One Devon

Devon Dementia Strategy

April 2025-March 2028

Acknowledgements

This document has been co-produced by a number of organisations including those listed below and most importantly, people with lived experience of dementia including unpaid carers.

More than 100 people have contributed to it's creation.

Contents

Foreword

Why Devon needs a dementia strategy

As a carer/journey partner for family members with dementia, and as an ambassador's voice for those with dementia and their journey partners, I welcome the Devon Dementia Strategy.

Clearly, this much-needed strategy is the result of a great deal of hard work and input from many stakeholders, and is the foundation for the future of dementia care in Devon. It has recognised the difficulties and the needs of those on the dementia journey, and their families, and its goals are to ensure meaningful support at every stage throughout that journey.

Having witnessed the passion and compassion shown in the production of the Strategy, it is my sincere belief that the dementia pathway in Devon will be smoother and easier to navigate than previously, and that those treading the path will find the support, compassion and hope that is so desperately needed.

Fiona Bladon
Volunteer and Trustee with responsibility for peer support groups for unpaid carers, Unite Carers in Mid-Devon

The number of people living with dementia in Devon is projected to grow by 54% between 2024 and 2040. While these conditions still evoke fear and stigma, many of the associated challenges can be effectively managed allowing people with a diagnosis to live more positive lives.

Devon needs a Dementia Strategy to bring together organisations across all sectors to work more cohesively to enhance the support available to people and to develop a care approach that is sensitive to the diverse communities across the county.

By doing so, we can create significant benefits for those living with dementia, their families, and the wider community. This is an initial three year strategy aimed at laying the foundations for ongoing growth and excellence with dementia care in Devon.

I am delighted that Devon now has a county-wide strategy which I hope will enact real and meaningful change for those living with dementia and their loved ones.

This strategy is not just a framework, it is a promise to empower, support and improve outcomes for individuals affected by dementia. I look forward to the journey ahead and the positive impact we will achieve together.

Dr Colm Owens
Medical Director for Devon
Mental Health, Learning Disability
and Neurodiversity Provider Collaborative

To be added - Fiona’s video

Executive summary

This Strategy aims to improve the quality of life for those affected by dementia in Devon. It is a call to action for health and social care professionals, community leaders, organisations, and all Devon residents to come together to make a meaningful impact in the lives of those facing the challenges of dementia.

This Strategy builds on the existing foundations that support people with dementia and unpaid carers* across Devon. It also outlines a proactive plan to:

- **Raise awareness** of dementia so people are educated and informed, reducing stigma
- **Ensure timely diagnosis** and access to appropriate support services
- **Enhance the quality of care** provided to those living with dementia
- **Provide robust support** for families and caregivers
- **Work towards dementia-inclusive communities** across Devon
- **Provide personalised end of life care** that reflects the wishes of the individual

"This strategy takes a positive approach towards creating a dementia-friendly communities across Devon. It encompasses increasing awareness, timely identification, ongoing care and support for those living with dementia. It is an exemplar of co-designing a much needed and constructive strategy for those living with the condition, alongside their carers and voluntary and statutory partners."

Dr Kevin Dixon Healthwatch Devon Plymouth Torbay

Purpose

Who is this strategy for?

"As society continues to age, there is an important challenge to improve both the quality and quantity of care for people with dementia."

Lord Darzi, 2024, Independent Investigation of the National Health Service in England.[1]

This Strategy is designed for anyone experiencing difficulties with their memory, or other symptoms of dementia and those that support them.

This includes, but is not limited to:

- Anyone with a type of dementia including rare dementias
- People who are concerned about their memory
- Those with mild cognitive impairment (MCI)
- People with Young onset dementia (under 65)
- And people who are at risk of dementia that have an existing learning disability.

This Strategy aims to establish a comprehensive framework that supports all stages of the dementia journey.

Vision

Devon will be a leading dementia-inclusive county

Our vision

People with dementia in Devon:

- **Will live fulfilling lives with dignity and respect**
- **Will be supported by integrated care and communities**
- **Families and unpaid carers will have access to the resources, guidance and support they need**

Values and Principles

This Strategy is grounded in understanding, compassion and proactive engagement. It has been co-designed with people living with dementia in Devon, their unpaid carers and key stakeholders across health, social care and the voluntary, community and social enterprise (VCSE) sector.

Core values:

Inclusion

- **Empowering** people to take control of their care
- Ensuring care is **meaningful** and personalised
- **Engaging** effectively with the community and those living with dementia
- Ensuring access to diagnosis and support is **equitable**

Innovation

- Fostering **creative thinking** in dementia care solutions, including use of digital and Artificial Intelligence
- **Adapting** to the evolving needs of people with dementia
- Driving **transformation** in care delivery and community support

Accountability

- Health and social care taking **ownership** of outcomes and responsibility of strategic deliverables
- Including **transparency** in communication and decision-making
- Including ensuring **clarity** in objectives, roles and expectation setting

What is dementia?

Dementia is a syndrome caused by several progressive neurological conditions, most commonly Alzheimer's disease (a neurodegenerative disease) or a Cerebrovascular disease (narrowing of blood vessels in the brain). Dementia affects cognitive functions in everyday life. Dementia is a long-term condition requiring a joint care response, it is **not classified** as a mental illness.

Symptoms of dementia can include:

- **Memory loss,** particularly with problems recalling recent events
- **Increasing difficulty** with organising and planning tasks and activities
- **Becoming confused** in unfamiliar busy or noisy environments
- **Difficulty finding the right words** during conversations
- **Challenges in managing finances** or understanding numbers
- **Changes in personality and mood,** which can include anxiety and depression

Any of the above symptoms that result in a sustained or noticeable change may be the first signs of dementia.

National strategies emphasise the importance of timely diagnosis and person-centred care to manage these symptoms effectively and support people and their families throughout the dementia journey.

National overview

Nationally, rates of dementia are growing; dementias (including those caused by Alzheimer's disease) are already the biggest driver of mortality, and place a significant burden across health and social care services. The national aspiration is that two-thirds (66.7%) of people estimated to be living with dementia should have a formal diagnosis recorded in their GP care record.

People with dementia visit a GP up to three times more each year than someone without dementia and are eight times more likely to use general community services.[2]

Alzheimer's disease is the most common sub-type of dementia. In December 2023, it was reported that Alzheimer's disease represented 44.6% of all dementia diagnoses.[3]

It is estimated that 1 in 5 people who develop dementia will be living alone, and of those living alone, possibly 1 in 5 will have little or no family support.[4]

25% of people with dementia living in their own homes were admitted to hospital with a potentially treatable condition over a one-year period.[5]

25% of acute hospital beds are occupied by people with dementia.[6]

People with dementia stay in hospital twice as long as other people over age 65.[7]

43% of people with dementia in hospital were due to urinary tract and chest infections (treatable in the community).

90% of people with dementia found admission to hospital frightening and confusing.[9]

The number of people living with dementia in the UK is expected to rise from 982,000 to 1.4 million by 2040.[8]

"Older age is becoming increasingly geographically concentrated in England, and services to prevent disease, treat disease and provide infrastructure need to plan on that basis. This should be seen as a national problem and resources should be directed towards areas of greatest need, which include peripheral, rural and coastal regions of the country." **Chris Whitty 2024** [11]

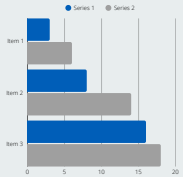
Devon overview

Dementia is a significant health and social care challenge in Devon, reflecting both national and global trends. With an ageing population, the prevalence of dementia in Devon will rise, necessitating this strategic and localised response. **The Dementia Strategy for Devon** is designed not only to meet the immediate needs of people with dementia and their carers, but also to support Devon to plan for future services and demands.

In Devon, as elsewhere, dementia affects not only those diagnosed but also their families, friends and carers. It impacts on every aspect of life, from daily routines to maintaining relationships and managing finances. The emotional, social and economic burdens can be immense, underscoring the importance of comprehensive support and understanding.

Dementia prevalence in the area covered by the Devon Integrated Care Board (ICB) is expected to rise by 54% between 2023 and 2040. This means that by 2040 it is expected that **33,734** people will be living with dementia in Devon.

Devon has higher levels of rural deprivation than the national average. National data suggests that dementia diagnosis rates are between 5 and 8 percentage points lower in rural areas.



The NHSE target for Dementia Diagnostic Rate nationally is 66.6% of predicted rate. At 58.5% Devon is below the England average of 65%.

In March 2024, there were **12,159** people with a dementia diagnosis in the area covered by the Devon ICB. Of these, **9,087** had a care plan or care plan review recorded within their GP records over the last 12 months (74.7%).

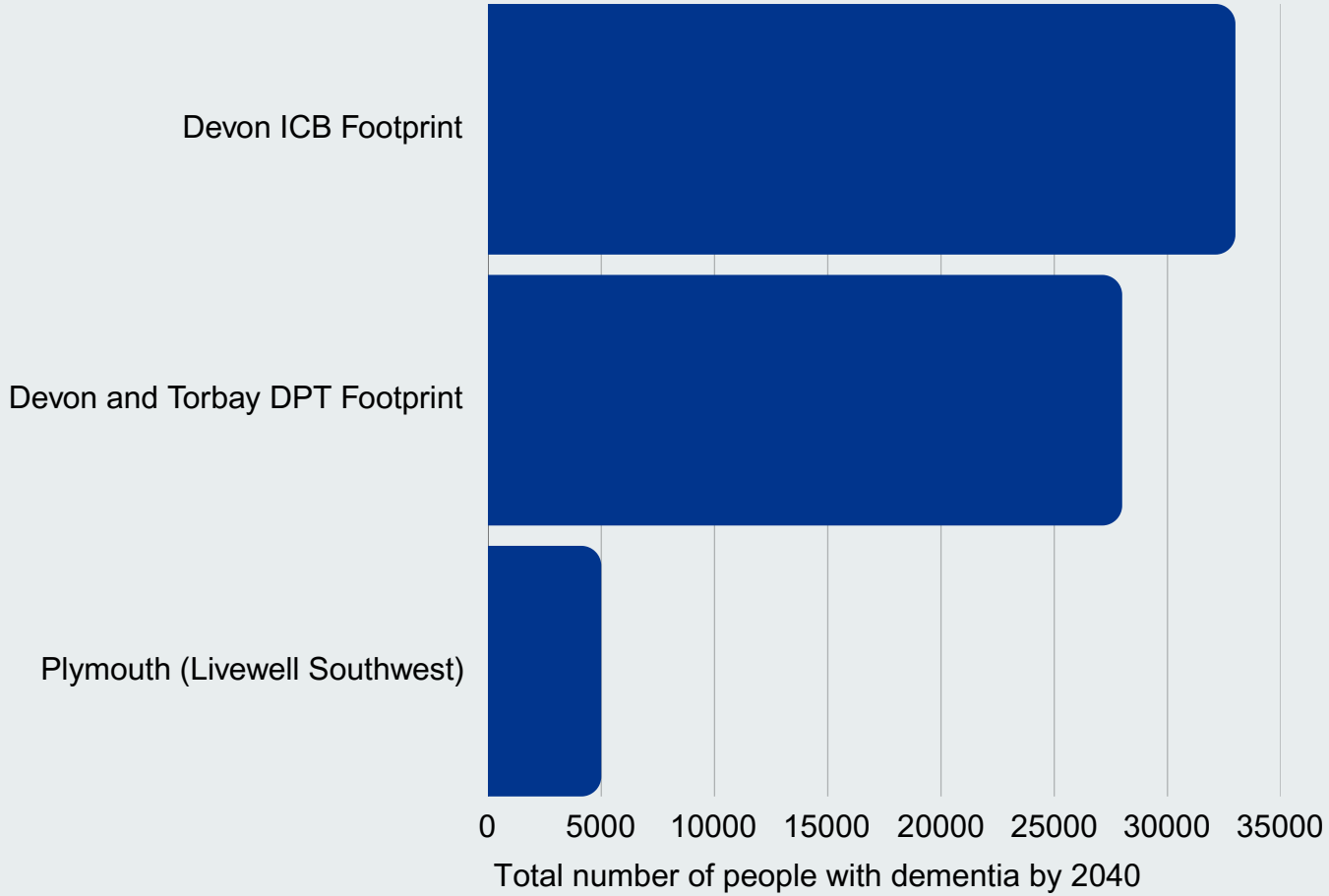
In Devon, 30% of adult and older adult beds in general hospitals are occupied by patients who have a dementia diagnosis.

There will be a 25% increase in the total over 65 population in Devon from **310,600** people in 2023 to **413,500** by 2040.

Dementia in Devon - 2024-2040

Projected case number increase in dementia by 2040

Total projected dementia cases by 2040 for Devon regions



The chart displays the total number of people expected to have dementia by 2040 in each region, with the Devon ICB footprint projected to reach the highest count at 33,734 cases.

Devon ICB Footprint: Estimated cumulative cost by 2040 is £17.5 billion, with an annual cost in 2040 at £1.08 billion.[10]

Promoting equitable care across Devon

This Strategy focuses on the expectation for delivery of effective dementia care across the county and is clear that these standards are expected regardless of cultural, economic or geographical barriers.

Areas for consideration

Geography – National data shows that diagnosis rates are lower in rural areas. People living in coastal and rural areas experience limited support options once they have a diagnosis. This leads to increased isolation and reduction in quality of life.

Age – It takes on average 4.4 years for a person to be diagnosed with Young-onset dementia.

Types of dementia – Following diagnosis, people who have rarer or Young onset dementias often have access to fewer resources. As such, their needs and those of their unpaid carers, are not always met within traditional support offers. This can lead to feelings of marginalisation and delays in timely care and support.

Equal access to support - There is strong evidence that people from ethnic minority backgrounds are often diagnosed at a later stage of dementia. This significantly impacts on the ability to support people to live well with dementia. There is a lack of understanding of barriers to seeking a timely diagnosis and how best to address them. These barriers are particularly evident among minority groups, where cultural differences in understanding views on dementia can lead to delays in diagnosis.

Furthermore, some evidence indicates that people who identify as lesbian, gay, bisexual, transgender or queer/questioning (LGBTQ+) may experience delays in dementia diagnosis and difficulties finding support due to stigma and social marginalisation.

Deprivation and ill health - Health inequalities in Devon heighten dementia risk, with deprived areas facing poorer cardiovascular health, higher smoking rates, obesity, and barriers to early diagnosis. Socio-economic disadvantage further limits access to dementia services, particularly in rural and coastal areas. Addressing these disparities demands targeted, inclusive strategies to ensure equitable dementia care and prevention.

To break down these barriers, commissioners, health and social care providers and voluntary, community and social enterprise (VCSE) organisations must understand the diverse needs of their local populations, including those of minority groups, and ensure these needs are met.

Well Pathway for Dementia- overview

The *Well Pathway for Dementia* was developed by NHS England as part of a five year transformation implementation plan. The following section outlines how we plan to implement the pathway in Devon to meet the needs of our populations.

Preventing well

The risk of people developing dementia is minimised

Diagnosing well

Timely and accurate diagnosis, care plan and review in the first year

Supporting well

Access to safe high-quality health and social care for people with dementia and unpaid carers

Living well

People with dementia can live normally in safe and accepting communities

Dying well

People living with dementia die with dignity in the place of their choosing

Supporting the person's network - family, friends and unpaid carers of those living with dementia

"Strategies to improve dementia care need to improve all parts of the pathway, including pre- and post-diagnosis experiences. Doing so could significantly improve the quality of life for those living with dementia and support those – often unpaid carers – who care for them." **The Kings Fund: Improving Dementia Diagnosis: Widening The Focus**

Strategic actions and deliverables

The following section outlines our plans to implement the *Well dementia pathway* here in Devon, who will be responsible for each of the key objectives, the actions to achieve each objective and how we will measure our success.

Strategic timeline

- Delivering our vision for dementia care over the next three years
- This Strategy runs until June 2028, requiring a revised strategy thereafter

Review and evaluation programme

- The National Institute for Health and Care Research (NIHR) Applied Research Collaboration for the South West Peninsula (also known as PenARC) to provide a mid-point (2026) and end-point (2028) review
- Supporting assessment of successes, gaps, and areas for additional focus

Key actions for commissioning and provision

- High-level asks of both commissioners and service providers
- Ensuring sustainable, high-quality dementia support

Identifying gaps and financial considerations

- PenARC to assess delivery gaps, including financial sustainability
- Insights to inform future improvements & resource allocation

Next steps: Embed, deliver and review for future success

Strategic actions and deliverables

Delivering our vision for dementia care over the next three years

2025

The Devon Dementia Strategy launch. This Strategy includes high-level asks of both commissioners and service providers and we have ensured that the plans deliver sustainable, high-quality dementia support Identifying gaps and financial considerations over the lifespan of the Strategy and beyond.

2026

The National Institute for Health and Care Research (NIHR) Applied Research Collaboration for the South West Peninsula (also known as PenARC) will provide a mid-point (2026) and end-point (2028) review. This will support assessment of successes, gaps, and areas for additional focus. These insights will inform future improvements and resource allocation

2028

This Strategy runs until June 2028, requiring a revised strategy thereafter.

Next steps: Embed, deliver and review for future success

Prevention - why?

Prevention is crucial because it offers the opportunity to reduce the risk of developing dementia.

Investing in prevention is a proactive approach that empowers people to take control of their health and wellbeing, ultimately leading to healthier, longer lives.

By focusing on preventive measures such as maintaining good cardiac health, promoting mental well-being and addressing modifiable risk factors like hearing loss, smoking, alcohol consumption and obesity, we can potentially delay or even prevent the onset of dementia.

This not only improves the quality of life for those with dementia, but also alleviates the future pressure on health and social care systems.

Nearly half of dementia cases could be prevented or delayed by treating or preventing 14 common risk factors: education age 11–12 years, midlife hypertension, midlife obesity, hearing loss, vision loss, high LDL cholesterol, later-life depression, diabetes, physical inactivity, visual loss, air pollution, smoking, excessive alcohol and social isolation. All of these areas can be modified or managed to reduce the risk of developing a dementia.

Livingstone* et al*, Lancet 2024 (Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission)

Preventing well

The risk of developing dementia is minimised

Key aims:

- Good cardiac health
- Maintaining hearing, eyesight and oral health
- Reducing loneliness and isolation
- Reducing Anticholinergic Burden (ACB)
- Promoting a healthy diet, reducing obesity and exercise
- Meeting the ambition of having a smoke-free generation
- Alcohol education and support
- Maintaining mental well-being
- Diagnosing MCI early to focus prevention measures on those most at risk of developing dementia.
- Supporting patients with MCI to reduce the risk of developing a dementia where possible. Without intervention, more than 30% of people with MCI might develop dementia - but this risk can be substantially reduced by better management of common treatable risk factors.

Current position in Devon:

There are many good examples across the county of health and wellbeing initiatives, all of which contribute to combatting some of the preventive causes of dementia.

These include:

- groups run by VCSE colleagues or colleagues with a focus on socialising and combatting loneliness and isolation, e.g. carer support groups
- Fitness and wellbeing groups which reduce the risk of obesity and encourage good cardiac health
- Health education provided by primary care, e.g. blood pressure treatment, cholesterol treatment, smoking and alcohol education

However, aside from engagement in research trials, there is currently very limited focus that explicitly addresses preventing cognitive decline.

Preventing well - the plan for Devon

Objective - what we want to do	Action - how we will achieve this	Who is responsible?	How we will measure success
Increase awareness of dementia and mild cognitive impairment (MCI).	Run targeted awareness campaigns for schools, businesses and communities. Train healthcare staff to recognise early signs of dementia.	Local authorities (via public health teams) and NHS organisations.	**Mid-point review:** Locality-based awareness campaigns up and running. **Mid-point review:** For dementia awareness e-learning to be developed. **Final review**: For the e-learning to be widely accessible for health and social care professionals.
Encourage NHS Health Checks to help detect dementia risks early.	Educating practitioners who complete these checks regarding the signs and symptoms of dementia and the cognitive benefits associated with a healthy lifestyle.	GP surgeries	Monitor completion rates of NHS Health Checks. Ensure dementia guidance is embedded in practice.
Reduce the use of high-risk medications Anticholinergic Burden (ACB).	Issue relevant guidance with healthcare teams on reviewing medications that may impact cognitive health.	NHS Devon ICB	Monitor through prescribing data via ePACT2.
Support dementia (and mild cognitive impairment) research to improve care and treatment.	Partner with NHS research teams and universities to expand dementia research and apply findings.	NHS organisations, National Institute for Health Research (NIHR),PenArc, Plymouth University, Exeter University.	Strengthen research collaborations and integrate findings into local guidance and delivery.

Diagnosis - why?

> *Its all new, so you don't know what you want or need.*
>
> Person living with dementia and their wife.

Diagnosing dementia is essential because it is the first critical step in accessing the appropriate care, support and treatment that can significantly improve the quality of life for people with dementia and their families.

Timely and accurate diagnosis allows for interventions that can slow the progression of the disease, manage symptoms more effectively, and help people plan for the future. It also reduces the uncertainty and anxiety that often accompany undiagnosed cognitive issues.

Moreover, a diagnosis enables health and social care providers to offer person-centred support and resources, ensuring that people receive the most suitable care. This also plays a vital role in reducing stigma by fostering greater understanding and awareness of dementia within communities.

"An early, accurate dementia diagnosis is the key to unlocking care, support and symptomatic treatment – and long waits for diagnosis leave people without this help. On top of this, more than a third of people living with dementia in the UK don't have a diagnosis at all."
Alzheimer's Society response to National Audit of Dementia Memory Services Spotlight Audit 2023-24

Diagnosing well

Timely and accurate diagnosis, care plan and a review in the first year

Key aims:

- **Ensure timely diagnosis** is accessible for all
- **Meet the 66.7% NHS National target for Dementia Diagnostic Rate (DDR).** For this to be a**ccurately recorded** on patients' health records, ensuring visibility across healthcare settings
- **Provide meaningful post-diagnosis support** to those diagnosed with dementia
- **Reduce the stigma** surrounding a dementia diagnosis and make people aware of the benefits of diagnosis
- **Ensure equitable access** to diagnosis for under-represented groups, people with Young onset dementia and those with learning disabilities
- **Clarify the diagnosis pathway** across health and social care to make it straightforward for patients, unpaid carers and professionals
- **Support people with MCI** by ensuring access to regular reviews
- **Ensure** that people who are diagnosed and their families are given information on how to participate in research

Current position in Devon:

As of January 2025, Devon's Dementia Diagnostic Rate is 58.9%, an improvement from 55.2% in April 2023.
Across Devon localities, the diagnostic rates vary significantly, ranging from 30% to 115% of the predicted need.*

Wait times for a dementia diagnosis in Devon also vary, with most diagnoses provided by Livewell Southwest (LSW) and Devon Partnership NHS Trust (DPT). The COVID-19 pandemic combined with an ageing population has increased demand for these services, leading to longer waiting times for diagnosis. For example, DPT has seen a 95% increase since 2019 for memory service referrals and LSW, a 17% increase since 2020.

Feedback from people with dementia and unpaid carers frequently indicates that accessing a diagnosis can be challenging. Many were initially unaware of how and when to seek a diagnosis, highlighting a need for better communication and education.

**Note: Diagnostic rates above 100% indicate practices exceeding the expected number of diagnoses based on population predictions, while lower rates may indicate under diagnosis.*

Diagnosing well - the plan for Devon

Objective - what we want to do	Action - how we will achieve this	Who is responsible?	How we will measure success
Meet set national standard for Devon dementia diagnosis rates.	Ensure unpaid carers can share concerns with GPs. Ensure diagnostic concerns, including delirium, are flagged in primary care. Ensure we are following national MCI guidance. System to utilise existing tools: • DiADeM tool • Dementia Diagnosis Support Pack • DeAR GP letter • Diagnosis Symptom Checklist	NHS Devon ICB, NHS providers, GP surgeries, local authorities and care homes.	Track DiADeM tool availability. Check use of the DeAR GP letter. Ensure GP surgeries receive support packs. Review adherence to MCI guidance.
To reduce the stigma associated with a diagnosis and ensure people recognise early signs of dementia, including Young onset (under-65) and rarer dementias.	Promote awareness campaigns targeting schools, businesses, and the public to foster dementia-friendly communities.	Local authorities, including public health teams	Increase dementia diagnosis rates. Increase sign-up of community engagement and uptake of dementia-friendly initiatives.
Increase baseline dementia assessments for people with Down's syndrome.	Recruit an assistant psychologist for the Baseline Dementia Assessment Programme for adults with Down's syndrome. Work with GPs to identify at-risk patients and offer cognitive assessments for those over 30.	Provider learning disability services.	Increase the number of completed assessments (data monitored by providers).
Reduce waiting times for dementia diagnosis	Ensure no one waits longer than 12 weeks for assessment after GP referral.	NHS Devon ICB, NHS providers, specialist memory services and primary care services.	Monitor provider-level data to ensure the 12-week target is being met or that actions are in place to achieve.

Support well - why?

> *This is one of the loneliest roads I've ever walked down.*
>
> Unpaid carer.

Supporting people with dementia well is essential to ensure that they receive the care and assistance they need to maintain the best possible quality of life.

Effective support helps those with dementia stay connected to their communities, reduces the likelihood of unnecessary hospital and care home admissions, and ensures their unique needs are recognised, understood and met.

Additionally, supporting well-trained and knowledgeable carers is crucial for providing consistent, compassionate care that respects the dignity and autonomy of people with dementia.

Strong support systems benefit those directly affected by dementia and ease the emotional and physical stress on families and caregivers, fostering a more inclusive and compassionate society.

Supporting well

Access to safe high-quality health and social care for people with dementia and unpaid carers

Key aims:

• Access to care support delivered by paid carers who have a good understanding of dementia and how this impacts on the person
• Sufficient numbers of high quality, specialist nursing and residential care facilities for those who require this support, with staff who have a good understanding of dementia, and are trained to support people living with dementia and their families
• Personalised, holistic assessments that identify the unique impact of dementia for the person
• People are able to access care close to their home community where they can be readily supported by their support network
• Reduce the number of people admitted to hospital or care homes with a dementia
• Ensure those who are admitted receive personalised care which recognises any additional needs due to their dementia diagnosis
• Ensure both pharmacological and non-pharmacological treatment options are utilised as appropriate to manage symptoms and to slow progression of the disease
• Ensure the integration of dementia specialist support into multi-disciplinary neighbourhood care teams bringing together health and social care and VCSE, mental and physical health services and primary and secondary care

Current position in Devon:

There is variable understanding and training available across the health and social care sector to support people living with dementia.

Care support can be provided by staff who are not effectively trained or experienced in dementia care provision. This can lead to variable outcomes for people with dementia and their unpaid carers.

Across Devon, there is a gap in the provision of 24-hour care provision for people with dementia, meaning that people with dementia might be cared for far away from their support network.

There is also a marked gap in replacement care (respite) provision which is suitable for people with dementia.

Care providers do not always feel readily supported by specialist support services and this can make it more challenging for people living with dementia to be supported well.

Supporting well - the plan for Devon

Objective - what we want to do	Action - how we will achieve this	Who is responsible?	How we will measure success
Deliver high-quality, person-centred dementia care across all comissioned care settings.	Promote innovative care models and technologies. Encourage care providers to use environmental assessment tools e.g. Stirling University self-assessment.	Local authorities and care providers.	**Mid-point review:** Devon and Torbay councils to consider introducing the Dementia Quality Mark in commissioned homes. **Final strategy review:** Defined outcome measures to identify high quality care.
Prioritise non-drug treatments to support wellbeing and manage symptoms.	Meet NICE compliance for cognitive stimulation therapy (CST). Regularly review antipsychotic use in line with national guidelines (every 8–12 weeks for behavioural and psychological symptoms of dementia BPSD).	NHS Devon ICB, NHS providers, VCSE providers, GP surgeries and care providers.	**Mid-point review**: The CST offer is defined. Monitor through prescribing data via ePACT2. **Final strategy review**: CST is routinely offered.
Embed John's Campaign across all care settings in Devon.	Implement John's Campaign principles in hospitals and care settings, ensuring providers commit publicly.	NHS organisations including hospitals, and care homes.	**Mid-point and final review**: Carers report better access to supporting their loved one with dementia during hospital stays, as defined through John's Campaign.
Improve post-diagnosis support for people with dementia and carers.	Develop post-diagnosis support packages with therapy, guidance and carer support.	NHS Devon ICB, NHS providers, VCSE organisations, local authorities and unpaid carer support groups.	Provider data evidences improved access to post-diagnostic support.

Living well - why?

Living well is crucial for people with dementia because it allows them to maintain a sense of normality, dignity and fulfilment, despite the challenges posed by the condition.

By focusing on living as well as possible with dementia, we aim to create safe, accepting and supportive communities that encourage continued participation in meaningful activities.

This approach fosters social inclusion, reduces isolation and promotes mental and emotional wellbeing.

Moreover, living well involves providing consistent and informed support to unpaid carers, ensuring that their needs are also met.

By fostering dementia-friendly communities, healthcare facilities and support systems, we can empower people with dementia to remain active, valued members of society.

This holistic approach benefits everyone involved, creating a more compassionate and understanding society.

Living well

People with dementia can live normally in safe and accepting communities

- For people with dementia to have access to a named worker as per NICE guidelines

- Regular (12-monthly) reviews focusing on how the person's dementia is impacting on their day-to-day life and offering appropriate signposting and support for this

- Access to robust and informed support for unpaid carers, ensuring their needs are also met and that they are recognised and respected for their invaluable support and knowledge

- Dementia-friendly communities which both enable and encourage people living with dementia and their supporters to be active, valued members of the community

- For people with dementia to continue to participate in the things that are meaningful to them

- Dementia-friendly hospitals and GP surgeries – for additional needs associated with dementia easily identified, e.g.: the National '*Forget me not campaign*'

Current position in Devon:

There is currently no structured long-term post-diagnostic support across the Devon and Torbay Local Authority footprint.

People diagnosed with dementia in Plymouth are supported by Livewell Southwest throughout their dementia journey. This support enables patients and their unpaid carers to reach out for support, as well as providing six monthly contact from the dementia support workers.

Across Devon, VCSE organisations continue to work hard to support people with dementia and their unpaid carers within their local community as well as working together to impact the wider Devon population (examples such as Devon Memory Cafes and local Dementia Alliances).

A number of organisations in Devon have been involved in recent research studies with the University of Exeter and University of Plymouth to ensure evidenced-based dementia support can be implemented across the county.

Living well - the plan for Devon

Objective - what we want to do	Action - how we will achieve this	Who is responsible?	How we will measure success
Make Devon a WHO age-friendly community that promotes people with dementia to live as independently as possible.	Work with local businesses, organisations and public services to adopt dementia-friendly practices.	NHS Devon ICB, local authorities and VCSE services.	**Final review:** All three local authorities aligned with WHO age-friendly community.
Recognise and support unpaid carers.	Ensure unpaid carers are recognised in their own right and have personalised care plans. Provide training and resources to help them manage caregiving demands.	NHS Devon ICB, local authorities, NHS organisations and care providers.	**Mid-point review**: Update **Devon Dementia Carers** booklet. **Final Review:** Ensure booklet is maintained and accessible. Improve access to carer support (see Healthwatch report).
Ensure adequate replacement (respite) care for people with dementia.	Conduct a strategic review of respite care across local authority footprints.	NHS Devon ICB and local authorities.	**Final review**: Develop and publish an action plan for improved respite care by end of 2027.

37% of unpaid carers in Devon report they do not know where to go for support and despite some being aware of where to go, they had either experienced difficulties or delays when trying to access support, support was unhelpful, unsuitable, or they didn't feel heard or understood.

Healthwatch, Devon, Plymouth and Torbay May 2024

Living well - the plan for Devon

Objective - what we want to do	Action - how we will achieve this	Who is responsible?	How we will measure success
Improve post-diagnosis support for Young onset and rare dementias.	Ensure post-diagnosis support is person-centred and includes specialist advice, peer support and resources.	NHS Devon ICB, NHS organisations and local authorities.	**Final review**: Percentage of people diagnosed with Young onset or rare dementias who receive specialist post-diagnosis support within three months. **Final review**: Patient and caregiver satisfaction with post-diagnosis support services with a target satisfaction rate of 80% or higher.
Promote use of assistive technology to help people live well with dementia.	Train health and social care staff to appropriately prescribe and support assistive technology. Engage in research on AI and dementia.	NHS Devon ICB, NHS organisations, health and social care staff and research organisations.	Track uptake: Increase in ‘prescribed AI technology’ through NHS Devon ICB. Evidence that research is embedded in delivery of the strategic aims in this strategy.

“We know that dementia is a condition where connection is key: connecting people to their families, and their carers, connecting people to their communities, and connecting people to themselves.” **Professor Alistair Burns, National Clinical Director for Dementia in England -** Dementia Toolkit English Guide April 2022

Dying well - why?

> *I've not got a fear of dying. What I've got a fear of is either dying in pain or living a life where I am not me...like that empty shell.*
>
> Person living with dementia.

Dying well is especially important for people with dementia, ensuring they experience the end of their life with dignity, in a setting that respects their wishes and values.

As dementia progresses, people may lose the ability to communicate their needs and preferences, making it essential to have clear, compassionate care plans in place.

Encouraging clear and early communication about people's wishes is key to good quality care. Care needs to be flexible, needs-based and take into account the unpredictable progression of dementia.

Dying well involves managing symptoms effectively, supporting unpaid carers and providing care in a familiar and comfortable environment, through specialist intervention, multi-disciplinary working and effective care co-ordination.

It also means respecting a person's end of life choices - whether at home, in a hospice or another preferred setting.

Ensuring a good death for people with dementia not only upholds their dignity, but also provides comfort and closure for their loved ones. This also helps to reduce the effects of trauma.

Dying well

58% of the public do not know dementia is a terminal condition.
Dementia UK Palliative Care

People living with dementia die with dignity in the place of their choosing

Key aims:

• For people with dementia to be supported to openly discuss their end of life wishes and ensure these wishes are recorded and receive care that aligns with their values and beliefs

• For unpaid carers to be supported throughout their caring journey and beyond, and for their voice and needs to be respected

• For people with dementia to be cared for in the place of their choosing wherever possible, where they feel safe, and where their physical and mental health needs can be met

• For distressing symptoms of dementia to be as well managed as possible, using non-pharmacological and pharmacological treatment options as appropriate

• To minimise the amount of time people with dementia spend in hospital in the last 12 months of their life

Current position in Devon:

In Devon there are a number of excellent examples, of both statutory and voluntary support offers which are supporting people with dementia to plan for the end of their life as well as supporting them during the end phases of their life. For example, admiral nurses, hospice care and carer peer support workers.

However, we know that experiences are often varied.

In the absence of robust post-diagnostic support, people with dementia have not been provided with information regarding how to plan for the end of their life at the point of diagnosis.

Due to the gaps in 24-hour care options, it can be challenging for people with dementia to remain in familiar environments near the end of their life if their symptoms significantly change, and/are more challenging to support.

Dying well - the plan for Devon

Objective - what we want to do	Action - how we will achieve this	Who is responsible?	How we will measure success
Ensure people with dementia can prepare for the end of life.	Use the Gold Standards Framework (GSF) to assess when someone is in their last year of life. Offer families end of life support and care coordination.	NHS organisations, GP surgeries and palliative care teams.	End of Life register and GSF coding in Devon and Cornwall Care Record (DCCR). Track referrals into palliative care support services.
For people to be able to plan well for their future including helping families understand end of life options and access the right support.	Include discussions on power of attorney and advanced care planning in post-diagnosis support.	NHS organisations and carer support organisations.	Patient and carer feedback on post-diagnosis support.
GPs and professionals to complete treatment escalation plans (TEP) and advance care plans.	GPs and other professionals to complete TEP and advance care plans with the patient and next of kin.	NHS organisations, GP surgeries and palliative care teams.	Review of electronic TEP forms in the DCCR.
Staff in care homes are skilled to support people with dementia at end of life and reduce avoidable changes in accommodation.	Train care home staff in dementia-specific end of life care, aligned with Dementia Training Standards Framework.	Local authorities and care home providers.	Audit training in care homes in dementia end of life care.
Reduce use of anti-psychotic prescribing for managing behavioural and psychological symptoms of dementia to minimise associated risks.	Promote non-pharmacological approaches to dementia care first. Ensure structured medication reviews (SMRs) and end of life care plans are in place.	NHS organisations, GPs, care homes and palliative care teams.	Reduction in antipsychotic prescribing (tracked via prescribing data). Monitor the number of SMRs for people with dementia.

Challenges and solutions to implementing the Dementia Strategy for Devon

Challenge	Solution
Funding constraints	Explore various funding sources such as government grants and community fundraisers. Advocate for comprehensive funding solutions, acknowledging it as a shared responsibility.
Lack of public awareness and stigma	Expand public awareness campaigns to reduce stigma. Collaborate with local media and organisations to promote dementia understanding.
Coordination between care services	Establish a centralised coordination body and implement a shared digital health record system to improve communication and care pathways.
Training and retention of skilled caregivers	Develop comprehensive training programs and provide incentives and support services to retain skilled caregivers.
Accessibility and inclusivity of services	Help to create dementia-friendly environments across Devon, especially in rural areas.
Monitoring and evaluation	Implement a monitoring and evaluation system to track progress, using data to adjust for continuous improvement.

Appendix 1

Strategy design

NHS 10-step process to working with people and communities

We have used the NHS England 10-step process to working with people and communities to help guide the development and co-production of this strategy, following the three key sections: understanding, engaging, impact, and the outcomes from this.

Understanding:

People: This is for everyone. We are all potentially someone who could develop, care for or work with people with dementia.

Our immediate focus is on:

- People with dementia, people caring for people with dementia
- People concerned about their memory (but don't yet have a diagnosis)

Equality and Diversity:

People not accessing services (even GP) small VCSE organisations who are not easily linked to statutory organisations

- Marginalised groups
- People with a learning disability

Info and insights (What we want to find out):

- From people with dementia and carers: What are the gaps? What's working for you? What would have made your dementia journey easier?
- Insight that only people with lived experience have - 'learning from people's experience, feelings, needs', that we might never have known

Engaging (methods):

- Devon Dementia and Memory Care Group
- VCSE Assembly
- Updates and feedback from existing dementia and old age specialist groups
- Primary care and dementia workshop
- Putting research in to action and learning from research outcomes
- Carers forums
- Feedback and engagement from people living with dementia

Impact:

Evaluation: Intend to have an evaluation by PenArc mid-way and at the end of the three years to measure against goals and impact.

Feedback: Through the Mental Health, Learning Disability and Neurodiversity Provider Collaborative and the Devon Integrated Care Board.

Outcomes (what is the aim of the engagement strategy):

- To develop a Dementia Strategy for Devon which has been co-developed by people with dementia, their families and unpaid carers as well as all key partners in the system
- To have one place where everyone comes to know this is the place to collaborate on dementia
- For people (services and support available) to feel included

Appendix 2

Golden threads

While designing this strategy, we identified two key areas that are imperative to making a meaningful impact to people living with dementia in Devon and their supporters:

Supporting unpaid carers

Carers provide an invaluable service that health and social care systems would struggle to replace. Without their support, the demand services would increase substantially, leading to higher costs and overstretched resources. Recognising and supporting carers is essential to maintaining the continuity of unpaid care, which in turn sustains the wider care system.

Research

Using evidence-based support and treatments across dementia care in Devon is vital to ensuring people can live fulfilling lives with resources utilised in the most efficient way.

Appendix 3

The economics of caring

> *"Just do the best you can today, and that's the best you can do. Try not to feel guilty about 'oh, I'm not doing as well as I was yesterday or last week', but just do the best you can do today because that's all anyone can ask of you."*
>
> ***Jane, a former carer***

Carers in the UK provide a significant economic benefit through unpaid care, which is essential to the sustainability of the health and social care system.

Estimated Economic Value

According to Carers UK, unpaid carers save the UK economy around **£132 billion per year** (based on 2021 figures), which is equivalent to the annual cost of running the NHS. This figure represents the value of care provided by an estimated **6.5 million unpaid carers** in the country

Per Carer Contribution

On average, each carer provides unpaid care worth approximately **£19,336 per year**, although this varies based on the intensity and duration of care

Hours of Unpaid Care

Carers UK estimates that carers provide around **13 million hours** of unpaid care every day. This contribution helps offset the need for formal social care and healthcare services, which would otherwise place a massive strain on public resources

Health and Social Care Cost Offset

Unpaid care delays and reduces the demand for more costly residential care and hospital admissions, which significantly reduces expenditure for local authorities and the NHS

Appendix 4

Economic and social benefits of supporting carers

Promas Community Interest Company case study

Significant Cost Savings to Health and Social Care Systems

Investing in wellbeing programmes for carers delivers a measurable financial return by reducing carers' need for healthcare interventions. By supporting carers in managing stress and maintaining their health, supporting carers helps avoid costly medical treatments and mental health services, creating substantial savings for the NHS and social services.

Enhanced Quality of Life and Resilience Amongst Carers

Carers who engage in structured support programmes experience improvements in their overall quality of life and are better able to cope with the demands of caregiving. This resilience contributes to more sustainable caregiving, reducing the likelihood of carers reaching a breaking point and needing to relinquish their role.

Reduction in Social Isolation

Support initiatives effectively reduce the isolation many carers feel by fostering connections with others in similar situations. Building these networks not only provides emotional support but also allows carers to share practical advice and experiences, helping to alleviate feelings of loneliness and enhancing their ability to continue in their role.

Improved Employment Retention and Economic Stability

Carers who receive adequate support are more likely to retain employment and manage their dual roles effectively. Support that offers flexibility and counselling supports carers in balancing work and caregiving, thereby reducing the risk of financial strain and promoting economic stability—particularly for women, who form a large portion of the caregiving workforce.

Preventative Approach to Healthcare Utilisation

Supporting carers' wellbeing acts as a preventative measure, helping them avoid severe health issues that could require costly treatment. By proactively addressing mental health challenges, such as stress and anxiety, these programmes decrease the demand for emergency care, hospital admissions, and mental health services among carers.

Empowerment and Skills Development for Carers

Support programmes provide carers with practical skills and tools to manage their responsibilities more effectively. This empowerment not only benefits carers directly but also improves the quality of care they provide, which can reduce the need for formal health interventions for those they care for.

Research

Across Devon, we have collaborated with Exeter and Plymouth universities, home to the National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula (also known as PenARC).

This partnership allows us to access new dementia research findings, highlight areas needing further investigation and ensure our work is research-driven.

We are committed to ensuring the good things we do are based on research.

By prioritising research, we not only enhance dementia care, but also create opportunities for those living with dementia to contribute to and shape the future of treatment and support.

Appendix 6

Evidence-based good practice

1. **Timely diagnosis and intervention**

I**mportance:** Timely diagnosis allows for timely intervention, which can slow disease progression and improve quality of life. This also provides an opportunity for people to plan and make informed decisions.

Good Practice: Implement community-based screening programmes and provide access to timely diagnostic tools in primary care settings.

2. Personalised and integrated care model

Example: The *D-PACT* (Dementia Personalised Care Team) approach developed by the universities of Plymouth and Manchester is a national model. This model focuses on personalised care for dementia patients, emphasising holistic support.

Good Practice: Encourage multidisciplinary cross-organisational working. Co-ordination between primary and secondary care providers ensures continuity and reduces stress for caregivers and patients.

3. Community support and rehabilitation programmes

Example: *The GREAT Cognitive Rehabilitation Project* offers cognitive rehabilitation programmes to help dementia patients maintain cognitive skills and independence. Rehabilitation techniques can aid in prolonging autonomy, delaying the need for more intensive, costly care.

Good Practice: Ensure availability of community-based post-diagnostic support alongside cognitive stimulation therapy (CST) programmes that are widely accessible, providing structured support to maintain cognitive and functional abilities.

4. Carer support and education

Importance: Carers often bear the burden of informal caregiving, leading to burnout. Supporting them helps improve patient outcomes and reduces reliance on formal care services.

Good Practice: Provide training and resources for carers on best practices for dementia care, through post-diagnostic support. Dementia system to consider use of tools such as *IDEAL Toolkit* and the *Living with Dementia Toolkit*. Support groups, respite care options, and mental health services for carers can help sustain their wellbeing.

Appendix 6

Evidence-based good practice

5. Promoting a dementia-friendly community environment

Example: Using the World Health Organisation (WHO) age-friendly communities to help people with dementia remain engaged and safe within their communities.

Good Practice: Local authorities to work with community organisations to create dementia-friendly spaces that accommodate cognitive and physical needs, such as clear signage, accessible facilities, and staff trained in dementia awareness.

6. Utilising technology and digital tools

Example: To use technology as demonstrated by the Interactive Smart Home Events run by the *Independent Living Centre* in Newton Abbot.

Good Practice: Incorporate digital tools for self-monitoring, telehealth and remote support. Apps and online resources can provide mental stimulation, reminders, and care coordination tools.

7. End of life and palliative care planning

Importance: As dementia progresses, planning for end of life care is essential to ensure the person's wishes are respected and reduce family burden.

Good Practice: Organisations like the *Anne Robson Trust* provide valuable resources on end of life care. Healthcare providers should integrate palliative care planning early in the dementia journey, discussing options and providing access to supportive services.

8. Education and awareness programme

Importance: Stigma and a lack of awareness can delay diagnosis and reduce community support for those with dementia.

Good Practice: Public education campaigns can raise awareness about dementia, encourage timely diagnosis and foster empathy within communities. Training programmes for healthcare professionals on dementia care best practices are equally important.

Supporting people with dementia to live at home

The overarching ambition of this strategy is to enable people with dementia to live at home for as long as possible, supported by their communities.

While there is a need to consider, build and commission housing and care options for those who need additional support, a key aim of this strategy remains to:

1. **Empower communities**

- Helping communities understand and meet the needs of people with dementia
- Building dementia-friendly environments that foster inclusion and support

2. **Strengthen home-based support**

- Providing the right services and resources to support people in their own homes
- Offering timely interventions to prevent unnecessary moves to care settings

3. **Balance innovation with individual choice**

- Exploring innovative care models while respecting the preferences of individuals and their families

These options complement the wider goal of fostering independence and ensuring that people with dementia receive compassionate, community-driven care.
The Strategy aims to encourage strategic commissioners to consider a needs-led assessment to support people to live at home as long as possible, following a diagnosis of dementia.

Exploring the role of AI in dementia care

The Devon system recognises the potential of Artificial Intelligence (AI) to improve dementia care and intends to consider its use as part of this strategy. While funding constraints remain a challenge, AI can provide cost-effective and scalable solutions to address some key issues in dementia care.

Potential areas for AI integration

Supporting early and accurate diagnosis

AI-powered imaging: Tools that assist clinicians in analysing brain scans for early signs of dementia, helping to reduce delays in diagnosis.

Predictive models: Using existing health data to identify individuals at higher risk of dementia, prioritising resources where they are most needed.

Enhancing care coordination

Personalised care planning: AI could support tailored care plans by integrating medical histories, current needs, and available resources.

Monitoring tools: AI-driven applications to track cognitive decline, enabling timely adjustments to care.

Assisting carers and families

AI chatbots: Low-cost digital assistants to provide carers with instant advice, guidance, and emotional support.

Remote monitoring: Affordable systems to monitor the safety and well-being of people with dementia, alerting carers to potential risks.

Enabling independence

Assistive technology: AI-powered devices that help people with dementia manage daily tasks, such as reminders for medication or appointments.

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Glossary

Artificial Intelligence - The ability of a digital computer or computer-controlled robot to perform tasks commonly associated with intelligent beings.

Advanced Care Planning - Advance care planning offers people the opportunity to plan their future care and support, including medical treatment, while they have the capacity to do so. (National Institute and for Health and Care Excellence)

Anne Robson Trust - The Trust was set up by Liz Pryor following the unexpected death of her mother, Anne Robson, and the impact it had on her family. The trust work to provide support to people nearing the end of their life, and those close to them. Through their work, the Trust hopes to prevent families from going through what Anne and her family experienced.

Baseline Dementia Assessment Programme - This baseline assessment tool can be used to evaluate whether practice is in line with the recommendations in Dementia: assessment, management and support for people living with dementia and their carers. It can also help to plan activity to meet the recommendations. NICE clinical guideline NG97.

Care plan – A care plan is a personalised plan that has been put together with an individual focusing on what needs they might have and their wishes.

Cognitive Stimulation Therapy (CST) - an evidence-based therapy for people with dementia. It is the only non-medical therapy endorsed by UK government guidelines for the cognitive symptoms of dementia.

DeAR GP letter - DeAR-GP (Dementia Assessment Referral to GP) is a simple case finding tool which has been developed by the Health Innovation Network (the Academic Health Science Network for South London) to assist primary and secondary care practitioners to identify residents with possible dementia in the care home sector. (Health Innovation Network).

Dementia Quality Mark - The Dementia Quality Mark is an accreditation process for care homes that provide a dementia service.
The Dementia Quality Mark can help families wanting to select a care home, giving them reassurance that the care being given meets the needs of those with dementia, and confidence that on-going improvements in practice will lead to better outcomes for those receiving care.

Glossary

Devon and Cornwall Care Record - The Devon and Cornwall Care Record brings together patient data from a number of health and social care providers and presents it as a single record.
This new system enables frontline staff to see details held by GP practices, hospitals, care homes and other organisations across Devon, Cornwall and the Isles of Scilly, giving them a more complete view of a patient's history.

Diadem tool - DiADeM Diagnosing Advanced Dementia Mandate is a tool to support GPs in diagnosing dementia for people living with advanced dementia in a care home setting.

D-PACT - The Dementia PersonAlised Care Team (D-PACT) programme is a five-year project, funded by a National Institute for Health and Care Research (NIHR) Programme Grant for Applied Research (PGfAR). The project aims to develop and evaluate a system for dementia support based in general practice for people living with dementia and their carers. The project is a collaboration between the Universities of Plymouth and Manchester.

EHCH – Enhanced health in care homes.

Electronic Palliative Care System – EPaCCS record people's care preferences and important details about their care at the end of life.

ePACT2 - ePACT2 is an online business intelligence platform which improves access to quality prescribing data.

GREAT Cognitive Rehabilitation project - Goal-oriented cognitive Rehabilitation GREAT Cognitive Rehabilitation is an evidence-based programme developed specifically to help people with mild and moderate dementia, and their families.. The aim is to enable people to function as well as possible in the everyday activities that are important to them. It is based on many years of research and cognitive rehabilitation has been recommended for people with dementia and their families in the NICE guidelines and by the MSNAP.

Integrated Care Board - integrated care boards (ICBs) are NHS organisations responsible for planning health services for their local population. There is one ICB in each Integrated Care system area. They manage the NHS budget and work with local providers of NHS services, such as hospitals and GP practices, to agree a joint five-year plan which says how the NHS will contribute to the Integrated Care Partnership's integrated care strategy.

Glossary

Living with Dementia Toolkit – A set of resources is based on research, and the expert experiences of people with dementia and their carers.

Provider Collaborative - Provider collaboratives are partnerships that bring together two or more NHS trusts to work together at scale to benefit their populations.

Mild cognitive impairment - Mild cognitive impairment is when a person starts to have problems with their memory or thinking. It can be a sign of a disease that will eventually cause dementia but MCI is not dementia and can be caused by other health problems.

MSNAP accreditation - Memory Services National Accreditation Programme (MSNAP).
MSNAP is a quality improvement and accreditation network for services that assess, diagnose and treat dementia in the UK.

NICE – National Institue for Centre of Excellence: produces useful and useable guidance for the NHS and wider health and care system.

NIHR PenArc - National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula (also known as PenARC).

Peer support - Peer support is a supported self-management intervention. It happens when people with similar long-term conditions, or health experiences, come together to support each other – either on a one-to-one or group basis. It is enabled through relationships that build mutual acceptance and understanding. NHS England.

Power of Attorney - A power of attorney is a way of giving someone you trust the legal authority to make decisions on your behalf if you're no longer able to make them yourself – or if you don't want to. Age UK.

Primary Care Networks - A Primary Care Network (PCN) is an alliance of GP surgeries that work collaboratively with other health, social care and voluntary organisations to improve patient services.

Glossary

Rare dementias - Alzheimer's disease is the most common cause of dementia, but there are many rarer diseases and conditions that can lead to dementia, dementia-like symptoms or mild cognitive impairment including Huntington's disease and CADASIL. More information is available on the Alzheimer's Soceity website.

Treatment escalation plan - A Treatment Escalation Plan (TEP) is a communication tool designed to improve quality of care in hospital, particularly if patients deteriorate. It records and communicates the personalised and realistic goals of treatment. It should reflect the values and preferences that are important to the person receiving care if their condition should deteriorate.

Unpaid carers -

Young-onset dementia - When a person develops dementia before the age of 65, this is known as 'young-onset dementia'. Over 70,800 people in the UK are living with young-onset dementia. (Alzheimer's UK)

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