

Dementia Strategy 2021 - 2026

Towards excellence in dementia care





For Use in:	Trustwide
Ву:	Complex Health Hub
For:	Medical staff Registered, non-registered nursing and midwifery staff and student nurses and student midwives
Division responsible for document:	Corporate
Key words:	Dementia, Strategy
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Assessed and approved by the:	Patient Engagement and Experience Sub- Board If approved by committee or Governance Lead Chair's Action; tick here □
Date of approval:	07/04/2021
Ratified by or reported as approved to (if applicable):	Trust Board
To be reviewed before: This document remains current after this date but will be under review	07/04/2025
To be reviewed by:	Patient Engagement and Experience Sub- Board
Reference and / or Trust Docs ID No:	18602
Version No:	2.0



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Foreword



Our aspiration is to provide the best possible care and support for people living with dementia and those who care for them.

Our 5-year strategy challenges us to go further for people by anticipating their core needs, from early diagnosis with regular assessment, to plan care with patients, carers and families.

It is critical that we continue to improve the experience and support of patients with dementia through the care journey, including a focus on palliative care.

Our eight goals have been constructed in partnership with our dementia champions, dementia specialist practitioners, dementia support team and our families who are experts by experience. The goals aim to develop a blended workforce that has specialist skills to enable delivery of an enhanced personalised experience for patients in hospital and then onward transfer to a community setting or home. We aim to expand a cadre of specifically trained volunteers to work alongside staff and carers, to ensure timely and connected support.

Finally, by investing in research, we can utilise our results to influence the future and the Norfolk and Waveney Strategic intent for improving dementia care in our county.

Professor Nancy Fontaine

Chief Nurse Norfolk and Norwich University Hospitals



Introduction

The Norfolk & Norwich University Hospital NHS Foundation Trust (NNUH) is one of the country's largest teaching hospitals and carries out almost one million outpatient appointments, day case procedures and inpatient admissions each year.

In recent years the NNUH has seen an increase in the number of patients requiring physical health treatment who also have a diagnosis of dementia. This document sets out the Dementia Strategy at Norfolk and Norwich University Hospitals for 2021 – 2026. It has been designed and developed for all patients, staff and stakeholders that provide care and services for people with dementia and their families/carers in order to provide integrated healthcare, designed to care for each person as a whole. A full list of stakeholders is provided at the end of this document.

The strategy describes the goals necessary to achieve our vision of excellence in dementia care. It builds on our current service provision to date and draws on both local and national guidance and policies, as well as what local people tell us is important to them (Norfolk and Waveney STP 2018).

Optimising health and wellbeing outcomes for people with dementia and their carers across Norfolk and Waveney cannot be done alone. We will continue to collaborate with our health, social care, voluntary sector, public service and university partners towards an overarching dementia strategy and unified operational plans which put people with dementia and their carers at the centre.





NNUH's Vision for Excellence in Dementia Care

We will provide dignified, compassionate, clinically effective and safe personcentred care for our patients living with dementia. This will be delivered by staff who are appropriately trained and who work in partnershipwith families and carers. This care will be provided in environments which promote safety, well-being and independence.

We aim to provide comprehensive and specialist assessments and services at the level required for each individual. We will work with our multi-agency partners to keep the length of in-patient stay as short as possible and enable safe and supported discharge.

Our care and services will demonstrate best practice principles by promotion of research and development in the fields of Ageing and Dementia studies and through co-production with people with dementia,

National Context

In England around 460,000 people are diagnosed with dementia with an additional 200,000 people estimated to be undiagnosed. (NICE 2019). The estimated number of carers of people with dementia in England is 540,000 (NHS England).

Hospital admission can trigger distress, confusion and delirium for people with dementia. This can contribute to a decline in function, a longer length of stay and reduced ability to return home to independent living (NICE 2019).

A key aspiration of **Challenge on Dementia 2020 (DoH 2015)** is to create dementiafriendly hospitals. The **National Dementia Action Alliance** and **Dementia Friendly Hospital Charter (NDAA 2019)** contribute to improving the experience and outcomes for people with dementia in hospital care.

NICE guidance on **dementia** supports these initiatives by setting out expectations, including appropriate admission to hospital, comprehensive assessments, personal history-taking, co-ordinated discharge, referral and diagnosis, advanced care planning and reducing the use of antipsychotic medication (NICE 2019).



The Dementia Statements (NDAA 2017) are endorsed by the Dementia Programme Board, which monitors and supports the implementation of the current Dementia Challenge across the NHS, social care, the research sector and wider society. They reflect the elements that people with dementia and carers say are essential to their quality of life. The Statements recognise that people with dementia should not be treated differently because of their diagnosis. The standards set out in the Dementia Statements are enshrined within the Equality Act 2010, the Mental Capacity Act 2005, health and social care legislation and human rights legislation. They are central to NNUH's Dementia Strategy 2021-26:

Dementia Statements

Identity We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

Community We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.

Carers We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

Care We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

Research We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.



Dementia Care at Norfolk and Norwich University Hospitals

The population of Norfolk is older than the East of England and England averages, with 25% of people being aged 65 or over compared to 20% and 18% respectively (see figure 1). The population increase in Norfolk over the last five years has been predominately in the 65 and over age range. This trend is predicted to continue with Norfolk population increasing by 50,700 by 2030, mainly within the older age groups.

By 2041, the population aged 85+ is predicted to double in size. This will mean there will be approximately 61,000 people in Norfolk aged 85 and over. The area of Norfolk with the highest numbers of older people is North Norfolk. (Norfolk Insight 2020).

Figure 1:	Age of	residents	(Norfolk	Insight 2020)
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	Norfolk	Norfolk		East of England		England	
	Count	%	Count	%	Count	%	
Persons aged 0 - 15	154,108	17	1,212,041	19.4	10,816,679	19.2	
Persons aged 16 - 64	530,986	58.5	3,785,525	60.7	35,116,566	62.4	
Persons aged 65+	222,666	24.5	1,238,506	19.9	10,353,716	18.4	
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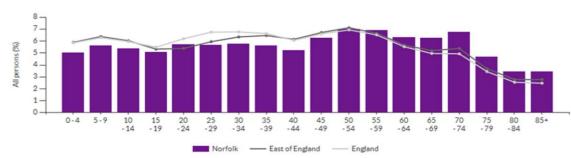
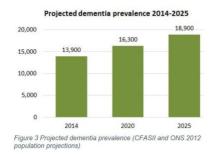


Figure 2: Percentage of residents within each age range (ONS, 2019)

Date: 2019 Source: ONS

There were 10,545 recorded cases of dementia in Norfolk and Waveney in January 2020, with the estimated number of actual cases at 16,652 (NHS Digital). In Norfolk the recorded dementia prevalence equates to 4.21% of the population of people aged 65 and over and 4.01 per 10,000 people aged under 65 (PHE 2020)

It is estimated that by 2025 the number of people living with dementia in Norfolk alone will exceed 18,900 (Norfolk JSNA 2016).



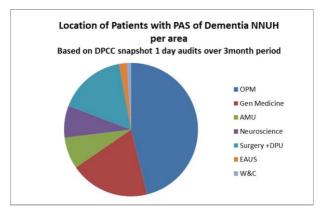
Document title: Dementia Strategy 2021-2026 Author/s: Liz Yaxley Approved by: Trust Board

Author/s title: Dementia Lead Clinician, Dementia Services Manager Date approved: 07/04/2021 Review date: 07/04/2025 Available via Trust Docs Version: 2.0 Trust Docs ID: 18602



In-Patient Care

5260 patients were admitted to NNUH with a diagnosis of dementia in 2018/19, with 14.41 people admitted on average daily. The daily average number of in-patients with dementia is 134 throughout specialities across NNUH (NNUH IS), which means that approximately 10-11% of NNUH inpatients at any one time have a dementia diagnosis. Approximately half of the in-patients with dementia in NNUH are located in Older People's Medicine (OPM) wards.



It is likely that these figures are an underestimate due to the fact that not all cases of dementia are diagnosed.

Out-patient Care

Currently we do not collate the numbers of people living with dementia who access out-patient services across specialities. Going forward our vision is to be able to identify all patients with dementia at the point of referral so that preparations and reasonable adjustments can be offered to maximise best quality care and patient experience.

Towards Excellence

The challenges for people with dementia in acute hospitals are well documented (NICE 2019, Alzheimer's Society 2016). Not only are people away from their usual environments, they will also be faced with different carers, new information to understand and decisions to make, whilst being physically unwell and undergoing treatment. Across our services at NNUH we see people at different stages along their journey with dementia; from those who live independently with mild cognitive changes, to those receiving end of life care. Some will be diagnosed with dementia; some we suspect may have dementia and require investigations. Some may be well supported at home; some not.



NNUH has made great strides in laying the building blocks for excellence, including the provision of the Older People's Emergency Department, embedding the NNUH's dementia identification scheme and the use of 'This is Me' booklets, as well as establishing 140 Dementia Links across in-patient and out-patient services. Through the generous support of charitable partners, we have further grown the Dementia Support Team and created an innovative post of dementia palliative care specialist nurse. The dementia perioperative pathway has been established and the NNUH's Carers Passport acknowledges and supports the importance of shared care. We have also built strong working relationships and pathways with community support services including the Alzheimer's Society and Admiral Nurses across Norfolk and Waveney.

The NNUH Dementia Strategy 2021-26 sets out how we build on these foundations to ensure excellence in dementia care and embrace the opportunities which digital technology offers both in terms of patient care, accessing appointments and in the ongoing task of educating our workforce.



Goals of the NNUH Dementia Strategy in Summary:

This is what the Norfolk and Norwich University Hospitals aim to provide if you are living with dementia. The word 'carers' relates your family or people you describe as being your carer.

Skilled Workforce

- We will ensure that staff are trained and skilled in dementia care
- We will provide specialist services which support you and your carers

Working Together

- We will treat you and your carers as partners in care
- We will work alongside your GP and community services
- We will promote dementia awareness and develop our services with our local community

Assessments

- We will ensure that you and your carers have a comprehensive assessment of your needs
- We will refer you for an assessment if we think you may have dementia
- We will support your decisions through use of the Mental Capacity Act

Person Centred Care

- We will ensure our staff are aware that you are living with dementia
- We will ensure your care is person-centred and meets your individual needs
- We will enable smooth transition between our services and as you are discharged home

Volunteer Support

 We will ensure trained volunteers are available who can offer additional support for activities and pastoral care

Environments

- We will provide your care in environments which are comfortable and supportive and promote your safety, well-being and independence
- We will enable you to find your way around the hospital sites

Research

• We will build on existing and develop new regional, national and international research collaborations so that you have the opportunity to participate in world-class research

Governance

- We will strive for continuous improvement in the quality of our care
- We will ensure that our governance structures and resources support staff to deliver care which is dementia–friendly





Skilled Workforce

NNUH Dementia Strategy Goals in Detail

We recognise that our staff are from many professional groups, with a wide variety of training and experience. We want to provide staff with training which will enable them to provide the best person-centred care in order to improve safety, patient and carer experience and outcomes.

To achieve this, we will ensure that:

Staff will participate in dementia training relevant to their role

- Training will be in line with the Dementia Training Standards Framework (Skills for Health, Health Education England and Skills for Care 2018) and in partnership with health and social care providers across Norfolk and Waveney.
- Training will be accessible, experiential and relate to acute hospital care.

Care will be provided by staff that are appropriately trained and skilled in dementia care.

- Dementia care competency framework will be developed and adopted.
- Preceptorship programmes and appraisal processes will identify staff that require competency development and link them to experienced or specialist services for practice development.

Specialist services are available and adequately staffed to support patients, families/carers and staff

- Mental Health Liaison Team, Dementia Support Team and the dementia palliative care specialist nurse will provide additional assessment and support where needed.
- The role of dementia links in wards and departments across NNUH will continue to be developed.
- Referrals to partner agencies for specialist mental health support will be made for those requiring it following discharge from hospital.



Working Together

We will continue to work alongside our health, social care and third sector partners to ensure the ongoing health and wellbeing of people with dementia and their carers.

We will promote the principles of 'Triangle of Care' (NHS England 2017) which recognises the benefits of collaboration between the person with dementia, with staff and their carer, in promoting safety, supporting communication and sustaining wellbeing.

To achieve this, we will ensure that:

People with dementia and their families/carers are partners in care

- Carers will be identified at point of admission or on consultation.
- We will keep carers involved and informed throughout assessment, treatment and discharge planning and give them the opportunity to be with the person they care for.
- Carers will be involved in assessments and best interest decisions as required under the Mental Capacity Act 2005.
- Carers will be offered Carers Passports and the opportunity to share care and flexible visiting.
- The perioperative pathway will enable carers to be by the side of the person up to the point of surgery and as they recover.
- Carers will feel supported by staff and be offered specialist services where required.
- Staff will refer people with dementia and their carers for ongoing support and advice.
- NNUH's Carers Forum will include representatives from the dementia leadership team to coordinate identified improvement plans.

Development of services in Norfolk and Waveney is influenced through participation in regional strategic dementia groups

Representatives of NNUH will promote a unified approach to dementia care, services and training across Norfolk and Waveney.

Dementia awareness is promoted in our local community

NNUH will work in partnership with local health, social care and third sector providers to:

- Host, advertise and participate in public awareness and educational events.
- Promote awareness of health and wellbeing initiatives in NNUHs and the community.





Assessments

We want to ensure that people with dementia and their carers have access to accurate assessment of their needs and that their care is delivered accordingly.

To achieve this, we will ensure that:

Assessments are comprehensive and person-centred:

- All patients aged 80 and over will undergo frailty screening and multi-disciplinary assessment as indicated.
- All patients aged 75 and over will undergo cognitive screening on admission and further investigation as indicated.
- Risks to health are identified and risk reduction strategies put in place.
- Person-centred care needs are identified as part of routine care assessments.
- Tertiary referral clinics are provided for atypical and young onset dementia diagnostics and treatment via NNUH Neuroscience Centre.

People with suspected dementia are referred for investigation:

Diagnostic pathways, including post-diagnostic support, will be in place for patients assessed at the NNUH and for those who are referred for investigation in the community. Follow up assessments will be arranged where investigations are inconclusive if clinically indicated.

Principles of the Mental Capacity Act 2005 are applied when asking people with dementia to make specific decisions:

Staff will understand their responsibilities in relation to the Mental Capacity Act and will record and share outcomes with all relevant stakeholders. Patients and carers will be involved in assessments and best interest meetings.



Person-

Centred Care

Providing the best possible care requires us to know which patients are living with dementia and to understand their individual needs, preferences and wishes. Care plans need to be adjusted accordingly and pathways in place to facilitate seamless transitions of care.

To achieve this, we will ensure that:

Staff will be aware of who is living with dementia and of their carers

Patients living with dementia will be identified and a PAS alert and bedside/personal identification scheme applied from point of admission or contact. Carer's details will be entered in healthcare records.

Care is person-centred and meets individuals' needs

- 'This is Me' personal profiles are completed and stored at the bedside to help all staff and volunteers get to know the person and what is important to them.
- Care and treatment planning is person-centred with patients fully involved in the decision-making process where possible.
- Reasonable adjustments are implemented to enable person centred care.
- Support is provided for people to retain independence, mobility and involvement in activities that support their health and wellbeing.
- Advice and support is provided on reducing risk, including health promotion strategies.
- Service provision for all patients and their carers is equitable, in a way which respects their age, sexual orientation, gender identities, race, ethnicity, religion and beliefs.
- Specialist palliative care will be provided for those reaching end of life.
- Preference for future care and end of life care are based on patients' personal wishes.

Care pathways are seamless through inter-agency collaboration:

- Care pathways are established and information is shared between GPs and community providers to facilitate admission and discharge.
- Transfers of care are supported both within the hospital environment and at point of discharge.



Volunteer

Support

Volunteers contribute to positive patient experience by providing additional support for activities and pastoral care which compliment those of paid staff. We want volunteers to have the appropriate training and support structures to help patients and carers across our hospital environments.

To achieve this, we will ensure that:

Structures are in place to support volunteers:

- There is a policy in place on the role of volunteers in supporting patients with dementia and their carers.
- Volunteer roles are clearly defined and understood by the volunteers, person living with dementia, their carers and staff.
- Volunteers are regularly supervised and supported in their role.
- Ward staff and the Dementia Support Team will support volunteers to enable wellbeing activities.
- Soluntary services will have a dedicated Dementia Link.

Volunteers participate in training relevant to their role:

- All volunteers will be Dementia Friends.
- Volunteers will be invited to participate in NNUH dementia awareness training.

Services are developed for volunteers to offer their support across NNUH:

Voluntary Services Manager will further develop services across NNUH with the support of the Dementia Strategy Group.





Environment

Adjusting to new surroundings can be particularly challenging for people living with dementia. We want our care environments to be comfortable and supportive and promote patient safety, well-being and independence.

To achieve this we will ensure that:

Structures are in place to support dementia-friendly principles:

- NNUH Estates Strategy incorporates dementia-friendly design principles for new build and refurbishment programmes
- PLACE audits (patient led assessments of the care environment) are used to meet the required standards.
- Policies are in place to minimise moves within the hospital which are audited.

People with dementia are enabled to find their way around Hospital sites:

Signage and orientation cues support navigation throughout buildings and grounds.

Ward and departments adopt dementia friendly design principles:

- Noise, distraction and visual clutter are minimised.
- Environments promote safety; encourage independence, activity and social interactions.



Research

Research helps us to understand the causes of dementia, develop effective treatments and improve care. NNUH wishes to build on existing research and develop new, regional and international research collaborations so that our patients and carers have the opportunity to participate in world class research.

To achieve this, we will ensure that:

- Improved access to research is enabled for patients and carers.
- Tertiary cognitive clinics are further developed.
- NNUHs' Neuroscience Centre will develop the use of CSF biomarkers in clinical practice.
- Research is developed in collaboration with UEA partners.
- Research ideas generated by staff and students of all disciplines are encouraged and supported.
- Staff are aware of latest published dementia research.



Governance

It is essential that systems are in place to enable continuous improvement in the quality of care for people with dementia and their carers, including resources and governance structures that support staff to deliver care that is dementia-friendly. To achieve this, we will ensure that:

Governance structures are in place

- The Chief Nurse has executive responsibility for dementia care.
- The dementia lead consultant and service manager guide and monitor delivery of the dementia strategy.
- Regular updates on dementia care and strategy are provided through the trust reporting structure at both divisional and executive level.
- The Dementia Strategy Group includes key clinical staff, voluntary services manager, community service providers and lay members that monitor delivery of care and includes perspectives of people with dementia and their carers.
- NNUH is signed up to the Dementia-Friendly Hospital Charter and the Dementia Statements are used to inform approaches to care.
- The Dementia Strategy Group will share learning from serious incidents relating to dementia care and formulate action plans.
- Dementia specialist leads have access to dementia links to support the delivery of care.
- Processes are in place for sharing best practice across NNUH, Norfolk and Waveney STP and the wider community.

Staff affected by dementia are supported

- Support will be provided for staff who require leave to care for a person with dementia.
- Policies and procedures will be in place to help combat stigma towards employees affected by dementia.
- Reasonable adjustments are made enabling people affected by dementia to continue working wherever possible.

Patients, carers and staff are engaged

- Meaningful feedback is regularly gathered on how people with dementia and their carers experience the hospital and its services and is scrutinised by the Dementia Strategy Group to identify areas for service improvement.
- Patient and carer voices are embedded into service improvements from the initial planning stages.
- Information from patients and carers on what is important to them will be shared with staff.
- Staff have opportunities to contribute thoughts on dementia care and ideas for service improvement.



Measuring our Success

Excellence in caring for people affected by dementia requires us to strive for continual improvement in all aspects of this strategy.

A detailed operational delivery plan will be agreed, prioritised and monitored by the Dementia Strategy Group.

There will be regular reporting of progress to both the NNUH Patient Experience and Engagement Governance Sub-board and the Mental Health Board. Importantly, the voice of our patients and carers will be heard both in helping to evaluate progress and by participation in audit and quality improvement initiatives.

Produced in consultation with members of:

- Norfolk and Waveney STP Dementia Working Group
- Norfolk and Waveney Dementia Partnership (includes representatives from Norfolk Older People's Strategic Partnership, Alzheimer's Society, Admiral Nurse Service, Norfolk and Suffolk Foundation Trust, Norfolk Community Health and Care, University of East Anglia, Norfolk Constabulary, Norfolk County Council)
- Roup NNUH Dementia Strategy Group
- 🞓 NNUH Patient Panel
- NNUH Patient Engagement and Experience Team

Thank you to the people living with dementia and their carers who voiced their needs and wishes at national level (leading to the development of the NDAA Hospitals Charter 2019) and at local level (over 150 participants attended Norfolk and Waveney STP Dementia Review Public Consultation events in 2018) on which this strategy is based.



Appendix 1: Stakeholder map

Stakeholders Supporting People affected by Dementia			
NHS Providers	Other Public Providers	Community Service Providers	Community Groups
 James Paget University Hospital Queen Elizabeth Hospital Norfolk Community Health and Care Norfolk and Suffolk Foundation Trust NNUH staff and volunteers NNUH Patient Engagement & Experience NNUH Dementia links 	 Norfolk Constabulary Norfolk & Waveney STP Dementia Review Group Norfolk County Council UEA 	 Age UK Norfolk Age UK Norwich Admiral Nurses Alzheimer's Society Carers Matter Norfolk 	 Priscilla Bacon Lodge Support Group Norfolk Older People's Strategic Partnership Norfolk & Waveney Dementia Partnership Healthwatch Charitable Partners



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