



Dementia Strategy:
Living well with
dementia in our
hospitals

Dementia is:

a long-term condition affecting memory, cognitions, health and behaviour experienced by the person and their family/carers that can benefit from proactive planning, timely treatment, support and compassionate care.

Department of Health, Making a Difference in Dementia: Nursing Vision and Strategy (refreshed September 2016)

Welcome to our strategy about living well with dementia in hospital

This document has been developed using the experiences of our patients and their carers as well as being shaped by our policies and guidelines.

Our approach to care is focused on meeting the needs of the person with dementia with 'person-centred' care.



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Foreword

Statement from our Chair and Nursing Director

Our Trust is one of the largest in the country with in excess of one million patient contacts each year and over 7500 staff. We are the main local provider of specialist acute health services to the people of Gloucestershire and others in the surrounding areas. We have a clear vision to deliver 'Best Care for Everyone', and this guides the development of all our strategies and plans.

High quality patient care is important because it:

- Is critical in helping to improve the lives of patients and that of their families
- Has been linked to better healthcare outcomes for patients
- Helps our Trust maintain and increase public confidence
- Is a key component of overall quality care, as demonstrated by the quality governance framework and the NHS Operating Framework
- Is a right under the NHS Constitution for England

A positive patient experience is about getting good treatment in a comfortable, caring and safe environment delivered in a reassuring way. It is about having information to make choices, to feel confident and feel in control. It is also about being talked to and listened to as an equal and being treated with honesty, respect and dignity. Our overarching Trust aim is to improve year on year the experience of our patients.

Improving assessment, investigation and referral to support access to timely diagnosis of dementia in Hospital is a core Trust Objective. Potentially 1 in 3 patients will be aged 65 or above and potentially 1 in 4

experience symptoms of confusion or are known to have dementia. Acute Hospital admission can be disorientating and hospital environments can present challenges.

Enhancing the healing environment presents a challenge; we are exploring action planning in relation to environment enhancements, developments which seek to promote social interaction and use of art to enhance wellbeing for patient and family/carers.

Our Trust Dementia Steering Group was established in 2010, with responsibility for development of and implementation of actions to support care of the patient with Dementia and support for family/carers. We have an Executive Lead and also a team of senior clinical champions. Gloucestershire Alzheimer's Society are core members of this Group and support our Dementia Care training programme. We are also committed to partnership working within Gloucestershire as part of the Countywide Dementia Strategy and Dementia Alliance Group.

Positively, we have a new and very significant opportunity to tackle some of our challenges in partnership with others. The county's Sustainability and Transformation Plan – or STP – provides a new focus for working together with our partners in primary, community and social care with the shared goals of prevention, promoting self care and reducing reliance on hospital-based care, all with the aim of delivering unprecedented improvements in health and health services.

Peter Lachecki
Chair

Maggie Arnold
Nursing and Midwifery
Director



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Purpose of the strategy

Purpose of this strategy

The current focus on dementia, both globally and nationally, has highlighted how much has been achieved in the development of dementia care since the launch of the National Dementia Strategy in 2009. However, dementia care remains a national challenge.

The Alzheimer's Society, 2015 report: 'Aiming higher to transform lives' states that; "what has been achieved needs to be maintained and what still remains to be done needs to be prioritised. Dementia needs to be seen as a national priority in its own right in order to ensure that ambitions are transformed into action."

We are very proud of what has been achieved so far in our Trust in the care of people with dementia, but we want to continue to develop and improve our services.

The purpose of this document is to provide a clear overview and understanding on how staff in GHNHSFT can support people with dementia to live well when they are in our hospitals. This support could be as an in-patient, attending our out-patient services or as family members or visitors to our hospitals.

It sets out our ambition and standards for excellent, compassionate care for people with dementia and recognises the vital role that carers and family provide.

For people with dementia, coming into hospital can be a very frightening and distressing time. It can also be an anxious experience for the family and carers.

Fundamental to how we can support people with dementia when in our Trust is the relationship between the person with dementia, the health care professional

and the carer/family member. This is often referred to as the triangle of care.

We have listened to what the carers of people with dementia have said to us through our carers surveys and we are privileged to have a carer of a person with dementia come to speak at our dementia care training sessions about their care experience in our Trust. This direct link to our patients reinforces the triangle of care.

The Triangle of Care describes a therapeutic relationship between the person with dementia (patient), staff member and carer that promotes safety, supports communication and sustains wellbeing.

Carers Trust, 2015



Introduction: about dementia

Dementia is a disease that affects the brain; it is not a normal part of ageing. There are 40,000 people in the UK under the age of 65 with dementia.

Age is one of the risk factors for developing dementia. Figures from the Alzheimer's Society state that one in 14 people with dementia are aged 65 years and over, rising to one in 6 people aged 80 years and over.

It is because of this link between ageing and dementia that people aged over 55 years are more afraid of dementia than any other health condition, including cancer (NHS Mandate, 2015). And we are living longer now than at any time in our history.

In the United Kingdom (UK) in the 1900s life expectancy for men was 44 years and for women 48 years. Current estimates on life expectancy are now 79.5 years for men and 83.2 years for women (ONS, 2014).

Age UK (2016) states that there are 11.6 million people aged 65 years and over in the UK and the number of centenarians living in the UK has risen by 72% over the last decade.

The number of people aged 65 years plus is expected to rise to 16 million by 2033 and one in five people currently in the UK will live to be 100 years old. (Age UK, 2016)

It is through the developments in public health, nutrition, hygiene and sanitation that have led to this increase in our longevity but the demands of an ageing population on health and social care resources are also increasing.

There were 18 million people admitted to

hospital in 2015 and 41% were over the age of 65 years, with many people having existing and complex medical conditions. Age UK (2016) states that "dementia is one of the main causes of disability in later life, ahead of some cancers, cardiovascular disease and stroke and is the leading cause of death for women in the UK."

There are 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025. This will soar to 2 million by 2051. That's one person every three minutes.

Alzheimer's Society 2016



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What is dementia and the national context

What is dementia?

The word dementia is used to describe a range of brain disorders. It is used as an umbrella term to group the many different types of dementia.

Dementia is a disease that affects the brain and is not a normal part of ageing, although age is a risk factor as described previously.

According to the Alzheimer's Society, there are over 100 different types of dementia and although there are differences in the causes and the development of each one, there are many similarities in how they affect the person diagnosed with a form of dementia.

The most common types of dementia are Alzheimer's disease, Vascular dementia, Mixed dementia (Alzheimer's disease and vascular dementia) and Lewy-body dementia.

The common difficulties all people with dementia experience are with memory, thinking, behaviour and emotions.

Dementia is a progressive disease. The symptoms people experience will get worse over time and there is currently no cure although research in dementia continues, aiming to understand the disease and develop treatments.

Each person's experience of dementia is unique to them and many people lead full and active lives for years after a diagnosis of dementia and a timely diagnosis is a key objective.

The Prime Minister's Challenge on Dementia, 2015 says, 'If diagnosed in a timely way, people with dementia and their carers can receive the treatment, care and support (social, emotional and psychological as well as pharmacological) to enable them to better manage the condition and its impact'.

In support of the Government's commitment to early diagnosis, if you are seventy-five years and over and admitted to our hospital in an emergency, a doctor will screen you to check for the early signs of dementia.

Alzheimer's Society have fact sheets explaining about the different types of dementia and their progression. They have also produced 'The dementia guide' which they recommend for people who have recently been diagnosed with dementia. It can be downloaded from their website or ordered from them.

“Relatives would appreciate a daily thumbnail bulletin as dementia patients cannot remember what has happened to them in the day”

Carer feedback

The National Context

Dementia is a global phenomenon and is recognised as one of the most important health and social care challenges of our generation.

Along with rising numbers of people with dementia in society, we also see increasing admissions into hospital of people with dementia. The number of emergency admissions to a general hospital of people with dementia increased by 48% from 2008/09 to 2012/13. (Public Health England, 2015) with the majority of admissions being through the Accident and Emergency department and referrals by GPs.

The hospital experience for people with dementia was highlighted back in 2009 with the Alzheimer's Society report, 'Counting the Cost'. This report stated that; 'People with dementia stay far longer in hospital than other people who go in for the same procedure. The longer people with dementia are in hospital, the worse the effect on the symptoms of dementia and the individual's physical health; discharge to a care home becomes more likely and antipsychotic drugs are more likely to be used.'

The aim following this report was to address the quality of care people with dementia received in hospital.

The National Institute for Health and Care Excellence (NICE) guidelines on dementia, first published in 2006, set out clear principles on the care of people with dementia. They recognise that the principles of person-centred care are key to good practice.

The principles state;

- **The human value of people with dementia**, regardless of age or cognitive impairment, and those who care for them
- **The individuality of people with dementia**, their unique personality and life experiences among the influences

on their response to the dementia

- **The importance of relationships and interactions with others to the person with dementia**, and their potential for promoting well-being

In 2009, when the Department of Health (DH), launched the UK National Dementia Strategy, it had three key aims;

- Ensure better knowledge about dementia and remove the stigma
- Ensure early diagnosis, support and treatment for people with dementia and their family and carers
- Develop services to meet changing needs better

The strategy was conceived as a five year plan to develop services for people with dementia and their carers regardless of their age, ethnic group or social status and that they should be 'fit for the 21st century'. The strategy set out 17 key objectives. Objective 8 was to: *Improve the quality of care for people with dementia in general hospitals.*

In 2012, The Prime Minister, David Cameron, although recognising the improvements made in dementia care since 2009, announced a further challenge for improvements in care and research by 2015; the three main aims of the Dementia Challenge were:

- Driving improvements in health and care
- Creating dementia-friendly communities that understand how to help
- Better research

In February 2015, the Department of Health (DH) published the Prime Minister's Challenge on Dementia, 2020. It sets out what the government wants to see in place by 2020 in order for England to be:

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

The document also sets out clearly the views of people with dementia; they want a society where they are able to say:

- I have personal choice and control over the decisions that affect me.
- I know that services are designed around me, my needs and my carers needs.
- I have support that helps me live my life.
- I have the knowledge to get what I need.
- I live in an enabling and supportive environment where I feel valued and understood.
- I have a sense of belonging and of being a valued part of family, community and civic life. I am confident my end of life wishes will be respected. I can expect a good death.
- I know that there is research going on which will deliver a better life for people with dementia, and I know how I can contribute to it.

A report in 2014 by the Care Quality Commission, 'Cracks in the Pathway', looked at examples of excellent dementia care and noted that services that recognise that a personalised approach is the key to high-quality care for people living with dementia. In addition:

- They know that care must be delivered by knowledgeable and skilled staff;
- Who have the time for the individual needs of the person living with dementia;
- They make sure that comprehensive assessments are carried out, updated and then shared when someone moves between services

The NHS Five Year Forward View document, published in 2014 stated that 'the NHS ambition over the next five years is to offer a consistent standard of support for patients newly diagnosed with dementia, supported by named clinicians or advisors, with proper care plans developed in partnership with patients and families; and the option of personal budgets, so that resources can be used in a way that works best for individual patients. Looking further ahead, the government has committed to new funding to promote dementia research and treatment'.

In 2016 the DH published a refreshed version of Making a Difference in Dementia: Nursing Vision & Strategy (October 2016). Building on the previous version, this refreshed edition supports all nurses to be responsive to the needs of people with dementia, 'to develop their skills and expertise and improve the contribution they make in achieving best outcomes for people with dementia, their carers and families, and communities'.

Apart from Government policies and guidelines there are other groups who support and promote the concerns and well-being of people with dementia. The Alzheimer's Society, formed in 1979, is at the forefront of raising awareness and improving the quality of care for people with dementia and their carers.

Others such as The Dementia Action Alliance state that they have one simple aim: to bring about a society-wide response to dementia. In our Trust we state that 'delivering high quality healthcare drives our strategy' (Gloucestershire Hospitals NHS Foundation Trust Operational Plan 2014/16).

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The local picture



The local picture

There are approximately 8,000 people currently diagnosed with dementia in Gloucestershire (Alzheimer's Society).

Within Gloucestershire, the ageing population increase is greater than the national average. The number of people over the age of 65 years is estimated to increase by approximately 70% between 2010 and 2035 with the number of people over the age of 90 expected to double over the same time period (Strategic Plan, 2014-2017).

Alongside the number of people with dementia are the families and carers. There are some 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime (DH, Prime Minister's Challenge on Dementia, 2020).

It is seen within Gloucestershire that having a shared vision on dementia care in partnership with other health and social care providers is a key component for providing 'high quality, safe care that focuses on the needs of people living with dementia and their carers'.

The Gloucestershire Dementia Strategy states the requirement to secure a continued commitment to co-production and collaboration between those living with dementia and those delivering health, social care, community and voluntary services.

Principles and values from Gloucestershire Dementia Strategy 2105-2018:

- Dementia is everyone's business
- People living with dementia are engaged, involved and informed
- The person living with dementia and their carer/family are the key focus

- Dementia is a long-term condition, ranging from prevention to end of life
- Ensuring the county workforce has the knowledge and skills

Dementia and delirium care are national priority areas and are key local safety and effectiveness objectives for our Trust. 'To improve the care of people with dementia and delirium' is a stated objective in our 'Framework for the Future' document.

Living well with dementia in our hospitals is shaped by policies and guidelines but also from the experiences of care of our patients and is explained under these four headings:

- **Person-centred care**
- **Promoting communication**
- **The caring environment**
- **Staff education and training**

Our care approach is focused on meeting the needs of the person with dementia with 'person-centred' care, ensuring the dignity, respect and wishes of the person with dementia alongside the support from carers and families. Underpinning this approach is staff trained in dementia in accordance with their role.



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Coming into hospital



Coming into hospital

An admission to hospital, whether it is a planned or emergency event can be an anxious and worrying experience for anyone and especially so for people with dementia.

Up to a quarter of hospital beds in acute general hospitals are occupied by people with dementia and they often stay in hospital longer than people without dementia.

Seven in ten people living with dementia are also living with another medical condition.

All-Party Parliamentary Group on Dementia, 2016

For people with dementia, a hospital admission may cause them to be more confused than normal. This mental confusion is called a delirium and can occur when people become medically unwell. It is thought that one in 10 patients in hospital have a period of delirium rising to one in three for people aged 70 years and over.

Delirium can affect anyone but people with dementia are more likely to develop a delirium and if people have experienced delirium in the past then they are likely to have further episodes. We have an information leaflet for patients and families on Delirium that explains more about this condition.

The Alzheimer's Society have produced a leaflet called 'Care on a hospital ward' that provides practical tips for the carer or families on how they can assist people with dementia in hospital and this may be of use to families.

One of the main suggestions they make is to write down information for the hospital staff so everyone is aware of the individual needs of the person. The Alzheimer's Society has a leaflet called 'This is me' that supports people with dementia, carers and families to do that. It can be downloaded from the Alzheimer's Society website and completed to bring into hospital or it can be obtained from our staff and completed on admission to hospital.

In areas of the hospital such as the Emergency Department and Out-Patients areas, there is another leaflet called 'Tell us about you'. This patient/carer held leaflet can be used by any person. It can be used to share key information with the care team to support a planned outpatient appointment. For a person with dementia, 'This is me' is the leaflet of choice, however 'Tell us about you' can support an unplanned hospital attendance whilst a 'This is me' is being completed.

There is a carer's emergency scheme for people unable to care because of an accident, emergency or illness. It is run on behalf of Gloucestershire County Council by a partnership of Guideposts Trust, Crossroads Care, Worcestershire Telecare and Carers Gloucestershire. The person you look after will be supported and the people who need to know informed. Contact Carers Gloucestershire on 0300 111 9000 for further information.

Our staff are fully committed to the [Leading Change, Adding Value](#) framework developed by NHS England in 2016. This is a framework for all nursing, midwifery and care staff and features ten universal commitments.

7 Person-centred care for people with dementia

Confusion Proforma

National Dementia QUIN: Emergency Admissions – 75 years and over
ON ADMISSION – Steps 1 + 2

Step 1: Dementia?

Patient has known dementia or is being assessed by memory service

If ticked, no further step or QOLH required

Step 2: Screening

Choose which of the following best describes the patient on admission

If 1 box ticked, proceed to Step 3.

Critical illness / coma / palliative / communication barrier

MMT score of 8 or more

If 1 box ticked, proceed to Step 3.

Unaffected delirium

Abbreviated Mental Test score (AMT) of 7 or less

Abbreviated Mental Test Assessment

Give address to recall

Count down 20 to 1

Name of hospital

Time of day

Date of birth

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Recognise location

Present mood

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Promoting communication, environment and education

Promoting communication

We have heard through our Carers' Survey that poor communication between the hospital, the person with dementia and carers or families can cause anxiety, frustration and misunderstanding about the patient's plan of care.

In recognising the valuable contribution of carers and family to the well-being of the person with dementia and their care whilst in hospital, we would suggest that families nominate a main contact for the ward to direct information through to help make sharing information easier for all.

This link can be especially helpful when planning for discharge which we aim to start from the early stages of admission (and at pre-admission clinics) with patient and carer involvement. The adult social care team and our discharge team are available to help support the discharge process. We also work closely with our palliative care team and end of life champions.

If you would like information about the care plan or to meet with the ward sister or charge nurse, then please ask on the ward. If they are unable to see you directly then an appointment can be made for you. Arrangements can also be made to speak to the ward medical team.

If you do have any concerns about the care on the ward the please speak to the ward sister about them. We would like to know your concerns so they can be addressed as soon as possible or if you wish to contact the [Patient Advice and Liaison Service \(PALS\)](#) via our website or their offices at each hospital.

There is a senior nursing leader with responsibility for overseeing a group of wards

or clinical departments. The matron can support you if you have any concerns or suggestions you wish to discuss at a more senior nursing level. Contact information is available from the nurse in charge of the ward and also on posters displayed within each ward area.

A carer for a person with dementia is entitled to an assessment from the adult social care team in their own right. Please ask a nurse for further information or if you are at home you can contact the adult social care help desk on 01452 426 868.

Our Trust supports [John's Campaign](#) and carers are welcome on all inpatient wards outside of our usual visiting hours. Please speak to the ward sister in charge.

We have a hospital information leaflet for carers and families called 'Information to support the carer or relative of a patient with dementia'; please ask staff for the leaflet if it is not given to you.

We have recently introduced a Hospital Diary as a resource for people during their hospital stay to support wellbeing and family/ carer relationships.

Supporting people with any hearing or visual difficulties is vital for good communication. With permission, we can use magnetic signs above a patient's bed to indicate that people may require assistance or adjustments.



The caring environment

We know that multiple ward moves can be distressing and disorientating to the person with dementia.

We aim to keep ward moves to a minimum and related to the clinical need of the person with dementia. If it is necessary to transfer a patient to another ward, then we would aim to do this in the day time and with the support of carers and families if possible.

In our Trust, we use a purple butterfly magnetic symbol above the patient's bed and on their wrist band that indicates to staff the person with dementia may require extra support or assistance. Please let us know if you do not wish this to be used.

We heard through the Carers' Survey the concerns from carers that too often there is little for patients to do during their stay in hospital. Although there are some activity groups for people with dementia already in our Trust, we have also introduced a programme of cognitive stimulation developed through a year-long project by a clinical psychologist. We are in the process of implementing these groups throughout our Trust. The aim of the groups is to enhance the cognitive ability for people with mild to moderate dementia through a variety of enjoyable activities such as word games, discussions of past and present events, puzzles and sensory stimulating exercises.

We have recently installed clocks in our General and Old Age wards that also display the date to help aid people with orientation when in the ward environment.

We are looking to improve the signage around our Trust to support people with dementia. Although there have been improvements made, this is an on-going project with further improvements in the future.

In partnership with Carers Gloucestershire, there is a Carers Gloucestershire Hospital Liaison Officer who helps advise people as to the support available to them.

In order to support the person with dementia in the ward areas, the Trust operates a Carer's Passport scheme. The Carer's Passport is available for carers (non-paid) who wish to stay and support the person with dementia, for example support with eating at mealtimes. Having a Carer's Passport also allows the carer a range of benefits including reduced or free car parking (with a completed passport).

Patient-Led Assessments of the Care Environment (PLACE) have, in 2015 added dementia information to their report. The aim of PLACE is to provide a snapshot of how an organisation is performing against a range of non-clinical activities which impact on the patient experience of care.



Cognitive Stimulation Se

Staff training and education

In February 2009, the National Dementia Strategy was launched, setting out the workforce requirements to attain an informed and effective workforce for people with dementia.

Health Education England (HEE) now has the responsibility for ensuring the quality of care for patients.

Staff recognise the reasonable adjustments that the person with dementia may require in their care and treatment and aim to ensure they are made.

In our Trust, we use the adapted Abbey Pain Scale tool to support staff in assessing pain in people with dementia. Staff can call on the support of our Acute Pain Team if required to ensure we are addressing a patient's pain.

We also support staff with regard to the assessment of mental capacity and with safeguarding. We will look to ensure that we continue our links with the end of life team and to support the work within their strategy.

We know that when people with dementia are in hospital, they may experience behaviour changes (or at a stage of their dementia progression) that can be distressing and concerning for them or their carers.

Training on delirium for our nursing staff is currently in progress. This not only raises awareness of delirium but helps our teams to identify early the signs and symptoms. The training needs analysis is currently being updated for 2017 and will be added as an appendix in due course.

As a Trust, we promote the principles of care set out in the Royal College of Nursing document; 'Commitment to the care of people with dementia in hospital settings'

- Staff will be informed, skilled and have enough time to care
- Family, carers and friends are seen as partners in care
- A dementia assessment will be offered to all those at risk, to support early identification and appropriate care
- Care planning will be person-centred and responsive to individual needs and support; nutrition, dignity, comfort, continence, rehabilitation activity and palliative care

In some of our dementia training sessions, the carer of a person with dementia has attended to speak about their hospital experiences. This has proved to be very valuable to staff in understanding dementia care in our hospital from the patient and carers perspective.



