NHS
Newcastle upon Tyne Hospitals
NHS Foundation Trust

Dementia care plan

2022 - 2026

Healthcare at its best
with people at our heart

Dementia Care Plan

2022-26

Executive Summary

The Trust Dementia Care Plan 2022-26 outlines how we will achieve our vision of providing the best possible care for people living with dementia and their families and carers, in all wards, teams and departments, over the next five years.

It sets out our priorities.

Each priority has a number of performance targets and key commitments. We have identified three high impact interventions.

Much work has taken place since the development of our first strategy in 2015.

Throughout 2021 we consulted with our key stakeholders, including Trust staff, people living with dementia, carers and professionals providing care and support for people with dementia in the local community.

Based on this consultation we have identified new priorities for the next five years.

The need to provide person centre care - Priority 1 - is not new, however achieving this, particularly in our acute hospital settings requires staff commitment, creativity and most importantly, an over-riding approach that values every patient with dementia as a person.

There is a need to apply the Mental Capacity Act in practice in order to assess capacity and ensure best interest decision making when there is a lack of capacity.

Priority 2 requires staff not only to involve carers and families, but also to work in partnership with them.

Priority 3 ensures that all staff are prepared for their role in providing high quality dementia care.

Although the Trust Dementia Care Plan focuses on direct patient care we will also continue to promote and develop dementia related research, audit and quality improvement initiatives and work closely with partners to develop local care pathways.

Our three key priorities (high impact interventions):

Priority One: To get to know every patient with dementia as a person and tailor the care we provide accordingly, including acting in the person's best interests when they lack the capacity to make a particular decision. [1]

Priority Two: To work in partnership with family/carers.

Priority Three: To provide high quality staff education/training on dementia care.

Introduction and context

Facts and figures

Dementia is a key priority for both NHS England and the UK Government. There are approximately 850,000 people with dementia in the UK (NHS England, 2021) and the majority of people (60%) living with dementia live at home (Luengo-Fernandez et al. 2010).

As the population ages and people live longer, dementia has become one of the most important health and care issues worldwide (NHS England).

Dementia mainly affects older people. After the age of 65, the likelihood of developing dementia roughly doubles every five years. However, for some dementia can develop earlier, presenting different issues for the person affected, their carer and their family.

In 2020 there were 3,736 people over the age of 65 living with dementia in the Newcastle Gateshead CCG geographical area. This equates to a prevalence of dementia in people over 65 of 4.43% (PHE, 2021).

During 2019/20 there were 3,139 patients living with dementia admitted to the Trust and 2,654 in the following year (2020/21).

The lower number in 2020/21 is almost certainly associated with the overall reduction in admissions to the Trust at the start of the Covid-19 pandemic in spring 2020.

There are around 540,000 carers of people with dementia in England (NHS England). It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed. A significant number of Trust staff care for a family member living with dementia.

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[1] See Trust Policy and Procedure on Application of the MCA Application of Mental Capacity Act and Deprivation of Liberty Safeguards Policy Deprivation of Liberty Safeguards

There is a considerable economic cost associated with dementia (estimate of £23 billion a year, predicted to triple by 2040). This is more than the cost of cancer, heart disease and stroke (NHS England).

Local collaboration and partnerships

One of the main themes emerging from our consultation with stakeholders (see Appendix 1 for a list of stakeholders who were involved) was the need to work in partnership with all the organisations and agencies who support, look after and care for people living with dementia and their carers in Newcastle.

This includes Newcastle City Council, Cumbria Northumberland Tyne and Wear (CNTW) NHS Foundation Trust, the many care homes and home care agencies providing care in the city, third sector organisations such as Newcastle Carers, Dementia Matters and the Alzheimer's Society and last but not least smaller organisations such as Silverline Memories.

After family carers, ongoing care providers for people living with dementia are almost entirely from the care home sector and home care agencies.

Working collaboratively and in partnership, for the benefit of every person with dementia is essential.

National policies, guidelines, standards and reports

A number of national policies, guidelines, standards and reports exist which will inform and guide implementation of our Trust Dementia Care Plan:

- *NICE Impact dementia*. NICE January 2020.
- *Dementia Friendly Hospital Charter*. National Dementia Action Alliance – updated 2020
- *Dementia Quality Standard*. NICE June 2019.
- *The Well Pathway for Dementia*. NHS England Transformation Framework (2019) https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf
- *Delirium: prevention, diagnosis and management* (CG 103) NICE guideline. Published: 28th July 2010. Updated 14th March 2019.
- Scottish Intercollegiate Guidelines Network (SIGN). *Risk reduction and management of delirium*. Edinburgh: SIGN, 2019 (SIGN publication no. 157).
- *Dementia: assessment, management and support for people living with dementia and their carers.* NICE guideline. Published: 20 June 2018.
- *Dementia Training Standards Framework.* Skills for Health, Skills for Care, Health Education England (2018). https://skillsforhealth.org.uk/wp-content/uploads/2021/01/Dementia-Core-Skills-Education-and-Training-Framework.pdf

How we developed our Trust Dementia Care Plan

We held online engagement meetings with a wide range of internal and external stakeholders and also gathered views and suggestions using two questionnaires, one for staff and another for carers.

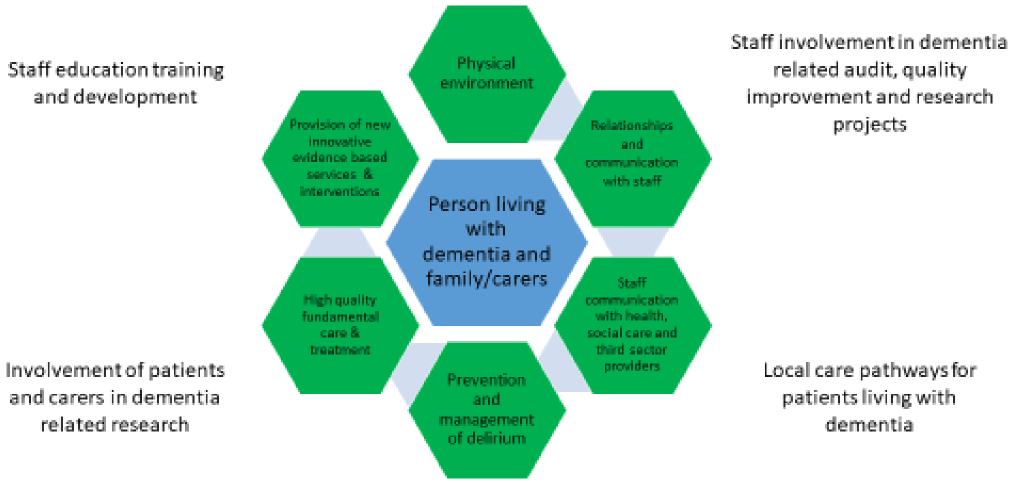
The stakeholders who contributed are listed in Appendix 1.

Appendix 2 includes a selection of the views, opinions and suggestions made by carers.

We are extremely grateful to those who have contributed and hope to continue working collaboratively with all stakeholders as we deliver on the Dementia Care Plan.

We used the framework below as a basis for our discussions with stakeholders and to develop the staff and carer questionnaires.

Factors affecting the care of patients with dementia and their families / carers



As well as our three key priorities, and based on the questionnaire responses we will also improve the fundamental care and treatment we provide for patients living with dementia, focusing on the following:

- Verbal and non-verbal communication with patients
- Preventing and managing delirium
- Assessment and management of pain.

We will also **optimise the patient experience** in emergency departments, on wards and at the time of discharge from hospital and **improve the care and support we provide for family and carers**.

This includes our commitment to having a dementia friendly hospital environment, as well as ensuring that the needs of people living with dementia are taken into consideration whenever improvements are made to the physical environment e.g. during ward and departmental refurbishments.

To achieve the above we have set the following performance targets associated with each priority.

Priority	Performance Targets
1. To get to know every patient with dementia as a person and tailor the care we provide accordingly.	• Every patient with dementia to have a completed Forget me not card. • Use information on FMN card to identify ways to empower and demonstrate staff value each patient with dementia as a person (enter details in e-record) • Identify ways to optimise each person’s social and physical environment whilst in hospital (enter in e-record). • Introduce Dementia Care Leaders’ Toolkit at ward level to achieve the above
2. To work in partnership with family/carers.	• Every patient with dementia to be asked if they wish to have a family member stay with them whilst in hospital (restrictions may be unavoidable eg. during Covid-19 pandemic)
3. To provide high quality staff education/ training on dementia care	• All new starters to the Trust to undertake dementia awareness training (Tier 1). • All staff providing care/support for patients with dementia to participate in Tier 2 training. • Dementia Care Team to develop ‘in-house’ bespoke dementia care training course (Tier 2) • Hold a Trust Dementia Care conference every 2-3 years.
4. Ensure all communication with patients living with dementia is appropriate to their needs and effective, paying attention to verbal and nonverbal communication.	• All dementia care training sessions to include best practice in communication. • Section on communication is completed on FMN card for all patients with dementia • Staff know each patient with dementia’s specific communication needs (as specified on FMN card).

Priority	Performance Targets
5. To correctly identify, prevent and treat/manage delirium, in order to minimise its impact on the individual.	• Every patient with dementia to be assessed for delirium during emergency admission to hospital utilising the 4AT assessment tool. • Staff to use the ‘cognition care plan’ on e-record, for all patients with dementia. • Consider referral to the specialist dementia care team if patient has delirium as well as an underlying diagnosis of dementia. • Trust’s Delirium Guideline (covers prevention, treatment and management) to be followed for all patients with dementia.
6. To assess and manage pain effectively.	• Introduce Abbey Pain Scale (including making it available on e-record). • Use Abbey Pain Scale to assess for pain in all patients with dementia.
7. To optimise the patient experience across all services and departments, including in the emergency department, on wards and at the time of discharge.	• Dementia care team to provide expert advice on all ward, clinical department and public space refurbishments, to ensure hospital environments are ‘dementia friendly’. • Patients with dementia to experience bed/ward moves only when necessary for their care/treatment. • Staff to support discussion with each patient with dementia about their personal preferences for future care, including support required post discharge.
8. To provide excellent care and support for family carers.	• Staff to discuss visiting times with family carers of all patients with dementia, to determine if visiting is required outside of core visiting hours. Arrangements to be documented in e-record and communicated to the ward team. • Staff to ensure there is family carer involvement throughout discharge planning.

Our consultation with external stakeholders led to the development of **15 key commitments**. These cover areas such as:

- Equality of access e.g. to rehabilitation
- Listening to carers
- Orientating patients when in hospital

- Meaningful communication with families
- ‘Refreshing’ awareness of John’s Campaign
- Improving assessment of pain
- Carer involvement in discharge planning

We have mapped these 15 key commitments against our priorities.

Priority	Our key commitments
1. To work in partnership with family/carers.	• We will ‘refresh’ awareness of John’s Campaign throughout the Trust, highlighting how working in partnership with carers has a positive impact on patients living with dementia. • We will ensure there is carer involvement in discharge planning. We will not make assumptions about the care a family can provide.
2. To get to know every patient with dementia as a person and tailor the care we provide accordingly.	• We will ensure meaningful communication with families, ensuring that their views and suggestions are central to decision making.
3. To provide high quality staff education/ training on dementia care	• We will continue to raise awareness across the Trust, of dementia and its impact on individuals.
4. Ensure all communication with patients living with dementia is appropriate to their needs and effective, paying attention to verbal and nonverbal communication.	• We will make time to involve and take time to listen to patients with dementia, so their voices are heard. • We will take every opportunity to provide orientation for patients with dementia whilst they are in hospital, providing visual prompts of the date, day and time and access to television as a minimum.
5. To correctly identify, prevent and treat/manage delirium, in order to minimise its impact on the individual.	• We will ensure patients with dementia get the assistance they need at mealtimes, so their nutrition and hydration needs are met wherever possible.
6. To assess and manage pain effectively.	• We will ensure that all patients with dementia are asked if they have pain as part of their assessment and that staff know how to recognise pain in patients with dementia. We will embed use of the Abbey Pain Scale in practice.

Priority	Our key commitments
7. To optimise the patient experience across all services and departments, including in the emergency department, on wards and at the time of discharge.	• We will ensure that people with dementia have the same access to rehabilitation as those who do not have dementia, ensuring equality of opportunity. We will do this by giving staff of all disciplines the skills required to work with people with dementia. • We will work collaboratively and in partnership with other organisations and agencies for the benefit of patients with dementia and their family carers • We will promote ‘joined up’ care with clear communication between relevant services, especially at the time immediately after diagnosis (service giving diagnosis / service providing patient follow up / service providing carer assessment). • We will provide accurate and timely information to families, carers and GPs.
8. To provide excellent care and support for family carers.	• We will proactively provide information for patients with dementia and their family carers on living well with dementia, including information about diet / nutrition and continence. • We will connect people living with dementia and their carers to the right people and services as quickly as possible, so they feel supported and know who to contact, when and how. • We will listen to carers, remembering that they are experts in their own right. We will discuss care options with them and give details of how to get more support if required.

Monitoring implementation

Every year wards, teams and departments will be asked to complete an audit of their progress against the 8 key priorities above.

We have developed an audit tool (see Appendix 4) which will be used by wards and departments to measure progress, highlight good practice and identify areas that require improvement.

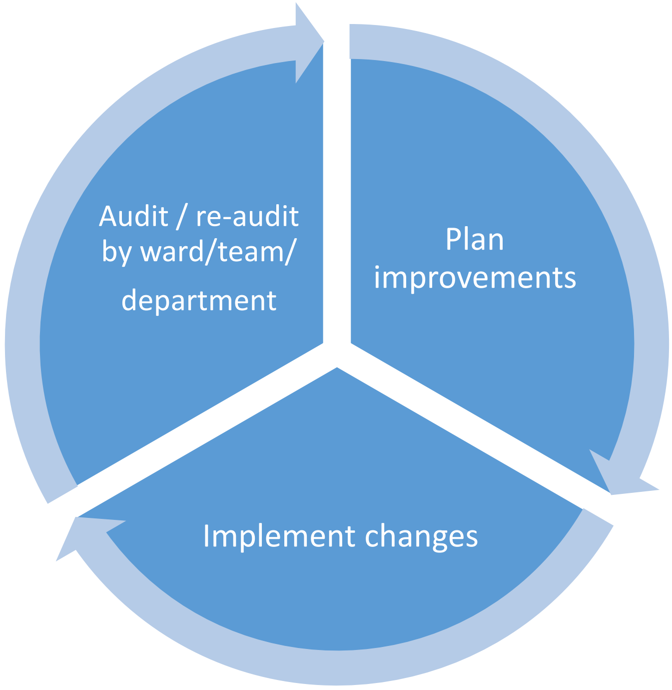
The Harm Free Care leaders will have an important role not only in the audit but also in leading improvements.

A trust wide audit will take place on an annual basis. The first audit will be within 3 months of the launch of the Trust Dementia Care Plan in 2022.

This will establish a baseline for each ward/team/department and for the Trust as a whole. Subsequent audits will measure progress against this baseline.

The dementia care team will provide support to wards/teams/departments (including to the Harm Free Care Leaders) in between each annual audit.

Audit and improvement cycle



Harm Free Care Leaders with support from clinical team

Harm Free Care Leaders / clinical team, with support from Specialist Dementia Care Team

Clinical team with support from Specialist Dementia Care Team

Appendix 1

Stakeholders involved in developing the Newcastle Hospitals' Dementia Care Plan

The following individuals were involved in one of several online stakeholder discussion groups:

- Claire Bamford, Senior Research Associate, Population and Health Sciences Institute, Newcastle University
- Jo Costello, Admiral Nurse, Dementia Matters
- Sandra Coulter, CEO, Silverline Memories
- Penny Easton, Alzheimer's Society
- Sue Hall, Specialist Dementia Care Team, Newcastle Hospitals
- Karen Inglis, Newcastle City Council
- Betty Lucas, Admiral Nurse, Age UK, North Tyneside
- Mohsin Malik, Pharmacist, Newcastle Hospitals
- Caroline McGarry, Patient Relations Team, Newcastle Hospitals
- Karen Nielsen, Newcastle Gateshead CCG
- Annie Osborne, Alzheimer's Society
- Rachel Parsons, Newcastle Carers UK
- Yvonne Probert, CEO, Age UK, North Tyneside.
- Fiona Richardson, Newcastle City Council
- Dame Louise Robinson, GP and Professor of Ageing and Primary Care, Newcastle University
- Claire White, Specialist Care Home Support Team, Newcastle Hospitals

The following also contributed ideas and suggestions through online meetings or by completing a questionnaire:

- People living with dementia (contacted by Silverline Memories)
- Carers known to a number of Newcastle based third sector organisations, including:
  - Dementia Matters
  - Newcastle Carers UK
  - Silverline Memories
- Clinical leaders and matrons at Newcastle Hospitals
- Members of the Trust Dementia Care Steering Group

Appendix 2

Comments from carers as part of consultation

In order to provide the best possible care…..what does the Trust need to focus on?
• The Trust needs to focus on supporting both the patient and the carers. The carers need training too how to best care for the patient.
• Ensuring that a carer is allowed to stay with the patient at all times.
• Allow the patient to 'wander' so that they don't become frustrated at being stuck in the same place for hours on end whilst waiting for consultations.
• Speed up the consultation process in the hospital for those with dementia, they don't understand why they are there and it's difficult to explain so it is a traumatic time for them.
• Communication with carers/relatives is really valuable in my experience. We need reassurance from professionals.
• Support with activities for dementia patients. I feel we are short of places which provides activities with dementia, people with dementia needs motivation too.
• Staff who understand what dementia is, more care around discharge and more options around this, more rehab before going home. Listen to carers - use their knowledge and experience.
• Tailored care package of support through their journey, from home based support and support for carers.
• Training and education of all staff.
• Dementia specialist in all hospitals available to those living with dementia and there carers to assist with bypassing some ward protocols (would have a significant impact on care and wellbeing).
• Improved dementia policies and procedures.
• Specific care pathways for patients living with dementia to include carer roles and responsibilities.

In order to provide the best possible care…..what does the Trust need to focus on?

- The environment that the patient with dementia is placed in.
- Admission, on going care and discharge to be simplified and undertaken in consultation with carers.
- Flexible visiting for carers.
- A role for carers in the care of their loved one on the ward or in clinic to assist professionals in daily routines.
- Dementia friendly surroundings.
- Allowing time to know the person not just the diagnosis.
- Physical wellbeing.
- Mental stimulation, involving them as much as possible to retain their worth and dignity.
- Ensuring there is adequate help for the carers when needed, to ensure carers are able to carry on their role as an unpaid carer.

Which aspects of care provided by the Trust need to improve?

- Patient and carers need support in incontinence care. As a carer I need to be aware of what to look out for to prevent pressure ulcers.
- My dad collapsed within the last 12 months and I was very happy with the care the hospital gave. I was allowed to stay with him so that he felt safe and was with someone familiar. The consultant did try to ask him questions which was pointless as he is at the stage where he can't understand and communicate and we were there all day. So the only thing I would suggest is to try to speed up the process for those in the latter stages of dementia.
- Infection and pain has a devastating effect on the family as a whole, managing this and the right medication is fundamental to the person with dementia and their recovery. More regular check- ups and better access to GP (or other) at the start of any pain/infection. Signs should be acted upon as part of the prevention of further rapid and possibly avoidable decline. This would take a lot of pressure off the carer and families.

Which aspects of care provided by the Trust need to improve?

- People living with dementia often need guidance with food choices. Presenting a menu can cause confusion and poor choices or none are made as a result. Assistance is required and could be provided by their carer, as a supportive role on the ward, along with many other tasks which may be overlooked due to (staff) time constraints.
- There may be disconnect between staff and patients with dementia when discussing pain and medication. For example if my wife has a sore knee she won't say that but will say ‘someone kicked me today’. I can translate that and locate the pain area but staff will not have the time or insight to do that. There is a considerable amount of non-verbal behaviour which can, if recognised quickly enough, prevent frustration, agitation and anxiety. This needs to be recognised and the possible role for carer support to staff. Verbal understanding may be entirely different from the norm and the person may need coaxing; time to understand what the patient is trying to convey.

Which parts of the care pathway need to improve?

- To keep patient’s file open, visit the patient and carer.
- We have not heard anything (about cataract operation) after a telephone assessment. It would help if we know what was happening.
- It would also help to know what is out there in the community for both patient and carer to live well with dementia in the community.
- My husband was never offered a scan or MRI to check how far his dementia had progressed.
- When a person is in hospital, the medical treatment as well as the social treatment can dictate how the person then recovers, or indeed behaves. Many have their routine disrupted. They can overcome the medical aspect but not the disruption. They need to be looked after, treated with a lot of patience, reassurance and time.
- My dad ended up in hospital 6 times, 3 of which were due to getting Covid in a care home. No one was able to see him in hospital to support his dementia. This was a huge failing. Dad suffered terribly with his isolation in hospital and ultimately back at the care home for 14 more days of isolation.
- Everything needs to be patient-centric. There are so many obstacles to good care for those living with dementia. Protocols for caring need to be specific for those living with dementia. Emergency admissions and care are scary for many people and become fraught with

Which parts of the care pathway need to improve?

difficulty for those patients with dementia. It's often too loud, noisy and frantically busy for the patient to deal with…..and waiting becomes inconceivable.

How can the Trust provide the best possible support and advice for families/carers?

- Training carers on how to give physical care and emotional / mental support to people with dementia, to be aware what to expect and how to respond.
- Provide regular reviews and a contact to support the carer and patient following diagnosis.
- Our experience of being in hospital with my dad has been relatively positive, so just continue what you are doing……
- Improve communication with relatives and other Trusts – e.g. community/mental health.
- Provide psychological support for carers, before they themselves breakdown, and breaks for carers especially if they care for somebody 24 hrs a day, 7 days a week.
- Communication. Listening. Engaging and involving. Planning. Timely interventions. Trained staff and volunteers.
- A comprehensive support package, clearly written that documents the support available and is integrated with other primary care interventions needed. We need to stop people stumbling through to find out what is or isn't available, often when they are at crisis point.
- Working together as a team utilising carer skills to assist staff. In order to achieve this carers need to be involved with all aspects of care and decision making. They have to be consulted and most importantly listened to. Provide assistance and support at all stages. Carers don't know what they don't know and can be afraid to ask.
- An advocacy service for those with no voice or who cannot use their voice effectively.
- Flexibility is key with absolutely everything and every stage. Plain, simple and easy to understand signposting to services, readily available. Explanations without acronyms. Plain English to explain medical and technical terms.
- A basic understanding of the stress, strains and anxiety of carers, who are often working unpaid 24 hours a day, day in day out. with limited help and support.

How can the Trust provide the best possible support and advice for families/carers?

- Aim for carer wellbeing to ensure they have quality of life. Relieve the stress some carers are under.

To provide care and support for families and carers, what do we (Trust staff) need to focus on?

- As a carer I need training in giving physical care and emotional support. I sometimes wonder if there are better ways of doing things.
- Case reviews as a matter of course.
- Meet with carers rather than just giving them a wad of literature after diagnosis.
- Give carers a named worker with whom they can develop an ongoing supportive relationship, to benefit the patient and carer.
- In my opinion the glossy advisory brochures are a complete waste of money as the information is available online. Also the telephone support lines don't really tell you anything new. Personal contact and support from an admiral nurse is the only thing that we have found helpful.
- I don't think that people understand the psychological damage that caring for someone with dementia has …….there should be more support out there.
- Providing psychological support should be a priority.
- Admiral nurses are key for advice and support. Most carers are new to dementia and are often not prepared for what is coming.
- Mental health concerns for carers are very real, as the behaviour of the person they are supporting can be extremely challenging.
- Without full and ongoing dialogue with carers there can be no meaningful way forward. Professionals may think they are the experts due to the volumes they see and research undertaken but nothing beats caring for someone living with dementia 24/7. It provides a whole new insight into a world out of the grasp of most people. As everyone's dementia journey is different, so too is every dementia carer’s journey. Build into this the complexity of personality and psycho-social behaviour and without the necessary training and

To provide care and support for families and carers, what do we (Trust staff) need to focus on?

development there is a recipe for disaster. People don't know what they don't know and signposting and referring are an essential element

- Carers know the person better than anyone, so their knowledge of what is required can help.

If you could improve one thing in relation to care of patients with dementia in the Trust, what would it be?

- To equip and support carers to support and care for family member with dementia.
- Set up a walking group for those with early diagnosis of dementia. We found very little available in this respect and I would have thought that exercise is one of the best ways to slow down the disease and help the mental wellbeing of patients. Not all dementia patients want to be sat in a chair at a day centre sitting around drinking tea!
- Proper education should be given to the community, because I feel once a person has dementia they are treated like crazy people, outcast from society.
- Better communication and sharing of patient history in clinical setting. It has been so frustrating to have to explain time and time again that my dad has Alzheimer's disease. If dad is asked a question he might not know the answer or give an incorrect answer. Often the assumption is that dad is giving factually correct information.
- Treating patients and carers as part of the team, with understanding and respect.
- To give confidence and peace of mind that the person is receiving the best possible care.

If you could improve one thing in relation to care of people living with dementia, in Newcastle generally, what would it be?

- To have more activities where people living with dementia can go and be stimulated mentally and physically.
- Give each person a named nurse/carer to access as needed. This should be part of the diagnosis/ assessment process.
- More money spent ……..
- More focus on exercise for people living with dementia. These sessions to be run for a couple of hours and the carers not needing to attend, giving them a much needed break (operating as a drop off service).

- More resources and support - however this has to be based on what is needed and not using the theory and research. Real communication with carers and those projects supporting both the carer and the person living with dementia. One size does not fit all. Choice of activity/support from the start of the journey through to the end. Sharing resources, avoid duplication and deliver what is needed.

- More general awareness and support for places like large shopping centres to be more dementia friendly. Help with shopping and finding items.

- One stop shop after diagnosis where all rights and responsibilities are explained; a pathway through the bureaucracy, that is state and local complexities, everything that MAY be available should be highlighted. I was worn down by researching what entitlements, support and help there was, before then having to fight and jump through hoops and over hurdles to obtain them. I appreciate that financial resources are finite but if things are available they should be explained if not offered.

- Ensure the help from care companies that the carers of people with Alzheimer’s receive in the community is high quality, as sometimes the standard is below reasonable and ends up causing more stress for the families and carers, instead of relieving the stress of looking after a family member with dementia.

What one thing would help you care better?

- To be trained on full support with personal care and mobility. I sometimes wonder if there are better ways of doing things like following an incontinent episode, help getting in and out of the car when legs seem heavy and stiff, moving in bed.

- Better larger house and garden. Currently coping with care of elderly mother and disabled brother with complex multiple disabilities……. but abandoned by N and S Tyneside Social Services departments.

- Easy access to someone qualified to listen and help with problem solving.

What one thing would help you care better?

- More places for the person living with dementia to go for a few hours without the need for the carer to go with them. I don't think people really understand the importance of a break for the carers, so that they can recover from sleepless nights and constant caring for their loved one.
- Open access to someone to advise when things are difficult.
- I am a full time carer for my husband and I struggle from day to day physically and emotionally. I need more places like Dementia Matters who offer activities for dementia, not only as a motivation for my husband, but it will give me a break to rest and do what I want to do, if I know he is in a secure place.
- Being listened to. Being involved in care planning - not to the detriment of the carer’s health.
- Knowing how and where to get help. Often when the all the wheels have fallen off and the carer is struggling and it is affecting their own family and personal lives…... It’s too late then. It must start from the point of diagnosis.
- Better, simpler all round care packages fully funded as a mix and match, including respite or as a minimum financial aspects explained simply and transparently.
- A cohesive system with no demarcation between health and social care for those living with dementia and their carers.
- More understanding/help from the family.
- More respite instead of less respite.

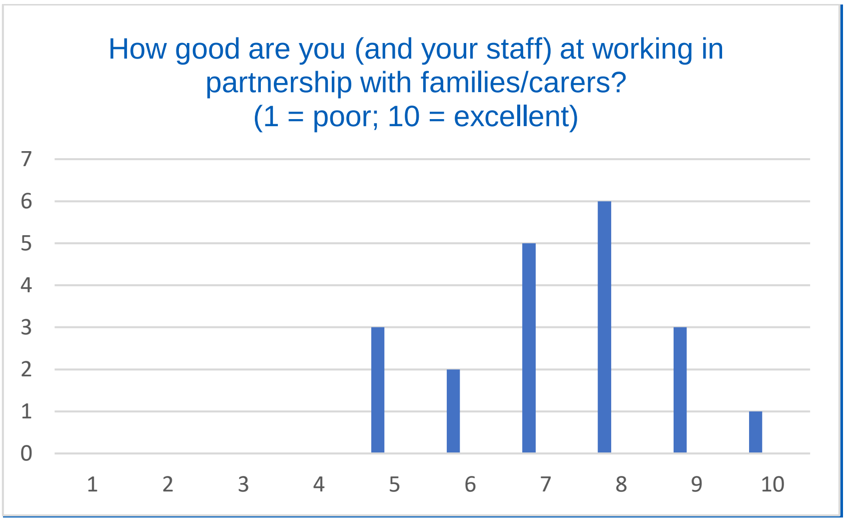
Appendix 3

Summary of staff consultation with clinical leaders

The following were prioritised as areas for development across the Trust:

- Make all wards/department environments ‘dementia friendly’ (colour contrast, signage, clocks etc): 88%
- Provide more stimulation for patients from visitors/volunteers/activity coordinators: 81%
- Provide 1:1 nursing for acute admissions with ‘extreme confusion’: 81%

Staff were asked to rate how good their teams were at working in partnership with families/carers on a scale of 1-10; were 1=poor and 10=excellent.



Staff were asked ‘What single thing can you do to improve partnership working with families/carers?’. Responses were as follows:

- Allow them to stay with patients on the ward
- Look for solutions that work for the whole household, as they are the patient’s ultimate carer
- Keeping families informed is definitely the key following episodes of ill health, hospital admissions etc.
- Can be dependent on the nature of the admission – either elective or emergency surgery. We can support elective patients better by planning care with family members prior to surgery. Emergencies- some patients are rushed for surgery so

this can make it quite difficult. We would always keep families and carers informed as much as possible.

- In my area which is outpatients, families and carers are encouraged to attend with patients who have dementia and are facilitated to go into consultations. I think we could do more for those who attend alone or with a carer from a care home. We could video or telephone a family member at home to include them.
- Working in critical care we form a close relationship with families and although we don’t see an awful lot of patients with dementia, a high proportion of patients do have acute delirium. Working with family members to identify the like and dislikes of the patient (abbreviated forget me not) is very useful as are patient diaries.
- I work in the urgent treatment centre. I feel we could improve access for dementia patients as a priority to reduce their wait. I’m not sure how this could be achieved, or how we can identify patients with dementia who attend. We see our patients for such a short time. It is hard to establish bonds at times.
- Ensuring regular discussion. Get to know the patient. Use the Forget me not cards to inform conversations.
- To continue to communicate well with families / carers and always take their views into consideration when making plans.
- Communication is key and this can always be improved. Ward leaders need to ensure effective communication is in place at all times and that families and carers feel valued.
- Since visiting has been restricted (due to Covid-19 restrictions) the relationship with carers has changed. Setting a plan with carers around communication (who and when) when the patient is admitted would improve this.
- Flexible visiting and decision making.
- I think we are very good on the trauma wards, but we could look more at how we support dementia patients on the elective wards, meeting with carers and patients before admission.
- I feel we do work well with families and carers, going above and beyond and accommodating visiting times; currently short staffed so more time with dementia patients would be a huge benefit.
- Structured approach and frequent communication with families.
- Maximise effective communication so the next nurse knows all the relevant information as quickly as possible.
- We could allocate more time to contacting families, instead of rushing onto the next patient.
- To have more time to spend with them.
- Make time to listen.
- Discussion pre-admission with family to plan care during elective stays.

Staff were asked to rate how good they were at getting to know every patient with dementia as a person, on a scale of 1-10; where 1=poor and 10=excellent.

The clinical leaders were asked 'What single thing can you do as a ward/team to get to know every patient with dementia as a person? Replies were as follows:

- Treat them like your family.
- Raise awareness to team members to help identify patients with dementia, taking time over their assessment and ensuring the best care is given to include carers and family as much as able.
- If we know in advance of appointment, a call to the carer could be advantageous. Longer appointment times in Outpatients. If no family, then information from care home.
- Difficult in Outpatients and we will not know the person has dementia as there is nothing in Powerchart to tell us. We are reliant on them having the insight to tell us. When we are aware we do whatever is needed, as with everyone, to make their appointment meaningful.
- Prioritise time when the person is first admitted to the ward to get to know them and their families and what they like, dislike, how they communicate and how they manage all their daily activities.
- In critical care with the majority of admissions being an emergency makes it very difficult, but planning and a good history of the patient is so important.
- Let them and their families know that we want to get to know them. Then find ways to make it easier for them to share important information about them as individuals.
- Increase awareness of importance of getting to know the patient by discussion with family or carers.
- Better contact with patients from care homes, who do not have anyone who is able to visit. Pictures, reminders of where they are from.

- Family/friends/carer involvement.
- Spending extra time with them, involving family with the consultation.
- Sit and talk to them. Try to provide continuity of staff where possible. Pass information on in handover, regarding them as a person rather than just medical information.
- Perform a comprehensive geriatric holistic assessment with collateral history from family, carers and friends.
- Be interested in them as a person, not just a patient. Take time to find out about them.
- Strong leadership and communication to ensure that all staff make this a priority, again with engagement with patient, families and carers and investing time in this.
- Forget me not cards, discussion with patients, families and carers around how we can best support everyone during the hospital admission.
- Recognise the person has dementia – often in Imaging we are not informed.
- Ask the patient/family/carers about the patient, their likes and dislikes etc.
- Speak to families and carers, use the Forget me not cards.
- Make time to talk and question.
- Involve their carers/family.

Finally the clinical leaders were asked for their views on dementia care related staff education and training. See table below for people’s ideas and suggestions.

‘The Trust provides a significant amount of education and training on dementia and delirium. What other education/training should be available for staff on dementia/delirium?’

- Would benefit from face to face teaching with dementia co-ordinators on the wards to ensure staff have awareness of how to manage patients with dementia holistically and how we manage and meet expectations of families as well as throughout the patient journey. Needs to be mandatory at Induction and at the Trust Healthcare Academy.
- Bespoke sessions for staff who don’t work on the ward.
- Frequent drop in sessions
- Start early, by including in student nurse training. Qualified staff could do online modules. Link to role of Harm Free Care Leaders.
- Use link nurses (Harm Free Care Leaders) better within wards and departments. Dementia team to come to the department.
- Bite size sessions/ online information about different types of dementia and their presentation, coping strategies etc.
- Screening for dementia and delirium.

‘The Trust provides a significant amount of education and training on dementia and delirium. What other education/training should be available for staff on dementia/delirium?’

- I think to get your staff who are carers of people with dementia involved in training for colleagues……. It makes it more real if a face you know is telling you about their experience of having their relative with dementia looked after by another nurse.
- I will be referring staff for training, now study seems to be getting back to ‘some sort of normality’.
- Walk rounds to the wards with poster boards and 10 min presentations to raise awareness of key points.
- Training around nutrition/mealtimes/eating and drinking for people living with dementia.
- More information on the training available currently.
- Online links for link nurses (Harm Free Care Leaders).

Appendix 4 Audit Tool

Audit Tool Trust Dementia Care Plan 2022-26.docx