“You matter because you are you”

A practical approach enhancing quality of life in advanced dementia

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Alzheimer Scotland

Advanced dementia: what do we know from research & experience in practice?

Dr Jenni Burton
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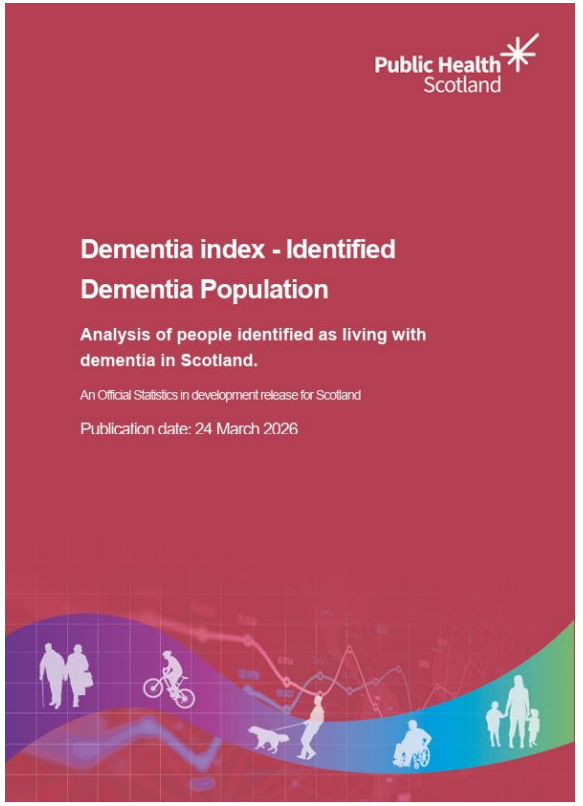
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Setting the scene

- **Dementia** – an umbrella term for a range of conditions
- Increased prevalence with **age**, **female** sex and **deprivation**
- As of 31st March – 60,176 people (**excluding primary care & outpatient diagnoses**)
- ~1% only identified based on death records



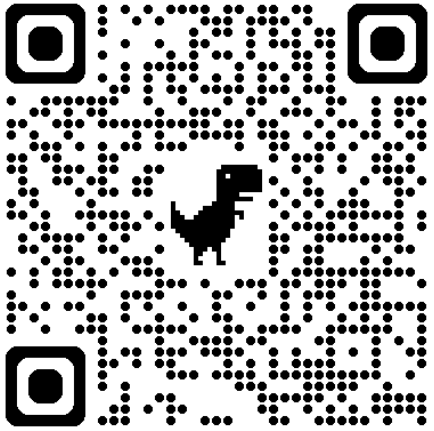
Public Health Scotland, Dementia Index, March 2026

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Setting the scene

- Two thirds of those who die from dementia in Scotland, die in care homes
- Dementia is the commonest cause of death among people living in care homes in Scotland
- But, time to mortality……0.1% die the day the move in, 3.2% within a month and 24.2% within a year

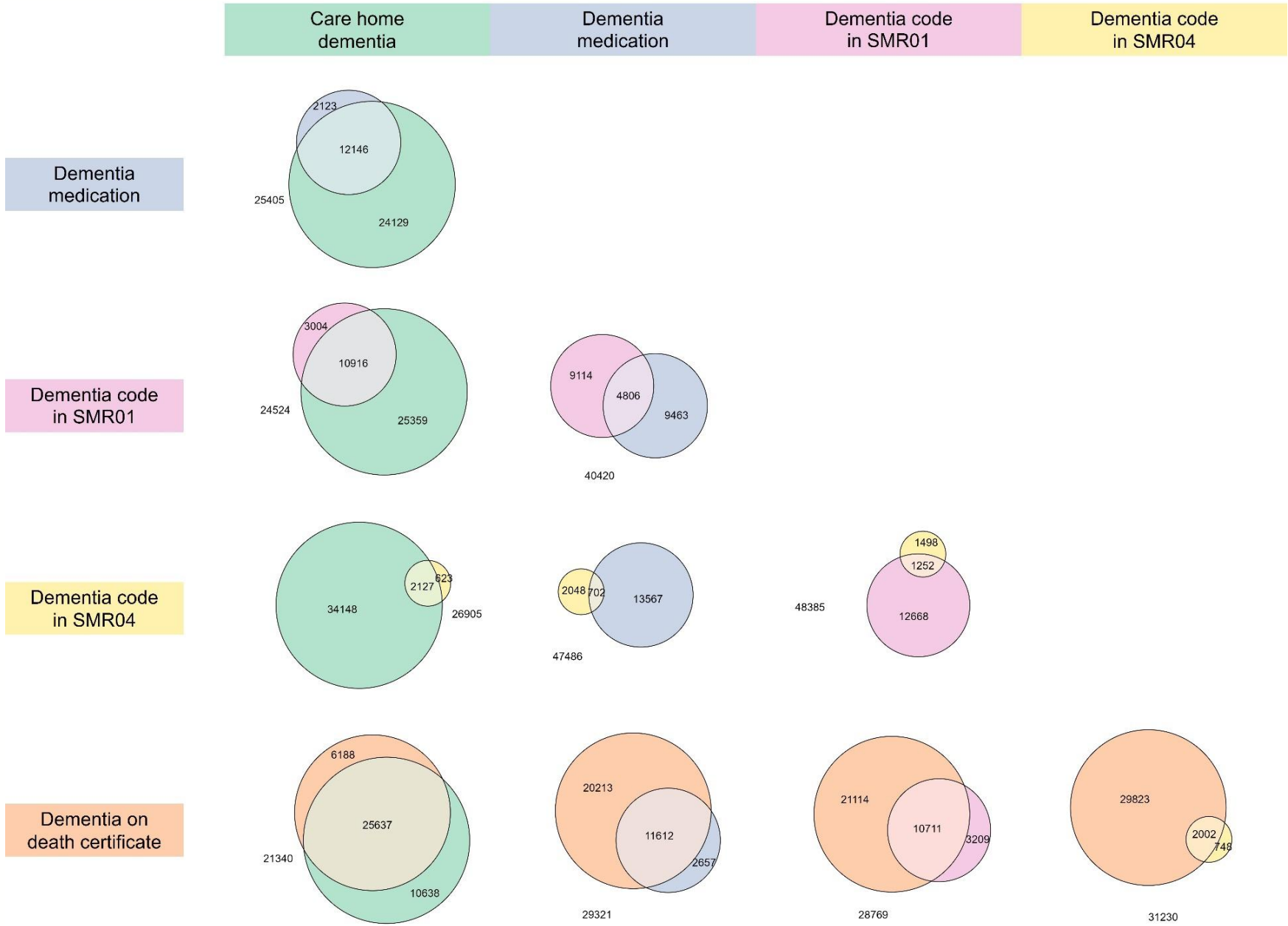


Macrae et al. BMJ Support Palliat Care 2025;16(1):188-97

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Identifying dementia



Mavromati et al. IJPDS; 2026:11(1)

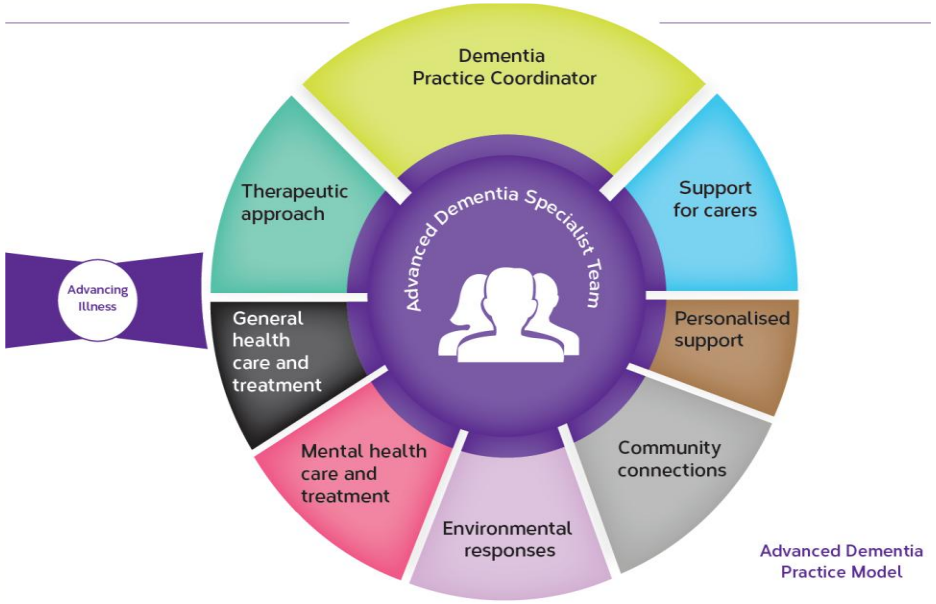
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What is 'advanced dementia'?

"unique to each individual and dependent on factors relating to underlying health, personality, biography and social context"

- Classification scores
  - *Often Alzheimer's disease-specific*



Advanced Dementia Practice Model, Alzheimer Scotland, 2015

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Adapted Gold Standards Framework Criteria

Triggers that indicate someone is entering a later stage are:

- Unable to recognise family members or consistently unable to have meaningful conversations
- Completely dependent on others for care or unable to do activities of daily living
- Recurrent episodes of delirium
- Aspiration pneumonia
- Urinary and faecal incontinence

Plus, any of the following:

- Weight loss
- Urinary tract infection
- Skin failure or stage 3 or 4 pressure ulcers
- Recurrent fever
- Reduced oral intake

Adapted from Gold Standards Framework Proactive Identification Guidance (7th edition, 2022)

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Feedback and results

Three-fifths **(61.5%)** of care homes are supporting people living with dementia who do not have a diagnosis.



Average prevalence of advanced dementia among survey respondents was **40.6%** *(all adult care home services)* and **41.6%** *(older peoples' services only).*



We estimate **14,826** people residing in older peoples' care homes in Scotland are living with advanced dementia.



Burton et al. Journal of Nursing Home Research:2026:12:24-32

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Prognostication in advanced dementia

Models for six-month mortality

Tool	Predictor domains included in identified tools								
	Age	Change in cognition	Comorbidity	Faecal incontinence	Functional decline or dependence	Oral intake, nutrition and weight loss	Sex	Symptoms	Resource use
Predictive tools specifically designed for predicting mortality in people living with dementia in care home settings									
Advanced Dementia Prognostic Tool (ADEPT)	✓		✓	✓	✓	✓	✓	✓	
Alzheimer's Hospice Placement Evaluation (AHOPE) scale		✓			✓	✓			
Mortality Risk Index Score	✓	✓	✓	✓	✓	✓	✓	✓	
Hicks 2010 model	✓	✓					✓		
McCusker 2014	✓	✓	✓				✓		
Volicer 1993 model	✓	✓							
Wong 2018 model	✓		✓			✓	✓		✓
Predictive tools designed for broader use in predicting mortality outcomes									
Changes in Health, End-Stage Disease and Signs and Symptoms (CHESS)		✓			✓	✓		✓	
NECPAL *(NECesidades PALiativas)* 4.0	✓		✓		✓	✓			✓
Palliative Prognostic Index (PPI)		✓			✓	✓		✓	
PROFOUND Index	✓	✓	✓		✓			✓	✓

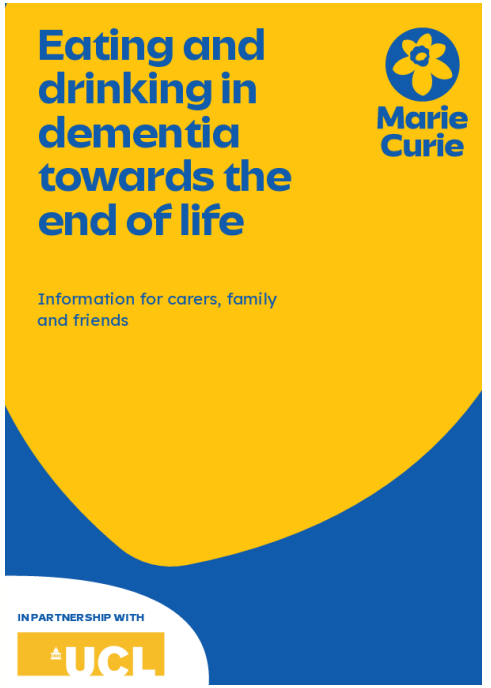
West et al. Age and Ageing. 2026;55(4):afag087

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Palliative care needs in dementia

- 9-month cohort study *(62% alive at end of follow-up)*
- Significant symptom burden
- Intercurrent infections – aspiration, septicaemia, pneumonia *(and other acute events including falls/fractures and delirium)*
- Mismatch between healthcare need and access
- Uncertainties around deterioration, decline and dying



Sampson et al. Palliative Medicine. 2017;32(3):668-81

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Summary

We have growing and significant population living and dying with advanced dementia in Scotland

Many are supported within care home settings

They have complex and changing needs

Supporting these requires skilled and specialist care and a holistic approach

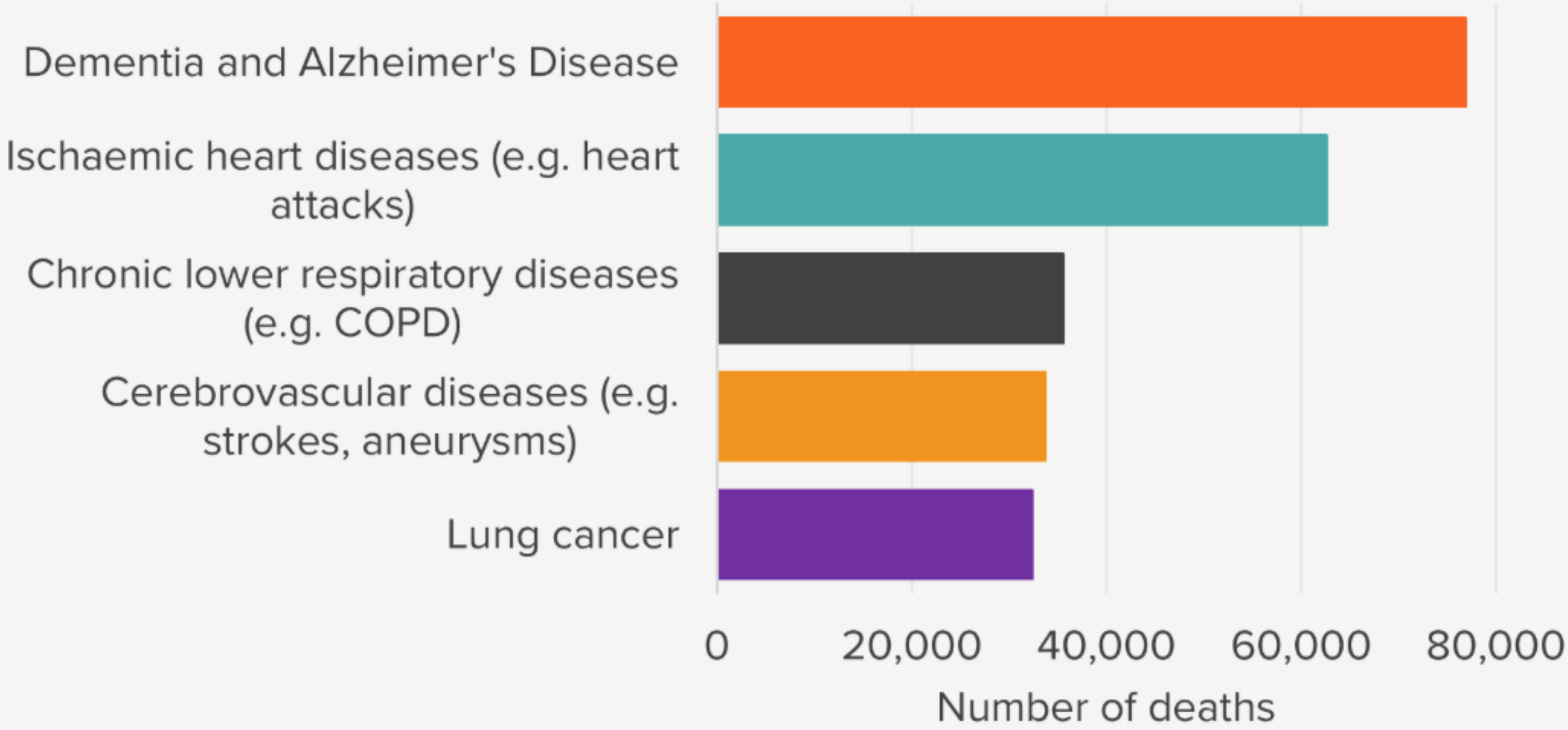
Namaste Care

a research informed model of end-of-life care for people with advanced dementia

Lorna Reid (PhD, RN)
Lead for Education and Training Prince and Princess of Wales Hospice, Glasgow

The Prince & Princess of Wales Hospice

DEMENTIA WAS THE UK'S LEADING CAUSE OF DEATH IN 2024



Research priorities for palliative and end of life care

Below are the top 24 priorities for palliative and end of life care 2025 guided by people with lived and/or professional experience, in order, starting with the highest priority.

1 How do **people with dementia** experience end of life? How can palliative and end of life care better meet their needs and those of their carers, friends and families?

2 How can NHS, social services and charities work more **collaboratively to provide joined-up** care that better meets the needs of people with a serious life-limiting illness and their carers, friends and families?

3 What kinds of palliative and end of life care and support need to be in place to **enable people to die well at home**? What skills do staff need? What helps or hinders the delivery of care at home?

4 What are the best **palliative and end of life care** that meets all the physical, mental, practical, social and spiritual needs of a person with a serious life-limiting illness?

5 How can palliative and end of life care better meet the complex needs of people with **multiple health conditions**?

6 How can **communication and care co-ordination be improved** across the teams of health and social care professionals caring for people with any serious life-limiting illness?

7 What **skills, training and information do carers, friends and family members** need to be able to care for someone who is dying at home (eg giving medicines safely by injection, managing incontinence, moving people)? What is the impact (pros and cons) of upskilling the people giving care?

8 How can the **quality of palliative and end of life care in hospital** be improved? What helps or hinders improvement?

9 What are the best ways to provide palliative and end of life care, **support and advice at all hours** (24/7 or out of hours)?

10 How can palliative and end of life care better meet the needs of people **who live alone, or are socially isolated**?

Marie Curie

11 What are the best ways to **train and support** staff who provide care at the end of life - either at home, in care homes or nursing homes?

12 How can it be ensured that **everyone has access to the palliative and end of life care they want or need**?

13 How can palliative and end of life care better meet the **needs of people with illnesses other than cancer** eg chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, organ failure, motor neurone disease (MND) or chronic fatigue syndrome (CFS)?

14 What are the best ways to **identify that a person is dying or is near to death** (in their last year, months, weeks, days of life)? How can health professionals better recognise these stages in people with any serious life-limiting illness?

15 What are the best ways to provide **emotional and psychological support to people with a serious life-limiting illness**, from diagnosis through to end of life?

16 What are the best ways to **prepare carers, friends and families for what will happen** while the person they care for is dying? What information about symptoms during the last few days and hours is helpful to know?

17 How can **symptoms** at the end of life be **managed in a timely way**, including by **rapid access to medicines**?

18 What are the best ways to manage people who are **restless, agitated or experience sudden confusion** (delirium) at the end of life?

19 What **stops people's wishes from being acted upon** (eg with future or advance care plans). How can any barriers be overcome?

20 How can **discharge from hospital** be improved for people with any serious life-limiting illness?

21 What are the best ways to provide **palliative and end of life care in the community**, for example what are the roles of different services and professions?

22 What are the best ways to ensure **adequate pain relief** for people with a serious life-limiting illness?

23 What are the **best ways to provide support to children** when someone important to them is dying, or has died (eg psychological and social support)?

24 Can **medicines** be changed so that they can be **more easily administered at home and in the community** at end of life eg through injection under the skin, or under the tongue?

Scan to view the full report:

The Journal of Nutrition, Health & Aging©
Volume 11, Number 6, 2007

SILENT AND INVISIBLE; NURSING HOME RESIDENTS WITH ADVANCED DEMENTIA

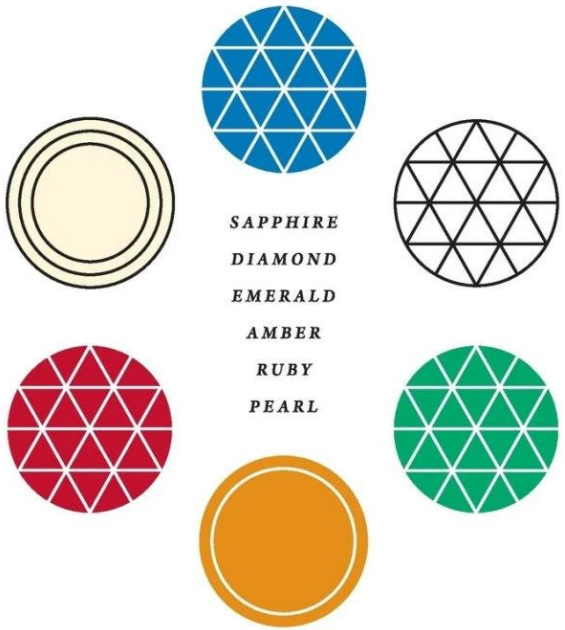
J. SIMARD

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Address correspondence to Joyce Simard 2337 Dekan Lane Land O Lakes FL 34639 USA, Phone 813-909-0539 or joycesimard@earthlink.net.

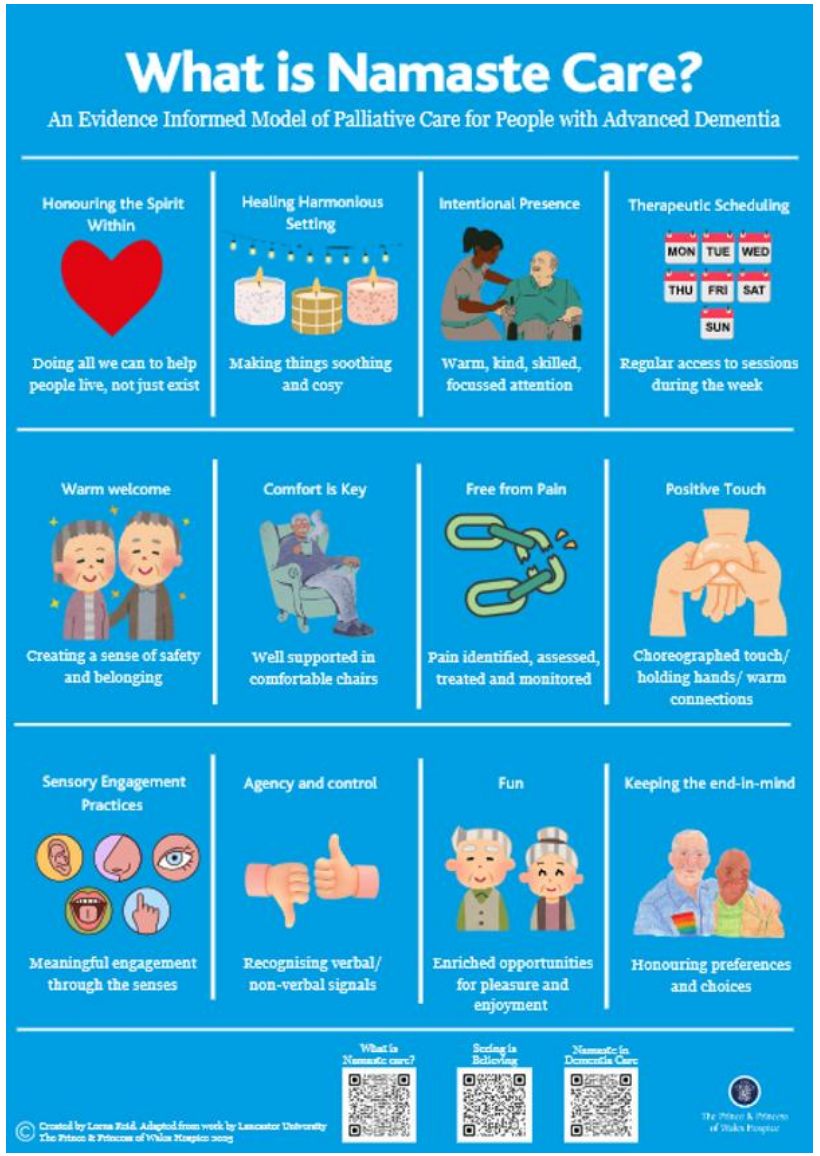
Abstract: The Namaste Care Program is designed to provide meaningful activities through therapeutic touch, music and life review to nursing home residents with advanced dementia. This program has improved resident care, staff and family satisfaction while increasing census. Namaste Care is easy to initiate and does not require additional staff or expensive supplies. The experience of one long-term care company EPOCH Senior Living of Waltham Massachusetts USA which offers Namaste Care in their skilled nursing facilities is explained. Management has concluded that program has been an important addition to the services they provide for residents and their families from both a business prospective and a quality of care standpoint.

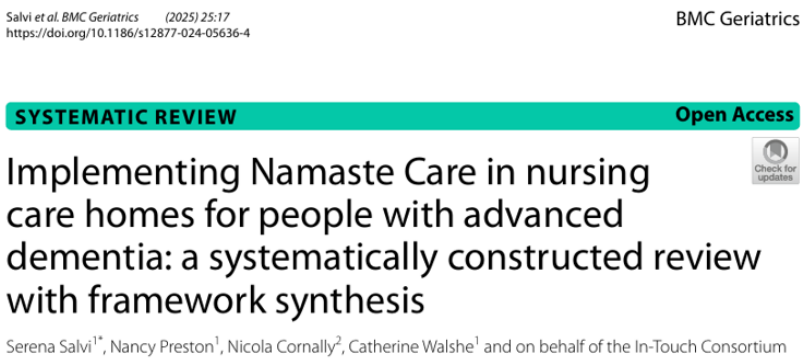
Key words: Advanced dementia, Alzheimer's disease, terminal care.

Developed by Joyce Simard for people most in need – i.e. amber, ruby and pearl



Core elements of Namaste Care





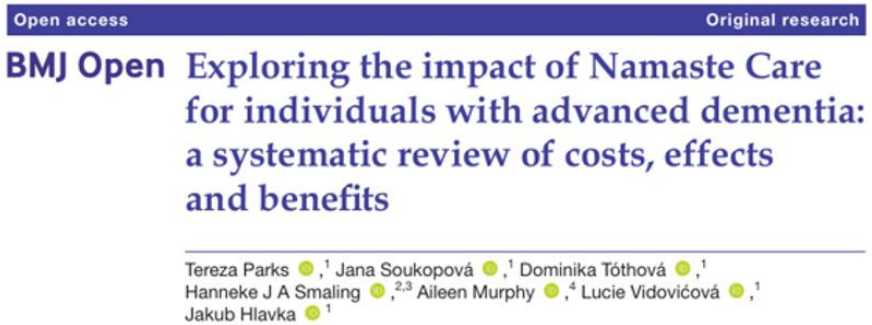
Salvi *et al. BMC Geriatrics* (2025) 25:17
https://doi.org/10.1186/s12877-024-05636-4

BMC Geriatrics

SYSTEMATIC REVIEW Open Access

Implementing Namaste Care in nursing care homes for people with advanced dementia: a systematically constructed review with framework synthesis

Serena Salvi[1*], Nancy Preston[1], Nicola Cornally[2], Catherine Walshe[1] and on behalf of the In-Touch Consortium



Open access Original research

BMJ Open

Exploring the impact of Namaste Care for individuals with advanced dementia: a systematic review of costs, effects and benefits

Tereza Parks ,[1] Jana Soukopová ,[1] Dominika Tóthová ,[1] Hanneke J A Smaling ,[2,3] Aileen Murphy ,[4] Lucie Vidovićová ,[1] Jakub Hlavka [1]

Benefits

- Increased emotional wellbeing (calmness, relaxation, improved mood, increased smiling).
- Increased positive behaviour (eye contact, touch, verbal response)
- Increased physical health and comfort (skin condition, hydration, sleep and swallowing)
- Increased QoL (comfort, calmness, pleasure)
- Increased social interaction, responsiveness and communication
- Increased familiarity with specific carers and with surroundings of NC space
- Increased individualised and tailored care and increased participation in individualised care
- Reduced agitation (reduced benzodiazepine use), and pain,
- Reduced falls and minor injuries.
- Reduced sense of fear.
- Reduced social isolation



Seeing is Believing

Improve QoL, maintain function and maximise comfort

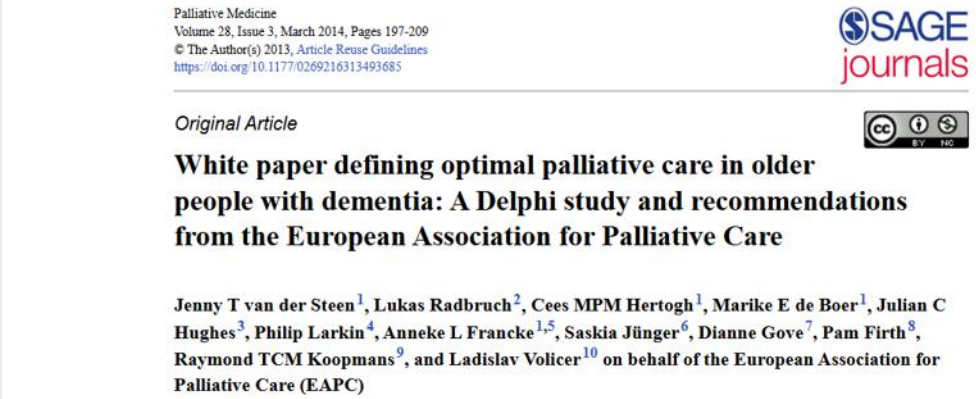
Person centred, communication and shared decision making

Optimal treatment of symptoms and providing comfort

Psychological and spiritual support

Family care and involvement

Education of the care team



Palliative Medicine
Volume 28, Issue 3, March 2014, Pages 197-209
© The Author(s) 2013, Article Reuse Guidelines
https://doi.org/10.1177/0269216313493685

SAGE journals

Original Article

White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care

Jenny T van der Steen[1], Lukas Radbruch[2], Cees MPM Hertogh[1], Marike E de Boer[1], Julian C Hughes[3], Philip Larkin[4], Anneke L Francke[1,5], Saskia Jünger[6], Dianne Gove[7], Pam Firth[8], Raymond TCM Koopmans[9], and Ladislav Volicer[10] on behalf of the European Association for Palliative Care (EAPC)

In-Touch: Implementation of a person-centered palliative care iNtervention To imprOve comfort, QUality of Life and social engagement of people with advanced dementia in Care Homes

Fact Sheet | Reporting | Results

Project description

DE | EN | ES | FR | IT | PL

Transforming dementia care in Europe

Caring for individuals with advanced dementia in care homes poses significant challenges, impacting their quality of life and causing distress among family members and caregivers. In this context, the EU-funded In-Touch project aims to develop an innovative intervention that combines 'in the moment' care for immediate needs and planning for future care needs. A cross-country trial across 56 nursing homes in seven countries aims to enhance comfort, social engagement, and overall well-being. If successful, this initiative could transform dementia care in Europe, providing better quality of life for patients, support for caregivers, and a cost-effective, evidence-based model for future implementation. This holistic approach promises a brighter future for those affected by advanced dementia.

Project Information

In-Touch
Grant agreement ID: 101137270

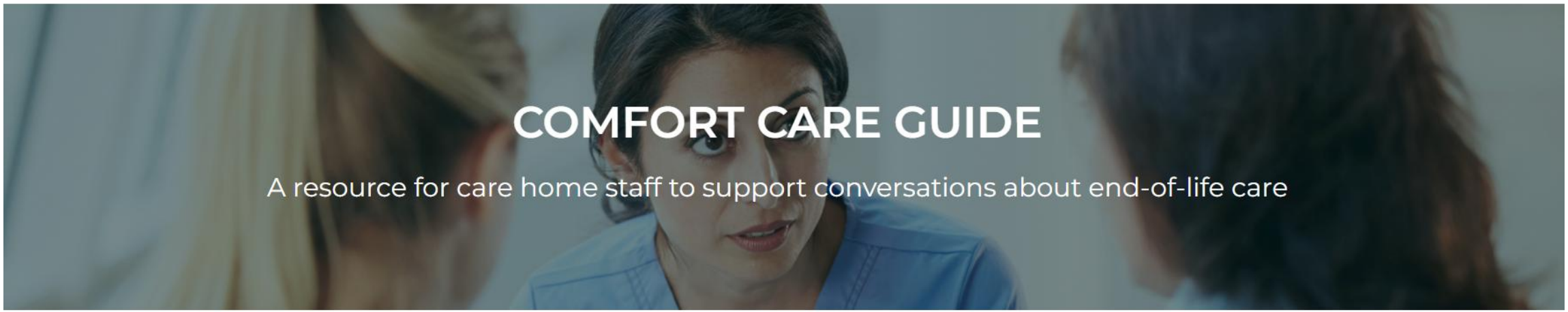
DOI
10.3030/101137270

EC signature date
29 November 2023

Start date
1 January 2024

End date
31 December 2028

Funded under
Health



Welcome to this online training resource. It is designed to support necessary discussions about comfort care with family carers of residents with advanced dementia.

As people living with advanced dementia may struggle to communicate their wishes and preferences for care, this training aims to equip nurses working in care homes to involve family carers in the shared decision-making process at the end-stage of life.

References

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2. Marie Curie – Research Priorities for Palliative and End of Life Care 24-research-priorities-for-palliative-and-end-of-life-care and james-lind-alliance-palliative-and-end-of-life-care-priority-setting-partnership-refresh-final-report.pdf
3. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care – PubMed
4. Exploring the impact of Namaste Care for individuals with advanced dementia: a systematic review of costs, effects and benefits Exploring the impact of Namaste Care for individuals with advanced dementia: a systematic review of costs, effects and benefits | BMJ Open
5. Implementing Namaste Care in nursing care homes for people with advanced dementia: a systematically constructed review with framework synthesis Implementing Namaste Care in nursing care homes for people with advanced dementia: a systematically constructed review with framework synthesis | BMC Geriatrics | Springer Nature Link
6. Comfort Care Guide to support communication and shared decision making with family carers of residents with advanced dementia – developed from the mySupport study About | Comfort Care Guide

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The Prince & Princess of Wales Hospice

