



Department
of Health

Making a Difference in Dementia

Nursing Vision and Strategy

Refreshed edition



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Author: Nursing, Midwifery & Allied Health Professions Policy Unit, Quality Division, Strategy and External Relations Directorate 32400
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Contact details: Dr Ben Thomas Mental Health, Learning Disability and Dementia Care Professional Officer Nursing, Midwifery & Allied Health Professions Policy Unit Strategy and External Relations Directorate Department of Health, 79 Whitehall, London, SW1A 2NS Email: ben.thomas@dh.gsi.gov.uk

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Introduction

The Making a Difference in Dementia: Nursing Vision and Strategy, published in March 2013, set out our vision of how nurses could maximise their unique contribution to high-quality, compassionate care and support for people with dementia and their carers/families. In the past three years a great deal has been achieved, including the following:

- There has been a continued increase in dementia awareness, with more than 515,967 NHS staff at the end of March 2015 completing Tier 1 training to better support people with dementia. Tier 1 training continues to be rolled out, with a view to reaching all NHS staff by the end of 2018. The publication of the Dementia Core Skills Education and Training Framework in October 2015 will help us to achieve this goal, by assuring the quality and consistency of dementia training for all health and care staff.
- More than one million people have become Dementia Friends across England. The Alzheimer's Society's Dementia Friends programme is the biggest ever initiative aimed at changing people's perceptions of dementia, transforming the way we all think, act and talk about dementia, to help improve awareness and understanding. Dementia Friends are helping to create communities in which people living with dementia feel more understood and included.
- The 2020 Dementia Challenge, published in February 2015, builds on the achievements of the previous 2012–15 Challenge. It identifies what needs to be done by the NHS, social care, voluntary, community sectors and society at large, to make sure that dementia care, support, awareness and research are transformed by 2020. The 2020 challenge focuses on risk reduction, health and care, continuing investment in research and expansion of dementia-friendly communities.
- The Implementation Plan published in March 2016, sets out priority actions to ensure that the commitments set out in the 2020 Dementia Challenge are delivered.

The spirit and values set out in Making a Difference in Dementia: Nursing Vision and Strategy remain as relevant today as three years ago. We want to build on these, while appreciating that emerging challenges require a fresh approach. This refreshed edition of Making a Difference in Dementia: Nursing Vision and Strategy reinforces the fundamental role nurses play in providing health promotion, care and support to people so they can live well with dementia. It aims to support all nurses, irrelevant of registration or specialty, to be responsive to the needs of people with dementia, continue to develop their skills and expertise, and improve the contribution they make in achieving best outcomes for people with dementia, their carers and families, and communities.

Part one: Refreshing our vision

Dementia facts

Dementia is **not** an inevitable part of ageing. However, as our population ages, the number of people living with dementia is set to increase. There are around 676,000 people with dementia in England, and this number is expected to double in the next 30 years.

Dementia mainly affects older people, though it can start before the age of 65.

People with a learning disability are at a much higher risk than the general population. For example, people with Down's syndrome aged 50-59 have a one in three chance of having dementia.

Dementia is progressive. Initial symptoms include memory loss and difficulties with thinking, problem-solving or language. The most common types are Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies.

Timely diagnosis along with support and treatment are helping more people with dementia stay active and independent; and younger people to stay in work for longer.

Dementia affects people differently and the level of support required will vary. It is important to recognise that no two people with dementia or their carers are the same, and individuals will have unique and differing needs.

There are around 540,000 carers of people with dementia in England. Half of them are employed and it is estimated that 66,000

people have already cut their working hours to make time for caring, while 50,000 people have left work all together.

The 2020 Dementia Challenge

The 2020 Dementia Challenge aims to transform dementia care, support and research.

By 2020 England should be:

- the best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
- the best place in the world to undertake research into dementia and other neurodegenerative diseases.

The Government's key aspirations include:

- improved public awareness and understanding of the factors which increase the risk of developing dementia and how people can reduce their risk by living more healthily
- in every part of the country, people with dementia having equal access to diagnosis as for other conditions
- every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National

Institute for Health and Care Excellence (NICE) quality standards. This care may include, for example:

- receiving information on what post-diagnosis services are available locally and how these can be accessed
- access to relevant advice and support to help and advise on what happens after a diagnosis and the support available through the journey
- carers of people with dementia being made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring
- all NHS staff having received training on dementia appropriate to their role
- all hospitals and care homes meeting agreed criteria to become a dementia-friendly health and care setting
- an increase in the numbers of people of Black, Asian and Minority Ethnic origin and other seldom heard groups who receive a diagnosis of dementia, enabled

through greater use by health professionals of diagnostic tools that are linguistically or culturally appropriate

- dementia research as a career opportunity of choice, with the UK being the best place for dementia research through a partnership between patients, researchers, funders and society.

The contribution of all registered nurses to achieving this vision is crucial given that they have regular contact with patients. Nurses are in a unique position to provide every person with dementia – and their carers and families – with high-quality, compassionate care from diagnosis through to end-of-life care.

Compassionate practice

Looking at the person with dementia, and dementia itself, with a fresh vision shapes the nurse's role and characterises it as person-centred, compassionate and proactive.

If dementia is seen as a long-term condition, it can be divided into phases, which helps articulate where the person might be in the process and how nurses can provide excellent nursing care and support. These phases overlap and are not necessarily distinct or always sequential, but they provide a framework for understanding and timely action.

Person with dementia

traditional view



an older person who is considered incapable of making decisions and going out

prevalent view

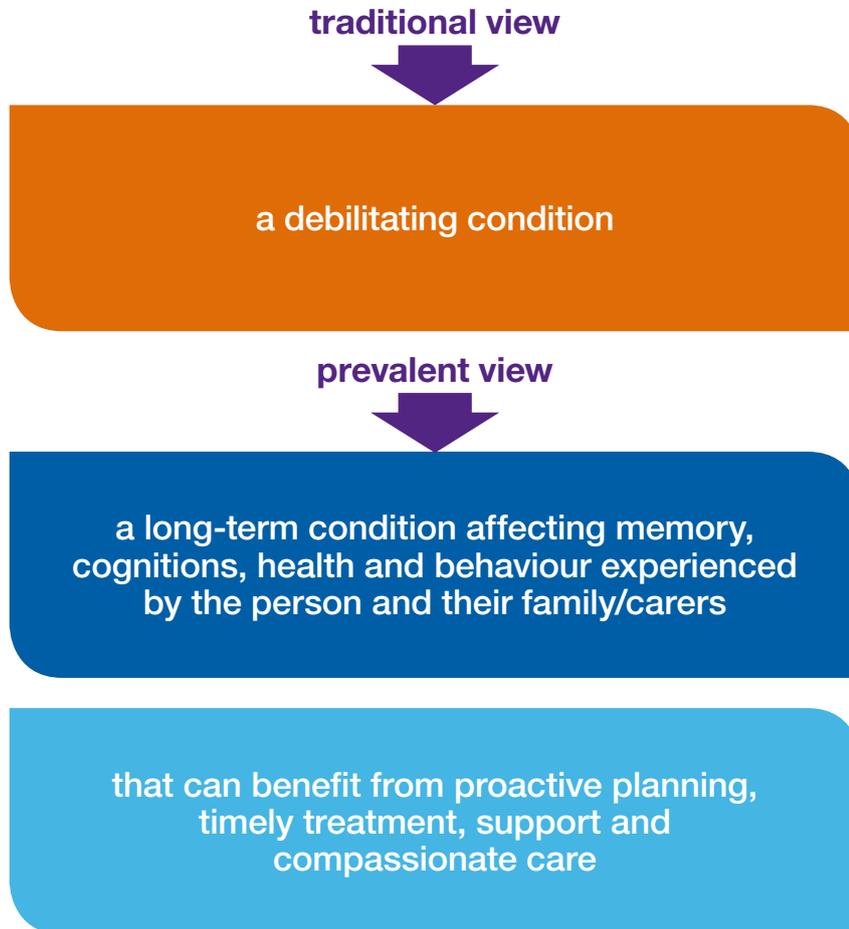


a person living well with dementia – with a life story, family, community and social network, who will need help and changing levels of support as the condition ebbs, flows and progresses

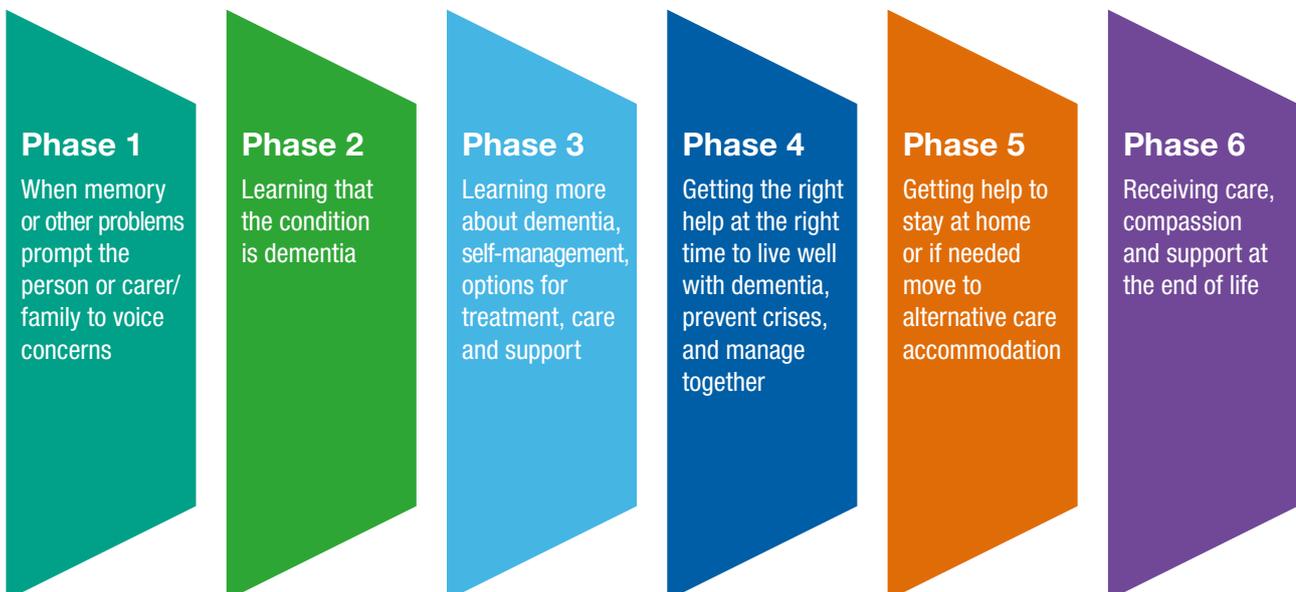
The phases reflect the experiences of people living with dementia, from recognising that there might be memory problems through to learning about how best to live well with the

condition, preventing and managing crises, and reaching the end of life with dignity and compassion. The phases are also relevant to partners, carers and families.

Dementia



Phases of dementia: a framework



Part two: The role of the nurse in dementia

The nurse's role

Our refreshed vision defines the nurse's role as:

- interpersonal
- varied in action and intensity
- taking place in a variety of settings
- welcoming individuals, family, significant others and carers and respecting their diversity and culture

to ensure that **all registered nurses** are able to deliver safe, high-quality, compassionate care within all care settings, including a person's own home.

The vision for the nurse's role in dementia is primarily an interpersonal and social model of care. This is not new, but applying it in practice along with the medical aspects of care requires a person-centred approach and commitment. Regardless of the setting or the nurse's registration or speciality, the interpersonal and psycho-social model of care in dementia includes:

- understanding the unique experiences of a person living with dementia
- building and maintaining a relationship with the person and their family
- respecting the person and their family and treating them with dignity and compassion, taking account of their culture – this is especially important when supporting people from ethnic minority communities

- recognising the person for who they are and taking the time to understand their life story, interests, preferences, wishes, social networks, and strengths and abilities
- developing person-centred outcomes with the person and their family that recognise and anticipate the phases of the condition
- promoting and providing a dementia-friendly environment
- seeking alternative sources of support, including signposting to non-medical services, if unable to provide direct assistance
- identifying and reporting any potential form of abuse that the person with dementia may be going through.



A new vision for the nurse's role in dementia

Nurses have a key role in providing health education to promote healthy lifestyles that reduce the risks of developing dementia and support people to remain active and live well

Nurses work within an interpersonal and psycho-social model, understanding the effects of dementia and having the skills to communicate with individuals and their family/carers

All nurses undertake dementia education or training to support development of their knowledge, skills and expertise

Nurses on all parts of the nursing register should be aware of relevant safeguarding protocols and how to refer vulnerable adults, in accordance with the Mental Capacity Act. This will ensure that people with dementia have safe, effective, compassionate care

The nurse's role includes welcoming and working in partnership with individuals, family and carers, respecting diversity and culture

The nurse's role varies in intensity and action depending on the phase of dementia and the person's specific needs

Nurses have a leadership role in developing dementia-friendly communities and reducing stigma

Nurses have an important role, regardless of area of registration.

For example:

- Nurses have a critical, leadership role in supporting and promoting dementia-friendly communities.
- Most people with dementia will have multiple long-term conditions, particularly older people. Nurses in primary and community care have a role in identifying health and wellbeing issues, such as eyesight and hearing problems, non-attendance at critical appointments and ensuring adherence to medication.
- Most people with dementia will have another long-term condition so may be in contact with nurses working in other specialist fields such as diabetes.
- Often people with dementia are admitted to hospital. Nurses in hospitals have a responsibility to recognise, understand,

respond to and support the needs of people with dementia and their family/carers, promoting person-centred care.

- Nurses are able to offer practical advice and support to help people live as well as possible with dementia, taking account of their medical and non-medical needs. This may include liaising with different parts of the social care system and the voluntary sector, to carry out housing improvements and adaptations, or to help individuals to stay at home for longer.
- Nurses working with people with a learning disability are able to support carers to be aware of symptoms of dementia, such as changes in behaviour and personality (e.g. becoming more inflexible, frustrated or withdrawn) or loss of daily living abilities. People with a learning disability who develop dementia generally do so at a younger age, and this is particularly the case for people with Down's syndrome, who tend to develop epilepsy as a symptom.

Dementia Core Skills Education and Training Framework

The Dementia Core Skills Education and Training Framework, published in October 2015, was commissioned and funded by the Department of Health and developed by Skills for Health and Health Education England (HEE) in partnership with Skills for Care.

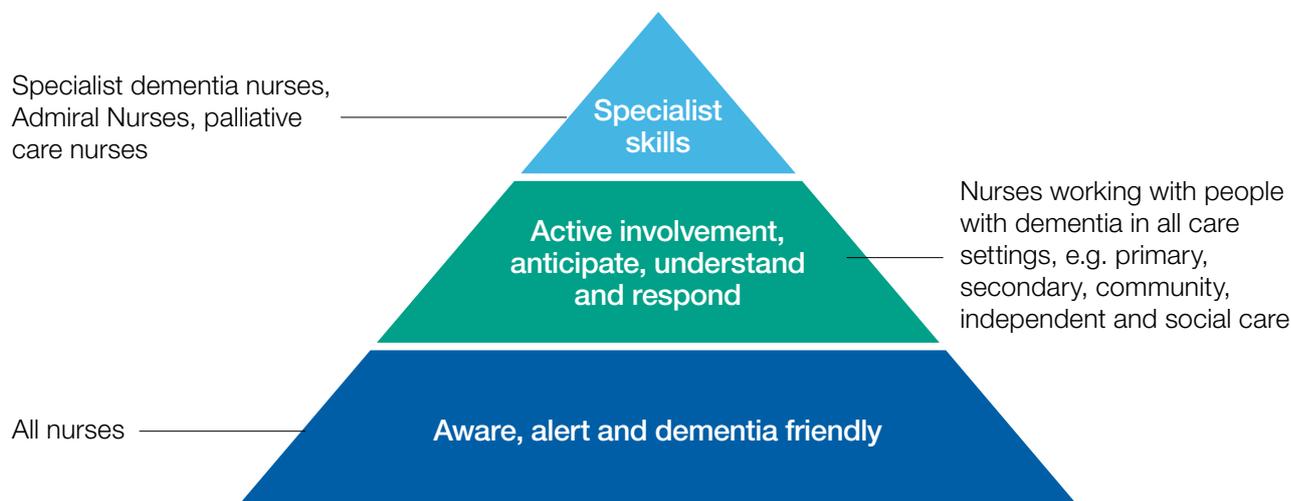
The framework sets out the core skills and knowledge that would be transferable and applicable across different types of service provision. It includes expected learning outcomes for training delivery, key policy and legal references and is aligned to related national occupational standards. The aim is to help ensure the quality and consistency of dementia training, and to help prevent unnecessary duplication of training.

The framework is structured in three tiers and is applicable to the entire health and care workforce, including registered nurses:

- **Tier 1:** dementia awareness raising, in terms of knowledge, skills and attitudes for all those working in health and care settings
- **Tier 2:** knowledge, skills and attitudes for roles that have regular contact with people living with dementia
- **Tier 3:** enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia designed to support them to play leadership roles.

This will ensure that all health and care staff, including nurses, can gain core skills and knowledge that can be used across different clinical areas and care settings, resulting in increased quality of care for people living with dementia and their families.

Levels of nursing involvement



Research

All registered nurses need to be aware of the relevant and most recent research and be committed to delivering evidence-based care.

Nurses who lead and deliver care can be trained to become researchers, able to lead research on issues that matter most to patients and carers, and to deliver results into clinical practice.

Nurses should consider opportunities to be part of the expanding dementia research workforce through:

- the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Health Research and Care (CLAHRCs), which train nurses, social care and allied health professionals to become dementia researchers
- the Health Education England (HEE) and NIHR Integrated Clinical Academic (ICA) Programme, which provides personal research training awards for healthcare professionals, including nurses, who wish to develop careers that combine clinical

research and research leadership with continued clinical practice and clinical development

- the Alzheimer's Research UK PhD Scholarship
- the Alzheimer's Society's networks of Doctoral Training Centres across the UK.

Nurses should also encourage patients and their families and carers to ask about research opportunities that could be available to them – reassuring them that it is “OK to Ask” about dementia research opportunities.

The NIHR-funded ‘Join dementia research’ project aims to get 25% of those diagnosed with dementia signed up to its database to make themselves potentially available for research into dementia.

Nurse's role within all phases of dementia

The nurse's role varies in intensity and action depending on the phase of dementia and the area of nursing practice.



Critical aspects of the nurse's role at different phases within the dementia phase 1: When memory or other problems prompt concerns

All nurses:

- are aware and alert to the signs, symptoms and progress of dementia
- understand and take account of other conditions a person may be living with and where they can access appropriate support
- signpost individuals to GP for assessment, to exclude all treatable causes of observed symptoms
- provide leadership and support to the development of dementia-friendly environments and communities, including in health and social care settings
- know about local memory assessment services and how to refer individuals – and be able to explain to the person and their family/carers how the service can help individuals to live with memory changes
- show compassion and understanding to those expressing concerns about memory, communication problems or other possible signs of dementia, including carers and family
- be aware and follow the Mental Capacity Act 2005 Code of Practice when acting or making decisions on behalf of someone who lacks capacity to make a decision for themselves.

Critical aspects of the nurse's role at different phases within the dementia phase 2: Learning that the condition is dementia

All nurses:

- provide compassionate support to people who have been given a diagnosis of dementia
- are prepared to advocate on behalf of the person with dementia and/or their family and carers
- know how dementia might affect the person, their family and carers, and their health and care needs
- recognise the person as a unique individual and citizen with strengths as well as needs
- know how the condition might affect any co-existing condition (e.g. diabetes) and take this into account in their practice to manage the person's care safely, compassionately and effectively.

Dementia or memory service nurses:

- work in partnership with colleagues in primary care and memory services to ensure that the person has a timely diagnosis delivered compassionately and taking into account their personal needs and circumstances.

Critical aspects of the nurse's role at different phases within the dementia phase 3: Learning more about dementia, self-management, options for treatment, care and support

Nurses working in dementia or memory service:

- provide information and advice about living well with a diagnosis of dementia at a time and in a way that the person wants
- engage with people from ethnic minority communities to ensure that people can access services and support that meet their needs
- work in partnership with the person to identify needs, preferences and outcomes
- know about local services, community resources and opportunities to enable people to get the support they need to live well with dementia
- support the person to overcome barriers and stigma
- seek out and know about imaginative and creative treatment and care options
- ensure that the person and their family and carers know who to contact in a crisis.

Critical aspects of the nurse's role at different phases within the dementia phase 4: Getting the right help at the right time, preventing crises and managing together

Nurses working in dementia services:

- work in partnership with the person, their family, carers and colleagues, to plan care, identify possible crisis situations and establish strategies to pre-empt or manage those crises
- work in partnership with colleagues and voluntary sector organisations, to identify a care coordinator to help the person and their family and carers navigate services
- work with the person and their family and carers to identify and articulate future needs, and, if wanted, support the family with lasting power of attorney and advance care planning
- support the person to access psychological and other relevant therapies, including exercise, creative therapies and meaningful activities relevant to the person's interests
- liaise with other relevant services to ensure that they know about dementia, the person, plans, possible crisis points and anything else that might affect their care
- understand carer needs and concerns, welcome and support the carer as a partner in the care of the person with dementia
- ensure that physical health and care needs are identified and met.

Critical aspects of the nurse's role at different phases within the dementia phase 5: Getting help to stay at home or, if needed, move to alternative care accommodation

All nurses working with the person:

- work with other relevant health, social care and voluntary sector services to enable the person to remain at home and maintain their independence for as long as possible
- where possible work to prevent admission to an acute hospital
- work to enable safe, timely discharge from hospital, if admitted, making sure there is appropriate community support
- support the person and/or their family and carers in decision-making regarding alternatives to living at home
- work with care home colleagues, including providing training and supervision, to ensure that the person receives compassionate and safe care, participates in stimulating activities, and continues to live as well as possible.

Acute hospital nurses:

- support the person with dementia on the ward or A&E with knowledge, understanding and compassion, ensuring that their particular needs are taken into account during their treatment and care.

Critical aspects of the nurse's role at different phases within the dementia phase 6: Receiving care, compassion and support at the end of life

All nurses working with the person:

- work to understand and record a person's wishes and preferences for end of life, including where they would like to die, and provide support to help achieve these preferences
- understand potential difficulties in communicating pain and distress, and work with medical colleagues and others to ensure effective pain relief
- ensure good communication between palliative care, primary care and other relevant colleagues and family and carers
- support the family and carers through the last days of the person's life and signpost them to relevant services and bereavement support.

Part three: Guidance and resources

Guidance documents

Carers Trust and Royal College of Nursing (2013), *The Triangle of Care: Carers Included: A Guide to Best Practice for Dementia Care* (<https://professionals.carers.org/triangle-care-dementia>)

Dementia UK – Admiral Nursing standards (www.dementiauk.org/how-we-help/admiral-nursing)

Department of Health (2009), *Living Well with Dementia: A National Dementia Strategy* (www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy)

Department of Health (2010), *Recognised, Valued and Supported: Next Steps for the Carers Strategy* (www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy)

Department of Health (2011), *National Dementia Strategy: Equalities Action Plan* (www.gov.uk/government/publications/national-dementia-strategy-equalities-action-plan)

Department of Health (2014), *Care and Support: Statutory Guidance: Issued under the Care Act 2014* (www.gov.uk/government/publications/care-act-2014-statutory-guidance-for-implementation)

Department of Health (2015), *Mental Health Act 1983: Code of Practice* (www.gov.uk/government/publications/code-of-practice-mental-health-act-1983)

Department of Health (2015), *Prime Minister's Challenge on Dementia 2020*

(www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020)

Department of Health (2016), *Prime Minister's Challenge on Dementia 2020: Implementation Plan*

(www.gov.uk/government/uploads/system/uploads/attachment_data/file/507981/PM_Dementia-main_acc.pdf)

National Institute for Health and Clinical Excellence (NICE) and Social Care Institute for Excellence (2006), *Dementia: Supporting People with Dementia and Their Carers in Health and Social Care*

(www.scie.org.uk/publications/misc/dementia)

NICE, *Dementia Pathway*

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

NICE Guidelines [CG42] (2006), *Dementia: Supporting People with Dementia and Their Carers in Health and Social Care*

(www.nice.org.uk/guidance/cg42)

NICE Guidelines [NG16] (2015), *Dementia, Disability and Frailty in Later Life – Mid-Life Approaches to Delay or Prevent Onset*

(www.nice.org.uk/guidance/NG16)

NICE quality standard [QS1] (2010), *Dementia: Support in Health and Social Care*

(www.nice.org.uk/guidance/qs1)

NICE quality standard [QS30] (2013), Dementia: Independence and Wellbeing [quality standard for supporting people to live well with dementia] (www.nice.org.uk/guidance/qs30)

Nuffield Council on Bioethics (2009), Dementia: Ethical Issues (<http://nuffieldbioethics.org/project/dementia>)

Office of the Public Guardian (2016), Mental Capacity Act Code of Practice (www.gov.uk/government/publications/mental-capacity-act-code-of-practice)

Royal College of Psychiatrists, National Audit of Dementia (www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/dementia/nationalauditofdementia.aspx)

Skills for Health, Health Education England, and Skills for Care (2015), The Dementia Core Skills Education and Training Framework (www.skillsforhealth.org.uk/projects/item/176-dementia-core-skills-education-and-training-framework)



Resources

Alzheimer's Research UK, PhD Scholarship
(www.alzheimersresearchuk.org/grants/phd-scholarship)

Alzheimer's Society, Doctoral Training Centres [network across the UK]
(www.alzheimers.org.uk/dtc)

Alzheimer's Society, Guidance and Criteria for the Recognition Process for Dementia-Friendly Communities
(www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=911)

Alzheimer's Society (2012), Factsheet 500: Communicating
(www.alzheimers.org.uk/factsheet/500)

Alzheimer's Society (2013), The Dementia Guide: Living Well
(www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2240)

Alzheimer's Society (2014), Factsheet 483: Deprivation of Liberty Safeguards
(www.alzheimers.org.uk/factsheet/483)

Alzheimer's Society (2015), Factsheet 430: Learning Disabilities and Dementia
(www.alzheimers.org.uk/factsheet/430)

Alzheimer's Society (2015), Factsheet 524: Understanding and Supporting a Person with Dementia
(www.alzheimers.org.uk/factsheet/524)

Alzheimer's Society (2015), This Is Me [tool for people with dementia receiving professional care]
(www.alzheimers.org.uk/thisisme)

Alzheimer's Society, Advice for Nurses and Other Healthcare Professionals
(www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1211)

Alzheimer's Society, Dementia UK: Update (2014 update report)
(www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2323)

Alzheimer's Society, Dementia Friends programme [initiative to change people's perceptions of dementia]
(www.dementiafriends.org.uk)

Alzheimer's Society, Factsheets
(www.alzheimers.org.uk/factsheets)

Care Fit for VIPS [free online toolkit that offers easy-to-use resources to understand and implement person-centred dementia care]
(www.carefitforvips.co.uk/#vips)

Central and North West London (CNWL) NHS Foundation Trust (2016), Memory Services: Dementia Information for Black, Asian and Minority Ethnic Communities
(www.cnwl.nhs.uk/wp-content/uploads/Memory-Services-Handbook-final.pdf)

Dementia Action Alliance [supports communities and organisations across England to take practical actions to enable people to live well with dementia and reduce the risk of costly crisis intervention]
(www.dementiaaction.org.uk)

Dementia First Aid [dementia care training for families and professionals]
(www.dementiafirstaid.info)

Dementia Roadmap [helping primary care to support people with dementia]
(<http://dementiaroadmap.info>)

Dementia UK [information, support, Admiral Nurses]
(www.dementiauk.org)

Dementia UK, Higher Education for Dementia Network [maintains a list of courses in dementia care, available at UK universities for qualified health and social care professionals]
(www.dementiauk.org/for-healthcare-professionals/hedn-and-curriculum-for-dementia-education)

Department of Health, Dementia challenge
(<https://engage.dh.gov.uk/dementiachallenge>)

Department of Health (2013), Dementia Self-Assessment Framework
(www.gov.uk/government/publications/dementia-self-assessment-framework)

Health Education England, e-Learning for healthcare [dementia training for health and social care staff]

(www.e-lfh.org.uk/programmes/dementia)

John's Campaign [helping people living with dementia and their carers]

(www.johnscampaign.org.uk/index.html)

National Institute of Health Research (NIHR) [information on dementia research]

(www.nihr.ac.uk/research/dementia.htm)

National Skills Academy, Stand By Me - Dementia [e-learning course for health and care staff to develop good communication and person-centred care]

(www.nsahealth.org.uk/e-learning/courses-we-offer/286:stand-by-me-dementia-free-e-learning-course)

NIHR, 'OK to Ask' [campaign aimed at encouraging more patients to ask about research opportunities]

(www.nihr.ac.uk/get-involved/ok-to-ask.htm)
www.nihr.ac.uk/get-involved/ok-to-ask.htm)

NIHR, Join Dementia Research [to register interest in participating in dementia research]

(www.joindementiaresearch.nihr.ac.uk)

Public Health England (2014), Framework for Personalised Care and Population Health [resource to support nurses, midwives, health visitors and allied health professionals to access best evidence for practice and deliver their public health role, including dementia]

(www.gov.uk/government/publications/framework-for-personalised-care-and-population-health)

Royal College of Nursing, Dementia: Professional Resources

(www.rcn.org.uk/clinical-topics/dementia/professional-resources)

Social Care Institute for Excellence (SCIE), Dementia Gateway

(www.scie.org.uk/dementia/index.asp)

The Butterfly Scheme [encourages staff to use a carer sheet as well as helping staff to understand the carer perspective]

(<http://butterflyscheme.org.uk>)

Unite the Union, Mental Health Nursing journal Dementia special, Oct/Nov 2014: Vol 34(5)

(www.unitetheunion.org/uploaded/documents/MHN%202014-10%20dementia%20Special11-20021.pdf)

University of Worcester -- Association for Dementia Studies, Enhancing the Healing Environment Programme [tools to help improve the care environment for people with dementia in hospital]

(www.worcester.ac.uk/discover/ads-enhancing-the-healing-programme.html)



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