

Dementia assessment and improvement framework

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We support providers to give patients safe, high quality, compassionate care within local health systems that are financially sustainable.

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Summary

Dementia is an umbrella term used to describe a range of progressive neurological disorders. Alzheimer's disease and vascular dementia are the most prevalent, accounting for 79% of all diagnoses. Other forms include frontotemporal, Lewy body, Parkinson's dementia, corticobasal degeneration, Creutzfeldt–Jakob disease and young-onset dementia (Alzheimer's Society 2017, Dementia UK 2017). Symptoms include change of thinking speed, mental agility, language, understanding, judgement as well as memory loss (NHS Choices 2017), but each affected person will experience dementia differently.

In 2015, 850,000 people were living with dementia and their number is predicted to increase. One in six of those aged over 80 will develop dementia, but 40,000 people living with dementia are younger than 65 years. Two-thirds are women. Dementia costs the UK an estimated £26 billion per year, despite 670,000 family carers providing the equivalent of £11 billion of care a year (Alzheimer's Society 2014).

The evidence-based dementia assessment and improvement framework is designed to support and enable directors of nursing and medical directors to achieve 'outstanding' care standards for those living with dementia during their stay in hospital. The framework describes what 'outstanding' care looks like to provide a system of assurance for trust boards.

The framework consists of eight standards and draws on learning from organisations that have achieved an 'outstanding' rating from the Care Quality Commission (CQC) (Appendix 1) and integrates policy guidance (Appendix 2) and best practice (Appendix 3) with opinion from patients and carers.

The framework is designed to be implemented using quality improvement methodology, embodying the principle of continual learning. Organisations should adapt it to meet their local population and workforce needs.

The framework

The dementia assessment and improvement framework supports organisational leaders in NHS provider organisations – for example, senior sisters/charge nurses, consultants and allied health professionals (AHPs) – to provide ‘outstanding’ care for people living with dementia during their stay in an acute, community or mental health setting.

The framework is evidence based and integrates national policy, practice guidance, best practice from organisations achieving an ‘outstanding’ rating from CQC and the patient and carer voice. The latter was captured through existing resources, including Healthwatch (2017), Patient Voices, the Alzheimer’s Society and meeting people and their carers living with dementia.

We recommend the framework forms part of an organisation’s quality improvement programme. The principles of the framework apply to all services and the framework should be adapted by organisations for local use.

As described in Table 1, the framework consists of eight standards for:

- diagnosis
- person-centred care
- patient and carer information and support
- involvement and co-design
- workforce education and training
- leadership
- environment
- nutrition and hydration.

Each standard has three sections:

- a description of what needs to be achieved to deliver ‘outstanding’ care
- the source linking each standard statement to policy, best practice guidance, patient and/or carer opinion and examples of innovative actions taken by NHS organisations

- the evidence clinicians/leaders might gather to self-assess and identify where improvements are required or if interventions have achieved the desired outcomes.

Table 1: The eight framework standards

Dementia assessment and improvement standard	Standard description	Source	Evidence	Met (state % to achieve)	Partially met	Not met
Diagnosis	There is an evidenced-based dementia care pathway which includes a delirium assessment where clinically indicated	<p><i>Living well with dementia: A national dementia strategy</i> (DH 2009)</p> <p><i>Delirium: prevention, diagnosis and management</i> (NICE 2010)</p> <p><i>The national dementia CQUIN</i> (DH 2012)</p> <p><i>Prime minister’s challenge on dementia 2020</i> (DH 2015)</p> <p><i>Dementia: supporting people with dementia and their carers in health and social care</i> (NICE and Social Care Institute for Excellence (2006; updated 2016)</p> <p><i>National audit of dementia</i> (Royal College of Psychiatrists 2017)</p> <p>Patient and carer voice – “there’s a reluctance to diagnose dementia”</p>	<p>Evidence of a comprehensive dementia assessment protocol (dementia strategy)</p> <p>Evidence of a comprehensive delirium assessment where clinically indicated</p> <p>Assessments are clearly documented in the patient notes</p> <p>The treatment of delirium follows evidence-based practice</p> <p>Assessment outcomes and treatment are recorded in the electronic discharge summary</p> <p>Speak to staff; can they articulate the assessment criteria and forward actions required? Is there a clear process ± SOP?</p>			

<p>Person-centred care</p>	<p>There is evidence that the person and their carers have been involved in care planning</p>	<p><i>Dementia-friendly hospital charter</i> (DAA 2012) <i>Dementia: Commitment to the care of people with dementia in hospital settings</i> (RCN 2013) Patient voice – “involve me, listen to me” CQC recommendation</p>	<p>Patients say they are involved Families/carers say they are involved and listened to Observation – staff are seen to involve patients and families/carers Staff can describe how they involve patients and families/carers</p>			
	<p>Clinical team completes the <i>This is me</i> booklet and involves patient and carer in this (if not already done in primary care)</p> <p>There is evidence of how this informs care delivery</p> <p>There is evidence of how this is communicated and shared across the multi-professional team</p> <p>There are processes to ensure <i>This is me</i> is stored and used for subsequent admissions/attendances</p>	<p><i>Dementia-friendly hospital charter</i> (DAA 2012) <i>This is me</i> (Alzheimer’s Society 2016) CQC recommendation</p>	<p>Patients say they are involved Families/carers say they are involved and listened to Observation – staff are seen to involve patients and families/carers Staff can describe how they involve patients and families/carers, and how this informs care delivery Patient record review Ward leaders monitor the use of the <i>This is me</i> booklet and can articulate how to reduce variance where it exists Staff can describe the process for storing and accessing <i>This is me</i> at subsequent admissions/attendances</p>			
	<p>Personalised care is delivered according to care plan meeting the patient’s needs</p>					

Person-centred care (contd)	Patient's wishes relating to personal care are respected. Evidence of discussion with relatives/ carers may be required					
	Key at a glance information is displayed above the bed (with person's or carer's agreement): preferred name, likes, dislikes and enhanced care needs (without breaching confidentiality)	Forget me not (Alzheimer's Society 2014) The Butterfly Scheme (2013) CQC recommendation	Observation Patients say they are addressed by their preferred name Staff can describe how this supports the whole team in meeting patients' needs			
	Evidence that the principles of the Mental Capacity Act (2005) are followed relating to: <ul style="list-style-type: none"> • consent • capacity assessment • best interest meeting 	<i>Dementia-friendly hospital charter</i> (DAA 2012) <i>Making a difference in dementia</i> (DH 2016)	Patient record review Mandatory training compliance meets trust standards Observational evidence that staff seek people's consent before providing care			
	Evidence that the principles of the Mental Health Act (2007) are followed relating to: <ul style="list-style-type: none"> • protection of patients' rights under the act • staff compliance with the code of practice 	<i>Mental Health Act</i> (DH 2007) <i>Mental Health Act code of practice</i> (DH 2015)	Patient record review Mandatory training compliance meets trust standards Staff can articulate their understanding and application of the Mental Health Act and the code of practice			

Person-centred care (contd)	People requiring deprivation of liberty safeguards (DoLS) are identified and appropriate documentation is in place	Mental Capacity Act (2005) <i>Dementia-friendly hospital charter</i> (DAA 2012)	Patient record review Staff can articulate their understanding and DoLS applications			
	Staff can articulate safeguarding processes and their responsibility in raising concern	Hospital policy <i>The fundamental standards</i> (CQC 2017)	Staff can describe safeguarding process and their actions Patient record review Incident report data Mandatory training compliance meets trust standards			
	An appropriate pain assessment tool is used, for example the Abbey Pain Score or the Pain Assessment in Advanced Dementia Scale (PAINAD)	<i>Dementia-friendly hospital charter</i> (DAA 2012) advises which pain assessment tools to use with people with advanced dementia	Patient record Staff can describe how and when to use Abbey Pain Score Where appropriate, ask patients if their pain is well controlled A patient's relatives and carers determine if the person's pain is well controlled			
	50% of acute admissions relate to falls, fractured hip, respiratory or urinary infection Evidence of multifactorial assessment and intervention with support from specialist dementia and delirium teams where they exist	<i>National audit of dementia</i> (Royal College of Psychiatrists 2017) <i>Falls in older people: assessing risk and prevention</i> (NICE 2013)	Patient record review			

<p>Person-centred care (contd)</p>	<p>Patients and carers are supplied with ward information in suitable formats</p> <p>Patients and carers know the name of the responsible clinician and ward/service staff</p>	<p>CQC recommendation</p>	<p>Patients and carers say they have access to the information they need</p> <p>Patients and carers know the name of the clinician they can speak to</p> <p>Patients and carers say they feel supported and informed about their care</p>			
	<p>Information is shared with relevant carers on discharge</p>	<p><i>National audit of dementia</i> (Royal College of Psychiatrists 2017)</p>	<p>Review the discharge summary</p> <p>Feedback from GPs/care homes/care agencies/families/carers</p> <p>Complaints</p> <p>Incident notifications relating to discharge processes</p>			
	<p>Evidence of a person-centred culture – labelling and depersonalised language is not used</p> <p>Staff use care delivery as an opportunity to engage positively with people to increase their wellbeing</p>	<p>CQC recommendation</p>	<p>Observe and listen to interactions between staff members</p> <p>Observe and listen to interactions between staff and patients</p> <p>Patients and carers say they are treated with respect and dignity</p>			

	Evidence of innovative ways to meet the person's individual needs; eg hair and nail treatments (where clinically appropriate). Patients and carers state "it's the little things which count"	Characteristic of trusts rated 'outstanding'	Patients and carers give examples of how their needs have been met Staff say how they go the 'extra mile' to meet people's individual needs			
Patient and carer information and support	Patients and families/carers feel supported at the point of diagnosis	Patient voice – "the support is not always there when you are diagnosed, there are so many questions" "we need specially trained staff to be with us following the diagnosis"	Patients and carers say they received the help and support they wanted when diagnosed			
	Use of different information and formats including video and audio	<i>Dementia-friendly hospital charter</i> (DAA 2012) <i>The triangle of care</i> (RCN 2016)	Patients and carers say they have access to the type of information they need in the best format for them Observation – information is available in different formats			
	Information should be available in the different languages that meet the needs of the local community <i>State the languages leaflets are available in</i>	<i>Accessible information standard</i> (NHS England 2016)	Speak to patients and carers Information is available to the public on wards Ask "what's missing?"			

Patient and carer information and support (contd)	Dementia café – jointly hosted by the Alzheimer’s Society and the clinical nurse specialist to provide support and education to people living with dementia and their carers <i>Cafés may not work in every organisation. Other mechanisms should be reflected here</i>	<i>The triangle of care</i> (RCN 2016)	Patients and carers say they feel supported and have access to the information they need			
	Forums exist to provide support and expertise to the carers of people living with dementia	Prevalent in trusts achieving an ‘outstanding’ rating	Observation – attend a forum Patients and carers say they feel supported and have access to the information they need Review complaints/ compliments Staff say how they meet patient and carer needs			
	Hospital staff who care for a person living with dementia are offered support and advice	Innovation adopted by some trusts	Staff in this position feel supported practically and emotionally			
	People living with dementia and/or their carers are signposted to Dementia Connect	Dementia Connect (Alzheimer’s Society 2017)	Patient, family and carer feedback Written guidance is available Speak to the local Alzheimer’s Society regarding referrals from hospital-based services			

Patient and carer information and support (contd)			Staff can describe why and how they signpost to Dementia Connect			
	People living with dementia are supported through the discharge process and put in contact with dementia advisors if not they are not known to the service Each organisation should provide details of the support services available locally. Dementia advisors may not be available in some areas	<i>Dementia advisors: A cost effective approach to delivering integrated dementia care</i> (Alzheimer's Society 2016)	Patients, families and carers say they connect to local services and receive/know how to access local support services Patient record review			
	The principles of John's campaign are supported	John's campaign (2014)	Staff can describe principles and how they apply them			
	Facilities are available for families/carers to stay overnight <i>Align to trust approach – folding bed, reclining chair, washing facilities</i>	<i>Dementia-friendly hospital charter</i> (DAA 2012)	Patients and carers are aware that families/carers can stay overnight if they wish			
Family/carers have access to: <ul style="list-style-type: none"> • open visiting • drinks on the ward • concessionary parking (where parking exists) 						

Patient and carer information and support (contd)	<ul style="list-style-type: none"> concessionary food in hospital canteen <p><i>Align to organisational policy where required</i></p>					
	Other innovative ways of involving and supporting patients and families are implemented; eg ward-based tea parties	Innovation adopted by some trusts	Patients, carers and staff can describe what these are and their impact			
Involvement and co-design	<p>Evidence of patient involvement in their care</p> <p>Evidence of family/carer involvement in patient's care</p> <p>Staff are 'carer aware' and can articulate how they engage with carers</p> <p>Carers are identified at first contact or as soon as possible after this. Staff can articulate how they do this and how it influences care, and what the outcomes are for patients</p>	<p><i>The triangle of care</i> (RCN 2016)</p> <p><i>Dementia-friendly hospital charter</i> (DAA 2012)</p> <p><i>Making a difference in dementia</i> (DH 2016)</p> <p>Patient voice – "speak to me not my relative"</p> <p>Patient voice relating to involvement:</p> <p>"don't involve me to tick a box, you need to listen"</p> <p>"I don't want to be a token"</p>	<p>Patients, families and/or carers say if and how they feel involved</p> <p>Staff say how they involve families and carers</p> <p>Patient record review</p> <p>Observation of conversations</p>			
	Patients, families/carers are involved in discharge planning	<i>Dementia-friendly hospital charter</i> (DAA 2012)				

Involvement and co-design (contd)	Care homes are actively involved with discharge plans	<i>Dementia-friendly hospital charter</i> (DAA 2012)	Speaking to care homes (retrospective audit) Patient record review			
	People living with dementia and carers sit on dementia strategy committee/other forums	A prevalent characteristic of trusts rated 'outstanding' <i>Dementia 2020 citizens' engagement programme</i> (DH 2016)	Evidence in terms of reference and committee minutes Speak to representatives			
	People living with dementia and carers are involved in service redesign and dementia pathway design and evolution	Patient voice: "if you want me to be involved you need to send me the briefing papers in advance"	Evidence of quality/service improvement involving patients and carers; evidence in terms of reference and meeting minutes Speak to representatives			
Workforce education and training	The workforce has right knowledge and skills to meet the needs of people living with dementia The workforce has right knowledge and skills in delirium and its relationship to dementia, manifestations of pain and behavioural and psychological symptoms of dementia	<i>Dementia-friendly hospital charter</i> (DAA 2012) <i>Dementia core skills, education and training framework</i> (Skills for Health/Skills for Care, HEE 2015) <i>Making a difference in dementia</i> (DH 2016) <i>National audit of dementia</i> (Royal College of Psychiatrists 2017)	The trust's education programme includes training in dementia and delirium Trust's education programme meets tiers 1, 2 and 3 training recommendations The agreed organisational education and training rates are achieved (dataset to support achievement) Staff say they are trained and equipped with the right knowledge and skills to care for people living with dementia and delirium on an acute ward			

Workforce education and training (contd)			<p>Evidence of how staff skills and competency are assessed on an ongoing basis, eg observational tools or audits</p> <p>Staff have access to specialist advice if and when they need it</p> <p>Patients and carers say that staff have the right knowledge and skills to care for person</p>			
	<p>Staff have the right knowledge and skills in:</p> <ul style="list-style-type: none"> • safeguarding • the Mental Capacity and Mental Health Act, including consent <p>Appropriate use of best interests decision-making</p> <p>Training and education addresses the administration of covert medication as per organisational policy</p> <p>Use of lasting power of attorney and advanced decision-making</p> <p>DoLS</p> <p>Supportive communication with family members and carers</p>	<p><i>National audit of dementia</i> (Royal College of Psychiatrists 2017)</p>	<p>Staff training records</p> <p>Staff say they have the right knowledge and skills following training</p> <p>Patients and carers say they feel informed, involved and supported</p> <p>Decisions are documented in the patient record</p>			

Workforce education and training (contd)	<p>Dementia strategy states all non-clinical staff are trained in care of people living with dementia, eg porters, reception staff, facilities and estates, and those working in hospital/trust shops, cafés, restaurants, volunteers</p> <p>Dementia Friends promoted as part of strategy; organisation can give number trained as dementia friends</p> <p>Dementia Friends sessions do not replace training. They support a dementia friendly service at all levels</p>	<p><i>Dementia-friendly hospital charter</i> (DAA 2012)</p> <p>Dementia Friends (Alzheimer's Society 2017)</p>	<p>Staff can articulate how they support and meet the needs of people living with dementia in all areas of the organisation</p> <p>Training records</p> <p>Number of dementia friends</p>			
	<p>Wider community is offered dementia training, eg care home staff, other public service providers</p>	<p>Feature of trusts rated 'outstanding'</p>	<p>Dementia strategy</p>			
Leadership	<p>An organisational dementia strategy is available, in date and meets national policy/best practice guidance</p>	<p><i>Dementia-friendly hospital charter</i> (DAA 2012)</p>	<p>Staff know of the dementia strategy and can state its overall aim</p> <p>Staff know their part in meeting the strategy aims</p> <p>Patients and carers say there is an organisational approach to meeting needs</p>			

Leadership (contd)	Evidence of dementia pathway development, working with GPs, CCGs, local authority, social services, voluntary and third sector to deliver a strategy to meet local needs	Feature of trust rated 'outstanding'	Dementia strategy and committee meeting minutes Staff say what they are doing to improve the dementia pathways locally Patients and carers can describe how the pathways are improving			
	Evidence of local application of the dementia strategy. Staff can articulate the improvements being made in line with the dementia strategy	Characteristic of trusts rated 'outstanding' by CQC	Staff can describe how they are contributing to improving care for their patients who live with dementia			
	Evidence of clinical leadership: <ul style="list-style-type: none"> • organisational (consultant, consultant nurse or nurse specialist) • ward/department (dementia champions/link nurses with evidence of enhanced training and development) Dementia champions/link nurses need to provide evidence of how they are improving care standards	Characteristic of trusts rated 'outstanding' by CQC <i>Dementia-friendly hospital charter (DAA 2012)</i>	Dementia strategy and the minutes from meetings Staff can say what they do and how they make a difference			

Leadership (contd)	Evidence of trust executive leadership	Characteristic of trusts rated 'outstanding' by CQC	Staff know which executive is the dementia champion at board level A culture in which all staff acknowledge their part in meeting needs of people living with dementia irrespective of role they play in organisation			
	The board sees data for the numbers of patients moved at night (between 23:00 and 06:00 hours) for non-clinical reasons and plans to reduce them	Feature of trusts rated 'outstanding'	Board reports Speak to the dementia strategy lead/director of nursing/medical director			
	People trained in the care of people living with dementia are available 24 hours a day, seven days a week	<i>National audit of dementia</i> (Royal College of Psychiatrists 2017)	Speak to the staff to understand their role and how it positively impacts patients Dementia strategy minutes			
Environment <i>Consider applying this standard to all areas</i>	Signage is appropriate for people living with dementia, including: <ul style="list-style-type: none"> words are supported by pictures areas are colour coded and supported by themed pictures 	<i>Dementia-friendly hospital charter</i> (DAA 2012) <i>Enhancing the healing environment</i> (King's Fund 2017) <i>Patient led assessments of the care environment: dementia friendly environments, guidance for assessors</i> (DH 2017) <i>Virtual hospital</i> (Sterling University 2017)	Peer inspection and assessment Patient and carer feedback/comment Staff feedback Business case – inclusion of environmental planning for people living with dementia			
	Environment promotes meaningful interaction between patients, their families/carers and staff					

Environment (contd)	Where possible a seating area is provided with things to engage with, eg art and music					
	The environment promotes wellbeing, including by: <ul style="list-style-type: none"> • using lighting that supports rest and sleep • allowing photographs and personal items to be kept near to the patient • encouraging eating and drinking, eg with areas where patients and families can eat together 					
	Flooring meets recommendations for people living with dementia					
	Ward is clutter free					
	People can see a working clock (shows time, day and date to orientate to time and place)					
	There is a therapeutic environment which					

Environment (contd)	<p>provides meaningful activity; eg:</p> <ul style="list-style-type: none"> • reminiscence activity • music – including local groups visiting the ward/Singing for the Brain (Alzheimer’s Society) • Pets as Therapy visit patients in hospital 					
	<p>People living with dementia and their carers/relatives are encouraged to bring their pet to hospital to visit the patient</p> <p>Pets as Therapy dogs visit wards so that patients can stroke a dog as a calming and therapeutic intervention</p>					
	<p>PLACE audit meets the required standard</p>		Improvement plans are in place where required to respond to the PLACE audit with leads and timeframes			

Nutrition and hydration	All healthcare professionals directly involved in patient care should receive education and training relevant to their posts	<i>Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition Clinical guideline 32 (NICE 2017)</i>	Training rates Speak to staff to find out if they have the right knowledge and skills to meet needs Ask patients and carers if staff support and enable people to meet their nutritional needs			
	Weight of all inpatients is assessed on admission. Include pre-assessment for elective admissions		Policy review Notes review Staff can describe the process for this and its importance			
	All inpatients are assessed using the malnutrition universal screening tool (MUST) <i>Trusts to amend this standard if they use a different nutritional assessment</i>		Policy review Notes review Minutes of relevant meetings; eg, a nutrition and hydration committee (<i>amend to align with existing organisational structures</i>)			
	Expert advice is available from the multidisciplinary nutritional team; eg, specialist nurse, dietician and speech and language therapist		Nutritional steering group minutes Staff can say how they access expert advice Patients and carers have confidence patients' nutritional needs are met Patient record review			

Nutrition and hydration (contd)	Care plans meet people's hydration and nutritional needs Evidence of discussion with family or carer	Carer voice – six out of 10 carers are concerned about the nutritional intake of a person living with dementia (<i>Dementia-friendly hospital charter</i> DAA 2012)	Patients and carers say patients' nutritional and hydration needs are met Staff can describe when and how they provide assistance The senior sister/charge nurses can describe the ways in which people are helped at mealtimes or when they indicate they want food or a drink' Patient record review Observation at mealtimes and when people ask for food or a drink			
	Patients with dysphagia are referred to a healthcare professional with the skills to manage swallowing disorders	<i>Nutrition support for adults: Clinical guideline 32</i> (NICE 2017)	Nutrition and hydration pathway Staff know the causes of dysphagia and can recognise signs and symptoms Staff identify poor oral hygiene as a factor to consider before changing nutritional support			
	Oral hygiene		Patients and carers say patients get help with oral hygiene if they need it Staff can describe how they assess oral hygiene and the actions they take			

Nutrition and hydration (contd)			<p>Any clinical need is documented in the patient's care plan</p> <p>Toothbrushes and toothpaste are available for patients who do not have these on admission</p> <p>Oral care kits are available and used where clinically appropriate</p> <p>Staff can describe the process for keeping dentures safe to avoid loss</p>			
	<p>A variety of foods are available 24 hours a day, including:</p> <ul style="list-style-type: none"> • finger food • snacks/biscuits • food that can be provided outside the routine mealtimes <p>Menus are routinely available in picture and large print format, and other formats if appropriate</p>	<p><i>National audit of dementia</i> (Royal College of Psychiatrists 2017)</p>	<p>Menu review</p> <p>Mealtime observation/audit</p>			
	<p>Appropriate crockery and cutlery is available for people requiring support,</p>		<p><i>A well-led team which places emphasis on meeting patients' hydration and nutritional needs</i></p>			

Nutrition and hydration (contd)	including: <ul style="list-style-type: none"> • coloured plates • adapted cutlery • coloured trays • water jugs with different coloured lids 		<i>is what makes the difference to patients; these are merely adjuncts to support delivery</i> Patients and carers say patients' nutritional and hydration needs are met Staff can describe how they assist patients The senior sister/charge nurses can describe how the team works to assist people at mealtimes or when people want food and drink Patient record review Observation at mealtimes and when people ask for food or a drink			
	Carers are not asked to leave at mealtimes/ stopped from helping patients with meals	<i>National audit of dementia (Royal College of Psychiatrists 2017)</i>	Observation Patients and families/carers say family members/carers are encouraged to stay if they wish			
	Carers and family members are supported to be as involved as they want to be in meeting patients' nutritional needs	<i>National audit of dementia (Royal College of Psychiatrists 2017)</i>	Observation Patients and families/carers say family members/carers can be as involved as they want to be			

References and other resources

Age UK (2016) Implementing John's campaign

<https://ageukblog.org.uk/2016/12/09/guest-blog-implementing-johns-campaign-improving-the-quality-of-care-and-experiences-of-people-with-dementia-in-hospitals/>

Alzheimer's Society (2014) Forget me not <https://www.alzheimers.org.uk/>

Alzheimer's Society (2016) *This is me* www.alzheimers.org.uk

Alzheimer's Society (2016) *Dementia advisors: A cost effective approach to delivering integrated dementia care*

https://www.alzheimers.org.uk/download/downloads/id/3429/dementia_advisers_a_cost_effective_approach_to_delivering_integrated_dementia_care.pdf

Alzheimer's Society Dementia Friends <https://www.dementiafriends.org.uk/>

Alzheimer's Society Dementia Connect

https://www.alzheimers.org.uk/info/20011/find_support_near_you#!/search

The Butterfly Scheme <http://butterflyscheme.org.uk/>

Care Quality Commission (2016) *The state of care in NHS acute hospitals: 2014-16*

http://www.cqc.org.uk/sites/default/files/20170302b_stateofhospitals_web.pdf

Care Quality Commission (2017) *The fundamental standards*

<http://www.cqc.org.uk/what-we-do/how-we-do-our-job/fundamental-standards>

Dementia Action Alliance (2012) *Dementia-friendly hospital charter*

http://www.dementiaaction.org.uk/assets/0001/8146/DAA_Dementia_Friendly_Hospital_Charter_Booklet_06-2015.pdf

Dementia UK (2017) <https://www.dementiauk.org>

Department of Health (2007) *Mental Health Act*

<https://www.legislation.gov.uk/ukpga/2007/12/contents>

Department of Health (2009) *Living well with dementia: A national dementia strategy*
<https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>

Department of Health (2012) *Using the commissioning for quality and innovation (CQUIN) payment framework. Guidance on new national goals for 2012-13*
<https://www.gov.uk/government/news/introducing-the-national-dementia-cquin>

Department of Health (2014) *Mental Capacity Act 2005: Making decisions*
<https://www.gov.uk/government/collections/mental-capacity-act-making-decisions>
(also see: Social Care Institute for Excellence (2016) *Mental Capacity Act at a glance* <http://www.scie.org.uk/mca/introduction/mental-capacity-act-2005-at-a-glance>)

Department of Health (2015) *Mental Health Act code of practice*
<https://www.gov.uk/government/news/new-mental-health-act-code-of-practice>

Department of Health (2015) *Prime minister's challenge on dementia 2020*
<https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

Department of Health (2016) *Dementia 2020 citizens' engagement programme. Toolkit for engaging people with dementia and carers*
<https://www.gov.uk/government/publications/talking-to-people-about-the-governments-work-on-dementia>

Department of Health (2016; refreshed edition) *Making a difference in dementia. Nursing vision and strategy*
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/554296/Dementia_nursing_strategy.pdf

Department of Health (2017) *Patient led assessments of the care environment: dementia friendly environments, guidance for assessors*
http://content.digital.nhs.uk/media/23450/PLACE-2017-Dementia-Friendly-Environments-Guidance/pdf/PLACE_2017_Dementia_Friendly_Environments_Guidance.pdf

Health Education England in collaboration with Skills for Health (2015) *Dementia core skills education and training framework*

<http://www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.pdf>

Healthwatch (2017) *What do people think of dementia services?*

<http://m.healthwatch.co.uk/news/what-do-people-think-dementia-services>

John's campaign <http://johnscampaign.org.uk/#/>

King's Fund (2017) *Enhancing the healing environment*

<https://www.kingsfund.org.uk/projects/enhancing-healing-environment>

National Institute for Health and Care Excellence (2013) *Falls in older people:*

assessing risk and prevention <https://www.nice.org.uk/guidance/cg161/chapter/1-recommendations>

National Institute for Health and Care Excellence (2010) *Delirium: prevention,*

diagnosis and management <https://www.nice.org.uk/guidance/cg103>

National Institute for Health and Care Excellence; Social Care Institute for

Excellence (2006; updated 2016) *Dementia: supporting people with dementia and their carers in health and social care* <https://www.nice.org.uk/guidance/cg42>

National Institute of Health and Care Excellence (2017) *Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition.*

<https://www.nice.org.uk/guidance/cg32>

NHS Choices <https://www.nhs.uk>

NHS England (2016) *Accessible information standard*

<https://www.england.nhs.uk/2016/08/accessible-information-standard/>

Patient Voices <http://www.patientvoices.org.uk/>

Pets as Therapy <http://petsastherapy.org>

Royal College of Nursing (2013) *Dementia: Commitment to the care of people with dementia in hospital settings*

https://my.rcn.org.uk/__data/assets/pdf_file/0011/480269/004235.pdf

Royal College of Nursing, RCN Foundation (2016) *The triangle of care. Carers included: a guide to best practice for dementia care*

https://professionals.carers.org/sites/default/files/the_triangle_of_care_carers_included_best_practice_in_dementia_care_-_final.pdf

Royal College of Psychiatrists (2016) *Memory services national accreditation programme*

<http://www.rcpsych.ac.uk/quality/qualityandaccreditation/memoryservices/memoryservicesaccreditation/msnapstandards.aspx>

Royal College of Psychiatrists (2017) *National audit of dementia*

<http://www.rcpsych.ac.uk/quality/nationalclinicalaudits/dementia/nationalauditofdementia.aspx>

Sterling University (2017) *Virtual hospital* <http://dementia.stir.ac.uk/design/virtual-environments/virtual-hospital>

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Appendix 1: Review of 104 CQC reports published before December 2016 and relating to dementia care

Introduction

The Care Quality Commission (CQC) is the independent regulator for health and social care in England. Its monitoring and inspection framework has five domains that together determine if organisations provide safe, effective, caring and responsive services which are well led. Each organisation is rated against the domains before being given an overall rating of ‘outstanding’, ‘good’, ‘requires improvement’ or ‘inadequate’, which must be on public display.

This appendix reports the findings of our thematic analysis of the written narrative relating to dementia care in 104 CQC reports published before December 2016, to identify the characteristics of organisations under each of the four ratings.

How we reviewed the CQC reports

Thematic analysis of the written narrative relating to dementia care identified the characteristics of organisations under each of the four ratings. The characteristics associated with organisations rated outstanding and good were cross-checked with policy guidance and the patient/carer voice (see Appendix 6).

In December 2016, 237 CQC reports were available for review, with CQC ratings as shown in Table 1.

Table 1: Breakdown of trusts by outcome rating

	Outstanding	Good	Requires improvement	Inadequate
Acute, community, specialist care trusts	8	61	99	13
Mental health and learning disability trusts	2	18	28	0
Ambulance trusts	0	2	4	2
Total	10	81	131	15

A purposive sampling method was used to obtain a representative sample of inspection reports; in total 104 reports (44%). All trusts rated outstanding and inadequate were reviewed due to their small numbers, but only 20% of trusts rated good or requires improvement. All mental health trusts were reviewed to identify any differences between mental health and acute trusts.

- Trusts rated outstanding – 100% (n=10) were reviewed: two mental health and learning disability, five acute and three acute specialist trusts.
- Trusts rated good – 20% of acute, specialist, ambulance and care organisations were reviewed (n=13): 11 acute trusts and two community trusts; and all mental health trusts (n=18).
- Trusts rated requires improvement – 20% of acute, specialist, ambulance and care organisations were reviewed (n=20): 12 acute trusts, four care trusts and four ambulance trusts; and all mental health trusts (n=28).
- Trusts rated inadequate – 100% (n=15) were reviewed: 13 acute trusts and two ambulance trusts.

Findings

Table 2: Example interventions and themes by trusts with different ratings

Themes	Trust characteristics for each CQC rating			
	Outstanding	Good	Requires improvement	Inadequate
Leadership	<p>Dementia care assessed as being a high priority</p> <p>Whole organisation approach – examples included ED, radiology, medicine, surgery, orthopaedics</p> <p>Evidence of proactive and co-ordinated approach to care delivery</p> <p>Clinical leadership by nurses and doctors, namely consultant nurses, consultants and dementia specialist nurses</p> <p>One trust has a hospital-wide Macmillan dementia nurse consultant</p> <p>Executive leadership relating to standards of practice</p>	<p>Some evidence of a trust-wide approach</p> <p>Variable trust board commitment</p> <p>Evidence of commitment to improve</p> <p>Organisational culture not referenced in the reports</p> <p>More variation than in trusts rated outstanding. There was variation both within and between organisations with this rating</p>	<p>No references to organisational culture in the reports</p> <p>Two trusts had leadership from psychologists</p> <p>One ambulance trust had no access to dementia specialist advice</p> <p>16 references to accessing expert advice</p>	<p>No references to medical leadership</p> <p>Dementia champions on wards; much lower prevalence of consultant nurses and dementia specialist nurses than in outstanding and good rated trusts</p>

<p>Patient and carer information</p>	<p>Varied information formats including audio</p> <p>Led through the dementia strategy; examples include dementia cafés, meaningful activities, dementia-friendly environment</p>	<p>Information handbooks – ‘What’s next for carers’ and ‘Help care more effectively’ – in mental health trusts</p>	<p>‘Let’s talk about dementia’ sessions for families and carers</p> <p>Access to psychological therapies for families and carers</p> <p>Lack of information in some trusts</p> <p>Information only available in English</p> <p>Relatives used as translators for patients</p>	
<p>Workforce training and education</p>	<p>Committed to training and achieved uptake</p> <p>Training extended to family members and carers</p> <p>One organisation provides training and education for carers working in care homes</p>	<p>Achieved workforce training rates with variation</p> <p>Trained other public sector workers, provided training for carers</p> <p>Uptake of training was inconsistent on older person service wards and staff reported they wanted more training</p> <p>One trust offered a course for relatives and carers – understanding dementia</p>	<p>Staff stated they lacked awareness and couldn’t access training</p> <p>Predominantly focused on workforce</p> <p>Two references to carer training</p> <p>Some examples of ‘good’ training</p> <p>Limited training available</p> <p>Two references to providing training to staff working in care homes</p> <p>Three-day training course for volunteers</p>	<p>Lack of training</p> <p>Poor training rate compliance; one trust achieved 21%</p> <p>Solely focused on workforce</p> <p>No patient, relative or carer training mentioned</p>

Workforce training and education (contd)			<p>Courses specifically for nursing assistants</p> <p>Minimal staff understanding</p> <p>Low mandatory training rates</p> <p>Significant variation between and within organisations: one area has good training rates with knowledgeable staff and another area the opposite</p>	
Involvement and co-design	<p>Services designed with patients and carers (six out of 10)</p> <p>Local system and voluntary sector involvement in the design of the dementia pathway</p> <p>ED redesign involved people living with dementia</p>	<p>Voluntary sector involvement in service design</p> <p>Evidence of working with GPs and clinical commissioning groups</p>	<p>No reference to co-design</p> <p>Three references to patient involvement</p>	<p>No reference to co-design</p>
Environment	<p>Refurbishments based on best practice guidance</p> <p>Whole organisation approach</p>	<p>Some trusts required improvements</p> <p>Some followed the Sterling University design standards</p> <p>Achieving above the national average for PLACE</p>	<p>17 references to environment</p> <ul style="list-style-type: none"> • under bed lighting to reduce falls at night • head of estates became a dementia champion • references included the need to improve to become dementia friendly 	<p>Significant variation across organisation:</p> <ul style="list-style-type: none"> • ‘inappropriate’ environments • a commitment to refurbish wards • some dementia-friendly wards

Environment (contd)			<ul style="list-style-type: none"> • some investment to create dementia-friendly wards • others required environmental improvements 	
Person-centred care	<p>Investment and innovation evident</p> <p>Embedded application of good practice; eg, the Butterfly Scheme, Forget me not and Patient Passports</p> <p>Sharing best practice through research</p>	<p>All used a system for person-centred care; eg, <i>This is me</i> booklet, Forget me not or the Butterfly System but there was significant variation in this category – from good planning and patient and carer involvement to a lack of identification and care planning</p> <p>Trusts had finger food available</p> <p>One reference to good assessment and documentation of needs and care planning</p> <p>Application of John’s campaign</p> <p>One ambulance trust was recognised as ‘working to become a dementia-friendly organisation’ by the Dementia Action Alliance and one did not have a triage protocol for vulnerable people living with dementia</p>	<p>Two trusts used the Butterfly Scheme, two used Forget me not, with reference to the use of Patient Passports</p> <p>Ambulance staff used the Abbey Pain Assessment Tool</p> <p>Evidence of dementia cafés</p> <p>Adaptation of the Friends and Family Test</p> <p>Drama therapy</p> <p>Singing for the Brain</p> <p>Use of PAT dogs</p> <p>Designed care pathways for people living with Down’s syndrome and learning disabilities, autism or both who are also living with dementia</p> <p>Six references to an active research portfolio, two references to auditing care</p>	<p>Inconsistent application of good practice; eg, the Forget me not system</p>

<p>Person-centred care (contd)</p>		<p>The memory services national accreditation programme being undertaken by one organisation was assessed as excellent</p> <p>Dementia pathways based on NICE guidance</p> <p>One organisation employed an admiral nurse</p> <p>Other services offered include: talking therapies, safe driving assessments, reminiscence therapy, computer systems to support people with memory problems</p> <p>Sensory and reminiscence therapy used</p> <p>Communication boxes, meaningful activities, developing intergenerational living</p>		
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CQC recommendations relating to ‘must do’ and ‘should do’

Two acute trusts rated ‘requires improvement’ rating were given a ‘must do’ and a ‘should do’ relating to dementia as follows:

- **must do** – comply with the national dementia strategy
- **should do** – ensure people living with dementia are appropriately screened and identified, and staff can access tools and advice to ensure care is consistent.

Differences between higher and lower ranked organisations

There are some notable differences as detailed below.

Co-design

Trusts rated ‘outstanding’ had a strong record of involving patients and carers in the design of services (co-design) and involving patients and carers in the planning and delivery of patient care; this reflects the findings in *The state of care in NHS acute hospitals* (CQC 2016). Co-designing of services was not found at any of the organisations rated ‘requires improvement’ or ‘inadequate’; their focus appeared to be more transactional, based on systems and processes, not the person living with dementia.

Leadership

Good leadership was shown in the delivery of the trusts’ dementia strategies and this appeared to influence organisational culture more widely in those rated ‘outstanding’ and ‘good’. Leadership at trusts rated ‘outstanding’ and ‘good’ was provided by consultants, consultant nurses and clinical nurse specialists. The inspectors noted visible executive leadership by the chief nurse at two trusts and this had a positive impact on the culture of the organisation generally. Leadership was rarely mentioned in reports on trusts rated ‘requires improvement’ or ‘inadequate’. Trusts with these rating categories focused on a system of link nurses and dementia champions.

Organisational culture

Organisational culture was commented on by the inspectors in the ‘outstanding’ rating and this correlated strongly with leadership and in some cases with executive

leadership specifically. In these trusts the inspectors noted a trust-wide focus on improving dementia care which permeated to service delivery and achieved consistency. This appeared to harness a culture of innovation and staff appeared empowered to transform care to meet patient needs.

Difference between acute, community, care or ambulance trusts and mental health trusts

A fundamental difference between acute, ambulance, care or specialist trusts and mental health trusts is the former's focus on managing the reason for a patient's admission; dementia may be one co-morbidity but is unlikely to be the primary reason for admission. For this group of trusts the outcome rating relates to their ability to treat the diagnosis requiring admission while also meeting the patients needs from living with dementia.

Mental health trusts differed from other trusts in their focus on research and modalities of care relating to diagnosis, treatment and behavioural management of people living with dementia, and carer support.

Appendix 2: Review of national policy relating to dementia care in England

This appendix reviews national policy and good practice guidelines to inform the dementia assessment and improvement framework.

Policies and guidelines are reviewed in chronological order of publication.

National Institute of Health and Care Excellence and the Social Care Institute for Excellence (2006; updated in 2016) *Dementia: supporting people with dementia and their carers in health and social care*

The guidance sets out the wider remit for health and social care.

In relation to caring for people living with dementia in an acute hospital facility the guidance states:

- Acute and general hospital trusts should plan and provide services that address the specific personal and social care needs and the mental and physical health of people with dementia who use acute hospital facilities for any reason.
- Acute trusts should ensure that all people with suspected or known dementia using inpatient services are assessed by a liaison service that specialises in the treatment of dementia. Care for such people in acute trusts should be planned jointly by the trust's hospital staff, liaison teams, relevant social care professionals and the person with suspected or known dementia and his or her carers.

The guidance focuses on two key elements:

- the environmental design for people living with dementia
- the clinical investigations required to diagnose dementia and pharmacological interventions for its management.

The guidance does not provide specific advice on how to achieve a system which consistently provides outstanding or good care for people living with dementia during an admission to a general hospital.

Department of Health (2009) *Living well with dementia: A national dementia strategy*

The strategy aims to ensure that significant improvements are made in dementia services across three key areas: awareness, earlier diagnosis and intervention, and quality of care.

It identifies 17 key objectives:

1. improving public and professional awareness and understanding of dementia
2. good quality early diagnosis and intervention for all
3. good quality information for those with diagnosed dementia and their carers
4. enabling easy access to care, support and advice following diagnosis
5. development of structured peer support and learning networks
6. improved community personal support services
7. implementing the carer's strategy
8. improved quality of care for people with dementia in general hospitals
9. improved intermediate care for people with dementia
10. considering the potential for housing support, housing-related services and tele care to support people with dementia and their carers
11. living well with dementia in care homes
12. improved end-of-life care for people with dementia
13. an informed and effective workforce for people with dementia
14. joint commissioning strategy for dementia
15. improved assessment and regulation of health and care services and how systems are working for people with dementia and their carers

16. a clear picture of research evidence and needs

17. effective national and regional support for implementation of the strategy.

Cross-checking with our review of CQC reports suggests that the strategy is variably implemented across England. Objective 2 is a national CQUIN; there was evidence of compliance with this objective across organisations.

The strategy recommends:

- identification of a senior clinician in the general hospital to take the lead for quality improvement in dementia in the hospital
- development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician
- the gathering and synthesis of existing data on the nature and impacts of specialist liaison older people's mental health teams to work in general hospitals
- thereafter, using specialist liaison older people's mental health teams to work in general hospitals.

Department of Health (2012) *Using the commissioning for quality and innovation (CQUIN) payment framework. Guidance on new national goals for 2012-13*

The aspiration of the national CQUIN was to develop a system in acute trusts that incentivised the identification of people with dementia, assessment and prompt appropriate referral and follow-up after they leave hospital.

This remained a national CQUIN until 2015/16. Dementia may be a local CQUIN for 2017/18.

Health Education England in collaboration with Skills for Health (2015) *Dementia core skills education and training framework*

This document sets out a framework to support the implementation of the Health Education England (HEE) mandate and the objectives for education, training and workforce development set out in the *Prime Minister's challenge on dementia 2020*.

The aim is to support the development and delivery of appropriate and consistent dementia education and training for the health and care workforce.

The scope of the framework acknowledged the care pathway for a person living with dementia, their families and carers will involve an extensive and diverse workforce. Care will be offered in a broad variety of settings including the person's own home.

The framework structure has three tiers with increasing levels of integration between health and social care services and their respective workforces.

The framework covers 14 topics and each consists of:

- an introduction
- suggested target audience
- key learning outcomes
- links to relevant guidance and/or legislation
- links to relevant national occupational standards, skills frameworks and regulated qualifications components.

Appendices include:

- sources of further guidance
- user guide
- links to relevant standards, curricula and qualifications
- suggested standards for training delivery
- guidance on frequency of refresher training or assessment.

The 14 topics are:

1. dementia awareness
2. dementia identification

3. dementia risk reduction and prevention
4. person-centred dementia care
5. communication, intervention and behaviour in dementia care
6. health and wellbeing in dementia care
7. pharmacological interventions in dementia care
8. living well with dementia and promoting independence
9. families and carers as partners in dementia care
10. equality diversity and inclusion in dementia care
11. law, ethics and safeguarding in dementia care
12. end-of-life dementia care
13. research and evidence-based practice in dementia care
14. leadership in transforming dementia care.

Department of Health (2015) *Prime Minister's challenge on dementia 2020*

Set out by David Cameron (Prime Minister between 2010 and 2016) this document articulates a vision to create a society by 2020 where every person with dementia, their carers and families receive high quality, compassionate care from diagnosis to end of life, irrespective of background, walk of life, geography, age, gender, sexual orientation, ability or ethnicity.

The document outlines the government's key aspirations; by 2020 it wishes to see:

- improved public awareness and understanding of the factors which increase the risk of developing dementia and how people can reduce this
- equity of access to diagnosis, with a national average of six weeks for initial assessment following GP referral

- GPs play a leading role in ensuring co-ordination and continuity of care for people with dementia
- every person diagnosed with dementia having meaningful care following their diagnosis in accordance with NICE quality standards. The care may include:
 - receiving information on available post-diagnosis services
 - access to relevant help and advice
 - carers being made aware of and offered opportunity for respite, education, training, emotional and psychological support
- all NHS staff being trained in dementia appropriate to their role. Care workers undertake the Care Certificate which includes dementia training
- all hospitals and care homes meeting agreed criteria to become a dementia-friendly health and care setting
- the Alzheimer's Society delivering an additional three million Dementia Friends in England
- over half of people living in areas recognised as dementia-friendly communities, according to the guidance developed by the Alzheimer's Society working with the British Standards Institute. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this
- all businesses encouraged and supported to become dementia friendly, with all industry sectors developing dementia-friendly charters and working with business leaders to make individual commitments. All employers with formal induction programmes are invited to include dementia awareness training within these
- national and local government taking a leadership role and public sector organisations becoming dementia friendly; all tiers of local government being part of a local Dementia Action Alliance

- dementia research being a career opportunity of choice
- funding for dementia research to be doubled by 2025
- an international dementia institute established in England
- increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors
- cures or disease-modifying therapies on track to be available by 2025, with development accelerated by an international framework for dementia research that enables collaboration and co-operation between researchers
- more research made readily available to inform effective service models and the effective pathway to enable interventions to be implemented across the health and care sectors
- open access to all publicly funded research publications
- more people living with dementia participating in research, with 25% of people diagnosed with dementia registered on Join Dementia Research and 10% participating in research, up from the current baseline of 4.5%.

Department of Health (2016) *Dementia 2020 citizens' engagement programme: Toolkit for engaging people with dementia and carers*

The Department of Health published its implementation plan for the Challenge on Dementia 2020 in March 2016. This sets out a number of key commitments to ensure that dementia care, support, risk reduction, awareness and research are transformed by 2020.

The document was co-produced by the Alzheimer's Society, Alzheimer's Research UK, the Dementia Engagement and Empowerment Project (DEEP), Innovations in Dementia and people with dementia and carers on behalf of the Department of Health's Advisory Group for the Dementia 2020 citizens' engagement programme.

One priority action is to establish a Dementia Citizens' Engagement Programme in England to find out first hand from people with dementia and carers if the actions in the plan are making a difference to their day-to-day lives. The feedback will be used

to check progress and to ensure that everything that can be done to make improvements is being done.

The toolkit outlines how to engage with individuals and groups of people living with dementia and/or their carers. It also provides a structure for planning engagement, including recruitment and consent, and practical tips. The section relating to consent is not transferable and any engagement would be likely to require local or organisational approval as per local policy.

Appendix 3: Review of best practice guidance relating to dementia care

Dementia Action Alliance (2012) *Dementia-friendly hospital charter*

One hundred and sixty-four acute and non-acute trusts committed to this charter, *Right care: a call to action to create dementia-friendly hospitals*, with 88 submitting action plans.

The purpose of the charter is to:

- act as a short, accessible and visible statement of principles that contribute to all dementia-friendly hospitals
- provide a minimum set of standards that people with dementia and their carers have when they access a dementia-friendly hospital
- build on the foundation offered by staff, partnership, assessment, care and environment (RCN SPACE) principles
- offer a framework to assist hospitals in their self-assessment against dementia-friendly principles and assist them to develop and update the DAA action plans.

The charter sets out a number of principles a person living with dementia or their carer can expect. These relate to:

1. staffing
2. staff have positive attitudes
3. partnership
4. assessments
5. care

6. environment
7. governance
8. system to routinely gather feedback on the patient and carer experience.

The Dementia Action Alliance' website includes a facility for participating organisations to upload their action plans (http://www.dementiaaction.org.uk/joint_work/dementia_friendly_hospitals/hospital_trusts).

Royal College of Nursing (2013) *Dementia: Commitment to the care of people with dementia in hospital settings*

Working with people living with dementia, their carers and stakeholders, the RCN developed a set of principles for the care of people with dementia in the hospital setting.

These principles are referred to collectively as SPACE:

Staff who are skilled and have time to care

Partnership working with carers

Assessment and early identification

Care that is individualised

Environments that are dementia friendly.

Each principle is backed by quotations from a person living with dementia or a carer, what an organisation may want to consider and signposted resources.

This valuable resource describes gold standard care and signposts the reader to advice on 'how to' achieve the principles of care.

The Butterfly Scheme

The scheme supports anyone whose memory is not as reliable as it used to be, or whose current medical condition is causing them to feel confused. A butterfly is placed on the board above the patients' bed or on the ward 'patient status at a glance' board to denote the patient has enhanced care needs.

John's campaign

The campaign calls for a policy that welcomes family and carers onto wards outside normal visiting times, according to the needs of the person with dementia.

Age UK (2016) has worked with John's campaign to produce useful information for organisations, strategy leads and ward leaders looking to better support carers and patients and reduce their sense of disconnection and isolation.

Department of Health (2016; refreshed edition) *Making a difference in dementia: nursing vision and strategy*

Part 1 – Refreshing our vision: The document challenges the nursing profession to think differently about the person living with dementia, moving from a traditional view that dementia is a 'debilitating condition' to a 'prevalent view' that it is a long-term condition affecting memory, cognitions, health and behaviour experienced by the person and their family/carers. The strategy aims to look at the person with dementia and dementia itself anew, focusing the nursing role toward person-centred, compassionate and proactive care.

The strategy describes the six phases of dementia, emphasising that dementia is a long-term condition:

Phase 1 When memory or other problems prompt the person or carer/family to voice concerns	Phase 4 Getting the right help at the right time to live well with dementia, prevent crises and manage together
Phase 2 Learning that the condition is dementia	Phase 5 Getting help to stay at home or if needed move to alternative care accommodation
Phase 3 Learning more about dementia, self-management, options for treatment, care and support	Phase 6 Receiving care, compassion and support at the end of life

Part 2 of the strategy defines the role of the nurse in dementia as:

- interpersonal
- varied in action and intensity

- taking place in a variety of settings
- welcoming individuals, families, significant others and carers, and respecting their diversity and culture.

The vision for the nursing role is primarily an interpersonal and social model of care, applied alongside medical aspects of care using a person-centred approach. It requires:

- 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 potential abuse of the person with dementia, whatever the form.

The new vision for the nursing role in dementia is described within each phase.

The strategy makes the point that the profile of nursing needs to be raised, regardless of the area of registration because:

- nurses have a critical leadership role in supporting and promoting dementia-friendly communities

- 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 have another long-term condition and will come into contact with nurses in other specialist fields such as diabetes
- nurses in hospital have a responsibility to recognise, understand, respond and support the needs of people with dementia and their family/carers, promoting person-centred care
- nurses can provide practical advice and support, taking into account the person's medical and non-medical needs. This includes liaising with different parts of the social care system and voluntary sector to carry out housing improvements and adaptations or help individuals to stay at home for longer
- nurses working with people with a learning disability can support carers to be aware of symptoms of dementia, such as behavioural and personality changes or loss of daily living abilities.

The strategy outlines the dementia core skills education and training framework which ranges from awareness training to creating experts across tiers 1 to 3.

The strategy recognises the need for nurses to be aware of relevant research programmes and evidenced-based care.

Lastly, the strategy identifies the 'critical aspects' of care for each of the six phases of the condition.

Royal College of Nursing, RCN Foundation (2016) *The triangle of care. Carers included: a guide to best practice for dementia care*

The triangle of care describes a therapeutic relationship between the person with dementia, staff member and carer that promotes safety, supports communication and sustains wellbeing. A meaningful involvement and inclusion of carers can lead to better care for people with dementia, ideally meeting the needs of the person with dementia and their carer. It was designed for use in mental health services, but the standards have been found to apply to other care settings.

The guide identifies six key standards required to achieve better collaboration and partnership with carers:

- carers and the essential role they play are identified at first contact or as soon as possible thereafter
- staff are 'carer aware' and trained in carer engagement strategies
- policy and practice protocols regarding confidentiality and sharing information are in place
- defined post(s) responsible for carers are in place
- a carer introduction to the service and staff is available, with relevant information available across the care pathway
- a range of carer support services is available.

Each standard gives good practice examples and resources that may be helpful.

The guide recommends a cycle of regular assessment and audit to ensure the six key standards of carer engagement are implemented and maintained. It includes a self-assessment tool for organisations to use to measure how well they include people with dementia and their carers.

Alzheimer's Society (2014) Forget me not

This is a visual trigger used in some healthcare settings to identify a person who may require more assistance than others. An image of a forget me not is placed above the person's bed, on the medical records, on menus, etc to ensure all staff recognise the person may need more support.

Alzheimer's Society (2016) *This is me*

This is a practical tool that people with dementia who are receiving professional care in any setting – at home, in hospital, in respite care or a care home – can use to tell staff about their needs, preferences, likes, dislikes and interests.

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