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NHS Foundation Trust

Dementia

Current Awareness Bulletin

December 2025

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What are the best practices for managing bedridden patients with dementia?

Managing bedridden dementia patients involves pain management, personalized activities, psychosocial support, dignity-preserving continence care, and interprofessional teamwork, though implementation challenges remain.

What are the most effective interventions for managing dementia in hospitalized elderly patients?

Interventions for hospitalized elderly dementia patients show potential benefits, yet evidence varies and underscores the need for more comprehensive and standardized research.

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1. **Co-design of an Online Mindfulness Program for Informal Carers of People Living With Dementia: A Qualitative Study of Co-designers' Experience**

Authors: Abeysinghe Mudiyanselage, Charunya A. K. R.;Ang, Seng Giap Marcus;Smyth, Aisling;Dickson, Joanne M. and Ewens, Beverley

Publication Date: 2026

Journal: Dementia (14713012) 25(1), pp. 153–172

Abstract: Introduction: Informal carers face significant challenges related to care provision for people living with dementia. Participating in a mindfulness-based stress reduction program could improve the wellbeing of informal carers. However, engaging in these programs can be difficult for informal carers due to the needs of their care recipients. Purpose: This study aimed to co-design an online mindfulness program in collaboration with a range of stakeholders and those with lived experience as carers. Methods: This co-design study adopted an interpretive descriptive qualitative approach to the development of the program. The stakeholders (co-designers) included people with lived experience as informal carers and experts with experience in delivering mindfulness programs. The co-designers reviewed the program content which comprised a range of resources including a booklet, online content and audio recordings of mindfulness activities and provided feedback on the content and delivery methods, via one-to-one interviews. The data were synthesised via inductive content analysis. Findings: Two main categories were formulated: support for participants and program delivery and content. Sub categories for support for participants included, recognition of participants' roles, promoting self-care and acceptance through mindfulness, accounting for participants' limitations, developing a virtual social support network and providing support beyond the program. Sub-categories for program delivery and content included tailoring the program to the practical needs of the participants, providing options for program delivery and ensure a culturally safe program. Conclusion: Co-design approaches in collaboration with people with lived experience is essential for the successful adaptation of authentic and appropriate programs which account for carers' complex care demands and individual challenges. Co-design is an approach that can provide valuable insight about tailoring online programs for end-users to minimise implementation challenges and maximise the potential benefits.

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2. **A 'personhood paradox': Care partners' experiences supporting people with dementia and incontinence**

Authors: Burholt, Vanessa;Orton, Yasmin;Awatere, Sharon A. and Daltrey, Julie F.

Publication Date: 2026

Journal: Dementia (14713012) 25(1), pp. 65–84

Abstract: Globally, 50 million people live with dementia and mostly receive care at home. Urinary, faecal and functional incontinence is common in this population and increases care demands. This study explores care partners' experiences managing continence care for people with dementia in Aotearoa New Zealand. The data are drawn from a cross-sectional qualitative study with 18 care partners of people with dementia and incontinence in mid and northern regions of Aotearoa New Zealand. Participants were interviewed face-to-face from June 2022 to April 2023. Data were analysed using Interpretive Phenomenological Analysis. Six Generalised Experiential Themes emerged. Care partners engaged in autobiographical and biographical meaning-making to interpret behaviours and maintain the personhood of people with dementia, focusing on dignity, identity, and social inclusion. However, caregiving often undermined care partners' personhood due to the physical and emotional demands of continence care. Access to resources was challenging, and healthcare support was often perceived as inadequate. Some care partners' strategies to find meaning and joy in everyday life contributed to resilience, while others experienced stress, fatigue, and burnout. Care partners used personal knowledge to support personhood, especially in social engagement. Uncertainty in managing incontinence led to self-doubt, exacerbated by the medicalised nature of continence care, which involves intimate attention beyond typical caregiving. Timely, credible advice could reduce uncertainty, but many found seeking resources overwhelming. Balancing their own well-being with caregiving highlights the need for support systems addressing the requirements of both care partners and people with dementia.

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3. **Family carers and the provision of person-centred dementia care for activities of daily living**

Authors: Carparelli, Chiara;Oyebode, Jan R. and Riley, Gerard A.

Publication Date: 2026

Journal: Dementia (14713012) 25(1), pp. 3–24

Abstract: Care provided by family members is not always consistent with the principles of person-centred dementia care (PCDC) and interventions to improve the quality of care are needed. A good foundation for the development of such interventions is provided by an understanding of how good and poor care practices are manifested in everyday care, and of the challenges to providing good quality care. Thirty people providing care to a spouse or partner with dementia were interviewed, and asked to describe examples of the care they provided for activities of daily living and the challenges to providing

good quality care. Framework analysis was used to guide and interpret the interviews. Interpretation was guided by the VIPS conceptualisation of PCDC which incorporates the principles of Valuing, Individual, Perspective, and Social. The quality of care varied, and examples of good and poor care practices are described. The principles of PCDC were sometimes in conflict with one another and with other considerations, such as personal safety and the wellbeing of the carer. Participants were often faced with challenging decisions in which they had to weigh up these different issues. To be credible, guidance for carers need to reflect the complexity of the issues they face.

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4. **Pilot of a multicomponent program for people with dementia and their care partners: Health services staff expectations, experiences and observations**

Authors: D'Cunha, Nathan,M.;Chelberg, Georgina;Holloway, Helen;Wiseman, Lara;Fearon, Angie;Kellett, Jane;Isbel, Stephen;Bail, Kasia;Huang, Ian and Gibson, Diane

Publication Date: 2026

Journal: Dementia (14713012) 25(1), pp. 25–45

Abstract: There is increased recognition of the need to improve post-diagnostic pathways for people with dementia and their care partners living in the community to access rehabilitation services to support independence and wellbeing. However, there is minimal evidence on implementing rehabilitation services for this population. The study aimed to present the expectations and experiences of allied health staff involved in piloting the Sustainable Personalised Interventions for Cognition, Care and Engagement (SPICE) program based at an outpatient clinic of a public rehabilitation hospital. Over twelve weeks, the program combines small group and dyadic evidence-based interventions including cognitive stimulation therapy, occupational therapy, physical activity, care partner education, and dietetics. A qualitative exploratory methodology was used with pre- and post-program interviews conducted with ten allied health staff. Questions were designed to elicit the expected and actual benefits and challenges of the initial implementation of the multicomponent program. The multidisciplinary team were motivated by the potential for the SPICE program to meet an important service gap, and confident people with dementia and their care partners would benefit. Staff reported enjoyment, satisfaction, and confidence in delivering the program, and believed the multiple components had synergistic effects on participants, particularly regarding social connection and functional engagement. While staff had pre-program concerns regarding retention, participant fatigue, and managing challenging situations, these were not realised. At times, staff observed program intensity to cause unintended stress for some care partners. Resourcing and strategies to ensure sustainability were identified as important by staff, as well as the need for ongoing support to participants post-program. Overall, the SPICE program exceeded expectations and was rewarding for staff. Further work to refine and evaluate the program is necessary to support its potential to continue providing dementia rehabilitation to promote the independence and wellbeing of people with dementia and care partners living in the community.

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5. **The impact of music therapy on agitation in elderly patients with dementia: A systematic review and meta-analysis**

Authors: Hu, Jing and Xu, Ling

Publication Date: 2026a

Journal: Archives of Gerontology & Geriatrics 140, pp. N.PAG

Abstract: • This review demonstrated that music therapy improves agitation behavior in older adults with dementia, showing moderate effect size in 10 RCTS and 4 pre-post controlled studies in the meta-analyses. There was no risk of publication bias. • Music therapy was effective in treating agitation in dementia patients regardless of heterogeneity, such as the time and type of music, which highlights the generalization of music therapy, especially in economically backward regions. • The encouraging findings provide a basis for futher studies and clinical trials, standardization of protocols and long-term efficacy studies are needed to optimize its clinical application. Agitation impacts 50 - 80 % of elderly dementia patients, imposing burdens on caregivers and healthcare systems. Pharmacological treatments are limited, whereas non-pharmacological music therapy (MT) holds promise. This study sought to evaluate MT's efficacy in alleviating agitation. A thorough search across multiple databases was carried out, incorporating 14 studies (10 RCTs, 4 pre-post trials; n = 847). Meta-analysis demonstrated that MT significantly reduced agitation with a moderate effect size (d = 0.42). Subgroup analyses yielded consistent findings. Heterogeneity was low, and publication bias was negligible. MT effectively mitigated agitation in dementia patients despite heterogeneity in aspects like music duration and genre, underscoring its generalizability, particularly in resource-constrained areas and households lacking professional nursing support. It offers evidence for integrating MT into patient care. The review was registered on PROSPERO (CRD420251033860).

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6. **The impact of music therapy on agitation in elderly patients with dementia: A systematic review and meta-analysis**

Authors: Hu, Jing and Xu, Ling

Publication Date: 2026b

Journal: Archives of Gerontology and Geriatrics 140, pp. 106048

Abstract: Competing Interests: Declaration of competing interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.; Agitation impacts 50 - 80 % of elderly dementia patients, imposing burdens on caregivers and healthcare systems. Pharmacological treatments are limited, whereas non-pharmacological music therapy (MT) holds promise. This study sought to evaluate MT's efficacy in alleviating agitation. A thorough search across multiple databases was carried out, incorporating 14 studies (10 RCTs, 4 pre-post trials; n = 847). Meta-analysis demonstrated that MT significantly reduced agitation with a moderate effect size (d = 0.42). Subgroup analyses yielded consistent findings. Heterogeneity was low, and publication bias was negligible. MT effectively mitigated agitation in dementia patients despite heterogeneity in aspects like music duration and genre, underscoring its generalizability, particularly in resource-constrained areas and households lacking professional nursing support. It offers evidence for integrating MT into patient care. The review was registered on PROSPERO (CRD420251033860). (Copyright © 2025 Elsevier B.V. All rights reserved.)

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7. **Antidiabetic agents and dementia risk in type 2 diabetes: A systematic review and network meta-analysis**

Authors: Kato, Sayaka;Ozu, Naoki;Yamakage, Hajime;Kato, Hisashi;Iuchi, Takujiro;Suzuki, Ryo;Noto, Hiroshi;Tanaka, Masashi;Fukui, Michiaki;Noda, Mitsuhiko and Satoh-Asahara, Noriko

Publication Date: 2026

Journal: Diabetes, Obesity & Metabolism 28(1), pp. 256–264

Abstract: Aims: Certain antidiabetic agents may prevent dementia in patients with type 2 diabetes mellitus (T2DM). The purpose of this study is to elucidate the relative effect of antidiabetic agents on reducing dementia risk in patients with T2DM.; Materials and Methods: PubMed, Cochrane Library and Igaku Chuo Zasshi-Web from inception to 31 December 2023 were searched. Trials reported in English or Japanese language that assessed the effects of glucose-lowering drugs on dementia were selected.; Results: Overall, 67 trials (4 088 683 individuals) assessing nine antidiabetic agent classes were included. Studies comprised monotherapies versus control (no use of antidiabetic agents or placebo) (three trials), monotherapies versus add-on therapies (one trial) and real-world database studies (63 trials). The analysis showed that the risk of dementia decreased with sodium-glucose cotransporter 2 inhibitors (SGLT2i), glucagon-like peptide-1 receptor agonists (GLP1-RA), thiazolidinediones (TZD) and dipeptidyl peptidase-4 inhibitors (DPP4i) compared with the reference (placebo, no use of antidiabetic agents or other antidiabetic agents). Conversely, insulin was associated with an increased risk of dementia, whereas no significant association was found with the use of metformin, sulfonylureas, glinides and α-glucosidase inhibitors. Analyses of treatment rankings further revealed the relative effect on reducing dementia risk in the following order: SGLT2i > GLP1-RA > TZD > DPP4i; insulin ranked the lowest.; Conclusions: The most effective antidiabetic agent in reducing dementia risk in T2DM is SGLT2i, followed by GLP1-RA, TZD and DPP4i, whereas insulin is associated with an elevated risk of dementia. (© 2025 John Wiley & Sons Ltd.)

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8. **Tooth Loss in Individuals with Dementia: A Swedish Register-Based Cohort Study**

Authors: Mohammadi, M.;Holmer, J.;Imberg, H.;Albrektsson, H.;Eriksdotter, M. and Buhlin, K.

Publication Date: 2026

Journal: Journal of Dental Research 105(1), pp. 149–155

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9. **Elder Clowning Interventions for Persons With Dementia in Long-Term Care: A Systematic Review and Metasynthesis of Qualitative Research**

Authors: Roberts, Sara-Jane;Luckett, Tim;Ivynian, Serra and DiGiacomo, Michelle

Publication Date: 2026

Journal: Dementia (14713012) 25(1), pp. 192–214

Abstract: Elder clowning is a psychosocial intervention delivered to persons living with dementia in long-term care. It aims to improve quality of life through interpersonal interaction and connection. This review aimed to synthesise international cross-disciplinary qualitative research regarding elder clowning specialist capabilities, engagement techniques, and potential benefits, for persons living with dementia, their families, and staff. The method was informed by systematic review methodologies. A comprehensive search of major health databases was undertaken. The search identified 198 studies, 15 articles from 10 studies were appraised and included in the review. Three major themes resulted from the synthesis: 1) understanding the elder clown, 2) journeying together to cultivate connection, and 3) promoting wellbeing through connection. Elder clowns were suggested to be perceptive, attuned, empathetic, present, adaptive, and performative. These capabilities supported a wide range of engagement techniques used to prepare for, approach, initiate, sustain, redirect, appeal for, and exit engagement with persons with dementia, which resulted in potential benefits across cognitive, behavioural, emotional, social, and experiential domains. The synthesis offers a common rubric for describing the components of elder clowning interventions for use across disciplines and identifies potential benefits to aid in the design of future trials of effectiveness.

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10. **Meaning making during bereavement as part of caregiver speaks, a narrative photo-elicitation intervention for Caregivers of persons living with dementia**

Authors: Yang, Annabelle R.;Washington, Karla T.;Benson, Jacquelyn J.;Bogdewiecz, Taryn L. and Rolbiecki, Abigail J.

Publication Date: 2026

Journal: Dementia (14713012) 25(1), pp. 85–109

Abstract: A majority of persons living with dementia rely on informal family and friend caregivers. These caregivers shoulder immense responsibility while the person living with dementia is alive, and during bereavement are at risk for complicated grief or other psychobiological complications. Meaning making, the process of accommodating worldviews and beliefs to make meaning of a death, can mitigate the risk for complications of grief during bereavement. This meaning making can be facilitated by storytelling photo-elicitation interventions, which invite caregivers to narrate their experiences and emotions using images. Caregiver Speaks is one such photo-elicitation intervention. In this study, we sought to understand how caregivers of persons living with dementia who participated in Caregiver Speaks made meaning of their experiences. Researchers conducted a secondary qualitative analysis of text and image social media posts made by bereaved caregivers, employing a hybrid deductive-inductive approach. Six themes were identified: grieving, remembering, benefit finding, reconstructing identity, religious and spiritual coping, and connecting. These themes demonstrate that meaning making in caregivers of persons living with dementia was supported by Caregiver Speaks and expand on understanding of bereavement specific to caregivers of persons living with dementia. Our themes emphasize the significance of complete remembrance–of positive memories, but also of complex familial relationships and difficulties in caregiving and end of life. Additionally, we identified overwhelmingly positive religious coping, speaking to the role of faith in this population. Our theme of connecting also identified the novel ways in which caregivers might communicate through use of images, metaphors, and emojis to convey their emotions. Our findings support the use of storytelling, photo-elicitation interventions like Caregiver Speaks to prevent or mitigate grief complications in bereaved caregivers of persons living with dementia. They also suggest possible complementary interventions in bereavement support, such as facilitating remembrance or faith-based community outreach.

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11. **The impact of involvement in social activities on dementia onset: The role of willingness**

Authors: Akaida, Shoma;Katayama, Osamu;Yamaguchi, Ryo;Yamagiwa, Daiki;Tomida, Kouki and Shimada, Hiroyuki

Publication Date: 2025

Journal: Journal of Alzheimer's Disease : JAD , pp. 13872877251400782

Abstract: BackgroundImplementing dementia prevention measures is a critical global health objective.ObjectiveThis study investigated the impact of social activity involvement and willingness on dementia onset in community-dwelling older adults, and potential differences across age and sex subgroups.MethodsLongitudinal analysis was conducted on 2247 community-dwelling older adults ≥65 years (mean age: 74) who participated in the National Center for Geriatric and Gerontology-Study of Geriatric Syndromes in Japan (2015-2016 baseline survey) and were followed up at onset of dementia, including Alzheimer's disease, over 60 months. The Lifestyle Activities Questionnaire was used to determine social activity involvement. Willingness to participate in social activities was determined by asking if participants were willing to engage in 12 specific activities. Participants were classified into three groups: low-involvement, high-involvement/low-willingness, and high-involvement/high-willingness. Statistical analysis was conducted using Cox proportional hazards analysis with dementia onset as the outcome variable, involvement and willingness groups as explanatory variables, and adjusted covariates. Subgroup analyses examined differences across age and sex groups.ResultsThe high-involvement/high-willingness group showed a significantly lower dementia incidence (p 75 group.ConclusionsHigher involvement and willingness to participate in social activities lowered dementia risk, while higher involvement but low-willingness showed no protective effect. This result was maintained in men and the age > 75 group.

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12. **Hospitalization Experiences Among Nursing Home Residents With Dementia**

Authors: Alpert, Jordan M.;Kovach, Jeffrey D.;Casacchia, Nicholas J.;Harris, David;Hashmi, Ardeshir;Kim, Luke Dogyun;Perez-Protto, Silvia;Pappas, Matthew A. and Rothberg, Michael B.

Publication Date: 2025

Journal: Journal of the American Medical Directors Association , pp. 106022

Abstract: Objectives: Hospital admissions among nursing home residents with Alzheimer's disease and related dementias (ADRD) are burdensome, expensive, and provide limited clinical benefit. Compared with other patients, those with ADRD are more likely to experience adverse events when hospitalized. Our objective was to comprehensively describe the in-hospital experience of nursing

home patients with ADRD.; Design: We analyzed 1 randomly selected hospitalization per patient from the electronic health record.; Setting and Participants: Adult patients with an ADRD diagnosis from a single health system in Ohio and Florida who resided in a nursing home and were transferred to a hospital from January 2013 to July 2023.; Methods: Descriptive statistics for each variable.; Results: Of 10,195 patients, median age was 84 years, 71% were White, 61% were female, and median length of stay was 5 days. During the hospitalization, 69% required a sitter, 34% a Foley catheter, 21% were diagnosed with delirium, and 4% died. Six percent were put in restraints, 4% experienced a fall, and 51% were administered at least 1 neuropsychiatric medication. Fewer than half of all patients (45%) had a do-not-resuscitate order, 5% had a consultation with palliative care, 2.4% with geriatrics, and 1.1% with hospice. Nearly 20% of all patients were admitted to the intensive care unit (ICU). Of these, 58% had do-not-resuscitate orders, 78% required a sitter, 53% had delirium, 17% had an order for restraints, 62% had a Foley catheter, and 10% had a long-term feeding tube inserted. Ten percent of ICU patients had a consultation with palliative care, 3.4% with geriatrics, and 2.2% with hospice.; Conclusions and Implications: Patients undergoing hospital admission suffered distressing experiences, but most patients did not have do-not-resuscitate orders, and referrals to hospice and palliative care were rare. Patients and their family members should be informed about the hospital experience before admission and offered appropriate care services. (Copyright © 2025. Published by Elsevier Inc.)

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13. **Differences in survival and healthcare utilization amongst nursing home residents with advanced dementia and frailty compared to other end-of-life conditions: a retrospective cohort study**

Authors: Cao, Yun;Pang, Bao Yu;Silva, Grace Olgado;Soh, Ling Ling;Chen, Wei Ting;Yang, Sze Yee;Leong, Lester Wen-Pin;Tan, Laurence Lean Chin;Leong, Ian Yi Onn;Lim, Wee Shiong and Lee, Joshua Shaowen

Publication Date: 2025

Journal: BMC Palliative Care

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14. **Listening to voices across cultures: non-pharmacological approaches to coping with sleep problems in dementia among ethnically diverse older adults in the UK**

Authors: Chan, Sunny H. W.;Steward-Anderson, Charlotte and Cheston, Richard

Publication Date: 2025

Journal: BMC Complementary Medicine and Therapies

Abstract: Background: Sleep disturbances are a common yet often overlooked challenge for people living with dementia and their caregivers, significantly affecting daily functioning and well-being. Existing interventions frequently prioritise pharmacological treatments, which may not align with the cultural values and preferences of ethnically diverse communities. This study explored how older adults with mild dementia and their caregivers from white British, Caribbean, Chinese, and South Asian backgrounds in the UK understand and manage sleep difficulties using culturally meaningful, non-pharmacological strategies.; Methods: A qualitative, cross-cultural design was adopted using focus group discussions with 12 dementia dyads (older adults and their caregivers) recruited from community organisations in a city in Southern England. Four focus groups were conducted using a topic guide to elicit participants' lived experiences and culturally informed coping practices. Transcripts were analysed using reflexive thematic analysis with NVivo 14, generating four overarching themes that captured shared and culturally specific perspectives.; Results: Analysis revealed four key themes: (i) Sleep as a holistic and relational experience, (ii) The importance of routine, ritual, and physical engagement, (iii) Emotional calm and non-drug coping with night-time worry, and (iv) Cultural fit and practical accessibility shape participation. Participants viewed sleep through a holistic lens, closely linked to emotional, spiritual, and relational harmony. Gentle, non-invasive approaches such as calming evening rituals, light physical activity, spiritual reflection, and mindfulness-like practices were described as

culturally rooted and preferable to medication. Participants valued familiar routines, trusted facilitators, and flexible, community-based delivery. Practical barriers, such as time constraints and caregiving demands, were highlighted alongside a strong desire for co-designed, culturally adaptive interventions.; Conclusions: This study underscores the potential of culturally grounded, mind-body approaches to address sleep disturbances in dementia care. By aligning interventions with communities' daily routines, spiritual beliefs, and emotional needs, non-pharmacological strategies can improve acceptability and relevance. Critically, these findings show that ethnicity and cultural background should not be overlooked in research and intervention design, as they shape how people experience and manage sleep. Community-embedded, participatory models can foster trust, sustain engagement, and ultimately support better sleep and well-being for people living with dementia and their caregivers. (© 2025. The Author(s).)

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15. **The cost of non-drug interventions that improve function and reduce dementia-related behaviors**

Authors: Jutkowitz, Eric;Pizzi, Laura T.;Shewmaker, Peter;Alarid-Escudero, Fernando;Epstein-Lubow, Gary;Gaugler, Joseph E. and Gitlin, Laura N.

Publication Date: 2025

Journal: BMC Geriatrics

Abstract: Background: To determine the net cost of non-drug interventions that maintain or improve a person with dementia's physical function and/or reduce challenging behaviors. Cost data are needed to inform the adoption of non-drug interventions in health systems and the development of policies to incentivize their use.; Methods: We modified a person-level microsimulation to model the cost of four non-drug interventions relative to usual care: Collaborative Care, Care of Persons with Dementia in their Environments (COPE), Tailored Activity Program (TAP), and Skills2Care. We also conducted a value of information analysis to quantify the optimal sample size of conducting a new randomized trial that would reduce uncertainty on the cost savings of each intervention from a societal perspective. Finally, we conducted sensitivity analyses.; Results: Collaborative Care, TAP and COPE were cost savings compared to usual care (-$572, -$1,816, and -$5,262, respectively). Skills2Care results in a $89 net increase in cost compared to usual care. The value of information analysis identified the optimal sample size of a potential future study: Skills2Care (optimal n = 8,560), TAP (optimal n = 5,650), COPE (optimal n = 3,910) and Collaborative Care (optimal n = 3,630). In one-way sensitivity analyses, when we applied a pessimistic assumption for the treatment effect, COPE and TAP were still cost saving, while Collaborative Care cost more than usual care. Conclusions did not materially change in sensitivity analyses that varied treatment cost.; Conclusions: Non-drug dementia care interventions that maintain or improve a person with dementia's function and/or reduce challenging behaviors present a viable clinical / economic model of care for health systems. (© 2025. The Author(s).)

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16. **Sepsis increases the risk of dementia in middle-aged and elderly adults: a large prospective cohort study**

Authors: Liu, Jie;Fei, Yunhan;Wang, Enquan;Guo, Taipu;Cong, Wei;Cui, Yan and Xie, Keliang

Publication Date: 2025

Journal: Journal of Affective Disorders 391, pp. N.PAG

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17. **"I tell you what it's the hardest job": the experiences of family carers providing support for people with dementia at home in the last year of life**

Authors: Mogan, Caroline;Dening, Karen Harrison;Dowrick, Christopher;McCarrick, Kelly and Lloyd-Williams, Mari

Publication Date: 2025

Journal: BMC Geriatrics

Abstract: Background: More people are dying at home with dementia. While there is growing recognition of the central role that family carers play when supporting people with dementia to die at home, knowledge gaps remain around how to best support them as they care for the person during the last year of life.; Aim: To explore the experiences of bereaved family carers who had provided care for a person with dementia living at home in the last year of life.; Design: A descriptive qualitative study based on a constructivist epistemology using in-depth semi-structured interviews. Data were analysed using reflexive thematic analysis.; Participants: Twenty-nine bereaved family carers who had supported a person with dementia living at home in the last year of life.; Results: Caring for a person with dementia at home in the last year of life can be emotionally, mentally, and physically overwhelming. Family carers described the challenges they faced when trying to ensure that they met the needs of the person with dementia so that they could remain at home. Three overarching themes were developed from the data: Managing end-of-life symptoms and associated conditions; Living with uncertainty; and Impacts on wellbeing.; Conclusions: Supporting a person with dementia at home in the last year of life can jeopardise family carers' own health, finances, relationships, and overall wellbeing. Many felt that they had limited understanding about the prognosis of dementia and how this would impact on caring at home, leaving them feeling unsupported amidst the incredible responsibilities placed on them. Family carers would benefit from training on how to provide practical aspects care for the person with dementia in the home, as well as support when making decisions for the person with dementia towards the end-of-life. (© 2025. The Author(s).)

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18. **The male approach to dementia caregiving: an exploratory study**

Authors: Poisson, Vincent O.;Poulos, Roslyn G.;Withall, Adrienne L.;Reilly, Ann;Emerson, Leanne;Huque, Md Hamidul and O'Connor, Claire,M.C.

Publication Date: 2025

Journal: Aging & Mental Health , pp. 1–12

Abstract: Most people living with dementia are supported by their spouse and/or an adult child, yet little is known about how husbands and sons approach dementia caregiving. Using an exploratory mixed method design, this study examined male dementia carers': approach to help-seeking; motivations to step-into the carer role; expectations of formal services; and appraisal of carer-burden. Qualitative thematic analysis of (n = 32) semi-structured interviews with male carers suggested that masculinity norms shape the male approach to caregiving, summarised under two themes: 'Help-seeking: The way blokes do it'; and 'Sons approach caregiving differently to husbands'. Findings suggest that males typically seek help at crisis point and expect professionals to provide directive task-focused support to manage the crisis. Husbands were motivated to care, as a commitment to their marriage vows, while sons cared as a form of 'pay-back' to their parents. Husbands articulated functional carer-burden, while sons expressed emotional carer-burden. However, quantitative analysis of (n = 22) responses on the 12-item Zarit Burden Interview scale showed no significant difference in carer-burden scores between husbands and sons. These findings could inform the tailoring of formal services for male carers of people with dementia

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19. **How do people living with dementia make decisions about their cancer care?: A meta-ethnographic systematic review**

Authors: Quinn, Georgie-Anne;Griffiths, Alys Wyn and Butchard, Sarah

Publication Date: 2025

Journal: Aging & Mental Health , pp. 1–16

Abstract: Objectives: Living with comorbid dementia and cancer is linked with communication and decision-making challenges across the cancer care pathway and poor health outcomes. This meta-ethnographic review aimed to explore the experiences of people living with comorbid dementia and cancer (PLWCDC) when making decisions about their cancer care.; Method: Six databases were searched using terms pertaining to dementia, cancer, decision-making and qualitative experiences. Studies that qualitatively explored cancer care decision-making experiences from the perspective of people living with comorbid dementia and cancer were included.; Results: Searches yielded 3424 unique records, with ten articles meeting eligibility criteria. After quality assessment, collated data was synthesised using a reciprocal synthesis. This produced four higher-order themes: 'challenges of processing cancer-related information', 'issues of inaccessible information and uninformed consent', 'the role of relatives', and 'the importance of individualised and consistent care', drawn together by a core concept of delivering and receiving person-centred cancer care in an inflexible healthcare system.; Conclusion: Decision-making experiences were complex and multi-layered. Dementia negatively influenced understanding and retention of information. Poor consistency in staffing and complexity of information provided were overwhelming. PLWCDC were not always meaningfully involved in their cancer-care decisions. Individualised, consistent care is required to improve outcomes for this population.

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