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[Review of dementia care funding urged](#)

Health Service Journal 19 August

Wide variations in NHS funding for the continuing care of people with dementia have been uncovered in a report by a Labour prospective parliamentary candidate.

The report, titled [Lost in the Process](#), has been put together by former MP Sally Keeble, who gathered information from 162 clinical commissioning groups.

The survey of all CCGs - which also included accounts from families caring for people living with dementia and Department of Health figures - uncovered a lack of funding for advocacy services to provide support for families applying for continuing healthcare support - with only four CCGs saying they funded advocacy.

Ms Keeble said the study highlights the need for a national review of dementia care.

She said: "People living with dementia should be able to get NHS support for their continuing healthcare needs. Yet many families get lost in the process of applying for funding. They put their own lives on hold to care for their relatives.

"These recommendations set out practical steps to improve things for the people living with dementia and their family carers, and are urgently needed to ease the heartache for these families."

A total of 800,000 people are living with dementia in the UK, with numbers expected to rise to more than one million by 2021.

The current bill for dementia care totals £23bn with this figure expected to reach £50bn over the same period.

[All-Party Parliamentary Group on Dementia \(APPG\) highlights urgent need for new long term National Dementia Strategy](#)

Members of the All-Party Parliamentary Group on Dementia (APPG) have joined Alzheimer's Society to call for an urgently needed long-term national plan for dementia.



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Five years on from the launch of the first ever [National Dementia Strategy](#), a new report from the All-Party Parliamentary Group (APPG) on dementia assesses progress made in three key areas of health and social care and calls for strong local leadership in executing plans, more integrated services and involvement of people with dementia in commissioning services.

'[Building on the National Dementia Strategy: Change, progress and priorities](#)' explores work done to improve diagnosis and post diagnosis support, commissioning of services and ensuring a skilled dementia workforce. The APPG outlines what priorities need to be set for the future, making a series of recommendations:

Every CCG and local authority should appoint a Dementia Lead to ensure high-quality integrated services

Commissioning of local services should be evidence based, involving people with dementia, encouraging cooperation between health and social care and other service providers

A culture shift in both the public and professionals' view of the dementia workforce, ensuring it is an attractive and fulfilling career choice

Prime Minister announces government will double dementia research funding by 2025

Government spending on dementia research will be doubled by 2025, Prime Minister David Cameron announced at the [Global Dementia Legacy event](#) in London (19 June 2014).

The announcement comes after the Prime Minister told the event that new action was needed to achieve last year's G8 summit pledge of a cure or disease modifying treatment for dementia by 2025.

Obesity in mid-life increases the risk of developing dementia

Obesity in mid-life is linked to a heightened risk of dementia in later life, concludes an observational study published online in [Postgraduate Medical Journal](#).

The researchers at the University of Oxford found that the age at which a person is obese seems to be a key factor - with an apparent tripling in the risk of developing dementia for people who are obese in their thirties. The increased risk of dementia declined as obesity was diagnosed later



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in life, and those who were obese over the age of 70 were not more likely to develop dementia than those without obesity.

Given that this is an observational study, no definitive conclusions can be drawn about cause and effect. However, the findings support existing published studies which report an increased risk of dementia in people who are obese under the age of 60, but a reduced risk in older obese people.

Low levels of vitamin D linked to higher dementia risk

People with very low levels of vitamin D in the blood may be twice as likely to develop dementia, according to a large British study published in [Neurology](#).

According to the research, those with low levels of vitamin D in the blood were 53 per cent more likely to develop any form of dementia, and those with severe vitamin D deficiencies were at a 125 per cent greater risk.

Led by Dr David Llewellyn at the University of Exeter, the study involved 1,658 people over the age of 65 who did not have dementia at the beginning of the study. The participants were followed for an average of six years, after which 171 participants developed dementia and 102 had Alzheimer's disease.

In addition to an increased risk of developing any form of dementia, people with low levels of vitamin D were also nearly 70 per cent more likely to develop Alzheimer's disease, and those with severe deficiencies were over 120 per cent more likely to develop the condition.

Further information: [Vitamin D deficiency linked to dementia](#)

Depression could be separate risk factor for dementia, study suggests

Depression could increase a person's risk of developing dementia independently of the biological factors thought to cause the dementia, according to new research published in [Neurology](#).

The research, led by Rush University Medical School, suggests that older people who had experienced some form of depression were more likely to develop mild cognitive impairment (MCI) - thought to be a precursor to dementia - and dementia.



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Researchers at the university studied 1,764 older people without cognitive impairment for an average of 7.8 years. During yearly follow ups the participants were asked a series of questions relating to their mental health, including whether they felt lonely on a regular basis. Incident mild cognitive impairment and dementia were associated with a higher level of depressive symptoms before diagnosis but not with a change in symptoms after diagnosis. In post-mortem examinations, the researchers found no association between depressive symptoms and the biological hallmarks which play a role in the development of dementia.

A fifth of people unaware of how to reduce their risk of dementia

More than a fifth of people do not think it is possible to reduce their risk of developing dementia, according to a YouGov poll commissioned by Alzheimer's Society.

Despite growing evidence that simple lifestyle factors can improve our chances of avoiding dementia, the poll found that 22 per cent of the general public are unaware of this and could be putting themselves at risk.

Alzheimer's Society is calling on people to take action now, and has revealed five simple things people can start doing straight away to reduce their risk of dementia. The most important of which is to take regular exercise:

- Exercise - there's more evidence that regular exercise will prevent dementia than for any other measure we might take. Walking regularly is an excellent way of keeping active.
- Eat Mediterranean food - eat plenty of fruit and vegetables, fish, olive oil and nuts, a little red wine and not much meat or dairy.
- Manage other health conditions – other conditions like type 2 diabetes and high blood pressure both increase your risk of developing dementia, so get these checked and follow medical advice to keep them under control.
- Avoid smoking - it significantly increases your risk of developing dementia, most likely because it damages blood vessels and reduces the amount of blood that reaches your brain.
- Use it or lose it – scientists believe that frequently challenging your brain with new things is the key, for example taking up a new hobby, learning a language or even walking an unfamiliar route.



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Number of patients with recorded diagnosis of dementia increases by 62 per cent over seven years

Provisional figures from the Health and Social Care Information Centre (HSCIC) show 344,000 patients had a recorded diagnosis of dementia in 2013-14. This is a rise from 319,000 in 2012-13 and from 213,000 in 2006-07, when the data was first collected.

These latest statistics show the numbers of patients registered with GP practices in England who have a recorded diagnosis of dementia and this is the first time the HSCIC has published a standalone report on this subject.

Quality Outcomes Framework, Recorded Dementia Diagnoses - 2013-14, Provisional statistics shows the increase in recorded diagnosis has been steady since this data was first collected. The rise may be due to the ageing population, an increase in the number of people being diagnosed, improved recording of diagnoses or a combination of factors.

Number of English communities working to become dementia friendly triples expectations

Alzheimer's Society announces that over 60 towns and cities in England have committed to become dementia friendly.

Commitment from 63 communities has exceeded the ambition set in the Prime Minister's Challenge on Dementia to engage 20 communities in the Dementia Friendly Communities programme by 2015 by more than three times. This news comes as the UK's National Standards Body, BSI ([British Standards Institution](#)) launches a new project with the charity to develop a standard defining exactly how communities work towards becoming dementia friendly, with the aim of inspiring more areas to get involved.

BSI is working with the leading charity for people with dementia, the Department of Health, community representatives and key stakeholders across government, industry and healthcare to develop the code of practice. It will act as a benchmark for all communities wanting to embark upon a journey to work towards being dementia friendly.

A dementia-friendly community is a city, town or village where people with dementia are understood, respected, supported, and confident they can contribute to community life. An economic analysis commissioned by the charity in September 2013 showed that Dementia



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Friendly Communities could save £11,000 per person per year by helping people with dementia to remain independent, stay out of care for longer and have a better quality of life.

UK Parliament pledges to become the first dementia-friendly parliament in the world

The UK Parliament is launching an organisation-wide effort, together with Alzheimer's Society, to become the first ever dementia-friendly parliament in the world.

The leading charity for people with dementia is supporting the initiative which will see all members, staff and the wider parliamentary community improve their understanding of dementia and take action to support those living with the condition.

With the aim of creating a supportive environment for people with dementia and those affected by the condition, the initiative calls for Parliament to work towards the following:

- Make dementia awareness part of all newly elected MPs' inductions
 - Deliver Dementia Friends awareness sessions to all public-facing staff so they can support external visitors living with dementia
 - Provide MPs and Peers with information and knowledge about dementia to help them assist constituents affected by dementia
 - Signpost staff with caring responsibilities for people with dementia to help through Alzheimer's Society
-

Cost of dementia to companies predicted to double, report reveals.

Department of Health / Dementia Challenge August 8th 2014.

Public Health England (PHE) and the Alzheimer's Society have released a report from the Centre for Economics and Business Research (Cebr) which attempts to quantify the financial burden falling on the nation's businesses from dementia.

Employers are advised of the need to adapt their working environment to support increasing numbers of employees, carers and relatives likely to be affected by the condition. Dementia caring obligations are projected to cost companies more than £3 billion per year by 2030.

Read coverage of the report in the [Independent](#)

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[Preventing dementia: a provocation. How can we do more to prevent dementia, save lives and reduce avoidable costs?](#)

Brett, K. Hope, P. [and] Beales, S. [et al] (2014).

London: The International Longevity Centre – UK (ILC-UK), July 2014.

This International Longevity Centre – UK (ILC-UK) report summarises current knowledge about how more can be done to prevent the scale of dementia prevalence in future, and to reduce avoidable costs. It considers the potential savings achievable by tackling the known risk factors for dementia, including physical activity, smoking, obesity and depression.

“...tackling lifestyle factors for dementia could save the UK state £42.9 billion between now and 2040”.

[Gardens Help Trigger Memories in Dementia Patients](#)

Journal of the American Medical Directors Association / Nursing Times / BT Lifestyle

Researchers at the University of Exeter Medical School have found that gardens and green spaces help care home residents with dementia to relax, resulting in reduced agitation. This review of 17 different international research studies indicates that having opportunities to relax in calming settings helps sufferers to “remember skills and habits which brought enjoyment in the past”. Gardens also offer welcome spaces for interactions with visitors, families and staff.

Reference

[What is the impact of using outdoor spaces such as gardens on the physical and mental well-being of those with dementia? A systematic review of quantitative and qualitative evidence.](#)

Journal of the American Medical Directors Association. July 15th 2014.

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Research

Statins for the treatment of dementia.

Cochrane Database Syst Rev. 2014 Jul. McGuinness B, Craig D, Bullock R, Malouf R, Passmore P.

The use of statin therapy in established Alzheimer's disease (AD) or vascular dementia (VaD) is a relatively unexplored area. In AD, β -amyloid protein ($A\beta$) is deposited in the form of extracellular plaques and previous studies have determined $A\beta$ generation is cholesterol dependent. Hypercholesterolaemia has also been implicated in the pathogenesis of VaD. Due to the role of statins in cholesterol reduction, it is biologically plausible they may be efficacious in the treatment of AD and VaD.

OBJECTIVES:

To assess the clinical efficacy and safety of statins in the treatment of AD and VaD. To evaluate if the efficacy of statins in the treatment of AD and VaD depends on cholesterol level, ApoE genotype or cognitive level.

SEARCH METHODS:

We searched ALOIS, the Specialized Register of the Cochrane Dementia and Cognitive Improvement Group, The Cochrane Library, MEDLINE, EMBASE, PsycINFO, CINAHL and LILACS, as well as many trials registries and grey literature sources (20 January 2014).

SELECTION CRITERIA:

Double-blind, randomised controlled trials of statins given for at least six months in people with a diagnosis of dementia.

DATA COLLECTION AND ANALYSIS:

Two independent authors extracted and assessed data against the inclusion criteria. We pooled data where appropriate and entered them into a meta-analysis. We used standard methodological procedures expected by The Cochrane Collaboration.

MAIN RESULTS:

We identified four studies (1154 participants, age range 50 to 90 years). All participants had a diagnosis of probable or possible AD according to standard criteria and most participants were established on a cholinesterase inhibitor. The primary outcome in all studies was change in Alzheimer's Disease Assessment Scale - cognitive subscale (ADAS-Cog) from baseline. When we

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pooled data, there was no significant benefit from statin (mean difference -0.26, 95% confidence interval (CI) -1.05 to 0.52, P value = 0.51). All studies provided change in Mini Mental State Examination (MMSE) from baseline. There was no significant benefit from statins in MMSE when we pooled the data (mean difference -0.32, 95% CI -0.71 to 0.06, P value = 0.10). Three studies reported treatment-related adverse effects. When we pooled data, there was no significant difference between statins and placebo (odds ratio 1.09, 95% CI 0.58 to 2.06, P value = 0.78). There was no significant difference in behaviour, global function or activities of daily living in the statin and placebo groups. We assessed risk of bias as low for all studies. We found no studies assessing role of statins in treatment of VaD.

AUTHORS' CONCLUSIONS:

Analyses from the studies available, including two large randomised controlled trials, indicate that statins have no benefit on the primary outcome measures of ADAS-Cog or MMSE.

Course for dementia carers reduces anxiety and depression in the long term

An [eight-week course](#) which provides education, stress relief and emotional support for dementia carers is the first cost-effective programme to reduce anxiety and depression for two years.

This is according to [new research](#) presented 16 July 2014 at the Alzheimer's Association International Conference (AAIC).

The study of 260 family caregivers, led by Gill Livingston, University College London, found that the START (STrAtegies for RelaTives) programme reduced caregiver's anxiety and depression, with benefits lasting for at least two years. This eight-week course delivered by psychology graduates included education about dementia, caregiver stress, and where to get emotional support, as well as techniques for managing challenging behaviours of people with dementia. The cost of delivering the course was no more expensive than standard care given to the control group, showing that this intervention is a cost-effective way to improve the mental health and well-being of carers.



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Clinical trial shows offering health guidance to people in later life may prevent early memory problems.

A comprehensive two-year clinical trial has shown a combined approach involving exercise, diet, cognitive training, social activities and management of heart health can significantly improve memory.

The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) research, carried out at the National Institute for Health and Welfare in Finland, involved 1,260 people aged 60 to 77. The participants were split into two randomised groups; one received simple health advice, the other half received in-depth guidance about nutrition, physical exercise, cognitive training and social activities, and management of vascular risk factors.

After two years, the group who had received the guidance and advice about healthy living demonstrated significantly better results on a range of cognitive examinations, including memory tests and speed of brain processing. The study plans to follow up with participants after seven years to reassess progress.

For further information, [‘Research advances from 2014 Alzheimers Association International Conference’](#)

Fewer cases of dementia reported in developed nations suggests possibility of prevention and risk reduction.

A series of new research studies exploring the prevalence and incidence of dementia worldwide has been presented at the [Alzheimer's Association International Conference in Copenhagen](#). (Tuesday 15 July 2014).

A [review](#) of five population studies of dementia incidence and prevalence by University of Michigan suggests the risk of developing dementia has decreased in the US, Stockholm, Rotterdam and England. Scientists suggest higher education levels and better treatment of cardiovascular disease may be improving brain health. Another study from Boston University School of Medicine, assessing participants for dementia over three decades, reported a reduction in incidence by 17, 32 and 42 per cent from the second to the fourth decade. The reduction was strongest in women and those aged 60-69.

Prevalence data taken from insurance claims by the German Center for Neurodegenerative diseases found the number of German women aged 74 and 85 with dementia declined from 2007



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and 2009. Overall dementia prevalence was 1.8 per cent higher in 2008 and 3.6 per cent higher in 2007.

Time spent playing games and puzzles correlates to brain volume in middle age.

This is according to a study from the Wisconsin Alzheimer's Institute and the Wisconsin Alzheimer's Disease Research Center presented at [Alzheimer's Association International Conference \(AAIC\)](#) (13 July 2014). More time spent engaging in mentally stimulating games was also associated with better performance on cognitive tests of learning, memory and information processing.

The study involved 329 middle-aged adults who were 'cognitively normal' but at an increased risk of developing dementia due to their genetic background or family history. Participants reported their current level of engagement in brain-stimulating activities such as reading books, visiting museums and playing games using the Cognitive Activity Scale. They also underwent MRI brain scans and a series of cognitive tests. Focusing on games such as cards, checkers, crosswords or other puzzles, the researchers found people who reported playing games more often had greater brain volume in several regions involved in Alzheimer's disease (such as the hippocampus) and higher scores on cognitive tests.

The authors of this study suggest that, for some individuals, participation in brain-stimulating activities like game playing could help prevent Alzheimer's disease by preserving vulnerable brain structures and cognitive functions.

One in three cases of Alzheimer's disease worldwide could be prevented, suggests new estimate

As many as one in three cases of Alzheimer's disease worldwide could be prevented by modifying lifestyle factors, according to a study published (14 July 2014) in the journal, [Lancet Neurology](#).

Such lifestyle factors include smoking, midlife-obesity and physical inactivity.

The study, led by researchers at the [Cambridge Institute for Public Health](#) at Cambridge University relied on an analysis of population-based data. It estimated that by reducing the relative risk posed by each lifestyle factor by just ten per cent, it would be possible to prevent nine million cases of dementia by 2050, reducing predicted global prevalence rates by 8.5 per cent. A previous



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study published in 2011 suggested as many as one in two cases of Alzheimer's disease could be prevented, but this earlier research is likely to be less accurate as it looked at each of the risk factors independently.

Smoking increases risk of dementia, according to World Health Organization

Smokers have a 45 per cent higher risk of developing all forms of dementia than non-smokers, according to a recent report.

The report, produced by the [World Health Organization](#) (WHO) in collaboration with Alzheimer's Disease International (ADI) also states that 14 per cent of Alzheimer's disease cases worldwide are estimated to be potentially attributable to smoking.

The report highlights that evidence shows:

The more a person smokes, the higher their risk of developing the condition.

Passive smoking may also increase a person's risk of dementia.

The report recognises that tobacco use is already recognised as the one risk factor common to four main groups of non-communicable diseases (NCDs): cancers; cardiovascular disease; chronic lung disease; and diabetes. ADI suggests that this information should influence countries to include brain health and dementia risk messaging into public health anti-smoking programmes and interventions.

View the full report: [Tobacco use knowledge summaries: tobacco use and dementia](#)

Training in care homes reduces prescription of harmful anti-psychotics to people with dementia by a third.

An innovative training programme for care home staff has cut the use of inappropriate anti-psychotic drugs, which double the risk of death in people with dementia, by a third.

This is according to research commissioned by Alzheimer's Society. Over 100 care homes were recruited to receive the [Focused Intervention Training and Support](#) (FITS) programme – which equips staff to understand complex behaviours in people with dementia and to deliver person-centred care as an alternative to harmful antipsychotics. When medication was reviewed, residents were more alert, communicative and active, with improvements in mobility, eating, sleeping and in achieving personal goals.



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Around 90 per cent of people with dementia will experience behavioural and psychological symptoms at some point. Often, people in care homes experiencing these symptoms are prescribed antipsychotic drugs as a first resort. For someone with dementia, antipsychotic drugs can worsen dementia symptoms, double the risk of death, treble the risk of stroke and can leave people unable to walk and talk.

Proven effective in a clinical trial in 2006, the FITS programme has now been scaled up and completed by staff in 67 care homes across the UK. The intensive nine-month training and supervision programme was delivered by specialist coaches and evaluated by the Association for Dementia Studies at the University of Worcester. Training courses focused on person-centred care approaches and alternative ways of managing the behavioural and psychological symptoms of dementia, which can include aggression.

The study reports that prescriptions of antipsychotic drugs were reduced by 30 per cent in care homes who were part of the programme. As well as showing benefits for people with dementia, the study led by Professor Dawn Brooker at the University of Worcester found that FITS also brought positive benefits to care home staff, residents' families and to the care environment.

The research identifies major barriers that exist to delivering dementia-specific training in care homes, but offers practical solutions to overcome them.

Further information:

[Reducing the use of antipsychotic drugs: A guide to the treatment and care of behavioural and psychological symptoms of dementia](#)

[A systematic review - physical activity in dementia: The influence of the nursing home environment.](#)

Appl Ergon. 2014 Nov; 45(6):1678-1686. Epub 2014 Jun 23.

Anderiesen H, Scherder EJ, Goossens RH, Sonneveld MH.

Most older persons with dementia living in nursing homes spend their days without engaging in much physical activity. This study therefore looked at the influence that the environment has on their level of physical activity, by reviewing empirical studies that measured the effects of environmental stimuli on the physical activity of nursing home residents suffering from dementia. The electronic databases PubMed, PsycINFO, EMBASE, CINAHL and the Cochrane Library were



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used for the search. The search covered studies published between January 1993 and December 2012, and revealed 3187 abstracts. 326 studies were selected as potentially relevant; of these, 24 met all the inclusion criteria. Positive results on the residents' levels of physical activity were found for music, a homelike environment and functional modifications. Predominantly positive results were also found for the small-scale group living concepts. Mixed results were found for bright or timed light, the multisensory environment and differences in the building footprint.

Does physical activity prevent cognitive decline and dementia? A systematic review and meta-analysis of longitudinal studies.

BMC Public Health. Blondell SJ, Hammersley-Mather R, Veerman JL.

BACKGROUND:

By 2050, it has been estimated that approximately one-fifth of the population will be made up of older adults (aged ≥ 60 years). Old age often comes with cognitive decline and dementia. Physical activity may prevent cognitive decline and dementia.

METHODS:

We reviewed and synthesised prospective studies into physical activity and cognitive decline, and physical activity and dementia, published until January 2014. Forty-seven cohorts, derived from two previous systematic reviews and an updated database search, were used in the meta-analyses. Included participants were aged ≥ 40 years, in good health and/or randomly selected from the community. Studies were assessed for methodological quality.

RESULTS:

Twenty-one cohorts on physical activity and cognitive decline and twenty-six cohorts on physical activity and dementia were included. Meta-analysis, using the quality-effects model, suggests that participants with higher levels of physical activity, when compared to those with lower levels, are at reduced risk of cognitive decline, RR 0.65, 95% CI 0.55-0.76, and dementia, RR 0.86, 95% CI 0.76-0.97. Sensitivity analyses revealed a more conservative estimate of the impact of physical activity on cognitive decline and dementia for high quality studies, studies reporting effect sizes as ORs, greater number of adjustments (≥ 10), and longer follow-up time (≥ 10 years). When one heavily weighted study was excluded, physical activity was associated with an 18% reduction in the risk of dementia (RR 0.82; 0.73-0.91).



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CONCLUSIONS:

Longitudinal observational studies show an association between higher levels of physical activity and a reduced risk of cognitive decline and dementia. A case can be made for a causal interpretation. Future research should use objective measures of physical activity, adjust for the full range of confounders and have adequate follow-up length. Ideally, randomised controlled trials will be conducted. Regardless of any effect on cognition, physical activity should be encouraged, as it has been shown to be beneficial on numerous levels.

Full text available at [BMC Public Health](#)

The role of reading on the health and well-being of people with neurological conditions: a systematic review.

Aging Ment Health. 2014;18(6):731-44.

Latchem JM, Greenhalgh J.

Abstract

OBJECTIVES: Little research has been conducted that investigates the benefits of reading for people with neurological conditions despite its age old use to improve well-being. The aim of this study was to identify and review the evidence of the effect of 'lone' reading, reading aloud and shared reading groups on the health and well-being of people with neurological conditions in clinical and long-term care settings.

METHODS: A literature search was conducted incorporating a systematic search of electronic databases, internet searching, 'snowballing' technique from references of relevant studies and consultation with clinicians and academics in the field.

RESULTS: Twelve studies (five quantitative, three qualitative and four mixed methods) met the criteria for inclusion in the review. No randomised controlled trials were identified. Significant heterogeneity in the results of the quantitative studies precluded statistical data synthesis. Thematic analysis and synthesis was applied to the three qualitative studies and the qualitative data of the mixed-method studies. All but one of the quantitative studies reported that the reading interventions had a positive effect. The evidence from the qualitative studies demonstrated multiple positive effects of shared reading groups.



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CONCLUSIONS: The effect of 'lone' reading, reading aloud and shared reading groups on the health and well-being of people with neurological conditions is currently an under-researched area. Although this review reports encouraging results of positive effects, the results should be viewed with caution due to the lack of randomisation, the small numbers of participants involved, and the limited and heterogeneous evidence base.

Related reference: [A literature-based intervention for older people living with dementia](#): an evaluation report by the Centre for Research into Reading, Information and Linguistic Systems. Liverpool: University of Liverpool Centre for Research into Reading, Information and Linguistic Systems (CRILS), May 2012.

Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales.

Aging Ment Health. 2014 Jun 2:1-19. [Epub ahead of print]

Bowling A, Rowe G, Adams S, Sands P, Samsi K, Crane M, Joly L, Manthorpe J.

Abstract

Objectives: Ascertaining the quality of life (QoL) in people with dementia is important for evaluating service outcomes and cost-effectiveness. This paper identifies QoL measures for people with dementia and assesses their properties. Method: A systematic narrative review identified articles using dementia QoL measures. Electronic databases searched were AMED, CINAHL, EMBASE, Index to Theses, IBSS, MEDLINE, PsycINFO, Sociological Abstracts, and Web of Science. All available years and languages (if with an English language abstract) were included. Results: Searches yielded 6806 citations; 3043 were multiple duplicates (759 being true duplicates). Abstracts were read; 182 full papers were selected/obtained, of which 126 were included as relevant. Few measures were based on rigorous conceptual frameworks. Some referenced Lawton's model (Dementia Quality of Life [DQOL] and Quality of Life in Alzheimer's Disease [QOL-AD]), though these tapped part of this only; others claimed relationship to a health-related QoL concept (e.g. DEMQOL), though had less social relevance; others were based on limited domains (e.g. activity, affect) or clinical opinions (Quality of Life in Late-Stage Dementia [QUALID]). Many measures were based on proxy assessments or observations of people with dementia's QoL, rather than their own ratings. The Bath Assessment of Subjective Quality of Life in Dementia (BASQID) was developed involving people with dementia and caregivers, but excluded some of their main themes. All measures were tested on selective samples only (ranging from community to hospital clinics, or subsamples/waves of existing population surveys), in a few



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sites. Their general applicability remains unknown, and predictive validity remains largely untested. Conclusion: The lack of consensus on measuring QoL in dementia suggests a need for a broader, more rigorously tested QoL measure.

Barriers to the management of pain in dementia care.

Chandler, R. Bruneau, B. Nursing Times. July 4th 2014, 110(28), pp.12-16.

Pain in people with dementia often goes undiagnosed, despite being a probable cause of distressed behaviour. It tends to be under-assessed and under-treated. This review covers the main barriers to effective assessment and management of pain in patients with dementia, and discusses strategies to overcome those barriers. Nurses are advised to use recognised pain assessment tools and tailor pain management to patients' needs.

The authors advise that further research is necessary to explore barriers in the management of pain for this patient group, aimed at developing improved evidence-based pain management strategies.

Epidemiologic studies of modifiable factors associated with cognition and dementia: systematic review and meta-analysis.

BMC Public Health. 2014 Jun 24

Beydoun MA1, Beydoun HA, Gamaldo AA, Teel A, Zonderman AB, Wang Y.

BACKGROUND: Cognitive impairment, including dementia, is a major health concern with the increasing aging population. Preventive measures to delay cognitive decline are of utmost importance. Alzheimer's disease (AD) is the most frequent cause of dementia, increasing in prevalence from <1% below the age of 60 years to >40% above 85 years of age.

METHODS: We systematically reviewed selected modifiable factors such as education, smoking, alcohol, physical activity, caffeine, antioxidants, homocysteine (Hcy), n-3 fatty acids that were studied in relation to various cognitive health outcomes, including incident AD. We searched MEDLINE for published literature (January 1990 through October 2012), including cross-sectional and cohort studies (sample sizes > 300). Analyses compared study finding consistency across factors, study designs and study-level characteristics. Selecting studies of incident AD, our meta-analysis estimated pooled risk ratios (RR), population attributable risk percent (PAR%) and assessed publication bias.



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RESULTS: In total, 247 studies were retrieved for systematic review. Consistency analysis for each risk factor suggested positive findings ranging from ~38.9% for caffeine to ~89% for physical activity. Education also had a significantly higher propensity for "a positive finding" compared to caffeine, smoking and antioxidant-related studies. Meta-analysis of 31 studies with incident AD yielded pooled RR for low education (RR = 1.99; 95% CI: 1.30-3.04), high Hcy (RR = 1.93; 95% CI: 1.50-2.49), and current/ever smoking status (RR = 1.37; 95% CI: 1.23-1.52) while indicating protective effects of higher physical activity and n-3 fatty acids. Estimated PAR% were particularly high for physical activity (PAR% = 31.9; 95% CI: 22.7-41.2) and smoking (PAR% = 31.09%; 95% CI: 17.9-44.3). Overall, no significant publication bias was found.

CONCLUSIONS: Higher Hcy levels, lower educational attainment, and decreased physical activity were particularly strong predictors of incident AD. Further studies are needed to support other potential modifiable protective factors, such as caffeine.

Full text available at [BMC Public Health](#)

Dementia care in the context of primary care reform: an integrative review.

Aging Ment Health. 2014 Jun 5:1-14. [Epub ahead of print]

Spenceley SM1, Sedgwick N, Keenan J.

Abstract

Objectives: The purpose of this review was to determine the influence of the growing body of evidence about the attributes of high-performing primary care systems on the literature related to the primary care of people living with dementia. Methods: In this integrative review, we examined a broad range of published and grey literature (2000-2013) about the primary care of dementia, using a systematic approach set up in advance of the literature search. The review was guided by two questions: What are the evident models of primary care for dementia? How do the models line up with the other attributes of high-performing primary care? Results: Three models were noted: carved-out, co-managed, and integrative-hub, all informed by different assumptions about the role of primary care in dementia. The models varied in alignment with the attributes of high-performing primary care, although we found very little attention to accessibility, relational continuity or comprehensiveness of care. Conclusions: We know what we need to pay attention to in building our primary care system - and no population will put the performance of primary care more to the test over the next two decades than the rapidly growing number of people who will be living with complex chronic conditions like dementia. Recent literature around primary care and dementia shows promise in attending to some of the attributes of high-performing



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primary care, yet much more work is needed if we are to truly leverage the potential value of primary care in addressing the needs of these complex and numerous future patients.

The disconnect between evidence and practice: a systematic review of person-centred interventions and training manuals for care home staff working with people with dementia.

Int J Geriatr Psychiatry. 2014 Aug;29(8):797-807.

Fossey J, Masson S, Stafford J, Lawrence V, Corbett A, Ballard C.

Abstract

OBJECTIVE: The overall objective is to determine the availability of person-centred intervention and training manuals for dementia care staff with clinical trial evidence of efficacy.

DESIGN: Interventions were identified using a search of electronic databases, augmented by mainstream search engines, reference lists, hand searching for resources and consultation with an expert panel. The specific search for published manuals was complemented by a search for randomised control trials focussing on training and activity-based interventions for people with dementia in care homes. Manuals were screened for eligibility and rated to assess their quality, relevance and feasibility.

RESULTS: A meta-analysis of randomised control trials indicated that person-centred training interventions conferred significant benefit in improving agitation and reducing the use of antipsychotics. Each of the efficacious packages included a sustained period of joint working and supervision with a trained mental health professional in addition to an educational element. However, of the 170 manuals that were identified, 30 met the quality criteria and only four had been evaluated in clinical trials.

CONCLUSIONS: Despite the availability of a small number of evidence-based training manuals, there is a widespread use of person-centred intervention and training manuals that are not evidence-based. Clearer guidance is needed to ensure that commissioned training and interventions are based on robust evidence.



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Effectiveness of computer-mediated interventions for informal carers of people with dementia-a systematic review.

Int Psychogeriatr. 2014 Jul 3:1-19. [Epub ahead of print]

McKechnie V, Barker C, Stott J.

Abstract

ABSTRACT Background: Caring for a friend or relative with dementia can be burdensome and stressful, and puts carers at increased risk of physical and psychological problems. A number of psychosocial interventions, some delivered by computer, have been developed to support carers. This review evaluates the outcomes of computer-mediated interventions. Methods: PsychINFO, MEDLINE, and CINAHL Plus were searched for papers published between January 2000 and September 2012. Study quality was evaluated using a modified version of Downs and Black's (1998) checklist. Results: Fourteen empirical studies, evaluating a range of complex, multifaceted interventions, met inclusion criteria. The most commonly measured variables were carer burden/stress and depression. In general, higher quality studies found that interventions did have an effect on these variables. Two higher quality studies also found that anxiety was reduced following intervention. Most studies found that positive aspects of caring were increased through these interventions, as was carer self-efficacy. There were mixed results in relation to social support, and physical aspects of caring did not seem to be affected. Program impact measures indicated general acceptability of these interventions. Conclusions: The findings support the provision of computer-mediated interventions for carers of people with dementia. Future studies would benefit from design improvements, such as articulating clearly defined aims, having a control group, having adequate statistical power, and measuring a greater range of factors important to carers themselves.

View the full text from [Cambridge Journals online](#)

Family involvement in decision making for people with dementia in residential aged care: a systematic review of quantitative literature.

Int J Evid Based Healthc. 2014 Jun;12(2):64-86.

Petriwskyj A1, Gibson A, Parker D, Banks S, Andrews S, Robinson A.



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Abstract

AIM: Ensuring older adults' involvement in their care is accepted as good practice and is vital, particularly for people with dementia, whose care and treatment needs change considerably over the course of the illness. However, involving family members in decision making on people's behalf is still practically difficult for staff and family. The aim of this review was to identify and appraise the existing quantitative evidence about family involvement in decision making for people with dementia living in residential aged care.

METHODS: The present Joanna Briggs Institute (JBI) metasynthesis assessed studies that investigated involvement of family members in decision making for people with dementia in residential aged care settings. While quantitative and qualitative studies were included in the review, this paper presents the quantitative findings. A comprehensive search of 15 electronic databases was performed. The search was limited to papers published in English, from 1990 to 2013. Twenty-six studies were identified as being relevant; 10 were quantitative, with 1 mixed method study. Two independent reviewers assessed the studies for methodological validity and extracted the data using the JBI Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI). The findings were synthesized and presented in narrative form.

RESULTS: The findings related to decisions encountered and made by family surrogates, variables associated with decisions, surrogates' perceptions of, and preferences for, their roles, as well as outcomes for people with dementia and their families.

CONCLUSIONS: The results identified patterns within, and variables associated with, surrogate decision making, all of which highlight the complexity and variation regarding family involvement. Attention needs to be paid to supporting family members in decision making in collaboration with staff.

[Self-efficacy and health-related quality of life in family carers of people with dementia: a systematic review.](#)

Aging Ment Health. 2014 Jun 19:1-16. [Epub ahead of print]

Crellin NE1, Orrell M, McDermott O, Charlesworth G.

Abstract

Objectives: This review aims to explore the role of self-efficacy (SE) in the health-related quality of life (QoL) of family carers of people with dementia. **Methods:** A systematic review of literature



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identified a range of qualitative and quantitative studies. Search terms related to caring, SE, and dementia. Narrative synthesis was adopted to synthesise the findings. Results: Twenty-two studies met the full inclusion criteria, these included 17 quantitative, four qualitative, and one mixed-method study. A model describing the role of task/domain-specific SE beliefs in family carer health-related QoL was constructed. This model was informed by review findings and discussed in the context of existing conceptual models of carer adaptation and empirical research. Review findings offer support for the application of the SE theory to caring and for the two-factor view of carer appraisals and well-being. Findings do not support the independence of the negative and positive pathways. The review was valuable in highlighting methodological challenges confronting this area of research, particularly the conceptualisation and measurement issues surrounding both SE and health-related QoL. Conclusions: The model might have theoretical implications in guiding future research and advancing theoretical models of caring. It might also have clinical implications in facilitating the development of carer support services aimed at improving SE. The review highlights the need for future research, particularly longitudinal research, and further exploration of domain/task-specific SE beliefs, the influence of carer characteristics, and other mediating/moderating variables.

Read the full text at [Taylor & Francis online](#)

Social support group interventions in people with dementia and mild cognitive impairment: a systematic review of the literature.

Int J Geriatr Psychiatry. 2014 Jul 3. [Epub ahead of print]

Leung P1, Orrell M, Orgeta V.

Abstract

OBJECTIVES: Despite the large number of studies evaluating social support groups for people with dementia, there are no systematic reviews of current evidence. The aim of this study was to evaluate the effectiveness of social support group interventions for people with dementia and mild cognitive impairment.

METHODS: A systematic review was performed. We searched electronic databases for randomised controlled trials. Two reviewers worked independently to select trials, extract data and assess risk of bias.

RESULTS: A total of 546 studies were identified of which two met the inclusion criteria. We were not able to pool data for further analyses, as the interventions tested in the studies meeting the



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inclusion criteria were too dissimilar in content. The first trial (n = 136) showed a benefit of early-stage memory loss social support groups for depression and quality of life in people with dementia. The second trial (n = 33) showed that post-treatment self-reported self-esteem was higher in the group receiving a multicomponent intervention of social support compared with that in the no intervention control group.

CONCLUSIONS: Limited data from two studies suggest that support groups may be of psychological benefit to people with dementia by reducing depression and improving quality of life and self-esteem. These findings need to be viewed in light of the small number, small sample size and heterogeneous characteristics of current trials, indicating that it is difficult to draw any conclusions. More multicentre randomised controlled trials in social support group interventions for people with dementia are needed.

[A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioural interventions for managing agitation in older adults with dementia.](#)

Health Technol Assess. 2014 Jun;18(39)

Livingston G, Kelly L, Lewis-Holmes E, Baio G, Morris S, Patel N, Omar RZ, Katona C, Cooper C.

BACKGROUND: Agitation is common, persistent and distressing in dementia and is linked with care breakdown. Psychotropic medication is often ineffective or harmful, but the evidence regarding non-pharmacological interventions is unclear.

OBJECTIVES: We systematically reviewed and synthesised the evidence for clinical effectiveness and cost-effectiveness of non-pharmacological interventions for reducing agitation in dementia, considering dementia severity, the setting, the person with whom the intervention is implemented, whether the effects are immediate or longer term, and cost-effectiveness.

DATA SOURCES: We searched twice using relevant search terms (9 August 2011 and 12 June 2012) in Web of Knowledge (incorporating MEDLINE); EMBASE; British Nursing Index; the Health Technology Assessment programme database; PsycINFO; NHS Evidence; System for Information on Grey Literature; The Stationery Office Official Documents website; The Stationery National Technical Information Service; Cumulative Index to Nursing and Allied Health Literature; and The Cochrane Library. We also searched Cochrane reviews of interventions for behaviour in dementia, included papers' references, and contacted authors about 'missed' studies. We included



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quantitative studies, evaluating non-pharmacological interventions for agitation in dementia, in all settings.

REVIEW METHOD: We rated quality, prioritising higher-quality studies. We separated results by intervention type and agitation level. As we were unable to meta-analyse results except for light therapy, we present a qualitative evidence synthesis. In addition, we calculated standardised effect sizes (SESSs) with available data, to compare heterogeneous interventions. In the health economic analysis, we reviewed economic studies, calculated the cost of effective interventions from the effectiveness review, calculated the incremental cost per unit improvement in agitation, used data from a cohort study to evaluate the relationship between health and social care costs and health-related quality of life (DEMQOL-Proxy-U scores) and developed a new cost-effectiveness model.

RESULTS: We included 160 out of 1916 papers screened. Supervised person-centred care, communication skills (SES = -1.8 to -0.3) or modified dementia care mapping (DCM) with implementing plans (SES = -1.4 to -0.6) were all efficacious at reducing clinically significant agitation in care home residents, both immediately and up to 6 months afterwards. In care home residents, during interventions but not at follow-up, activities (SES = -0.8 to -0.6) and music therapy (SES = -0.8 to -0.5) by protocol reduced mean levels of agitation; sensory intervention (SES = -1.3 to -0.6) reduced mean and clinically significant symptoms. Advantages were not demonstrated with 'therapeutic touch' or individualised activity. Aromatherapy and light therapy did not show clinical effectiveness. Training family carers in behavioural or cognitive interventions did not decrease severe agitation. The few studies reporting activities of daily living or quality-of-life outcomes found no improvement, even when agitation had improved. We identified two health economic studies. Costs of interventions which significantly impacted on agitation were activities, £80-696; music therapy, £13-27; sensory interventions, £3-527; and training paid caregivers in person-centred care or communication skills with or without behavioural management training and DCM, £31-339. Among the 11 interventions that were evaluated using the Cohen-Mansfield Agitation Inventory (CMAI), the incremental cost per unit reduction in CMAI score ranged from £162 to £3480 for activities, £4 for music therapy, £24 to £143 for sensory interventions, and £6 to £62 for training paid caregivers in person-centred care or communication skills with or without behavioural management training and DCM. Health and social care costs ranged from around £7000 over 3 months in people without clinically significant agitation symptoms to around £15,000 at the most severe agitation levels. There is some evidence that DEMQOL-Proxy-U scores decline with Neuropsychiatric Inventory agitation scores. A multicomponent intervention in participants with mild to moderate dementia had a positive monetary net benefit and a 82.2% probability of being cost-effective at a maximum willingness to pay for a quality-adjusted life-year of £20,000 and a 83.18% probability at a value of £30,000.



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LIMITATIONS: Although there were some high-quality studies, there were only 33 reasonably sized (> 45 participants) randomised controlled trials, and lack of evidence means that we cannot comment on many interventions' effectiveness. There were no hospital studies and few studies in people's homes. More health economic data are needed.

CONCLUSIONS: Person-centred care, communication skills and DCM (all with supervision), sensory therapy activities, and structured music therapies reduce agitation in care-home dementia residents. Future interventions should change care home culture through staff training and permanently implement evidence-based treatments and evaluate health economics. There is a need for further work on interventions for agitation in people with dementia living in their own homes.

[The value of personalized psychosocial interventions to address behavioral and psychological symptoms in people with dementia living in care home settings: a systematic review.](#)

Int Psychogeriatr. 2014 Jul;26(7):1083-98.

Testad I, Corbett A, Aarsland D, Lexow KO, Fossey J, Woods B, Ballard C.

Several important systematic reviews and meta-analyses focusing on psychosocial interventions have been undertaken in the last decade. However, they have not focused specifically on the treatment of individual behavioral and psychological symptoms of dementia (BPSD) with personalized interventions. This updated systematic review will focus on studies reporting the effect of personalized psychosocial interventions on key BPSD in care homes.

RESULTS:

641 studies were identified, of which 40 fulfilled inclusion and exclusion criteria. There was good evidence to support the value of personalized pleasant activities with and without social interaction for the treatment of agitation, and reminiscence therapy to improve mood. The evidence for other therapies was more limited.

CONCLUSIONS:

There is a growing body of evidence indicating specific effects of different personalized psychosocial interventions on individual BPSD and mood outcomes.

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Dementia pathways.

NICE

The following NICE pathways are available open access at the following urls. Clicking on a section within the pathway will bring up explanatory notes and additional material such as 'implementation tools' and 'source guidance'

Dementia overview

<http://pathways.nice.org.uk/pathways/dementia>

Dementia diagnosis and assessment

<http://pathways.nice.org.uk/pathways/dementia/dementia-diagnosis-and-assessment>

Dementia interventions

<http://pathways.nice.org.uk/pathways/dementia/dementia-interventions>

Map of Medicine

The Map of Medicine is a collection of evidence-based, practice-informed care maps which connect all the knowledge and services around a clinical condition.

The Map of Medicine 'Dementia' care map has recently been updated to include the latest guidance from NICE, WHO, and the European Federation of Neurological Societies (EFNS). It provides succinct, accessible information on the diagnosis, assessment, and management of people with dementia, as well as advice on dealing with co-morbid emotional disorders and supportive information for carers.

An NHS Athens username/password is required to view this resource

<http://directaccess.mapofmedicine.com/evidence/terms.htm?next=/map/dementia1.html>

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Clinical Pathways ... Knowledge Management ... Books ... Journals ... Critical Appraisal ... Bulletins ... Alerts ... DynaMed ...

Map of Medicine ... Health Education Resources ... Athens ... Laptops ... Literature Searching ... MEDLINE ... Referencing ...



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Latest Guidance

Delirium: NICE Quality Standard 63

London: National Institute for Health and Care Excellence (NICE), July 2014.

The National Institute for Health and Care Excellence (NICE) has published a new quality standard “Delirium: Quality Standard (QS63)”, which covers the prevention, diagnosis and management of delirium in adults (aged 18 years and over) in hospital and long-term care settings.

“Older people, and people with cognitive impairment, dementia, severe illness or a hip fracture, are more at risk of delirium. About 20–30% of people on medical wards in hospital have delirium, and between 10% and 50% of people who have surgery develop delirium, with considerable variation across different types of surgery and settings. In long-term care settings, the prevalence of delirium is under 20%”.

This quality standard is expected to help improve the detection and incidence of delirium, and should help in reducing length of hospital stay, falls and mortality in hospitals. QS63 might also improve the overall experience of hospital care and carer involvement in healthcare.

There is an accompanying [Delirium NICE Care Pathway](#), originally issued in September 2012 and now updated.

Disability, Dementia and Frailty in Later Life: Mid-Life Approaches to Prevention (NICE Guideline Consultation)

The National Institute for Health and Care Excellence (NICE) is developing a public health guideline on disability, dementia and frailty in later life. It concentrates on mid-life approaches and public health interventions to prevent or delay the onset of these conditions.

Supporting evidence / documentation available [here](#)

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Supporting the health and wellbeing of adult carers.

Community Nursing Programme: Professional pathway for community nurses.

This Department of Health guidance covers support for adult carers by community nurses. It is aimed at district and general practice nurses, health professionals generally, commissioners and service providers.

There have been no further updates to the below UK guidelines since the last Dementia bulletin

Dementia: Supporting people with dementia and their carers in health and social care.

Issued: November 2006 last modified: October 2012 Next review date: April 2014

<http://www.nice.org.uk/nicemedia/live/10998/30318/30318.pdf>

Clinical Knowledge Summaries: <http://cks.nice.org.uk/dementia#!topicssummary>

Department of Health: Living Well With Dementia: a national dementia strategy

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

Department of Health: Improving care for people with dementia

<https://www.gov.uk/government/policies/improving-care-for-people-with-dementia>

International Guidance:

Improving Dementia Long-Term Care and Support (RAND Corporation)

This report from the United States identifies 25 policy options covering five broad objectives to improve and support the delivery of “long-term services and supports” (LTSS). The five top-level objectives comprise:

Objective 1: Increase public awareness of dementia to reduce stigma and promote earlier detection of signs and symptoms.

Objective 2: Improve access to and utilization of LTSS for persons with dementia.

Objective 3: Promote high-quality, person- and family caregiver-centered care.

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Objective 4: Provide better support for family caregivers of people with dementia.

Objective 5: Reduce the burden of dementia LTSS costs on individuals and families.

Reference: *Shih, RA. Concannon, TW. Liu, JL. [and] Friedman, E. (2014). Improving dementia long-term care: a policy blueprint. [United States]: RAND Corporation, June 2014. ISBN: 978-0-8330-8630-3.*

Useful links

NHS Evidence dementia:

<https://www.evidence.nhs.uk/topic/dementias?q=dementia>

NHS Choices – Dementia Choices:

<http://www.nhs.uk/conditions/dementia-guide/Pages/dementia-choices.aspx>

Supporting people to live well with dementia: information for the public:

<http://www.nice.org.uk/nicemedia/live/14141/63423/63423.pdf>

This bulletin draws from a number of sources including The Alzheimer's Society and Dementia and Elderly Care News. You are welcome to reuse and share the content of this bulletin, but please acknowledge the TRFT Library and Knowledge Service as originating source.

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The evidence you need