=25%	Moderate
Counselling									
Brodaty 2009	Australia UK USA	5 sessions in 3 months, then ad hoc for 2 years	24 months	Five counselling sessions (2 with dyad, 3 with family) plus ad hoc counselling on for up to 2 years after intervention period (including education and group sessions).	Donepezil and standard services	I=79 C=76	Age: 71.3 F=55%	All spouse	Mild
Bruvik 2013	Norway	5 sessions first three months, then 2 education sessions, then 6 group sessions	12 months	Counselling to identify needs and family resources, dementia education, group meetings for structured problem solving.	Treatment as usual	I=115 C=115	Age: 63.5 F = 77%	S=53% AC=40%	Mild
Charlesworth 2008	England	Weekly	12 months	Information; companionship and conversation (emotional support).	Usual care	I=100 C=103	Age: 68 F=64%	S=67% AC=25%	Not reported
Fortinsky 2009[e]	USA	Monthly	12 months	Regular counselling and support with dementia care consultant, development of care plans.	Dementia management educational materials	I=54 C=30	Age: 61.3 F=69%	AC=47% S=43%	Moderate

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Gaugler 2013	USA	Monthly (approx.)	24 months	Individual and family counselling, support groups, and ad hoc telephone counselling.	Treatment as usual (however, if an immediate or a critical need was raised counsellors could provide ad hoc consultation)	I=54 C=53	Age: 50 F = 94%	All adult child	Moderate
Joling 2012	Netherlands	Every 2–3 months	12 months	Counselling sessions for problem solving techniques and counselling for managing behavioural problems of care recipient, and the burden and workload of the primary caregiver.	Usual care (range of health & welfare services)	I=96 C=96	Age: 70 F=70%	S=94%	Mild
Koivisto 2016	Finland	16 days during first 2 years	24 months	Individual assessments, individual counselling, education and support groups (individual and groups) and encouragement to do physical exercise.	Basic counselling	I=84 C=152	Age: 65.6 F=67%	S=70% AC=23%	Mild

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Menn 2012[e]	Germany	At least 10 meetings per year; support from 12–24 months	24 months	GPs (who had received training on drugs and nonmedical treatment options, as well as evidence-based dementia treatment and therapy) suggested carers attend support groups (at least 10 formal meetings a year) and attend caregiver counselling to provide case and care management. There were two treatment groups, differentiated by the time at which counselling was provided (0/12 months).	Usual care from GP	I=219 C=171	Age: 59.1 F=73%	AC=59% S=32%	Mild
Mittelman 1993, 1996	USA	Intensive support for 4 months, then as needed	At least 12 months, up to 8 years	Six individual and family counselling, caregiver support group sessions. Additional ad hoc counselling was available to treatment group caregivers and family members. Counsellors actively assisted caregivers to obtain support and encouraged them to join groups.	Standard assistance (details of support and further information if participants asked for it). No participants were deprived of treatment.	I=103 C=103	Age: 86.9% over 60; 43.7% 70–79. F=58%	All spouse	Moderate
Mittelman 2006	USA	Intensive support for 4 months, then as needed	At least 12 months, up to 10 years	Same as Mittelman 1993, 1996.	Same as Mittelman 1993, 1996.	I=203 C=203	Age: 71.3 F=60%	All spouse	Moderate

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Phung 2013	Denmark	Seven counselling sessions, outreach telephone counselling 5–8 times within 3–4-week intervals, five standard courses	8–12 months	Counselling, information and support to patients and their caregivers.	Treatment as usual	I=163 C=167	Age: 66 F=67%	S=65% AC=26%	Mild
Woods 2012	UK	Weekly for 12 weeks then monthly for 7 months	10 months	Joint reminiscence group meeting weekly for 12 weeks then monthly for 7 months.	Usual care	I=268 C=219	Age: 72 F=67%	S=71% AC=21%	All mild to moderate
Education and skills building									
Belle 2006	USA	Fortnightly (approx.)	6 months	9 in-home support sessions, 3 telephone individual support sessions, and 5 telephone group sessions; provision of information, didactic instruction, role playing, problem solving, skills training, stress management techniques, telephone support groups.	Educational materials and 2 brief ‘check-in’ telephone calls	I=323 C=319	Age: 60.6 F=82%	AC=47% S=43%	Moderate

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Brodaty 1991, 1993, 1997	Australia	10 days residential, then 2-weekly to 6-weekly telephone conferences and follow up	12 months	Carer received 10-day intensive residential program with skill development and coping skills. Care recipient also attended residential program and received general activities and specific memory programmes.	10 days respite and follow up conference calls. Care recipient received patient part of program.	I=33 WL(I)=32 C=31	Age: 67.7 F=54%	S=93%	Moderate
Farran 2004	USA	12 weekly sessions	12 months	5 group and 7 individual sessions with 2 booster sessions and support as needed. Topics covered skill building to understand and manage behavioural symptoms of dementia.	Standard assistance with generalised education, information and support.	I=154 C=141	Age: 64.4 F=76%	S=54% NS=46%	Moderate
Graff 2008	Netherlands	10 sessions over 5 weeks	5 weeks	10 occupational therapy sessions including cognitive and behavioural interventions to train care recipients and carers.	Usual care	I=68 C=67	Age: 63.7 F=70%	S=59% AD=32%	Moderate
Hébert 1995	Canada	Weekly for 8 weeks	8 weeks	Information, role-playing and discussion, training and relaxation.	Enhanced usual care — 8 weekly, 15-minute phone calls.	I=24 C=21	Age: 60.3 F=67%	S=64%	Not reported
Kunik 2017	USA	45-minute weekly home visits for 6–8 weeks	6–8 weeks	Home visits, psychosocial — didactics, skills building, discussion and role playing.	Enhanced usual care – 8 weekly, 15-minute phone calls	I=101 C=102	Age: 66 F=92%	S=65% OF=32%	Moderate

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Kurz 2010	Germany Austria Switzerland	7 biweekly group sessions of 90 min with 6 bimonthly refresher meetings	15 months	Group education and information, and targeted needs support	Standard counselling procedure	I=156 C=136	Age: 62.3 F=69%	S=58% AC=39%	Moderate
Laakkonen 2016	Finland	Weekly	8 weeks	Group sessions focusing on shared information, self-management and goal setting.	Usual care	I=67 C=69	Age: 74.9 F=63%	All spouse	Mild
Livingston 2014	UK	Weekly for 8 sessions	8 weeks	Dementia psychoeducation, management and coping techniques, future needs information, activity planning, skills maintenance, stress reduction.	Treatment as usual	I=173 C=87	Age: 59 F=68%	AC=43% S=42%	Mild
Mohide 1990	Canada	Weekly (adjusted to need)	6 months	Home visits, care planning and coordination, carer education, and in-home respite and carer support group.	Care as usual	I=30 C=30	Age: 67.8 F=72%	S=77%	Moderate
Nobili 2004	Italy	Two home visits	Not Reported	Two home visits (1 psychologist (60 minutes) and 1 occupational therapist (90 minutes)), covering family dynamics, nonverbal communication, behaviour management, and home modification.	Free help line and information	I=35 C=34	Age: 56 F=82%	S=47% AC=42%	Moderate

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Spijker 2011[e]	Netherlands	Variable, based on caregiver need	Not reported	Training of health professionals in the Systematic Care Program for Dementia (SCPD) and its subsequent use. The SCPD consists of a systematic assessment of caregiver problems and alerts health professionals in flexible, connecting, proactive interventions to address them.	Treatment as usual	I=155 C=140	Age: 58.8 F=74%	AC=50% S=28%	Moderate
Teri 2003	USA	12-hour long sessions: 2/week for 3 weeks; then 1/week for 4 weeks; then fortnightly for 4 weeks	3 months	Exercise program for person with dementia and behaviour management program and general information for carer	Routine medical care	I=76 C=77	Age: 70 F=70%	S=80% AC=6%	Moderate[e]
Tremont 2017	USA	16 telephone contacts	6 months	Psychoeducation, problem solving and other directive approaches	Supportive therapeutic strategies	I=133 C=117	Age: 63.1 F=78%	Not reported	Mild
Ulstein 2007	Norway	15 hours over 4.5 months	4.5 months	Three-hour education program followed by six group meetings of two hours on structured problem solving.	Treatment as usual	I=87 C=84	Age: 64.8 F=64%	S=70% AC=28%	Mild

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Voigt-Radloff 2011	Germany	2 per week for 10 sessions	5 weeks	10 occupational therapy sessions – diagnostic, goal setting, cognitive behavioural therapy	1 hour cognitive behavioural therapy plus leaflet and short discussion	I=71 C=70	Age: 64.7 F=71%	S=57% AC=37%	Mild
Wray 2010	USA	10 1-hour sessions	10 weeks	Telephone group sessions comprising education, emotion and problem-solving coping strategies and group support.	Usual care	I=83 C=75	Age: 73.9 F: not reported	All spouse	Moderate
Wright 2001	USA	Variable from biweekly gradually declining to 6 monthly	12 months	Care education and counselling, behavioural management education, medication monitoring, in-home counselling	Phone calls without education, counselling or mediation monitoring	I=68 C=25	Age: 58.8 F=76%	S=41% AD=40%	Moderate
Respite									
Engedal 1989	Norway	3 days a week	12 months	Day care – social, physical and occupational activities, medical services from visiting doctor and two meals a day	In-home nurse care	I=38 C=39	Not reported	Not reported	Not reported

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Table B.1 (continued)

		Intervention				*Participants*			
Study	*Country*	*Frequency*	*Duration*	*Key features*	*Control group*	*No.*[b]	*Carers average age and gender*	*Carer type*[c]	*Dementia severity*[d]
Lawton 1989[e]	USA	Variable	12 months	Face to face case management and institutional respite, day care or in-home respite.	Usual care and a list of local agencies and resources	I=317 C=315	Age: 60 F=79%	S=45% AC=38%	Not reported

[a] Baseline data as represented in the papers. [b] I=intervention group; C=control group. [c] Carers predominant relationships to the care recipient. S=spouse; AC=adult child; NS=nonspouse; AD=adult daughter; OF=other family. [d] Dementia severity was taken either to be that provided by a study or, where only the raw dementia score was provided, determined based on comparison with the relevant dementia severity assessment scale, for example, the Mini-Mental State Examination (MMSE), Blessed-Roth Dementia Scale and the Global Deterioration Scale. [e] Cluster RCT.

Sources: Belle et al. (2006); Brodaty et al. (2009); Brodaty and Peters (1991); Brodaty et al. (1993; 1997); Bruvik et al. (2013); Callahan et al. (2006); Charlesworth et al. (2008); Chien and Lee (2008, 2011); Chodosh (2015); Chu et al. (2000); Duru et al. (2009); Eloniemi-Sulkava et al. (2001, 2009); Engedal (1989); Farran et al. (2004); Fortinsky et al. (2009); Gaugler et al. (2013); Graff et al. (2008); Hébert et al. (1995); Joling et al. (2012); Koivisto et al. (2016); Kunik et al. (2017); Kurz et al. (2010); Laakkonen et al. (2016); Lawton (1989); Livingston et al. (2014); Menn et al. (2012); Miller et al. (1999); Mittelman et al. (1993, 1996, 2006b); Mohide et al. (1990); Nobili et al. (2004); Phung et al. (2013); Samus et al. (2014); Specht et al. (2009); Spijker et al. (2011); Tam-Tham et al. (2013); Teri et al. (2003); Thyrian et al. (2017); Tremont et al. (2017); Ulstein et al. (2007); Voigt-Radloff et al. (2011); Weinberger et al. (1993); Woods et al. (2012); Wray et al. (2010); Wright et al. (2001).

Table B.2 **Results of low risk of bias studies**[a]

Measures of preventing or delaying entry to residential care

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
Case management						
Callahan 2006	Proportion institutionalised	Calculated	At 6 months	I=3.6% C=1.4%		
			At 12 months	I=8.3% C=2.9%		
			At 18 months	I=8.3% C=7.2%		
	Odds ratio	Calculated	At 6 months	2.52	(0.26, 24.77)	🟦
			At 12 months	3.05	(0.61, 15.16)	🟦
			At 18 months	1.16	(0.35, 3.84)	🟦
Chien 2011	Mean difference (rate of institutionalisation)[d]	Reported	At 6 months	-2.2	P = 0.1	🟠
			At 12 months	-3.5	P = 0.005	✚
			At 18 months	-3.4	P= 0.001	✚
	Mean difference (duration of institutionalisation)[d]	Reported	At 6 months	-5.8	P = 0.05	✚
			At 12 months	-5.7	P = 0.005	✚
			At 18 months	-5.5	P= 0.07	🟠
Eloniemi-Sulkava 2001	Hazard ratio	Reported	Up to 24 months	1.18	(1.02, 1.4)	▣
	Odds ratio	Calculated	At 12 months	0.34	(0.1, 1.21)	🟠
			At 24 months	1.11	(0.48, 2.61)	🟦
	Estimated probability of staying in the community	Reported	At 6 months	I=0.98 C=0.91	(0.9, 1.0) (0.8, 0.98)	

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Table B.2 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
			At 12 month	I=0.92 C=0.81	(0.8, 0.98) (0.69, 0.92)	
			At 24 months	I=0.63 C=0.68	(0.49, 0.77) (0.53, 0.83)	
Eloniemi-Sulkava 2009	Hazard ratio (adjusted)	Reported	Up to 24 months	0.53	(0.23, 1.19)	●
	Hazard ratio (unadjusted)	Reported	Up to 24 months	0.66	(0.31, 1.4)	●
	Proportion institutionalised	Reported	At 12 months	I=6.6% C=15.2%	P = 0.13	●
			At 18 months	I=11.9% C=24.4%	P = 0.05	✚
			At 24 months	I=24.2% C=28.3%	P = 0.64	●
	Odds ratio	Calculated	At 12 months	0.39	(0.12, 1.33)	●
			At 18 months	0.42	(0.16, 1.09)	●
			At 24 months	0.81	(0.36, 1.8)	●
Samus 2014	Hazard ratio[e]	Reported	Up to 18 months	0.63	(0.42, 0.94)	✚
			Up to 26 months (median)	0.70	(0.49, 0.90)	✚
	Time remaining at home (mean)[e]	Reported	Up to 18 months	I= 496 days C=445 days	P = 0.02	✚
	Time remaining at home (median)[e]	Reported	Up to 26 months	I=948 days C=660 days	P = 0.043	✚
	Proportion institutionalised	Calculated	At 9 months	I=12.7% C=19.7%		
			At 18 months	I=21.8% C=26.4%		

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Table B.2 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
	Odds ratio	Calculated	At 9 months	0.59	(0.31, 1.15)	●
			At 18 months	0.78	(0.45, 1.35)	●
Counselling						
Brodaty 2009	Hazard ratio	Reported	Up to 8.5 years	1.06	P = 0.835	▲
	Time to nursing home admission	Reported	Up to 8.5 years	I=4.1 years C=4.3 years	P = 0.998	●
	Odds ratio[f]	Reported	At 8.5 years	0.91	(0.47, 1.66)	●
	Proportion institutionalised — Australia	Reported	At 8.5 years	I=50% C=77%	P=0.044	✚
	Proportion institutionalised — United Kingdom	Reported	At 8.5 years	I=56% C=42%		■
	Proportion institutionalised — United States	Reported	At 8.5 years	I=27% C=23%		■
Charlesworth 2008	Proportion institutionalised	Calculated	At 6 months	I=13% C=11%		
			At 15 months	I=23% C=17%		
			At 24 months	I=30% C=27%		
	Odds ratio	Reported	At 6 months	1.18	P = 0.717	■
			At 15 months	1.41	P = 0.388	■
			At 24 months	1.05	P = 0.911	▲
Gaugler 2013	Hazard ratio[g]	Reported	Up to 3.5 years[h]	0.53	(0.28, 0.99)	✚
	Time to institutionalisation[g]	Reported	Up to 3.5 years[h]	I=971.6 days C=743.24 days	P < 0.05	✚

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Table B.2 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
	Proportion institutionalised[g]	Reported	Up to 3.5 years[h]	I=37% C=66%	P < 0.01	✚
	Proportion institutionalised[i]	Reported	Up to 3.5 years[h]	I=20.4% C=26.4%	P > 0.05	🟠
	Odds ratio[g]	Reported	Up to 3.5 years[h]	0.31	(0.13, 0.76)	✚
Joling 2012	Hazard ratio	Reported	Up to 18 months	1.46	(0.78, 2.74)	🟦
	Proportion institutionalised	Reported	At 18 months	I=24% C=18.8%		
	Odds ratio	Calculated	At 18 months	1.37	(0.68, 2.73)	🟦
Koivisto 2016	Hazard ratio	Reported	Up to 36 months	1.3	(0.69, 2.45)	🟦
	Proportion institutionalised	Reported	At 36 months	I=21% C=16%		🟦
	Odds ratio	Calculated	At 36 months	1.45	(0.74, 2.87)	🟦
Mittelman 1993	Odds ratio	Reported	At 12 months	0.4	P < 0.05	✚
	Proportion institutionalised	Reported	At 12 months	I=10.7% C=23.3%	P < 0.05	✚
Mittelman 1996	Hazard ratio	Reported	Up to 8 years[j]	0.65	(0.45, 0.94)	✚
	Difference in median time to institutionalisation	Reported	Up to 8 years[j]	329 days	(47, 611)	✚
Mittelman 2006	Hazard ratio	Reported	Up to 10 years[k]	0.72	P = 0.025	✚
	Difference in median time to institutionalisation	Reported	Up to 10 years[k]	557 days		
Phung 2013	Hazard ratio	Reported	Up to 36 months	0.97	(0.64, 1.47)	▲
	Odds ratio	Calculated	At 36 months	0.89	(0.55, 1.44)	🟠

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Table B.2 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
Woods 2012	Mean nights spent in residential home	Reported	At 10 months	I=1.71 nights C=0 nights		○
	Mean nights spent in nursing home	Reported	At 10 months	I=0 nights C=0 nights		▲
Education and skills building						
Belle 2006	Proportion institutionalised	Reported	At 6 months	I=4.3% C=7.2%	P = 0.118	●
	Odds ratio	Calculated	At 6 months	0.58	(0.29, 1.15)	●
Farran 2004	Time to institutionalisation	Reported	At 18 months		P > 0.75	◆
Graff 2008	Proportion institutionalised	Calculated	At 3 months	I=9.0% C=13.8%		
	Odds ratio	Calculated	At 3 months	0.61	(0.21, 1.83)	●
Hébert 1995	Difference in proportion institutionalised	Reported	At 24 months	11.0%	(-21.0, 45.0)	●
	Odds ratio	Calculated	At 24 months	0.55	(0.16, 1.84)	●
Kunik 2017	Proportion institutionalised	Reported	At 12 months	I=4% C=7%		
	Odds ratio	Calculated	At 12 months	0.98	(0.54, 1.79)	▲
Laakkonen 2016	Days spent in nursing home	Reported	At 24 months	I=626 days C=151 days		○
Livingston 2014	Hazard ratio	Reported	Up to 24 months	0.83	(0.44, 1.56)	●
	Odds ratio	Calculated	At 8 months	1.91	(0.52, 7.04)	■
			At 24 months	0.91	(0.47, 1.75)	▲
	Proportion institutionalised	Reported	At 8 months	I=6.4% C=3.6%	P=0.56	■

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Table B.2 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
			At 24 months	I=18.7% C=20.2%		
Mohide 1990	Time to institutionalisation	Reported	At 6 months	I=17.2 weeks C=10.4 weeks	P>0.05	●
	Proportion institutionalised	Reported	At 6 months	I=16.7% C=16.7%		
	Odds ratio	Calculated	At 6 months	1.00	(0.26, 3.89)	▲
			At 12–18 months[l]	1.00	(0.35, 2.86)	▲
Spijker 2011	Hazard ratio	Reported	Up to 12 months	0.93	(0.57, 1.53)	▲
	Mean time to institutionalisation	Reported	Up to 12 months	I=307 days C=300 days	P=0.87	▲
	Proportion institutionalised	Reported	At 12 months	I=52.2% C=47.8%	P=1.00	▲
	Odds ratio	Reported	At 12 months	0.98	(0.54, 1.79)	▲
Teri 2003	Proportion institutionalised	Reported	At 24 months	I=68% C=67%	P=0.84	▲
	Odds ratio	Calculated	At 24 months	0.95	(0.47, 1.93)	▲
Tremont 2017	Proportion institutionalised	Reported	At 6 months	Total = 6% (not reported by group)	P = 0.7	◆
Voigt-Radloff 2011	Proportion institutionalised	Reported	At 12 months	I=2.8% C=1.4%		
	Odds ratio	Calculated	At 12 months	2.00	(0.18, 22.57)	■

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Table B.2 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
Wray 2010	Average number of nursing home admissions	Reported	At 12 months	I=0.2 per person C=0.1 per person	P>0.05	🟦

[a] ✚ = positive, statistically significant; ● = positive, not statistically significant; ▲ = neutral effect, not statistically significant; ▣ = negative, statistically significant; 🟦 = negative, not statistically significant; ◆ = not statistically significant, direction of effect not reported; ◎ = negative, statistical significance not reported and unable to be determined. [b] The terms 'residential care placement' and 'institutionalisation' are used interchangeably in this table. Where another term is used, such as 'nursing home', this is the term used in the original study. [c] The assessment of effect was determined using the information on results combined with the 95 per cent CIs, P-values or information provided in the original article (but not reported here). Where all the required information was not available the assessment of effect is not reported (that is, the cell is left blank). [d] Institutionalisation rate = Average number of residential placements and hospital admissions. Duration of institutionalisation = Average number of days per month in residential care and hospital. [e] Result includes deaths and residential care placements. These results are not comparable with other studies. [f] Reported in Tam-Tham et al. (2013). [g] Any residential care. [h] Not all participants had been in the study for the full 3.5 years. [i] Nursing homes only. [j] Not all participants had been in the study for the full 8 years. [k] Not all participants had been in the study for the full 10 years. [l] The follow-up measurement period varied by participant.

Sources: Belle et al. (2006); Brodaty et al. (2009); Callahan et al. (2006); Charlesworth et al. (2008); Chien and Lee (2011); Eloniemi-Sulkava et al. (2009); Farran et al. (2004); Gaugler et al. (2013); Graff et al. (2008); Hébert et al. (1995); Joling et al. (2012); Koivisto et al. (2016); Kunik et al. (2017); Laakkonen et al. (2016); Livingston et al. (2014); Mittelman et al. (1993, 1996, 2006b); Mohide et al. (1990); Phung et al. (2013); Samus et al. (2014); Spijker et al. (2011); Tam-Tham et al. (2013); Teri et al. (2003); Tremont et al. (2017); Voigt-Radloff et al. (2011); Woods et al. (2012); Wray et al. (2010).

Table B.3 Results of high risk of bias studies[a]

Measures of preventing or delaying entry to residential care

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
Case management						
Chien 2008	Mean difference (rate of institutionalisation)[d]	Calculated	At 6 months	-2.2		✚
		Calculated	At 12 months	-3.5		✚
Chodosh 2015	Number of placements	Reported	At 12 months	Total = 1 (not reported by group)		◆
Chu 2000	Proportion institutionalised	Reported	At 18 months	I=12.1% C=27.8%		
	Odds ratio	Calculated	At 18 months	0.36	(0.1, 1.28)	●
Duru 2009	Proportion institutionalised[e]	Reported	At 18 months	I=14.1% C=12.7%		
	Odds ratio	Calculated	At 18 months	1.13	(0.57, 2.23)	■
Miller 1999	Hazard ratio (univariate)	Reported	Up to 36 months	1.01	(0.95, 1.08)	▲
	Hazard ratio (multivariate)	Reported	Up to 36 months	1.01	(0.94, 1.07)	▲
	Proportion institutionalised	Reported	At 36 months	I=44.1% C=42.9%		
Specht 2009	Proportion institutionalised	Calculated	At 36 months	I=40.1% C=36.6%		
	Odds ratio	Calculated	At 36 months	1.16	(0.67, 2.0)	■
Thyrian 2017	Proportion institutionalised	Reported	At 12 months	I=5.5% C=6.9%		
	Odds ratio	Calculated	At 12 months	0.79	(0.33, 1.89)	●
Weinberger 1993	Mean nursing home stays per patient	Reported	At 12 months	I = 0.11 C= 0.13	+/- 0.31 +/- 0.34	▲

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Table B.3 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
Counselling						
Bruvik 2013	Proportion institutionalised	Calculated	At 12 months	I=26.1% C=28.7%	P = 0.657	●
	Odds ratio	Calculated	At 12 months	0.88	(0.49, 1.57)	●
Fortinsky 2009	Proportion institutionalised	Reported	At 12 months	I=16% C=33%		
	Odds ratio (adjusted)	Reported	At 12 months	0.4	(0.14, 1.18)	●
Menn 2012	Proportion institutionalised (Group B and control)	Calculated	At 24 months	I=11.0% C=10.5%		
	Proportion institutionalised (Group C and control)	Calculated	At 24 months	I=15.5% C=10.5%		
	Odds ratio (Group B and control)	Calculated	At 24 months	1.05	(0.49, 2.28)	▲
	Odds ratio (Group C and control)	Calculated	At 24 months	1.55	(0.76, 3.16)	■
	Hazard rate (unadjusted)	Reported	Up to 2 years		P=0.31	▲
	Hazard rate (Group B to control)	Reported	Up to 4 years	0.86	(0.47, 1.56)	●
	Hazard rate (Group C to control)	Reported	Up to 4 years	1.13	(0.64, 2.01)	■
Education and skills building						
Brodaty 1991[f]	Survival at home (Lee-Desu statistic) (I >C)	Reported	At 39 months	8.6	P = 0.003	✚
	Survival at home (Lee-Desu statistic) (I>WL)	Reported	At 39 months	2.4	P = 0.12	●

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Table B.3 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
	Survival at home (Lee-Desu statistic) (I+WL>C)	Reported	At 39 months	5.9	P = 0.02	✚
	Proportion institutionalised	Calculated	At 39 months	I = 42.4% WL= 56.3% C=80.6%		
	Odds ratio (I to C)	Calculated	At 39 months	0.18	(0.06, 0.55)	✚
	Odds ratio (I to WL)	Calculated	At 39 months	0.57	(0.21, 1.53)	●
	Odds ratio (WL to C)	Calculated	At 39 months	0.31	(0.1, 0.96)	✚
	Odds ratio (I+WL to C)	Calculated	At 39 months	0.23	(0.08, 0.64)	✚
Brodaty 1993[f]	Odds ratio[g] (I to C)	Reported	At 5 years	0.24		
	Odds ratio[g] (WL to C)	Reported	At 5 years	0.43		
	Odds ratio[h] (I to C)	Reported	At 5 years	0.30		
	Odds ratio[h] (WL to C)	Reported	At 5 years	0.52		
Brodaty 1997[f]	Proportion institutionalised	Reported	At 8.5 years	I = 79% WL = 83% C = 90%		●
	Odds ratio (I to C)	Calculated	At 8.5 years	0.41	(0.1, 1.77)	●
	Odds ratio (I to WL)	Calculated	At 8.5 years	0.74	(0.21, 2.65)	●
	Odds ratio (WL to C)	Calculated	At 8.5 years	0.56	(0.12, 2.57)	●
	Odds ratio (I+WL to C)	Calculated	At 8.5 years	0.47	(0.12, 1.82)	●
	Time to institutionalisation	Reported	At 8.5 years	I = 47.5 months WL= 35.7 months		●

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Table B.3 (continued)

Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
				I + WL combined (no estimate given) C = 27:6 months	P < 0:05	✚
Kurz 2010	Proportion institutionalised	Calculated	At 15 months	I=21.8% C=16.9%		
	Odds ratio	Calculated	At 15 months	1.37	(0.76, 2.46)	🟦
	Mean time in the community	Reported	At 15 months	I=676 days C=712 days	P = 0.25	🟦
Nobili 2004	Proportion institutionalised	Calculated	At 12 months	I=11.4% C=11.8%		
	Odds ratio	Calculated	At 12 months	0.97	(0.22, 4.23)	▲
Ulstein 2007	Proportion institutionalised	Calculated	At 12 months	I=11.5% C=19.0%		
	Odds ratio	Calculated	At 12 months	0.55	(0.23, 1.3)	●
Wright 2001	Proportion institutionalised	Reported	At 12 months	I=28% C=22%		🟦
	Odds ratio	Calculated	At 12 months	1.39	(0.45, 4.34)	🟦
	Time to institutionalisation	Reported	At 12 months	I= 121 days C=126 days	P = 0.891	🟦
Respite						
Engedal 1989	Proportion institutionalised	Reported	At 12 months	I=37% C=46%		
	Odds ratio	Calculated	At 12 months	0.68	(0.27, 1.69)	●
	Time at home	Reported	At 12 months	I > C[i]		▲
Lawton 1989	Proportion staying in community	Reported	At 12 months	I=64% C=59%		●

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Table B.3 (continued)

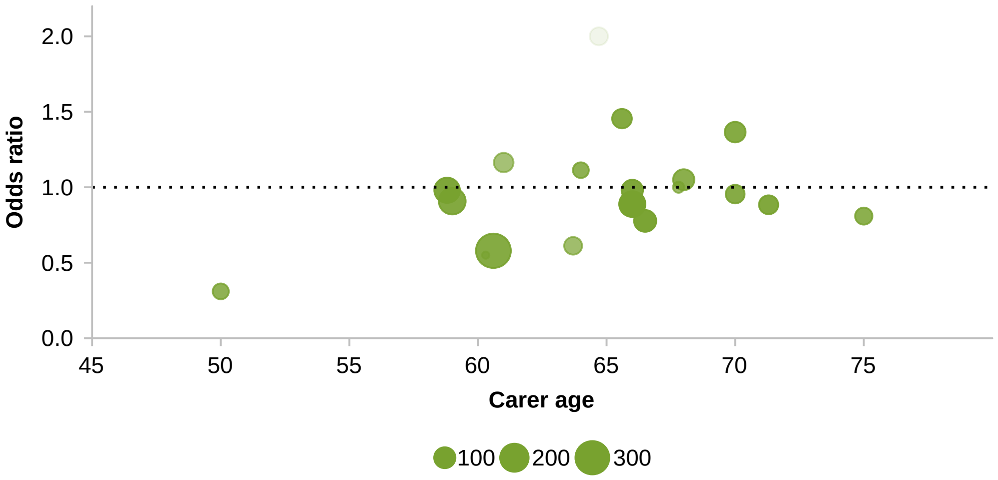
Study	*Measure/s of residential care placement*[b]	*Source*	*Measurement period*	*Results*	*95 per cent CI or P-value*	*Assessment of effect*[c]
	Community tenure (odds of staying in the community)	Reported	At 12 months	2.63	P<0.01	✚
	Community tenure (time spent in the community)	Reported	At 12 months	I= 309 days C=285 days		✚

[a] ✚ = positive, statistically significant; ● = positive, not statistically significant; ▲ = neutral effect, not statistically significant; ▣ = negative, statistically significant; ■ = negative, not statistically significant; ◆ = not statistically significant, direction of effect not reported. [b] The terms ‘residential care placement’ and ‘institutionalisation’ are used interchangeably in this table. Where another term is used, such as ‘nursing home’, this is the term used in the original study. [c] The assessment of effect was determined using the information on results combined with the 95 per cent CIs, P-values or information provided in the original article (but not reported here). Where all the required information was not available the assessment of effect is not reported (that is, the cell is left blank). [d] Average number of residential placements and hospital admissions. Article reports that the results are statistically significant (not p-value provided). [e] Proportion with any nursing home stays of visits. [f] Intervention included three groups: I = Dementia Carers’ Program; WI = Waitlist (6 months delay) for intervention; C = Memory Training Group. [g] Adjusted for baseline characteristics of dementia severity and carer functioning. [h] Adjusted for baseline characteristics as above and change in the patient’s dementia and caregiver stress at 12 months. [i] The patients in the intervention group stayed slightly longer at home than those in the control group, but statistical analysis (Mantel-Cox test) of the distributions showed no significant difference between the groups.

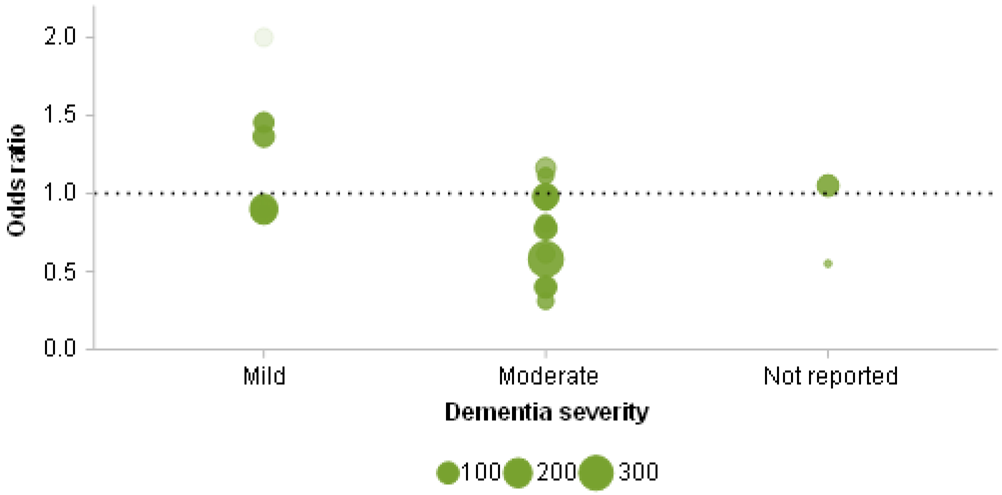
Sources: Brodaty and Peters (1991); Brodaty et al. (1993; 1997); Bruvik et al. (2013); Chien and Lee (2008); Chodosh et al. (2015); Chu et al. (2000); Duru et al. (2009); Eloniemi-Sulkava et al. (2001); Engedal (1989); Fortinsky et al. (2009); Kurz et al. (2010); Lawton (1989); Menn et al. (2012); Miller et al. (1999); Nobili et al. (2004); Specht et al. (2009); Thyrian et al. (2017); Ulstein et al. (2007); Weinberger et al. (1993); Wright et al. (2001).

Figure B.1 **Odds ratios by age of primary carer and dementia severity**[a,b,c,d,e]

Age of primary carer[f]



Dementia severity[g]

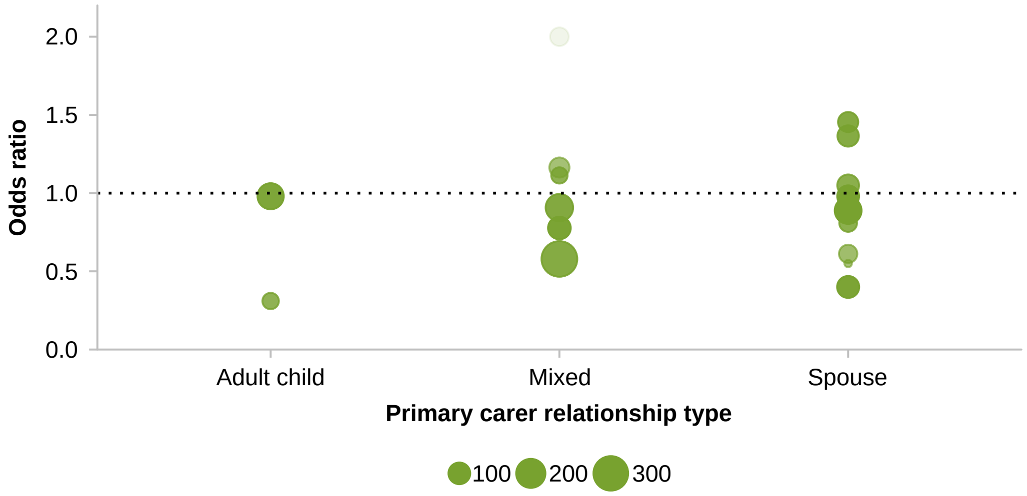


[a] Includes studies rated at low risk of bias that included odds ratios, or odds ratios could be calculated based on information provided in the paper. [b] Where studies had odds ratios for multiple time periods, the odds ratio for the longest follow-up period is included. [c] An odds ratio of less than one indicates the intervention group is less likely to be in residential care than the control group. [d] The size of dots represents the size of intervention group. [e] The shading of dots represents the relative precision of the estimates (based on the standard error of the estimate). Lighter shaded dots indicate the estimate is less precise. [f] Mittelman et al. (1993) is not included as the average age of carers was not reported. [g] Dementia severity was either provided by a study or determined based on comparison with the relevant dementia severity scale.

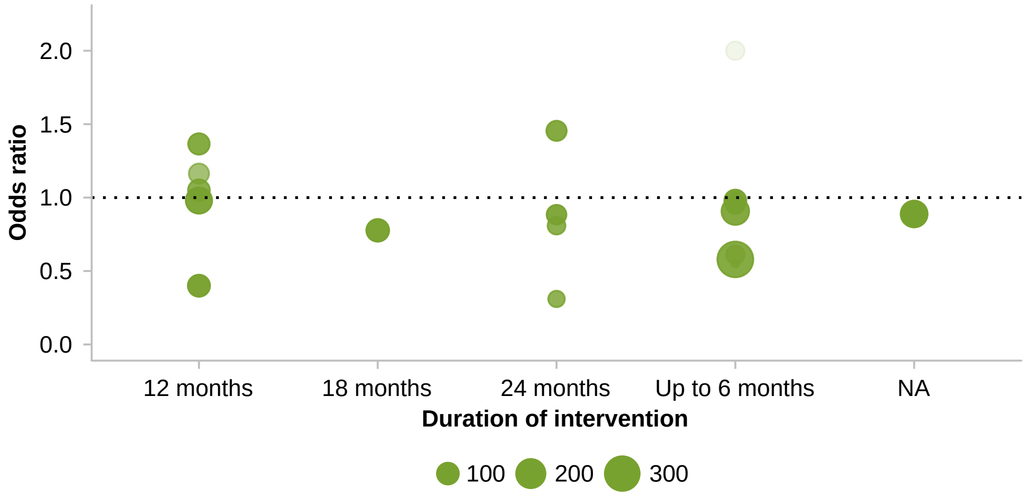
Source: Productivity Commission estimates.

Figure B.2 Odds ratios by primary carer relationship type and duration of intervention[a,b,c,d,e]

Primary carer relationship type



Duration of intervention

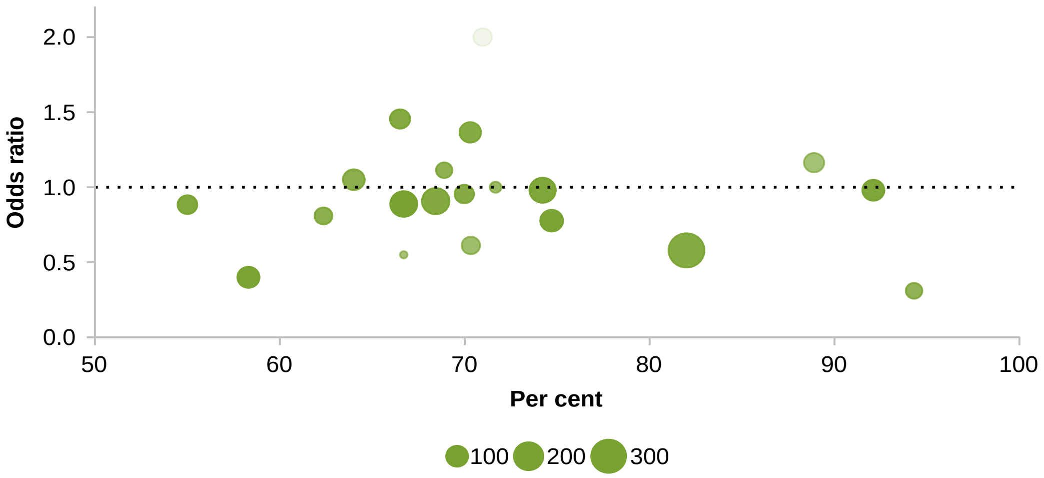


[a] Includes studies rated at low risk of bias that included odds ratios, or odds ratios could be calculated based on information provided in the paper. [b] Where studies had odds ratios for multiple time periods, the odds ratio for the longest follow-up period is included. [c] An odds ratio of less than one indicates the intervention group is less likely to be in residential care than the control group. [d] The size of dots represents the size of intervention group. [e] The shading of dots represents the relative precision of the estimates (based on the standard error of the estimate). Lighter shaded dots indicate the estimate is less precise.

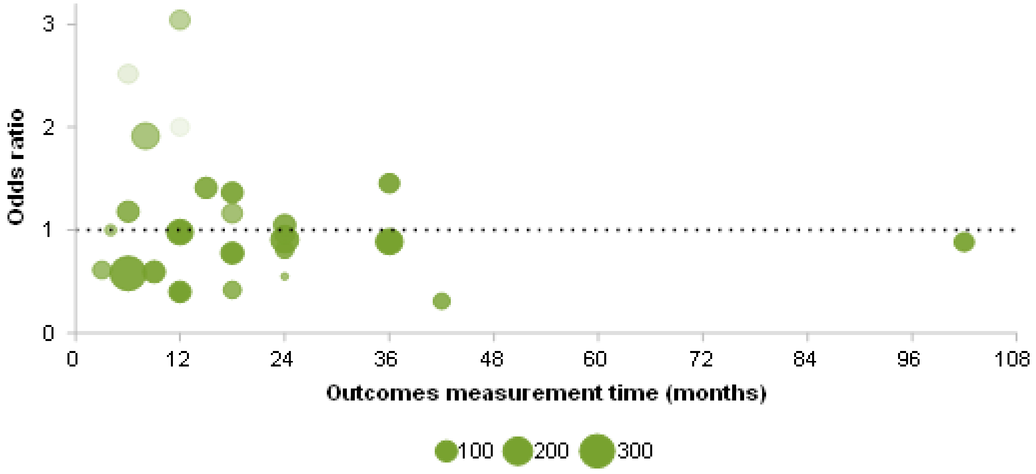
Source: Productivity Commission estimates.

Figure B.3 **Odds ratios by the percentage of carers who are female and outcome measurement time**[a,b,c,d,e]

Percentage of carers who are female



Outcome measurement time[f]



[a] Includes studies rated at low risk of bias that included odds ratios, or odds ratios could be calculated based on information provided in the paper. [b] Where studies had odds ratios for multiple time periods, the odds ratio for the longest follow-up period is included. [c] An odds ratio of less than one indicates the intervention group is less likely to be in residential care than the control group. [d] The size of dots represents the size of intervention group. [e] The shading of dots represents the relative precision of the estimates (based on the standard error of the estimate). Lighter shaded dots indicate the estimate is less precise. [f] Studies that have odds ratios for more than one time period are included for each time period.

Source: Productivity Commission estimates.

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