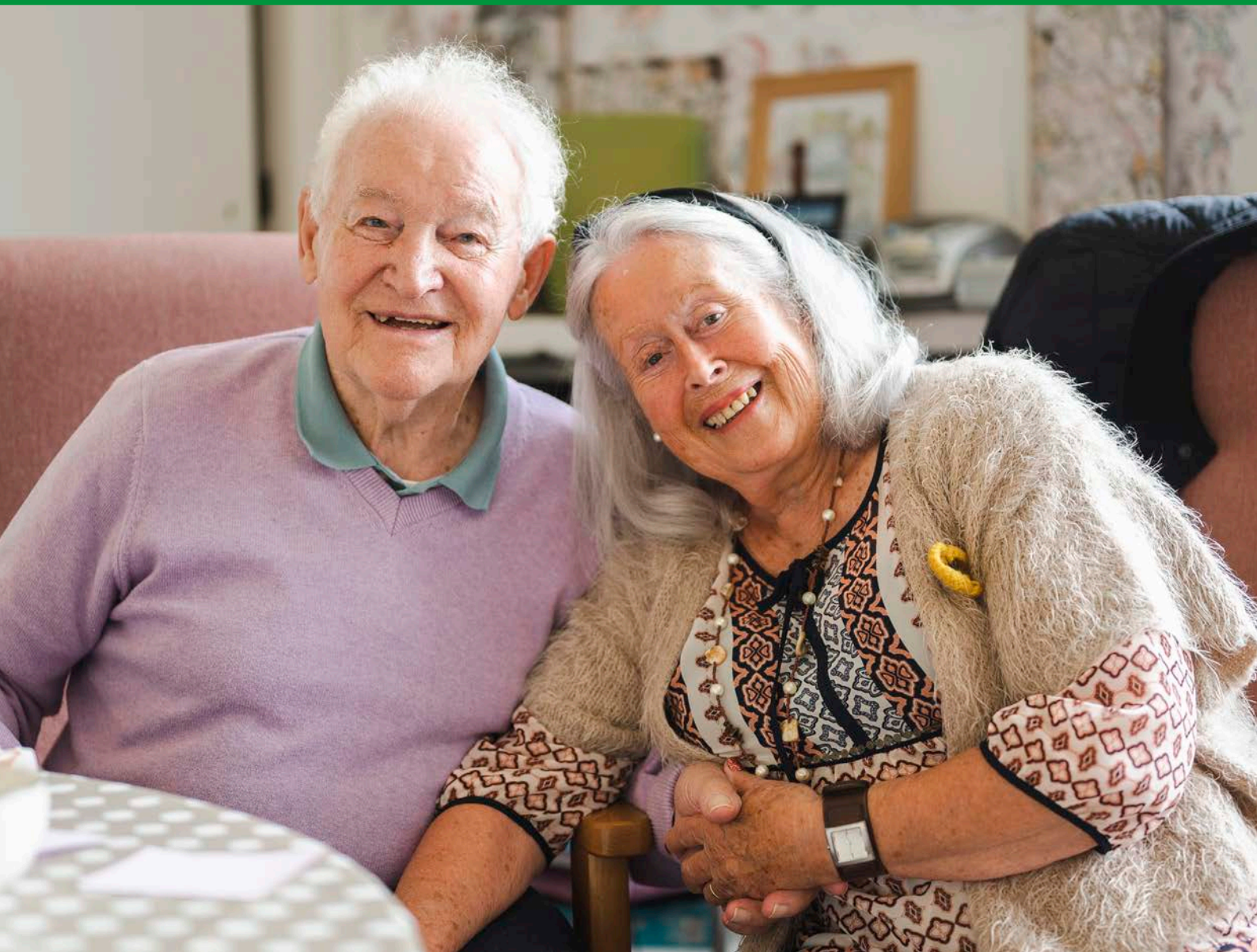


Dementia Strategy

2023 - 2028

*Improving the lives of people
affected by Dementia in
Gloucestershire*



Improving the lives of people affected by Dementia in Gloucestershire

Foreword:

Steve Shelley-King – One Gloucestershire Clinical Lead for Dementia

In Gloucestershire, we are working hard to improve the care and support that people affected by dementia receive but acknowledge there is still much to do. I have the privilege of saying that I am the County Clinical Lead for Dementia and over the past 18 months or so, we have been developing this strategy and are committed to improving the experiences of those living with and affected by dementia. Working with people living with dementia has been a passion of mine throughout my career, and I have personally been affected by the condition.

This strategy has been developed in partnership with local services, teams and inspirational people affected by dementia. It sets out our plans for the next 5 years and we are proud of our vision for the County. During this time, we shall continue to engage with our workforce, communities and those affected by dementia to measure how we are meeting those aims, identify what we are doing well and act on areas that need further development.

Jennifer Bute - retired GP, living with dementia in Gloucestershire

I am honoured to have been asked to be involved in developing this comprehensive

document. I am a retired medical doctor who used to be involved with medical education and have been living with a diagnosis of dementia myself for over 12 years. Since moving to Gloucestershire at the beginning of 2022 I have found the enthusiasm and commitment of those involved in dementia care and services in the area to be outstanding. This document has been well researched and put together in a readable, understandable way, explaining the wide vision for the County. It demonstrates that there is a great deal of help available at all stages, for people living with dementia as well as their supporters. It provides hope for everyone in what can be a difficult and bumpy journey.

Jane Haros Deputy Director of Integrated Commissioning

Dementia can affect all aspects of a person's life and the impact on the people around them should not be under-estimated. We have taken a collaborative approach to developing this Strategy which clearly aims to improve the experiences of individuals in Gloucestershire across the life stages. It seeks to enable the delivery of a personalised and proactive community or neighbourhood model of care that will help to better support people affected by dementia and provide high quality provision when needed. We are committed to implementing the Strategy aims over the next 5 years.

Acknowledgements:

We thank the following organisations, services and groups for their contribution to the development of this Strategy.

Age UK Gloucestershire, Alzheimer's Research UK, Alzheimer's Society UK, Cultural and Diversity Dementia Network, Gloucestershire Dementia Training and Education Strategy Group, Dementia UK, Gloucestershire Collaborative Partnership Board, Gloucestershire County Council, Gloucestershire Dementia Action Alliance, Gloucestershire Health and Care NHS Foundation Trust, Gloucestershire Hospitals NHS Foundation Trust, Gloucestershire Integrated Care Board, Gloucestershire Managing Memory Together Service, Young Onset Dementia Network, Your Voice Matters (Dementia Experts by Lived Experience Group), Gloucestershire Healthwatch Readers Panel.



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Executive Summary

One Gloucestershire Vision for Dementia

The One Gloucestershire vision is to work together as a whole system providing high quality and appropriate support to people affected by dementia throughout a person’s dementia journey

NIH National Institute on Aging (NIA) July 2021 www.nia.gov/health/what-is-dementia






In Gloucestershire there are currently:

- 5909 people over the age of 65 years with a dementia diagnosis
- 157 people under the age of 65 years with a dementia diagnosis
- 6066 people with a dementia diagnosis
- An estimated 9559 people living with dementia

Data from our local Dementia Dashboard up to end of March 2023– from the NHS England National Publication.

Gloucestershire has an ageing population with approximately 21% of our residents aged over 65 years. Whilst dementia is not a consequence of ageing, advancing age does increase the risk of developing the condition and with the population of this age group predicted to at least double by 2043, we must plan support and services accordingly.

The Dementia Strategy 2023-2028 sets out this vision by providing a framework informed by the NHSE Dementia Well Pathway.

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>“I was given information about reducing my personal risk of getting dementia”</p>	<p>“I was diagnosed in a timely way” “I am able to make decisions and know what to do to help myself and who else can help”</p>	<p>“I am treated with dignity & respect” “I get treatment and support which are best for my dementia and my life”</p>	<p>“I know that those around me and looking after me are supported” “I feel included as part of society”</p>	<p>“I am confident my end of life wishes will be respected” “I can expect a good death”</p>



We have engaged with our system partners across the Integrated Care Partnership, people living with dementia, their carers, and members of the public to develop our priorities over the next 5 years.

This Dementia Strategy seeks to promote dementia positive communities and enable the delivery of a personalised proactive approach to support and care at a local community or neighbourhood level that will

help to prevent, slow, or reduce the impact of dementia. We aim to ensure that wherever you live in the County and regardless of your age, socio-economic status, ethnicity, sexuality or gender, you have access to information, support and care that is appropriate for you and will result in positive outcomes for you, your family, carers and friends.

Introduction

From 1 July 2022, our One Gloucestershire Integrated Care System (ICS) became a legal entity - an existing partnership that brings together NHS provision, social care, public health and other public, voluntary, charity, community and independent sector organisations across Gloucestershire.

We have published our Interim Integrated Care Strategy (December 2022) to help us structure our priorities going forward. The strategy has three overarching pillars which include:

- ✓ Making Gloucestershire a better place for the future – focusing on the range of things that can impact on health and wellbeing including existing priorities like physical activity, healthy lifestyle, adverse childhood experiences and housing.
- ✓ Transforming what we do – supporting prevention at a local level, joining up services close to home, reducing differences in people’s experience, access to care and health outcomes and a One Gloucestershire approach to developing our workforce – ensuring services can access the skills and people they need.
- ✓ Health and care services today – improving access to care and reducing waiting times for appointments, treatment and operations, improvements in urgent and emergency care and supporting people’s mental health.

Working Better Together - in a more collaborative way to transform the quality of support and care we provide to people affected by dementia.

Through this Strategy we aim to:

- help people to take action to reduce the risks of developing dementia
- ensure early identification and timely diagnosis
- improve the support available to people living with dementia and their families and carers, to maintain independence to live at home for as long as possible
- provide high quality care through our community, hospital and independent care provision
- support people who are approaching the end of their life to have a dignified and peaceful death in the place of their choice.

The One Gloucestershire vision is to work together as a whole system providing high quality and appropriate support to people affected by dementia throughout a person’s dementia journey.



Background

What is dementia?

Dementia is the loss of cognitive functioning, (thinking, remembering and reasoning) to such an extent that it interferes with a person's daily life and activities. Some people with dementia experience alterations in sensory perception (such as hallucinations); some cannot control their emotions and their personalities may change.

Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage when the person will be completely dependent on others for basic activities of living.

NIH National Institute on Aging (NIA) July 2021 www.nia.gov/health/what-is-dementia



**Dementia is an umbrella term.
It is a syndrome or group of
related symptoms associated with
a decline of brain functioning.**

ALZHEIMER'S DISEASE

This is the most common cause of dementia, affecting around 6 in every 10 people with dementia in the UK.

Involves a build up of protein which forms tangles in the brain. Tangles impair the function of brain cells and can cause the cells to die

Alzheimer's disease is a brain disorder which slowly destroys memory and thinking skills affecting the ability to carry out tasks.

VASCULAR DEMENTIA

Around 17% of people diagnosed with dementia will have vascular dementia.

Caused by conditions which reduce blood flow to the brain such as stroke and narrowing of the arteries. Leads to damage and death of brain cells.

Vascular dementia causes problems with reasoning, planning, judgement and memory.

MIXED DEMENTIA

At least 1 in 10 people with dementia is diagnosed as having more than one type.

Alzheimer's disease and vascular dementia is the most common type. Other combinations are possible such as Alzheimer's disease and Lewy Body dementia.

DEMENTIA WITH LEWY BODIES (DLB)

For every 100 people with dementia, 10-15 will have DLB.

Caused by abnormal deposits of protein called 'Lewy Bodies', which damage nerve cells, affecting the way our brain cells communicate.

DLB causes impairment of thinking, memory and body movement.

FRONTOTEMPORAL DEMENTIA

Frontotemporal dementia is thought to account for less than 1 in 20 of all dementia cases.

Abnormal amounts of certain proteins accumulate inside neurons in the frontal and temporal lobes of the brain. It tends to start at a younger age with most cases being diagnosed in people aged 45-65.

Causes problems with behaviour and language.

OTHER TYPES OF DEMENTIA INCLUDE:

Parkinson's disease, Huntingdon's disease, Normal pressure hydrocephalus, Progressive supranuclear palsy, HIV associated neurocognitive disorder, Creutzfeldt-Jakob disease, Corticobasal syndrome, Posterior Cortical Atrophy, Wernicke- Korsakoff syndrome, Chronic traumatic encephalopathy, Picks disease



Demographics and Dementia



944,000

people are estimated to be living with dementia in UK (2023)

52%

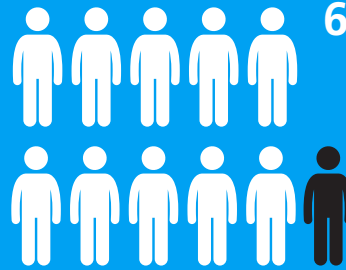
of the UK public (34.5 million people) know someone who has been diagnosed with a form of dementia (2019)



By 2050, this figure is predicted to rise to **1.6 million** (2023)



1 in 11 people over **65 years** have dementia in UK (2023)



Data from Alzheimer's Research UK Dementia Statistics Hub www.dementiastatistics.org

In Gloucestershire there are currently:

5909

people over the age of 65 years with a dementia diagnosis



157

people under the age of 65 years with a dementia diagnosis



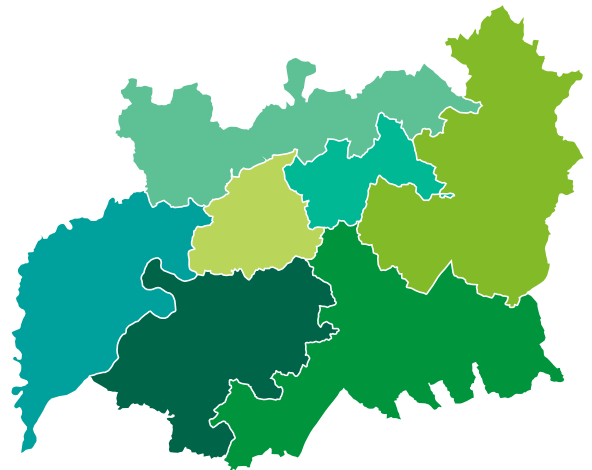
6066

people with a dementia diagnosis



9559

An estimated 9559 people living with dementia



Data from our local Dementia Dashboard up to end of March 2023 – from the NHS England National Publication.

In March 2023 there were 157 people under the age of 65 years in Gloucestershire who are living with a young onset dementia diagnosis. Dementia UK/Young Onset Dementia Network estimates people whose symptoms develop under 65 years of age accounts for 7.5% of the total population of people living with dementia.

This equates to approximately 559 people in the County.

Our current dementia diagnosis rate for those over 65 years is 63.2% with the NHSE ambition being 66.7%. All areas saw a drop in diagnosis rate due to changes in provision during the Covid 19 pandemic. A formal diagnosis is critical as it enables care needs to be assessed and appropriate treatment to be delivered.

Population projections estimate that:

By 2025

- there will be 155,800 people over 65 years living in the County, rising to 173,300 by 2030; that is 21.79% of the local total population in 2025 and 25.33% in 2030
- 11,249 people will be living with dementia rising to 12,929 people by 2030
- the number of those over 65 years providing unpaid care for partners, family members or friends will be 22,239, rising to 24,964 by 2030
- 10,266 men and 22,000 women over the age of 75 will be living alone

Projecting Older People Population Information (POPPI), Oxford Brookes University, Institute of Public Care (IPC)

Data as at 2020

There is, therefore, a compelling need to comprehensively plan ahead to ensure we maximise opportunities for prevention.

Dementia and Health Inequalities

We know that people from certain groups experience poorer health outcomes than others across our diverse population. This is true of dementia. Understanding health inequalities and the populations more likely to be adversely affected is key in reducing the risks for all. One Gloucestershire must use this knowledge to target resources, support, and information specifically for these identified 'at risk' groups.

- **Gender** – 62% of those with dementia in the UK are women, which is likely to be linked to life expectancy. Dementia in those under 65 years, however, affects more men than women
- **Ethnicity** – the 2021 Census showed there was growing diversity in the UK both in ethnicity and in white non-UK born residents. People from black and minority ethnic backgrounds are known to be more likely to develop dementia and develop it at a younger age than the white British population overall. People from black and ethnic minority backgrounds tend to access dementia services much later, when they are in crisis, or no longer able to cope alone.
- **Disabilities and pre-existing conditions** – the risk of developing dementia is around 4-5 times greater for people with a learning disability and onset of dementia is typically at a younger age.
- **Socio-economic risks** – dementia is linked to factors such as health behaviours (smoking, physical inactivity, alcohol use and diet), and psychosocial aspects (isolation, depression, low self-esteem, lack of social support and networks). There are also wider determinants of health including income and employment, education, debt and environmental considerations such as housing and air quality which can also increase the risk.

- **Sexual Identity** – LGBTQIA+ individuals with dementia may experience different challenges and concerns compared to the general population. This could be due to a range of factors including historical prejudice, discrimination and a lack of culturally sensitive care. Social isolation can be linked to dementia, LGBTQIA+ people are more likely to live alone than their heterosexual peers, therefore, may be at a higher risk of developing dementia, further research in this area is needed.
- **Age** – whilst advancing age increases the risk of developing dementia, in Gloucestershire there are currently 157 people diagnosed with young onset dementia. Younger people with dementia have unique challenges which may include employment, livelihood and supporting dependants. Diagnosis for this group may take significantly longer, their symptoms may be attributed to other conditions such as depression, menopause, or anxiety. Younger people experiencing memory problems may also be reluctant to engage with memory or dementia services due to their association with older age.

The Strategy aims to deliver an effective framework for meeting the needs of these different groups.



National Policy Context

National Policy influencing this Strategy includes:

The Care Act 2014, The Challenge on Dementia 2020 (published 2015), The National Institute for Health and Care Excellence (NICE) Guidance NG16 (2015), The Dementia Care Pathway (2017), NICE Guideline NG97 Dementia: assessment, management and support for people living with dementia and their carers (2018), Universal Personalised Care (2019), The NHS Long Term Plan (2019), NICE Dementia Quality Standard QS184 (2019), The Framework for Enhanced Health in Care Homes (V2.0) (2020), The Health and Care Act (2022), Deprivation of Liberty Safeguards (DoLS) – due to be replaced by Liberty Protection Safeguards (LPS). Supporting People Living with Dementia: Evidence and Research (2023). NHSE Proactive Care Framework (due for publication 2023)

Our Guiding Principles - The Dementia Statements

The following statements were developed by people affected by dementia. These rights are enshrined in The Equality Act, Mental Capacity Act, Health and Care legislation, International Human Rights Law, and underpin the development of our Strategy:

“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.”

“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.”

“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.”

“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.”

“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.”



The Gloucestershire Approach to Dementia

Gloucestershire has a tradition of developing collaborative local responses to national strategies including the Prime Minister’s Challenge on Dementia 2020 and more recently the Healthy Ageing theme of the NHS Long Term Plan.

The One Gloucestershire Dementia Strategy objectives have been developed using the NHS England Well Pathway for Dementia from the PM’s Challenge as a framework (see Appendix I) in conjunction with the Gloucestershire Dementia Experts by Lived Experience Group (now known as Your Voice Matters Group).



Preventing Well: the risk of people developing dementia is minimised

Diagnosing Well: timely accurate diagnosis, care plan and review within the first year

Supporting Well: access to safe high-quality care for people affected by dementia

Living Well: people living with dementia can live normally in safe and accepting community

Dying Well: people living with dementia die with dignity in the place of their choosing

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>“I was given information about reducing my personal risk of getting dementia”</p>	<p>“I was diagnosed in a timely way” “I am able to make decisions and know what to do to help myself and who else can help”</p>	<p>“I am treated with dignity & respect” “I get treatment and support which are best for my dementia and my life”</p>	<p>“I know that those around me and looking after me are supported” “I feel included as part of society”</p>	<p>“I am confident my end of life wishes will be respected” “I can expect a good death”</p>

As One Gloucestershire continues to develop its vision for the County, the Dementia Strategy will align with and support local and national policy and the following documents:

- Gloucestershire Health & Wellbeing Strategy – Fit for the Future
- Interim Integrated Care Strategy (2022)
- One Gloucestershire’s response to Health and Care Act 2022
- One Gloucestershire 5 Year Strategy/Forward Plan
- Gloucestershire Market Sustainability Plan

One Gloucestershire's:

- All age Palliative and End of Life Care Strategy
- Housing with Care Strategy
- Frailty Strategy
- Integrated Care Strategy
- Research Strategy (currently under development)

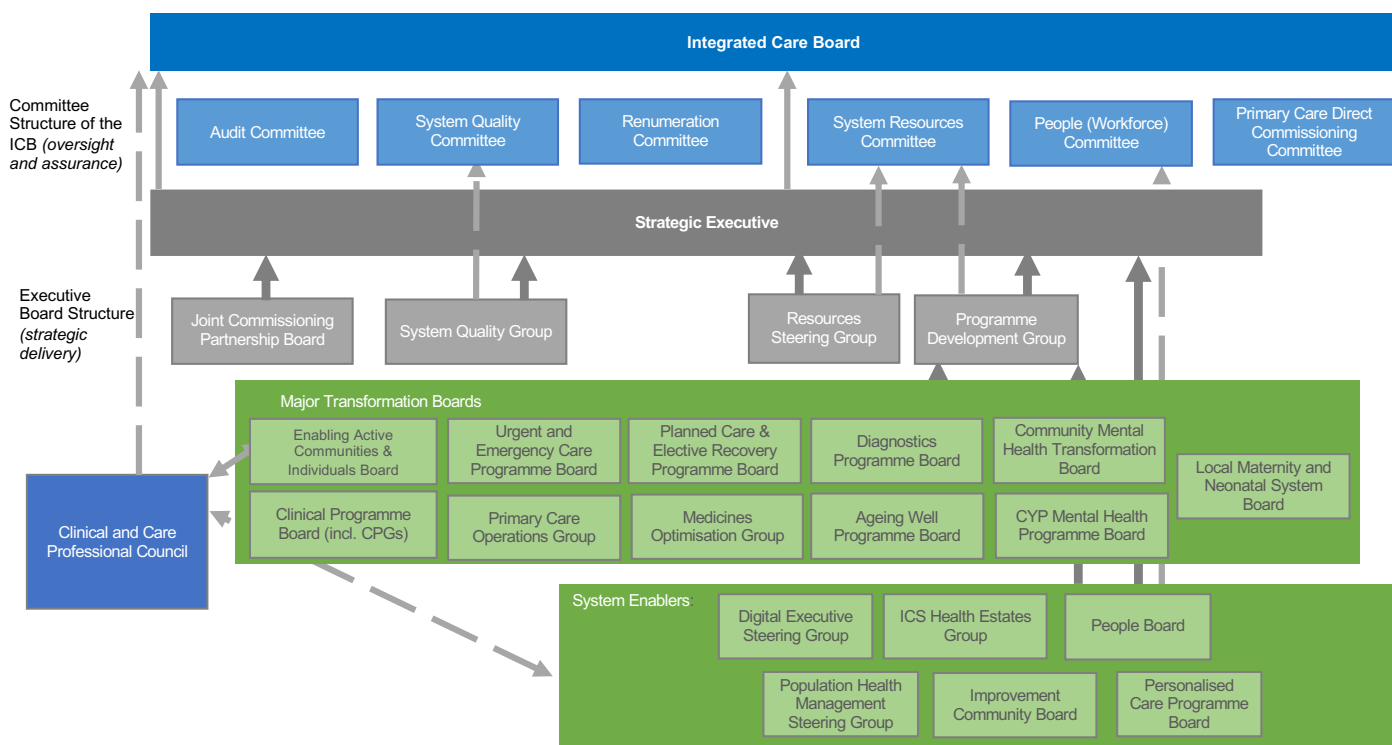
The Strategy aligns to the following One Gloucestershire programmes of work:

- Ageing Well Programme
- Clinical Programme Groups (Frailty and Dementia, Palliative and End of Life Care, Learning Disability and Autism)
- Adult Social Care – Fit for the Future Transformation Programme
- Enabling Active Communities and Individuals Partnership
- Personalised Care Programme “all it took was to ask what matters to me”



Oversight of the One Gloucestershire Dementia Strategy (governance)

NHS Gloucestershire Integrated Care Board – Transformation Programme Structure



Developing the One Gloucestershire Dementia Strategic Plan

We have engaged with our system partners across the Integrated Care Partnership, people living with dementia, their carers and members of the public.

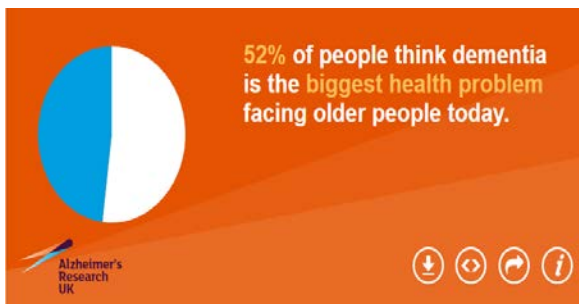
A comprehensive Dementia Needs Assessment was completed, mapped to the Dementia Well Framework and highlighted our draft priorities for the revised Strategy.

A series of workshops with participants from health, social care, public health, community and VCSE (voluntary, community and social enterprise) organisations focused on the current strengths in our system, identified gaps in provision and developed priorities.

These were reviewed by the “Your Voice Matters Group” comprised of people with lived experience of dementia. A public dementia survey was opened between April and June of 2022, designed to raise awareness, and ran alongside Dementia Action Week activities. The Strategy outline was presented to the Gloucestershire Collaborative Partnership Board in February 2023. Alongside this, a service mapping exercise has been carried out, which is helping to identify countywide and locality specific services for those affected by dementia.

The Strategic Plan: Preventing Well

Preventing Well: to raise awareness of the opportunities to reduce the risk and recognise the early signs and symptoms of dementia.



“I was given information about reducing my personal risk of developing dementia”

NHSE Dementia Pathway

The aim is to reduce the number of people who develop dementia and to reduce the impact of dementia through early identification and development of proactive care plans and interventions.

There is currently no cure for dementia, and increasingly it is described as a

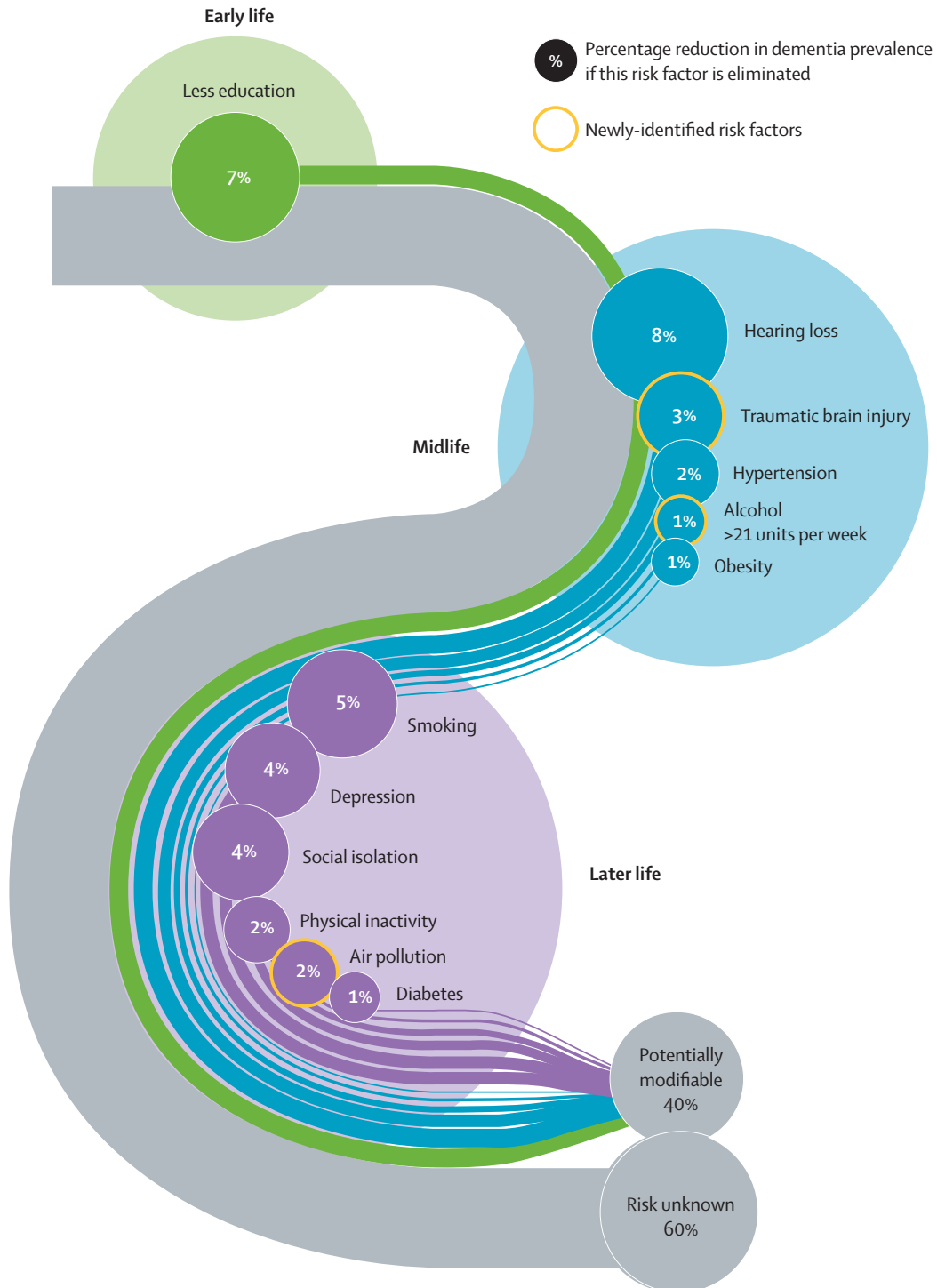
neurodegenerative disease to better reflect the life-limiting and diverse nature of the condition beyond memory loss. Dementia is reported to be, alongside cancer, one of the most feared diseases. Dementia is progressive so it is important to obtain a diagnosis and understand the support and treatments that are available to stabilise or improve symptoms that can affect day to day life. It is important to understand that it is possible for people to live as well as they can with dementia, and this starts with a timely diagnosis.

Whilst some factors for developing dementia cannot be changed, addressing those that can be through a healthy lifestyle creates potential to reduce the prevalence of dementia by up to a third. Improving social and emotional wellbeing can improve resilience for those living with dementia and frailty.

In 2017 The Lancet Commission listed poor education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes and low social contact as modifiable factors for dementia. Excessive alcohol consumption, traumatic brain injury and air pollution were added to the list of 12 in 2020 and are thought to account for 40% of dementia globally.

Risk factors for dementia

An update to the *Lancet* Commission on Dementia prevention, intervention, and care presents a life-course model showing that 12 potentially modifiable risk factors account for around 40% of worldwide dementias



Lancet Commission 2017

Additional factors known to affect modifiable risk include cardiovascular conditions such as having high cholesterol, as well as poor sleep, poor diet, and not keeping mentally active.

**Dementia isn't
an inevitable
part of ageing**

Mr P

Mr P is 53 years old and was invited into his GP Surgery for a Health Check. He was found to be overweight and has been regularly drinking around 27 units of alcohol a week.

Mr P had his cholesterol tested which was elevated and his blood pressure was taken which was found to be high. He reported that he smoked around 5 cigarettes per day. Mr P was also found to have pre-diabetes – where blood sugars are raised but not yet in the range for diabetes.

Mr P agreed to an assessment to determine his risk of cardiovascular disease. The results strongly indicated that he was at risk of a heart attack or stroke within the next 10 years. This also puts Mr P at risk of developing dementia. Since finding out this information, he has been working with the multi-disciplinary team at his GP practice to make some changes including reducing his weight, increasing his exercise, giving up smoking and reducing his alcohol intake.

Mr P was shocked to learn that he could be at risk of developing dementia in addition to heart problems and is now making good progress on his health goals.

Our aims include:

- Promoting health and wellbeing throughout the life course
- Raising awareness of modifiable risk factors
- Promoting uptake of NHS Health Checks including targeting those from diverse backgrounds and linking the conversation about dementia during these health checks
- Using national and regional campaigns to raise risk awareness across all age groups including children and young people
- Delivering public awareness sessions including risk reduction, signs and symptoms, how to access support and connecting with services
- Proactive targeted promotion of activities across the groups which may be disadvantaged

The Strategic Plan: Diagnosing Well

Diagnosing Well: to promote a partnership approach to timely diagnosis of dementia

“I am able to make decisions and know what to do to help myself and who else can help”

NHSE Dementia Well Pathway

“I was diagnosed in a timely way”

NHSE Dementia Well Pathway

Diagnosing Well means identifying those who have dementia during the early stages of the condition. This will ensure they and their supporters – family, friends and carers - receive timely access to high quality post-diagnostic support including access to a Dementia Advisor. This service provides information, advice, signposting to other services including emotional and spiritual support, help with navigating the health and care system and planning for the future.

NHS England’s ambition is for two thirds of the over 65’s population that are estimated to have dementia to have a diagnosis.

The challenge to achieving timely diagnosis lies in part with stereotypes, myths and misconceptions that are still held about dementia including: ‘memory loss always means dementia’, ‘only older people develop dementia’, ‘dementia is a normal part of ageing’. Many people have a fear of being diagnosed and it can cause difficult emotions – such as the thought of being unable to enjoy some of the things you used to, having

to give up driving, fear of losing your partner or friends. There is also a lack of awareness of the support that is available for those living with dementia to enable hope and opportunity to participate in things that are meaningful and enjoyable.



1. Identifying & treating causes for reversible cognitive impairment

There are certain conditions that can lead to a reversible dementia such as those caused by hypothyroidism, Vitamin B12 or Vitamin B6 deficiency. There are also other temporary states such as a delirium that can produce dementia-like symptoms. Depression can also cause symptoms similar to dementia

2. Accessing Health and Care Services

Diagnosing a person living with dementia will support better continuity of care. It promotes shared-decision-making as other services, including acute and community hospitals, will be aware that the person is living with dementia. They will be better informed to respond in an appropriate and personalised way

3. Interventions and treatment options

Prompt diagnosis enables clear and planned consideration of possible psychological, behavioural and drug interventions that may be available for the person. This can be an enormous support to family and carers as well as the person themselves. It may also open the door to dementia research projects. Taking part in research ensures that the research process is relevant and shaped by the needs of those living with dementia. Research allows development of new treatments and potential cures and helps us improve the care of people with dementia

4. Support for carers

A diagnosis of dementia will lead to referrals for a range of support services for the person with dementia and the family member or friend who may become the primary carer (supporter) for them. A prompt diagnosis will ensure that a carer has relevant information and emotional support at the earliest opportunity. They can be added to the GP practice carer register, make choices and access support in a planned way before a potential crisis occurs. A carer should be seen as a partner in providing care for the person living with dementia

5. Support groups, therapies and wellbeing

There is a wide range of support options which can be accessed by the person living with dementia both with and without their carer. Most options are therapeutic and promote cognitive stimulation and wellbeing. It is generally easier for the person living with dementia to access networks and groups at earlier stages in the disease which then becomes the norm for them as the disease progresses. It is also an opportunity for those living with dementia and their supporters to make new friends and try new things

6. Being informed will lead to better planning

People can start planning ahead of time and fully involve the person living with dementia in the planning process including lifestyle changes to reduce risk factors. All close family members can be included in the planning to help create the best possible support system including respite and other care options moving forward

7. Financial benefits

The person living with dementia and their carer may be eligible to apply for a number of different benefits including carer's allowance. Some people with dementia are eligible for a discount on their council tax bill which can also apply to the carer, as well as potentially being eligible for a Blue Badge for accessible parking spaces

8. The home environment

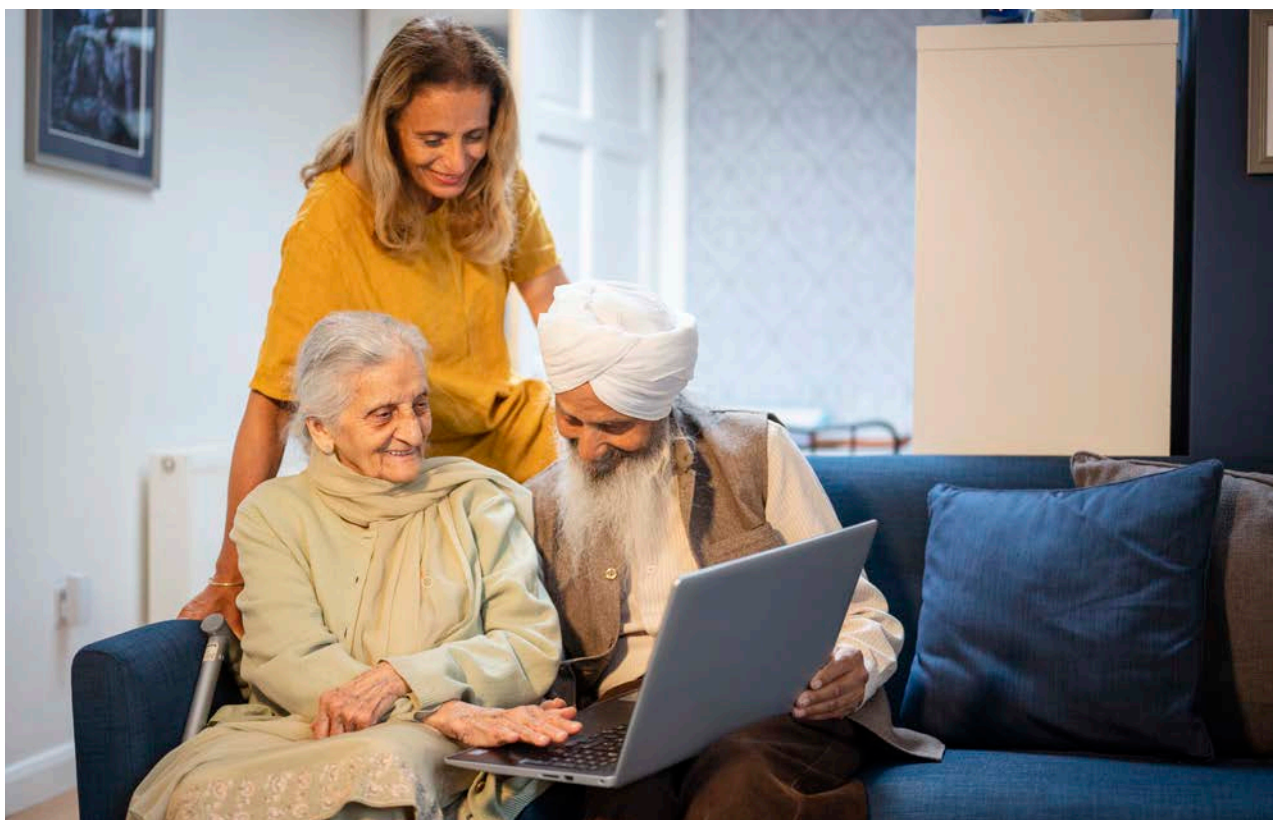
A person with dementia may need assistance in day to day activities as the disease progresses. It may be necessary to make modifications to the home or install assistive technology such as sensors and memory aids to support orientation, mobility and safety. A timely diagnosis should enable early consideration of such support

9. Advance care planning and ReSPECT

Advance care planning (ACP) means people thinking about, discussing and recording their wishes and decisions for their future care. It is about planning for a time in the future when they may not be able to make these decisions themselves. If adequate ACP is not completed, the family or carer may have to make decisions on their behalf, but with the person's best interests in mind. It can be difficult to involve the person with dementia and ensure their autonomy at a later stage, hence the importance of the opportunity to be involved positively at an earlier stage. Some of the decisions are about treatment options, wellbeing support and their living situation. The ReSPECT process refers to personalised recommendations for a person's clinical care and treatment in a future medical emergency.

10. Wills, Advance Decisions and Lasting Power of Attorney

If the person diagnosed with dementia has not yet written a will, he or she can decide to take that step when they have capacity to make such a decision. They may also choose whom to formally assign Lasting Power of Attorney for both property and financial issues and health and welfare



It is estimated that there are approximately **9,500** people living with dementia in Gloucestershire but only around **6,100** have received a diagnosis.....

Mrs D

Mrs D is 78 and had noticed over the last year that her memory wasn't as good as it had been – especially her short-term memory. She felt she wasn't able to remember things that happened very recently but could remember things that happened years ago very clearly.

Her husband had noted some loss in her day-to-day functioning, such as, forgetting where things were in the kitchen and becoming withdrawn at times. Mrs D and her husband contacted the GP with their concerns and a subsequent referral was made to the memory assessment team. She was assessed and received a diagnosis of dementia.

Mrs D was started on medication and referred to appropriate support services. Mr and Mrs D felt that the timely diagnosis allowed them to start making plans and decisions for the future which they feel will benefit them both.

Our aims include:

- Recovering the Dementia Diagnosis Rate (DDR) to pre-pandemic levels and meet the NHS National target for diagnosis (66.7%)
- Reducing waiting times for the Memory Assessment Service to pre-pandemic levels
- Supporting and promoting the co-diagnosis model where people with non-complex symptoms receive assessment closer to home by GP's and staff already involved in their care
- Offering support to those waiting for diagnosis
- Increasing awareness of the signs and symptoms of Young Onset Dementia (YOD, people under the age of 65)
- Improving the diagnosis rate of those living in care homes
- Raising awareness of the importance of an early diagnosis with our black and minority ethnic groups

The Strategic Plan: Supporting Well

Supporting Well: to ensure consistent information on dementia, support and services is accessible to all of Gloucestershire's diverse communities.

"I am treated with dignity and respect"

NHSE Dementia Well Pathway

"I get treatment and support which are best for my dementia and my life"

NHSE Dementia Well Pathway

Supporting Well ensures people living with dementia are enabled to live as well as they possibly can. The person living with dementia and their supporter need to be put at the centre of care; they should know how to access information and the services that they need throughout their dementia journey so that physical, emotional, spiritual, social and psychological needs can be met in a timely and co-ordinated way. It means that individuals will get the right care, at the right time, in the right place according to need, preferably as close to home as possible.

Care should be co-ordinated with teams sharing information appropriately including preferences and choices known as personalised care and support planning. Support after diagnosis needs to be tailored to the individual, should encompass their supporters, and be adaptable as needs change.

Those living with dementia are more vulnerable than the general population with over 90% having one or more other health conditions. Giving staff and carers support and knowledge will improve early recognition of deterioration and help minimise the risk of crisis and hospital admission.

Our well-established One Gloucestershire Dementia Training and Education Programme is widely available to people working in health, social care and third sector

organisations which includes domiciliary and residential and nursing care provision as well as housing and supported living. Families and supporters of people with dementia are also able to access this training and education. The programme provides a range of courses and information resources to improve, knowledge, skills and understanding to better support people living with dementia.

A key priority for Gloucestershire Hospitals NHS Foundation Trust is to provide the workforce with the right skills and expertise to support people living with dementia in receipt of their care. The Trust's eLearning for staff includes Dementia Awareness sessions with appropriate cross referencing to training in delirium and conflict resolution. Delirium is known to have a detrimental impact on those with dementia and the Trust continues to develop clinical tools and approaches to improve the recognition and response to delirium.

This work is further supported by the Trust's Admiral Nurse who works directly with people with the most complex care needs and provides advice and guidance to clinicians. Admiral Nurses are specialist dementia nurses supported and developed by Dementia UK. The Admiral Nurse also supports the individual's family/carer and works collaboratively with community teams such as Dementia Advisors and Community Dementia Practitioners.

Mr S

Mr S is 66, living with Alzheimer's disease in supported housing. He had memory issues and was not engaging with services. He was at risk of self-neglect and losing his tenancy.

He was assessed by the multidisciplinary health and social care team. His family were invited to assist with a comprehensive assessment of his needs including emotional support and practical support with mobility and finances. Further specialist referrals were made. Mr S is a skilled and articulate communicator. He was found to have significant cognitive impairment which had previously been overlooked. He was assessed as lacking capacity due to the level of his cognitive impairment.

It was discovered that Mr S, had a deep love of drama and he was supported to attend a local drama group. In his best interests, he was provided with a full package of care following specialist mental capacity assessments and his housing tenancy has been maintained.

Our aims include:

- Identifying carers early and signposting to support; recognising individual need including details of appropriate carer's wellbeing payments
- Providing information tailored to the person's needs which is communicated to people living with dementia and those that support them in a person-centred and timely way
- Ensuring people living with dementia and their supporters are kept informed of what support is available across Gloucestershire
- Developing the 'Frailty & Dementia Toolkit' for health and social care practitioners to provide best practice advice and consistency of approach for those delivering care and support
- Delivering a high quality accessible personalised Dementia Advisor service that works across Gloucestershire's communities
- Further developing our Dementia Training and Education Programme ensuring it is promoted widely to increase its reach
- Increasing the number of people living with dementia that receive personalised and proactive reviews and ensuring the opportunity for care plan review at every stage of the pathway
- Working with our partners to improve the use of the Gloucestershire 5 step approach in order to prevent or reduce symptoms of distressed behaviour
- Reducing unnecessary medication prescribing including antipsychotic medication
- Increasing the number of people living with dementia with Advance Care Plans in place, including "What Matters to Me" and ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) plans to support future care needs
- Ensuring that people affected by dementia are encouraged to register with Join Dementia Research, giving people the opportunity to make a real difference to the future of dementia care, diagnosis and treatment
- Supporting carers to better understand the disease as experienced by the person living with dementia, enabling them to identify triggers which may lead to increased needs.

The Strategic Plan: Living Well

Living Well: To support the growth of dementia inclusive communities-across Gloucestershire.

“I know that those around me and looking after me are supported”

NHSE Dementia Well Pathway

“I feel included as part of society”

NHSE Dementia Well Pathway

Living Well means having the opportunity to stay socially active and connected to the community, keeping healthy and well, being able to engage in meaningful activity and for supporters to receive the help they need to continue in their valuable caring role.

One of the concerns of people affected by dementia is the stigma that may be associated with it. People report being misunderstood because of the myths and misconceptions others have about the disease. By raising awareness, myth busting, education and interaction and becoming more dementia inclusive in our communities we can ensure that stigma is reduced.

A key aspect of quality care in dementia is recognising the contributions of the person living with dementia and the value they bring

to their community.

There are a range of opportunities to participate and enjoy music, art, literature, and sensory experiences for people living with dementia. These dementia inclusive activities enable individuals and their supporters to participate together and engage with local groups.

Improving physical and mental wellbeing is invaluable and individuals living with dementia often say that they may have forgotten who they were with, and where the activity was, but they retain and remember the feeling of being uplifted. Spirituality is an important aspect in dementia care which can improve meaning and quality of life



Mr L

Mr L is in his 90's with a number of health issues including dementia. He is a retired businessman with interests in politics and gardening. He was referred for comprehensive assessment of his needs and input was received from the multi-disciplinary team. During assessment, he was found to be experiencing depression and hearing impairment.

After starting medication for his low mood and getting hearing aids, he began to interact more with his surroundings and, with support from the therapists his mobility and confidence improved around his home environment.

A plan was discussed with Mr L and his family to arrange for him to visit the Vale Hospital garden. Despite what was felt to be an ambitious goal, Mr L visited Anne's Garden and was able to touch and smell the various flowers and share advice on planting and growing vegetables. Photographs were taken and shared with the family. On his return, Mr L's family were overwhelmed with his achievements – commenting "he is back".

Our aims include:

- Promoting partnerships and co-ordination at a local and neighbourhood level (for example, Gloucestershire Dementia Action Alliance and Dementia Friends Programmes and with social prescribers) to support people to live well with dementia in their communities. Helping people stay connected, active and as independent as possible
- Linking with local employers to raise awareness of dementia in relation to their staff including those who may develop dementia and those who have caring responsibilities for someone living with dementia
- Supporting non-medical interventions such as music therapy and psychological support
- Working with our partners across health, social care and the third sector to explore and enable the use of technological solutions which are helpful for people
- Enabling access to a range of affordable, flexible activities that reflect a person's interests and needs that are appropriate to their age, culture and stage of dementia
- Working with our independent care sector to support high quality holistic care for people in receipt of domiciliary care services, those living in care homes and supported living and high-quality respite options for carers
- Working with our housing partners to ensure they take account of the needs of people affected by dementia in their planning and provision

The Strategic Plan: Dying Well

Dying Well: to engage early in difficult conversations with those living with dementia to begin planning end of life care based on an individual's wishes and preferences

"I am confident my end of life wishes will be respected"

NHSE Dementia Well Pathway



The aim is for palliative and end of life needs to be identified as soon as possible due to the progressive nature of dementia. People diagnosed with dementia should be given the opportunity to plan for their care in advance. If this takes place early in the course of the condition, it means that the person living with dementia and their supporters are fully involved in decisions on care at end of life. Having a personalised care and support plan in place can reduce the likelihood of making difficult and emotional decisions, in respect of the persons care in a crisis, which may not reflect the person's wishes.

There are key issues that dementia presents at end of life. Those with advanced dementia

may have complex needs and frequent hospital admissions. This has both human and economic costs. Inability to communicate needs and wishes can affect the care that a person living with dementia receives and it is crucial that the needs of the supporters are considered to potentially facilitate dying at home for example. Having those conversations early can mean a better experience at the end of life. By knowing the person's values, wishes and beliefs it can help when decisions need to be made on their behalf. People are more likely to die in the place of their choice if their wishes are known and documented in advance.

Mrs E

Mrs E was 90 years old, living at home with her family. She had recently been supported by the Complex Care at Home team and had previously been diagnosed with frailty and dementia. Deteriorating physical health issues resulted in Mrs E being admitted to the local acute hospital for treatment where it was found that she was approaching the end of her life.

The team had started conversations with Mrs E and her family with regard to Advance Care Planning and it was established that what she wanted most was to die peacefully at home.

As Mrs E's wish was known, the hospital and community teams were able to get Mrs E home with full support including changes to her home environment to allow her to have a hospital bed overlooking her much-loved garden. Her end of life plan reflected her wishes which gave much comfort to her and her family.

Our aims include:

- Understanding the end of life needs of all those living with dementia, specifically from diverse communities, and those who may be at greater risk of discrimination and disadvantage, by engagement with the public, stakeholders and service providers
- Reviewing and improving the end of life dementia information, guidance and literature currently available to the public to ensure it is accessible and available to all
- Increasing the number of people living with dementia who have Advance Care Plans and have completed Recommended Summary Plan for Emergency Care and Treatment Forms (ReSPECT).
- Increasing the number of people living with dementia who are identified as nearing the end of life to enable the individual and those providing care to them to be made aware and prepared
- Increasing the knowledge and skills of the workforce across the Gloucestershire in supporting people living with dementia at end of life and aligning with the frailty and end of life education frameworks
- Increasing the number of people who die in the place of their choice
- Ensuring that supporters of people living with dementia are provided with timely, co-ordinated support before and after death and bereavement

Implementing the strategy and measuring success

The strategy will be delivered via an outcome based annual Dementia Delivery Plan which will be overseen by the Dementia Steering Group and Frailty & Dementia Clinical Programme Group. Collaboration with stakeholders including health and social care providers, service users, voluntary, independent and community service sectors, national and local policy will ensure that the implementation plan remains on target. Adherence to national and local policy will ensure the Strategy remains relevant and responsive to need and demand.

Progress against objectives to deliver the plan will be assessed on a quarterly basis by the Dementia Steering Group and the delivery plan will be evaluated at year end with priority actions agreed for the subsequent year. A further commitment to review progress annually will include a public survey as one of the actions for Dementia Action Week.






Many thanks to everyone who has contributed to the development of this Strategy, either through the provision of data, insight, views or experience. The Strategy seeks to capture this knowledge and develop it into a shared vision, with priorities, aims and outcomes that ultimately improve the lives of those affected by dementia in Gloucestershire.

For more information on the Dementia Strategy for Gloucestershire please contact; glicb.ageingwell@nhs.net

APPENDIX I

The Well Pathway for Dementia

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	"I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	"I know that those around me and looking after me are supported" "I feel included as part of society"	"I am confident my end of life wishes will be respected" "I can expect a good death"
STANDARDS: Prevention ⁽¹⁾ Risk Reduction ⁽⁵⁾ Health Information ⁽⁴⁾ Supporting research ⁽⁵⁾	STANDARDS: Diagnosis ⁽¹⁾⁽⁵⁾ Memory Assessment ⁽¹⁾⁽²⁾ Concerns Discussed ⁽³⁾ Investigation ⁽⁴⁾ Provide Information ⁽⁴⁾ Integrated & Advanced Care Planning ⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾	STANDARDS: Choice ⁽²⁾⁽³⁾⁽⁴⁾ , BPSD ⁽⁶⁾⁽²⁾ Liaison ⁽²⁾ , Advocates ⁽³⁾ Housing ⁽³⁾ Hospital Treatments ⁽⁴⁾ Technology ⁽⁵⁾ Health & Social Services ⁽⁵⁾ Hard to Reach Groups ⁽³⁾⁽⁵⁾	STANDARDS: Integrated Services ⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers ⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite ⁽²⁾ Co-ordinated Care ⁽¹⁾⁽⁵⁾ Promote independence ⁽¹⁾⁽⁴⁾ Relationships ⁽³⁾ , Leisure ⁽³⁾ Safe Communities ⁽³⁾⁽⁵⁾	STANDARDS: Palliative care and pain ⁽¹⁾⁽²⁾ End of Life ⁽⁴⁾ Preferred Place of Death ⁽⁵⁾
References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.				
RESEARCHING WELL				
<ul style="list-style-type: none"> Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change. Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries. 				
INTEGRATING WELL				
<ul style="list-style-type: none"> Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care. 				
COMMISSIONING WELL				
<ul style="list-style-type: none"> Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice. Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources. 				
TRAINING WELL				
<ul style="list-style-type: none"> Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community. Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes. 				
MONITORING WELL				
<ul style="list-style-type: none"> Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each. Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation. 				

For more information on the Dementia Strategy for Gloucestershire
please contact: [**glicb.ageingwell@nhs.net**](mailto:glicb.ageingwell@nhs.net)