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Desktop search – Holistic Care and Connectivity in Dementia.

**Holistic Care –**

**Theoretical Perspectives**: Watson’s (2007) Theory of human caring/caring science, Person-Centred Care (PCC) for people with dementia, and spiritual needs as theoretical and conceptual frameworks have been used to guide the nursing practice such as nursing homes, hospitals, and specialist dementia care units. The theory of human caring has been used to understand nurses’ experiences providing care for patients with dementia. Human caring is associated with knowledge, interpersonal interaction, values, and compassion and relates to individual’s experience. Person-Centred Care (PCC) has been used to be the clinical guideline in dementia nursing. Holistic care is the principle of person-centred model care to preserve or improve the quality of life for people living with dementia. Another theoretical perspective that has been used to conduct in dementia nursing care is spirituality as spiritual needs.

Systematic reviews of PCC find: An increase in self-management of care, a reduction in health service visits, improvement in clinical outcomes, a better quality of life, and care behaviors (Da Silva, 2011). Shared decision-making improves patient satisfaction and may improve clinical outcomes and resource use (Da Silva, 2012).

**Government documents, policy & legislation:**

1. **NHS England (2020). The Framework for Enhanced Health in Care Homes.**

7.3.3 Best practice includes:

c. The dementia diagnosis and holistic needs of individuals should be recorded in a single personalised care plan as part of an integrated care record, accessible to all involved in the person’s care (primary care, secondary care, social care, VCSE, and relatives, etc), in line with principles outlined in the Dementia Good Care Planning Guide. The care plan should be developed in partnership with the resident where this is possible, with input from the family/carer where appropriate, and include advance care planning/end of life care needs and preferences, as well as timescales for review. Care home staff should consider

using personalised support tools such as the “This is Me” document and memory boxes to enable person-centred care and avoid potential distress.

f. Residents living with dementia and cognitive impairment should have access to a wide range of NICE-recommended therapies and post diagnostic services, including cognitive stimulation therapy, cognitive rehabilitation therapy, reminiscence therapy, and music therapy. Consideration should also be given to therapies that can support the functional mental health needs of residents living with dementia, including depression and anxiety.

4.3 Personalised Care and Support Plans (PCSPs)

4.3.3 The plan will also be developed with the person and/or their carer(s). It is good practice to include family members in the assessment when this is appropriate, taking into consideration issues such as mental capacity, vulnerability or coercion. Including family members helps where there may be cognitive impairment and also helps to give a holistic picture of a person’s preferences and goals, rather than simply their medical needs.

4.3.4 In developing the personalised care and support plan, it is good practice to follow the standard model of personalised care and support planning set out in [Universal Personalised Care.](https://www.england.nhs.uk/publication/universal-personalised-care-implementing-the-comprehensive-model/)

1. **NICE Guidelines (2018). Dementia: assessment, management, and support for people living with dementia.**

This guideline offers best-practice advice on care and support for people living with dementia and their families and carers. The principles of **person-centred care** underpin good practice in dementia care, and they are reflected in the recommendations. These principles assert:

• the human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers

• the individuality of people living with dementia, and how their personality and life experiences influence their response to dementia

• the importance of the person's perspective

• the importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's [information on making decisions about your care](https://www.nice.org.uk/about/nice-communities/nice-and-the-public/making-decisions-about-your-care).

1. **Dementia Quality Standards, NICE (2020). Update from 2013/2010**

Focus on mid-life prevention -

S.1 “the risk of developing Dementia can be reduced by making lifestyle changes”.

S.5 - “People with Dementia are supported to choose from a range of activities to promote wellbeing – tailored to their preferences”

S.7 – “Carers of people with Dementia are offered education and skills training”. (List of training and support criteria p.39)

“There is limited awareness among the public that the risk of developing some types of dementia can be reduced via lifestyle changes. (Information should be accessible to people who do not speak or read English & be culturally/age appropriate)”.

**Supporting research/ journal articles (Search history Appendix 1):**

**Austin, S. (2017) A dementia care philosophy that puts people at its centre. Nursing & residential care. [Online] 19 (1), 34–36.**

**Key points:**

* The care sector needs to rise to the challenge of providing a better

quality of life for the increasing numbers of people living with dementia

* Creative approaches are required with care targeted at the individual

and not just the condition; it must be person-centred and not process-driven

* Recruiting and training staff with the right qualities to deliver and ‘buy in’ to new ways of working is key
* Creating a less regimented model of care and encouraging staff to spend time with residents will have beneficial results
* It is important to involve families by explaining practices and the

philosophies behind them

**Beech, R. et al. (2017) Delivering person-centred holistic care for older people. Quality in ageing. [Online] 18 (2), 157–167.**

**Key points:**

* With the rise in levels of multimorbidity and the challenge of designing appropriate care (Porter et al., 2015) person-centred approaches have become more prominent as they can address the complexity of care required.
* The Health Foundation (2014) offers a model of person-centred care, based on affording patients respect, dignity and compassion; offering coordinated and personalized care and support, and helping people to recognize their own strengths and abilities so that they can live a fulfilling life (p. 6).

**Ødbehr, L. S. et al. (2015) Spiritual care to persons with dementia in nursing homes; a qualitative study of nurses and care workers experiences. BMC nursing. [Online] 14 (1), 70–70.**

**Key points:**

* Spiritual care for people with dementia who are in nursing homes is one aspect of the holistic care provided by nurses. Several studies have explored the concepts of spirituality and religiosity, but fewer studies describe how nurses provide spiritual care in practice. The Purpose of the study was thus to investigate how nurses and care workers can provide spiritual care for people with dementia who live in nursing homes.
* This study demonstrates the need for nurses and care workers to discuss and reflect on how to understand and describe spiritual care for people with dementia in practice. There is a need to develop and expand the knowledge about how to teach carers to recognize resident’s spiritual needs and expressions of spirituality and to establish a comprehensive view of spiritual care for people with dementia in nursing homes.

**Jenkins et al. (2014) How can training interventions for nurses promote person-centred dementia care in nursing homes? Mental Health Nursing (Online). 34 (5), 16.**

**Key points:**

* ‘New culture’ or person-centred care is individually designed recognising personal preferences for practical assistance, the importance of life history and engagement in meaningful conversation and activity with the aim of providing a social environment that supports identity or ‘personhood’.
* Government priorities include provision of high-quality dementia care for people living in care homes (DH, 2009; DH, 2013) while the Social Care Institute for Excellence (SCIE, 2013) states that research into high-quality care is as important as that into prevention.
* Educational interventions need to be creative, stimulating, challenging, emotionally engaging and relevant to address these core aspects. Therefore, training programmes need to consider the organisational contexts within which outcomes are expected to be applied and take steps to anticipate and address barriers within these contexts, then develop strategies that will increase the likelihood of training making a long-term difference to practice.

**Connectivity/Dementia Friendly Communities.**

**Government documents, policy & legislation:**

1. **Prime Minister's challenge on dementia 2020 (DOH, 2015).**

[**https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020**](https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020)

1. **NHS Guide: How to make your home dementia friendly. (NHS UK, 2022)**

[**https://www.nhs.uk/conditions/dementia/home-environment/**](https://www.nhs.uk/conditions/dementia/home-environment/)

1. **Dementia Friendly Communities: A guide for Councils. (Local Government Association, 2014).** The purpose of this guide is to help councils play their part in developing communities where people can live well with dementia. <https://www.local.gov.uk/sites/default/files/documents/dementia-friendly-communi-8f1.pdf>
2. **Dementia 2020 Challenge, Review 1. (Dept of H&SC, 2019)**Update on the progress set out from the 2015 “Dementia 2020 Challenge”. 18 key commitments under four themes. 10 revised actions added, these include:

Risk reduction & Prevention. Health & Care Delivery. Dementia Awareness & Social Action and Research: “An additional 3 million Dementia Friends to be made, England leading the way into a global movement” “More people living with dementia participating in research, currently 4.5% - target of 10%”

“Continued engagement with businesses to encourage a dementia friendly society”, “Funding for Research on track to be doubled by 2025” <https://www.gov.uk/government/publications/dementia-2020-challenge-progress-review>

**Supporting research/ journal articles (Search history Appendix 2)**

**Birt, L. et al. (2020) Maintaining Social Connections in Dementia: A Qualitative Synthesis. *Qualitative health research*. [Online] 30 (1), 23–42.**

**Key Points:**

This qualitative review investigated how people with mild to moderate dementia managed social connections. A systematic search of social science databases retrieved 13 articles; data were synthesized using thematic analysis**.** Establishing and managing social connections are complex and dynamic; often the person with dementia requires support from family or friends to access social opportunities and to manage their presentation of self. However, this can come with costs to them of fatigue and social burden (Bartlett, 2014; MacRae, 2010). Understanding this can help health practitioners and researchers to be alert to, and appropriately support.

**Buckner, S. et al. (2019) Dementia Friendly Communities in England: A scoping study. *International journal of geriatric psychiatry*. [Online] 34 (8), 1235–1243**

**Key Points:**

Buckner et al. (2019) provide a first look at Dementia Friendly Communities, how they operate and what they hope to achieve. Thus, this review constitutes a snapshot of the current situation in England, and a useful overview to evaluate the current progress made. While building community support through awareness can be a helpful starting point, the authors report it was difficult to measure tangible progress.

**Jenkins, C. and Smythe, A., 2013. Reflections on a visit to a dementia care village. Nursing Older People (through 2013), 25(6), pp. 14-9.**

**Key Points:**

Hogewey village in Holland offers an alternative lifestyle for people with dementia. The model minimises disability and maximises wellbeing by providing a physical and social environment congruent with people's lifestyles. Residents live with those who have shared similar previous lifestyles and take an active role in all aspects of daily life, reflecting their interests and social norms.

**Turner, N. & Cannon, S. (2018) Aligning age-friendly and dementia-friendly communities in the UK. Working with older people (Brighton, England). [Online] 22 (1), 9–19.**

**Key Points:**

The purpose of this paper is to set out the history and origins of dementia-friendly communities (DFCs) and age-friendly communities (AFCs) in the UK, the differing frameworks and how they compare, and set out some key messages about how they might learn from each other.

**Buckner, S. et al. (2018) An evaluation tool for Age-Friendly and Dementia Friendly Communities. Working with older people (Brighton, England). [Online] 22 (1), 48–58**

**Key Points:**

The purpose of this paper is to report how an evaluation tool originally developed for Age-Friendly Cities was pilot-tested in the context of the Dementia Friendly Community (DFC) initiative of the city of Sheffield/UK.

It presents finding and outputs on which other communities with dementia friendly agendas can draw. The evidence indicates areas of strength in Sheffield’s approach to dementia friendliness: involvement of older people. Recommendations for policy and practice include enhancing pooling of resources, more detailed recording of resources allocated to dementia-related activity, and collection of evidence on how people affected by dementia have shaped the city’s DFC initiative.

**Mendes, A. & Palmer, S. (2018) Communities and institutions becoming dementia-friendly. Nursing & residential care. [Online] 20 (7), 319–321.**

**Key Points:**

Many people with dementia still live in their local communities and can perform various day-to-day tasks. Mendes and Palmer discuss recent initiatives that will help people living with the condition stay independent for longer. It is encouraging that so much work is being done in the community to develop a better understanding and better support for people who are living with dementia.

**Heward, M. et al. (2017) Dementia‐friendly communities: challenges and strategies for achieving stakeholder involvement. Health & social care in the community. [Online] 25 (3), 858–867.**

**Key Points:**

PWD are often not meaningfully engaged in their local community, reporting loneliness and a fear of going out and being involved in their local community. Dementia-friendly communities (DFCs) are a policy mechanism that enables PWD to be recognised and included within their community. Stakeholder involvement is unpredictable and changeable; therefore, reliance on this approach questions the long-term sustainability of DFCs and must be considered in future policies designed to enhance quality of life for people affected by dementia.

**Crampton, J. & Eley, R. (2013) Dementia-friendly communities: what the project ‘Creating a dementia-friendly York’ can tell us. Working with older people (Brighton, England). [Online] 17 (2), 49–57.**

**Key Points:**

York as a city is already responding in many positive ways to the needs of people with dementia and their carers, but there is much more that can be done, there and elsewhere. The project proposes a model – People, Places, Networks and Resources – for analysing the suitability and helpfulness of existing arrangements or features of a place or an organisation in order to realise a more dementia-friendly community.

**Shannon, K. et al. (2019) Dementia‐friendly community initiatives: An integrative review. Journal of clinical nursing. [Online] 28 (11-12), 2035–2045.**

**Key Points:**

People with dementia are at the centre of dementia‐friendly initiatives,

and this fosters social inclusion. Collaborations and partnerships enhance development of dementia‐friendly communities; however, lack of resources and difficulty ensuring representation of marginalised groups provide challenges. : An understanding of the impact of marginalisation and inequality on community participation for people with dementia is important for practitioners, enabling them to support those people.

**Orgeta, V. et al. (2019) *Behavioural activation for promoting well-being in mild dementia: feasibility and outcomes of a pilot randomised controlled trial*.**

**Key Points:**

Recent interventions to support people living with dementia have included a focus on community participation and engagement. The fundamental rationale behind Behavioural Activation is the importance of value-driven and meaningful activities, supporting individuals to identify and engage in activities that are reinforcing and consistent with their long-term goals. This is particularly important for people living with dementia, which often experience disengagement from every day rewarding activities and opportunities for community participation. As a result, people with dementia can have limited access to meaningful and purposeful activity, which stems partly due to loss of skills, but also due to lack of confidence, and stigma associated with the disease. In this study we report on the feasibility and acceptability of a BA intervention developed after extensive consultations and piloting with people with mild dementia and their families.

**Shannon, K. et al. (2019) Dementia‐friendly community initiatives: An integrative review. Journal of clinical nursing. [Online] 28 (11-12), 2035–2045.**

**Key Points:**

Collaborations and partnerships enhance development of dementia friendly communities; however, lack of resources and difficulty ensuring representation of marginalised groups provide challenges. An understanding of the impact of marginalisation and inequality on community participation for people with dementia is important to support people.

**Appendix 1:**

**Search History / Search Terms for Holistic/Person Centred Care:**

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**Appendix 2:**

**Search History / Search Terms for Connectivity/Dementia Friendly:**

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Da Silva, D. (2011), “Helping People Help Themselves”, The Health Foundation.

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Orgeta, V. et al. (2019) Behavioural activation for promoting well-being in mild dementia: feasibility and outcomes of a pilot randomised controlled trial. Journal of Alzheimer's Disease , 72 (2) pp. 563-574.

Shannon, K., Bail, K. & Neville, S., 2019. Dementia‐friendly community initiatives: An integrative review. Journal of clinical nursing, 28(11-12), pp.2035–2045

Turner, N. & Cannon, S. (2018) Aligning age-friendly and dementia-friendly communities in the UK. Working with older people (Brighton, England). [Online] 22 (1), 9–19.

Watson, J., 2007. Context for theory development. *Nursing: Human science and human care.(2nd. ed., p. 1-12). Sudbury: Jones and Barlett Publishers*.