



# **LANCASHIRE AND SOUTH CUMBRIA INTEGRATED CARE SYSTEM DEMENTIA STRATEGY 2025 – 2030**

This strategy sets out the intentions and commitment to improving the lives of people living with dementia and their carers across Lancashire and South Cumbria.

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## Foreword

Dementia is a growing challenge. It is a condition that affects millions of people worldwide, and its impact on individuals, families, and communities is profound. As the population ages and people live for longer, it has become one of the most important health and care issues facing the world. In England it is estimated around 676,000 people have dementia. In the whole of the UK, the number of people with dementia is estimated at 850,000.

Dementia mainly affects older people, and after the age of 65. However, for some, dementia can develop earlier, presenting different issues for the person affected, their carer and their family. There are around 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime.

In Lancashire and South Cumbria, we are committed to improving the lives of those living with dementia and their carers. This strategy outlines our vision and plans to transform the way we support those affected by dementia. It is built on the foundation of the NHS Well Pathway for Dementia, focusing on five key pillars: preventing well, diagnosing well, supporting well, living well, and dying well. We aim to raise awareness, improve diagnosis and care, and ensure people with dementia and their carers receive the highest quality of support throughout their journey.

We recognise the importance of collaboration, and this strategy has been developed by the following organisations: Blackpool Teaching Hospitals NHS Foundation Trust, East Lancashire Hospitals NHS Trust, Lancashire Teaching Hospitals NHS Foundation Trust, Lancashire and South Cumbria NHS Foundation Trust, NHS Lancashire and South Cumbria Integrated Care Board, Blackburn with Darwen Borough Council, Blackpool Council, Lancashire County Council, Age UK Blackburn with Darwen, Age UK Lancashire, Alzheimer's Society, Carers Link Lancashire, Dementia Action Alliance and Trinity Hospice. Our approach has been guided by national policies and frameworks, ensuring that our efforts are aligned with broader health and social care priorities.

This strategy is not just a plan, it is a commitment to action. We will monitor our progress through a detailed action plan, holding ourselves accountable for the improvements we aim to achieve over the next five years. By working together, we can make a significant difference to the lives of people living with dementia and their carers in Lancashire and South Cumbria. We invite you to join us on this journey, as we strive to create a more supportive and inclusive community for all.



## Executive summary

This strategy sets out our intentions and commitment to improving the lives of people living with dementia and their carers – by this we mean people with a diagnosis of dementia and their family and carers across Lancashire and South Cumbria.

The aim of this strategy is to transform the health and social care system for the better, both for those living with dementia today and those who may receive a diagnosis in the future. This will include clear activities contained in the action plan, as well as setting out our ambition and vision for the future of dementia services across Lancashire and South Cumbria. The action plan will enable us to identify specific actions required across the system and identify the appropriate leads for each action and the timescale for completion. The action plan will also enable us to monitor and provide assurance that the necessary work has been completed.

Dementia is a key priority across health and social care. In 2023 the Government launched the Major conditions strategy: case for change and strategic framework<sup>1</sup> which aims to improve outcomes across six major health conditions, including dementia, over the next five years.

The strategy also considers legislation and guidance included in the Care Act 2014<sup>2</sup>, the ADASS (Association of Directors of Adult Social Services) Time to act: a roadmap to reform care and support in England 2023<sup>3</sup>, which proposes how care and support could be transformed in England, focusing on 10 key areas for change, and the National Institute for Health and Care Excellence (NICE) guidance, Dementia: assessment, management and support for people with dementia and their carers 2018<sup>4</sup>.

[The NHS Long Term Plan](#) sets out the ambition to improve the care provided to people with dementia through a more active focus on supporting people in the community, working closely with the voluntary sector to improve advice and support for people following a dementia diagnosis.

Additionally, there are a number of national policy statements and pieces of legislation and stakeholder engagement reports that have formed the strategy's development including those listed below:

- The Prime Minister's Challenge on Dementia in 2020
- Dementia 'A state of the nation report on dementia care and support in England'
- Alzheimer's Society reports: 'Worst hit – Dementia during coronavirus; Dementia diagnosis to end of life; Ethnic minorities increasing access to Dementia Strategy 2022-2027 6 diagnosis, Hospital and care homes-increasing access to diagnostics; Report on regional variations and access to diagnostics'

<sup>1</sup> [Major conditions strategy: case for change and our strategic framework - GOV.UK \(www.gov.uk\)](#)

<sup>2</sup> [Care Act 2014 \(legislation.gov.uk\)](#)

<sup>3</sup> [Time to act to save social care in England - ADASS](#)

<sup>4</sup> [Overview | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE](#)

These strategic documents and legislation recognise the projected increase in dementia prevalence and the need to focus on dementia diagnosis for all ages, highlighting the importance of ensuring that people who have dementia, their carers, families, and friends receive the highest quality of care and support.

The NHS Well Pathway for Dementia will be considered, ensuring the five pillars of the dementia well pathway is reflected in the commitment this strategy will deliver.

<https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

This Lancashire and South Cumbria five-year strategy focuses on five pillars of the dementia well pathway.

1. Preventing well
2. Diagnosing well
3. Supporting well
4. Living well
5. Dying well

To ensure the strategy aligns with other strategic priorities, it has also been driven by the same three themes behind the reforms to health and care <sup>5</sup>:

- i) Prevention,
- ii) Personalisation,
- iii) Performance.

For social care the Care Act 2014 has an emphasis on preventing need or reducing and or delaying the onset of need.

**Wellbeing Principle.** The principle applies equally to individuals with eligible needs and those who do not have eligible needs and states the importance of preventing or delaying the development of needs for care and support and the importance of reducing needs that already exist include but are not limited to:

- a. Personal dignity (including treatment of the individual with respect)
- b. Physical and mental health and emotional wellbeing
- c. Control of the individual over day-to-day life
- d. Participation in work, training, education, training or recreation
- e. Social and economic wellbeing
- f. Domestic, family and personal wellbeing
- g. Suitability of living accommodation
- h. The individual's contribution to society

Ensuring our social care workforce will use best practice including work within the Skills for Care Common Core Principles for Dementia.

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<sup>5</sup> [Health and Social Care Secretary speech on Health Reform - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/speeches/announcing-the-new-national-care-plan)

We have an entire section on prevention, a real focus on people and the importance of personalisation in our theme focused on improving the experience of being diagnosed, living with, and dying with dementia, with the role of hospices in providing palliative and end of life care. Our section on research cuts across all three of the themes.

By 2029 this new five-year strategy on dementia will aim to deliver:

i) **Prevention**

The considerate promotion of risk factors linked to dementia and the promotion of healthier living messages across the system and the life course (**raising awareness promotion of campaigns working together**) and other statutory partners via a range of methods, social media etc., that many cases of dementia can potentially be prevented or delayed, currently only 33% of people are aware that dementia can be prevented or delayed ([Dementia Attitudes Monitor](#), 2021). We want to raise this to 75% in line with cardiovascular disease.

Ensuring we are aware of the outcomes of research into dementia risks, so we understand more about the associations, causes and mechanisms linking them to different diseases that cause dementia and communicate this to the population of Lancashire and South Cumbria as part of the overall early intervention and prevention programme.

Reducing dementia inequalities, such as those that exist between different ethnic groups, people with young onset dementia, and those with learning disabilities, in particular those with Downs Syndrome, and exploring opportunities to develop community interventions. For people with a learning disability the average life expectancy in years for males is 66, females 57 and for people with Downs Syndrome 66. All of these are 15 to 20 years lower than the general population.

ii) **Personalisation**

A significantly improved health and care experience for people living with dementia and their carers that considers the wider system, linking in with the health checks for adults with learning disabilities. For people with a learning disability, annual health reviews with the GP are already well embedded within the service offer; early identification for people with higher risk factors; reforms that have personalisation at its heart, utilising the experience and skills of a variety of organisations, including local dementia hubs, to support people living with dementia and their carers to live within their own communities. Ongoing support provided throughout the pathway by designated dementia navigators.

Ensure that all frontline workforce groups and volunteers who provide care and support for people with dementia and their carers in multiple health and social care settings, those interacting with the diagnosed and their carers at home (where independence needs to be supported as long as possible),

have access to the appropriate training, enabling them to develop the necessary skills and knowledge.

Ensuring that people living with dementia and their carers needs are included in an overall physical and mental health care plan, linking with the Integrated Care Board (ICB) frailty programme and other relevant programmes and timely and appropriate reviews. The use of data sharing agreements across organisations ensuring that people and their carers do not have to repeat their story and ensuring that the annual health review incorporates both physical and mental health/dementia needs.

The NHS Long Term Plan stipulates personalised care to improve the quality of end-of-life care, helping to reduce avoidable hospitalisations and enable people to die in their preferred place of death. However, the quality of end-of-life care for people with dementia remains variable. Most will experience unnecessary emergency hospitalisation, which is often very distressing and can be detrimental overall. Recent high-quality evidence identifies ways to improve care for people with dementia approaching the end of their lives. Based on this evidence four calls to action have been identified:

- Prioritise dementia as a life-limiting condition.
- Ensure equitable access to integrated palliative dementia care.
- Optimise investment in community and primary care closer to home.
- Invest in palliative dementia care research (Right to be Heard; better palliative and end of life care for people by dementia 2023)

### iii) Performance

Commitment to meet the dementia diagnosis rate target of 66.7% by March 2026 and following this, we will strive to meet a new diagnosis rate target of 75% by 2029.

Work as an Integrated Care System (ICS), demonstrating how we can use the system to improve outcomes for people with dementia and their carers to help reduce and move towards eradicating variations in diagnosis rates and patient experience across Lancashire and South Cumbria.

Activities to ensure the health and care system is prepared and ready to deliver any new treatments for dementia (as they become available).

Commit to linking with research which meets the needs and aspirations of people living with dementia and their families and carers, together with the current and future needs of the health, social care, and related systems.

One of the major difficulties dementia researchers continue to face is recruiting the most appropriate participants for their studies. At the same time, many people are looking for studies to contribute to and take part in, but do not know how to find out about them as there is no clear pathway for people living with dementia to become involved.

The ICS will work with many organisations, including the voluntary sector, to enable opportunities for everyone living with dementia to be made aware of the opportunity to participate in dementia research. Information will be made available to individuals as part of the diagnostic materials provided upon diagnosis. The information provided will include contact details of organisations who can provide more details about the variety of research programmes and what individuals can expect if they choose to be involved.

**iv) People**

Bold actions to ensure we have a health and social care workforce that are equipped with the skills they need to provide high quality care and support to those living with dementia and their carers.

An increased number and diversity of people participating in dementia research to ensure what is delivered is relevant across the different populations living within Lancashire and South Cumbria.

## Why we need a five-year dementia strategy: Our vision

Dementia affects people from around the world, with more than 55 million people living with the condition globally and 10 million new cases every year ([World Health Organization](#), 2021). In England, an estimated 750,000 of over 65s had dementia in 2019. This is set to rise to over 1 million by 2030. If the upward incidence trend continues, along with population ageing, the number of people with dementia in England and Wales is projected to increase to 1.7 million in 2040. The burden on health and social care might be considerable larger than currently forecast.

The number of people aged 65 and over in the UK who have dementia, costs the UK economy £34.7 billion a year<sup>6</sup>, with increasing life expectancy a driving force behind this projected rise.

In 2022, dementia was the leading cause of death across England and Wales, with the Office for National Statistics identifying dementia as accounting for 11.4% of all deaths ([www.alzheimersresearchuk.org/dementia-leading-cause-of-death-in-2022](#)).

The Alzheimer's Society estimates that people with dementia make up at least 70% of care home residents (Alzheimer's Society. Dementia UK: Update 2014: [www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia\\_uk\\_update.pdf](#)) and over 60% of home care recipients.

Our priority across health and social care is to ensure that we have a preventative approach that supports people while maximising their independence and wellbeing. Local Authorities Health Improvement Teams lead on this approach.

To reduce the risk of developing dementia the system actively promotes healthy lifestyles and behaviour change programmes such as:

- Stop smoking services
- Substance misuse services
- Weight management services
- Prevention work around alcohol and drugs
- Health checks every 5 years for residents over 40 years old
- Ensure we capture carers of all ages
- Promoting five steps to wellbeing

Dementia has, and will continue to have, a huge impact on people living with the condition, their carers, families, and society more generally. For example:

It is estimated that 1 in 3 people born in the UK will develop dementia in their lifetime. This figure is much higher for certain groups e.g., people with a learning disability but without Down's syndrome (e.g., 10% age 50-65 years; 14% 65-75 years; 25% age 75-85 years – likely to be underestimates due to complexities around identifying dementia in this client group; due to clinical and aetiological

<sup>6</sup> [Dementia incidence trend in England and Wales, 2002–19, and projection for dementia burden to 2040: analysis of data from the English Longitudinal Study of Ageing - The Lancet Public Health](#)

factors such as level of learning disability different syndromes, behaviours that challenge, life events, non-learning disability assessments being used). For people with Down's syndrome the prevalence rates are much higher (10% 40-49 years; 33% 50-59 years; 50% years' and above 7% 70+ years) ([Estimation of Future Cases of Dementia from Those Born in 2015 \(ohe.org\)](#)) Office of Health Economics (OHE)

Excluding COVID-19, dementia and Alzheimer's disease are the leading cause of death, accounting for 11.5% of all deaths in England and Wales in 2020 ([Deaths registered in England and Wales: 2020, ONS](#)). Office for National Statistics (ONS)

More than half of us know someone living with dementia ([Dementia Attitudes Monitor](#), 2021)

With the number of older people living with dementia in England set to rise to over 900,000 by 2025, in addition to the impact on people, the cost of dementia will also have an impact on the economy ([Dementia Statistics Hub](#)). Although there are different estimates for costs of dementia, all experts agree that costs are substantial and are set to increase<sup>7</sup>. A model produced by the Care Policy and Evaluation Centre (CPEC) at the London School of Economics estimated that the cost of dementia in England was just under £35bn in 2019, with the cost expected to reach over £94bn by 2040 (in 2022 prices) These are the aggregate health, social care and unpaid care costs associated with supporting older people with dementia. The largest proportion of this cost, 45%, is social care, which totalled £15.7 billion in 2019. These are set to nearly triple to £45.4 billion by 2040.

Such estimates do not cover the costs of supporting those with young-onset dementia. Based on evidence from the United Kingdom (UK), those with young-onset dementia are estimated at 7.5%, or 70,800 of the estimated 944,000 people living with dementia in the UK<sup>8</sup>.

This could have been an additional cost of just under £2 billion in 2019 and just over £5 billion in 2040 (in 2022 prices), assuming that the cost of dementia per person would be the same for all those living with dementia (older and younger onset).

In addition to a person diagnosed with dementia, there are around 540,000 carers of people with dementia in England. The Carers Trust estimate that there are seven million carers in the UK, with approximately 770,000 of those caring for someone living with dementia. It is estimated that one in three people will care for a person with dementia in their lifetime. Half of these are employed, and it is thought that some 66,000 people have already reduced their working hours to care for a family member, whilst 50,000 people have left work altogether.

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<sup>7</sup> Alzheimer's Society. What are the costs of dementia care in the UK? November 2019. Available at: [What are the costs of dementia care in the UK? | Alzheimer's Society \(alzheimers.org.uk\)](#). (Accessed 11/05/22).

<sup>8</sup> [www.dementiauk.org/information-and-support/young-onset-dementia/young-onset-dementia-facts-and-figures/](#)

The CPEC model also estimates that families are providing £13.9 billion a year in unpaid care for people living with dementia, which is projected to increase to £35.7 billion by 2040.<sup>9</sup>

The latest National Audit of Dementia published in August 2023 ([Dementia Care in General Hospitals Round 5 Audit 2022 \(NAD\) – HQIP](#)) shows that positive feedback from carers for loved ones with dementia decreased compared to the previous round of the audit for all questions. More specifically, the rating for the overall quality of care decreased from 72% in 2019 to 66% in 2023, and the rating for quality of communication with carers decreased from 65% in 2019 to 60% in 2023.

In February 2015 [the Prime Minister's Challenge on Dementia 2020](#) for dementia included a commitment to increase the number of people living with dementia who have a formal diagnosis. The rationale being that a timely diagnosis enables people living with dementia, their carers and healthcare staff to plan accordingly and work together to improve health and care outcomes.

In recent years, the national diagnosis rate has dropped from 67.4% to 62% which is well below the national target of 66.7%. As a result, there are now 30,000 more people living with undiagnosed dementia within the UK and consequently unable to access the vital care and support that is needed.

The care market for people with dementia has changed significantly over the years and part of any dementia pathway requires support to the market to ensure sustainable and resilient services are in place, with assurance that care providers have full dementia training.

The visions for this strategy are to improve the lives of people living with dementia and their carers now, and for those who may be affected in the future, as well as awareness raising for early intervention, across Lancashire and South Cumbria. We will:

- Take action to support people to reduce their risk of developing dementia.
- Work to ensure all people living with dementia and their carers are receiving accurate and timely diagnosis and the high-quality health care, they need; with a jointly agreed care plan once diagnosis is made; which is reviewed within the initial 12 months of it being agreed; then reviewed every 12 months in accordance with changes in the persons' needs. Revisions of the care plan should be jointly developed and agreed with the person (and if applicable, their carer).
- Identify earlier those with palliative and end of life care needs to ensure equitable access to integrated palliative dementia care.
- Ensure involvement in research is offered to people diagnosed with dementia.

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<sup>9</sup> [Dementia care \(lse.ac.uk\)](#)

- Ensure workforce groups supporting people with dementia and their carers are equipped with the knowledge and skills to deliver appropriate care and support as well as ensuring the workforce is supported to deliver excellent quality care.
- Ensure examples of good practice are shared to ensure all services which may be required to support people living with dementia at some point during the dementia pathway all have high quality provision e.g., acute hospital settings etc.

The ICS have asked people living with dementia, their carers, and our partners in health and social care, hospices, and the voluntary sector, what we should focus on to improve the care and support we provide to people, from activities aimed at preventing dementia, through to care at the end of people's lives, reflecting the palliative care ambitions framework.<sup>10</sup>

Lancashire and South Cumbria ICB, Lancashire County Council, Blackburn with Darwen Council, Blackpool Council, Westmorland and Furness Council, and District Councils, will work in collaboration with stakeholders including Acute hospitals, emergency services (e.g. Lancashire Fire & Rescue) and Voluntary, Community, Faith and Social Enterprise (VCSFE) organisations. We will use this strategy, with its detailed action plan, to hold the system accountable for improvements we will make over the next five years. Whilst ensuring that where individual organisations have a dementia strategy it is reflected in the overall LSC strategy.

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<sup>10</sup> [NHS England » Ambitions for palliative and end of life care](#)

## Chapter 1: Introduction

The term ‘dementia’ is an umbrella term used to describe a set of symptoms that include loss of concentration and memory problems, mood and behaviour changes and problems with communicating and reasoning. These symptoms occur when the brain is affected and damaged by certain diseases, such as Alzheimer’s disease, a series of small strokes, predisposing to vascular dementia, or other neurological conditions such as Parkinson’s Disease.

Dementia is a complex and progressive neurological condition and the specific symptoms experienced by people with dementia will vary from person to person. There are over 200 subtypes of dementia ([Dementia: policy, services and statistics](#), 2021). Around 60-70 per cent of people with dementia have Alzheimer’s disease, which is the most common type of dementia ([World Health Organization](#), 2021). Another major form of dementia is vascular dementia, which results from problems with the blood supply to the brain.

Throughout this document, the term dementia will be used as shorthand for this broad range of conditions. However, we recognise that no two people with dementia or their carers are the same and people will have unique and differing needs and experiences.

Many people with dementia also have other medical conditions with 77% of people with dementia having at least one other specific health condition; hypertension, diabetes and depression are fairly common, secondary prevention of these conditions could improve dementia prevention ([Dementia: comorbidities in patients - data briefing](#), 2019) The percentage of people with a learning disability and dementia, as well as other co-morbid conditions is higher than 77%. For people with a learning disability, they include thyroid conditions, depression, pain, vitamin deficiencies such as B1.

While the likelihood of developing dementia increases significantly with age It is estimated that there are over 70,500 people living in the UK with young onset dementia<sup>11</sup>. There are important differences in how dementia affects younger people. For example, younger people with dementia are more likely to have a rarer form of dementia and 10% of people living with young-onset dementia have inherited it.

People with a learning disability having the genetic syndrome Down’s syndrome leads to a higher prevalence rate for Alzheimer’s disease from the age of 40 years<sup>12</sup>. There are also wider considerations required when supporting people and the carers/family who have received a diagnosis of young-onset dementia as the person may still be working and have financial commitments, such as mortgages and young children.

We need to ensure that the Post Diagnostic Support (PDS) for this group of people include information which will aid them in not only coming to terms with the diagnosis, but information and advice for the wider implications of receiving the

<sup>11</sup> [Young onset dementia: facts and figures - Dementia UK](#)

<sup>12</sup> [Dementia and Down's syndrome | Alzheimer's Society \(alzheimers.org.uk\)](#)

diagnosis. There needs to be specific support for the young onset Dementia community, such as groups tailored to their social and emotional needs.

It is also the case that some groups of people in the population are at higher risk of developing dementia and at earlier ages, such as people with a learning disability. Understanding this, and how dementia may present, is essential in the provision of appropriate care and support for people with a learning disability. There is much published evidence around the increased risk in people with Down's syndrome and how this presents, however there is less research around how this presents for the general learning disability population. In addition, 65% of people living with dementia are women and, before COVID-19, dementia was the main cause of death for women ([Prevalence by gender in the UK - Dementia Statistics Hub](#)). People of Black ethnicity are also more likely to develop dementia than White ([Trends in dementia diagnosis rates in UK ethnic groups: analysis of UK](#), 2018), and people from more deprived backgrounds are also at greater risk ([The Influence of Socioeconomic Deprivation on Dementia Mortality, Age at Death, and Quality of Diagnosis](#), 2021).

Currently, dementia is not curable. If diagnosed in a timely way, people with dementia and their carers can receive the treatment, care, and support (social, emotional, and psychological, as well as pharmacological) to enable them to better manage the condition and its impact. Compassionate, personalised treatment, care, and support throughout the progression of the condition is essential. This includes timely and appropriate advance care planning so that those living with dementia and their carers can discuss their wishes, needs and preferences for their future care, to enable people with dementia to 'live well' and, one day, 'die well.'

PDS should include enabling the person with strategies, communication tools, enhanced understanding, and problem-solving approaches. These promote and encourage the ability to continue living well, living independently for longer, and responding with reduced risk as the disease and symptoms progress. It will act preventatively against crisis, or limit its effect/quicken effective response, and help people to feel understood and able to navigate the care system.

The NHS Long Term Plan stipulates personalised care to improve the quality of end-of-life care, helping to reduce avoidable hospitalisation and enable people to die in their preferred place of death. There remains unacceptable inequalities and inequities in access to palliative care and end of life care, particularly for those with learning disabilities, dementia, and non-malignant long-term conditions. There is a collective responsibility on all of those involved in commissioning and provision of end-of-life care for this to change. <https://kcl.ac.uk/nmpc/assets/a-right-to-be-heard-policy-brief.pdf>. Part of enabling people with dementia at the end of life to 'die well' is the provision of high quality, personalised Palliative and End of Life Care<sup>13</sup> (PEoLC) when appropriate, that is accessible to all. With our ageing population we

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<sup>13</sup> [How many people will need palliative care in 2040? Past trends, future projections and implications for services - PubMed \(nih.gov\)](#)

know that the need for PEoLC will only increase over the coming years<sup>14</sup> and so as an integrated care system we must provide people with the support they need. Recent high-quality evidence identifies ways to improve care for people with dementia approaching the end of their lives. Based on this evidence the 'Right to be Heard' policy - End of Life care for people with dementia policy recommends four calls to action:

- 1 Prioritise dementia as a life-limiting condition.
- 2 Ensure equitable access to integrated palliative dementia care.
- 3 Optimise investment in community and primary care closer to home.
- 4 Invest in palliative dementia care research.

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<sup>14</sup> [Number of dementia cases could be 42% higher than previously estimated by 2040 | UCL News - UCL – University College London](#)

## Chapter 2: Where are we now?

Across Lancashire and South Cumbria 15,477 people over the age of 65 have received<sup>15</sup> a recorded diagnosis of dementia.

Across Lancashire and South Cumbria there is still a gap between the number of people estimated to have dementia and those who are being fully supported through the health and care system.

There are estimated 22,714 people over the age of 65 living with dementia in Lancashire and South Cumbria. By 2030 this will be much higher: 24,327 in Lancashire; 11,654 in Cumbria (note full county not only South); 2,646 in Blackpool; 1,993 in Blackburn with Darwen.

Lancashire and South Cumbria ICS currently has a diagnosis rate of 68.1%.

52.0% people have reported having a dementia care plan review in the last 12 months in NHS Lancashire and South Cumbria ICS.

In the NHS Lancashire and South Cumbria ICS approximately 73.6% of people die at their usual place of residence.

In Lancashire and South Cumbria NHS Older Adult mental health services are provided by Lancashire and South Cumbria Foundation NHS Trust (LSCFT). They offer a range of services including a memory assessment service (MAS), in-patient assessment and treatment, by the mental health liaison team (MHLT) community assessment and treatment for urgent and scheduled care provided by the older adult mental health community services: Rapid Intervention and Treatment Teams (RITT), Older Adult Community Mental Health Team (OA CMHT), Care Home Liaison (CHL). There are also Dementia Specialists/Leads within our Acute hospital settings. For people with a learning disability there are local community learning disability health teams that can provide bespoke specialist assessments and interventions. These services are not exhaustive and many of the wider mental health services commissioned with LSCFT are available to support the person with dementia.

Upon receipt of a dementia diagnosis personalised care and support planning takes place as soon as possible ensuring the needs of the individual diagnosed with dementia are included. Work will be completed to ensure this is carried out consistently. Upon completion of the initial plan a review date is agreed, and this takes place minimum annually, with the person living with dementia and their family/carers to reflect changes in needs and wishes.

Primary care also provides dementia services to the population. Within the national general practice contract Quality and Outcomes Framework (QOF) practices are incentivised to maintain a Dementia register and to review Dementia Care Plans annually, face to face. Primary care work with local communities to develop bespoke support for their population groups, they use connections within practice-based

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<sup>15</sup> [Local dementia statistics | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk)

services and those that wrap around groups of practices to ensure a range of services are available.

The ICB is working with LSCFT and other providers to design and deliver the community transformation programme to enhance the mental health trust offer and to collaborate with community and voluntary groups to offer an integrated service offer.

Adult Social Care undertake statutory functions under the Care Act, including strengths-based assessment of need, care, and support planning, and safeguarding. Our Adult Social Care approach is underpinned by personalisation, enablement and independence. What does the person, their family, their friends and neighbours, and local community have that can help? We understand and respect that people are the expert in their own life and our approach encourages you to enable people to express their own wishes and preferences. Where the need for a formal service is identified, adult social care can explore a range of commissioned services:

- Home care to support people to live well at home – Local authorities have an 'approved provider list' of high-quality domiciliary agencies.
- Technology enabled care (TEC) – Technology to enhance human relationships and interactions.
- Equipment and adaptations to support independence in the home.
- Short term help and support, including care at home (Intermediate Care Services) to support hospital discharge.
- A range of suitable specialist housing options to compliment current housing:
  - Extra Care
  - Residential Care and Nursing Care

Social Care input to assessment and treatment plans is a key element of support required and working as a partner in the ICB dementia programme and pathway developments, local authorities offer a strength to the range of support possible.

PDS is provided at point of diagnosis to support good clinical care, with further PDS by commissioned VCSFE providers and this has recently been reviewed as part of the overall work programme. This work has highlighted differences in historical commissioning and showed inequity in what is available across each locality in Lancashire and South Cumbria, including people with learning disabilities. The offer from these services will be flexible dependent on the type of dementia and needs of the person and carer. The PDS pathway will be from point of diagnosis to end of life.

## Chapter 3: Our plan for the next five years

We want to achieve our vision both for those who are currently living with dementia and their carers, but also consider how we can improve the health of the population into the future so we can minimise the number of people developing dementia. To do this, we need to look at where we are now, where we want to be by 2029 and identify what we need to do to get there. We will be doing this by looking at the following aims in turn:

1. Raising awareness, understanding, providing information and advice.
2. Improving people's experience of receiving a diagnosis of dementia, living with dementia, and dying with dementia.
3. Improved performance against the national diagnosis rate target.
4. Championing innovation and participation in research.

### 1. Raising awareness, understanding, providing information and advice

There is growing evidence that people can reduce their risk of developing certain types of dementia, or delay onset by 40%, by making changes to their lifestyle, particularly in mid-life<sup>16</sup>. It is important that our approach to dementia prevention is informed by the latest research and evidence about dementia risk factors. Tackling these risk factors will require action across the ICS. Prevention is one of the key strategic priorities driving our health and care reforms and our local District Councils play a big part in getting the population moving.

The voluntary, community, faith and social enterprise (VCFSE) sector has a clear role to play in prevention, particularly regarding reducing later life risk factors. Many VCFSE organisations are undertaking preventative work as their core work and opportunities should be sought to commission this work across the ICS footprint.

As dementia is a disease highly related to age, prevalence is higher in areas with a substantial proportion of older people. The prevalence of dementia is anticipated to grow in parts of the county where populations are ageing and where health is poor due to deprivation, with the greatest increases in projected prevalence driven by growth in the older adult population. Again, people with a learning disability are at an increased risk due to wider social determinants of health.

Even though dementia prevalence is expected to increase due to the ageing population, the evidence in the Lancet Commission's review<sup>17</sup> of the latest evidence into dementia shows that up to 40% of cases of dementia might be prevented or delayed if action is taken in twelve areas:

- Risk factors during early life
  - less education
- Risk factors during middle life
  - hearing loss

<sup>16</sup> [Dementia prevention, intervention, and care: 2020 report of the Lancet Commission - The Lancet](#)

<sup>17</sup> [Dementia prevention, intervention, and care: 2020 report of the Lancet Commission - The Lancet](#)

- traumatic brain injury
- hypertension
- excessive alcohol
- obesity
- Risk factors during later life
  - smoking
  - depression
  - social isolation
  - physical inactivity
  - air pollution
  - diabetes

Exposure to many of these twelve risk factors are not just a matter of personal choice, they can also be the social and physical environments people grow up in. People from some ethnic minorities and from more deprived backgrounds, along with those with learning disabilities, are more likely to get dementia because they are more likely to be exposed to things that raise their dementia risk. For example:

- the least well-off are twice as likely to be physically inactive than the most well-off.
- ([Physically inactive adults](#), Office for Health Improvement and Disparities (OHID) Fingertips)
- the least well-off are 1.7 times more likely to smoke than the most well-off ([Smoking prevalence in adults \(15+\)](#), OHID Fingertips)
- the least well-off are almost twice as likely to feel lonely than the most well-off ([Loneliness](#), OHID Fingertips)

The symptoms of dementia occur when the brain is affected by certain diseases, and by keeping our brains healthy we may be able to prevent many cases of dementia.

By the end of this five-year strategy, we want to see a significant reduction in the number of people who develop dementia through reducing their risk factors, by scaling up our ambition on prevention. We also want to focus on reducing dementia amongst those at greatest risk – people from deprived and ethnic minority backgrounds. To achieve these aims, we will work over the next 5 years to make progress in:

1. raising awareness and understanding that people can reduce or delay their risk of developing dementia.
2. reducing dementia inequalities, such as those that exist between different ethnic groups, and exploring opportunities to develop community interventions.
3. taking action across the twelve risk factors for dementia, through public health approaches.
4. ensure individuals with a diagnosis of dementia continue to live well and access support enabling them to enjoy life whilst living with dementia.

## **Raising awareness, understanding, providing information and advice regarding dementia risk factors**

The ICS will work to raise public awareness of dementia risk factors. Promotion in schools, Personal, social, health and economic education (PSHE) sessions ensuring education on the importance of knowing how to reduce risks in later life. Local District Councils will promote via leisure centres, Active Lives and Comms teams etc. This will encourage people to take action to reduce their risk factors for heart and brain health. This will build on the message of ‘what’s good for the heart is good for the brain,’ and vice versa. This will include a communication plan for Lancashire and South Cumbria tailoring appropriate messages and interventions to differing audiences, linking with all communities, developing messaging designed to support behaviour change.

The availability of NHS Health Check includes information to raise awareness of dementia risk factors and the Integrated Care System will be taking action to put in place the recommendations from the NHS Health Check review to maximise its impact through digitisation and increasing participation. By improving participation, the NHS Health check will not only raise awareness of dementia risks but support more people to make changes and access the treatment they need to address dementia risk factors such as high blood pressure, obesity, and physical inactivity.

As experimental treatments are developed for Alzheimer’s Disease the ICB needs to recognise the importance of being proactive in identifying individuals who due to family medical history are more likely to develop dementia. Once individuals are identified genetic studies, especially in our young-onset patients and their relatives can commence. This will enable individuals to access appropriate new drug treatments which may aid the slowing down of the decline for these individuals.

## **Reducing dementia inequalities and support offer**

Certain groups of people will have different levels of risk of developing dementia and specific needs such as those with young-onset dementia, people with ethnic diverse backgrounds and people with learning disabilities. Stigma around dementia means that it is a taboo subject for many diverse ethnicities living with dementia and their family carers. So, family carers and the person with dementia hide it and do not easily seek support. This leads to service providers sometimes thinking the ethnic diverse communities are happy to look after their own because their numbers are very low at the point of needing help and support. The ICS will use data available to understand the variance across Lancashire and South Cumbria, identify areas of the ICS which require work to ensure all communities are aware of the support available for individuals living with dementia.

The NHS is working on addressing health inequalities at both national and system level through its ‘Core20PLUS5’ approach<sup>18</sup>. This is a contribution to a wider system effort led by Local Authorities, communities and the Voluntary, Community and Social Enterprise sector. This approach targets the most deprived 20% of the population as well as five areas of focus, including hypertension.

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<sup>18</sup> [NHS England » Core20PLUS5 \(adults\) – an approach to reducing healthcare inequalities](#)

Alongside this action for specific groups, we will help people to resume some of the activities they used to do before the COVID-19 pandemic by launching a ‘reconditioning programme’ aimed at building up strength. Public Health England’s (PHE) [‘wider impacts’](#) report showed that the decline in physical activity (especially strength and balance) during the pandemic had caused a loss of conditioning amongst older people, with a predicted extra 254,000 falls a year at a cost of £211m to the health and care system. Using this evidence, £3 million funding from the Adult Social Care White Paper<sup>19</sup> was allocated to a prevention initiative to address ‘reconditioning’ of older adults. The ‘innovation fund’ will be for local areas to tackle deconditioning over 3 years. People with a learning disability are at increased risk in this area due to often being reliant on others to access activities alongside not always having the funding for carers to support these types of activities and not always being accessible.

## **2. Improving people’s experience of receiving a diagnosis of dementia, living with dementia, and dying with dementia.**

We want to improve the experiences that people face when being diagnosed and living with dementia, both for themselves and their carers. There are examples of where this is currently working well, but we know there is some way to go.

Consideration needs to be given to the differing needs dependant on the age of the person receiving diagnosis and background around their dementia, for example Korsakoff and alcohol/ drug dependency or a 50-year-old with Lewy body dementia because of Parkinson’s disease will have very different needs to a 95-year-old with vascular dementia. We need different support for each of these types of people and need to involve those people in the development of the services rather than what we think they would need.

Part of the work taking place in the development of this ICS strategy is to incorporate individual organisations strategies and ensure that examples of good practice currently being delivered in areas of Lancashire and South Cumbria are recognised and implemented across the whole of Lancashire and South Cumbria.

We want to ensure that people who have received a diagnosis of dementia are treated and supported as a whole person. People and their carers are experts in their lives and their knowledge, views and wishes and should be respected as such and at the centre of identifying support and care planning. Good practice for people with a learning disability and Downs Syndrome is that baseline screening is recommended due to limitation of using standardised assessment processes for the general population for this client group. People need to be assessed against their own baseline; this is currently occurring only in parts of LSCFT. For this to occur investment would be needed in a baseline screening programme. Therefore, we want to ensure that the ICB frailty programme is linked to the dementia programme, enabling people to have one care plan reflecting both their physical and mental health needs. This will assist all health care professionals to understand the whole persons needs and ensure the most appropriate support is provided.

Coordinated pathways between services for people with a learning disability (memory assessment services, older adult mental health, learning disability services)

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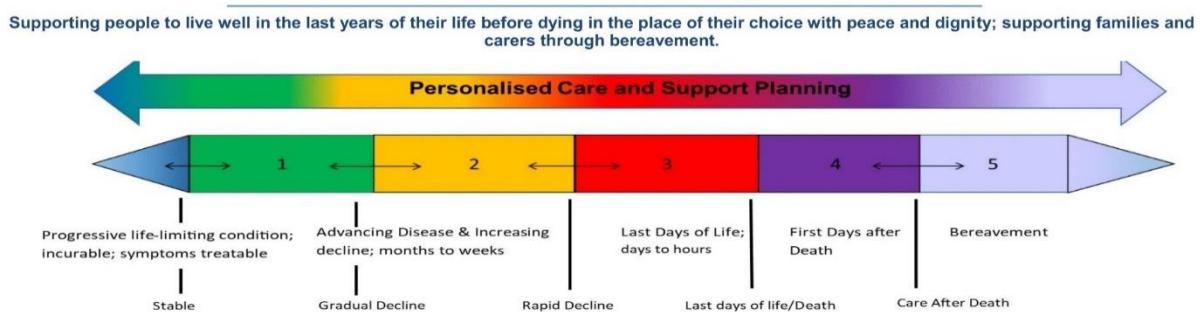
<sup>19</sup> [People at the Heart of Care: adult social care reform white paper - GOV.UK \(www.gov.uk\)](#)

with clear roles and responsibilities. Consideration needs to be given regarding reasonable adjustments for people with learning disabilities to enable them to access interventions for people with dementia available to the general public e.g., cognitive stimulation therapy groups.

Recognising that some people live for significant periods following diagnosis before they need to access formal care services or dementia related health care, the importance of supporting people living with dementia and their carers to have opportunities to have an active life and remain involved, utilising a strength-based approach, is essential and ensure that people with dementia and their carers continue to have a good quality of life, living well in their communities. Ensuring that people living with dementia and their carers are supported to continue to access community groups and community activities which enhance their quality of life and reduce social isolation and the increase in levels of anxiety.

Dementia as a cause of death and as a mention of dementia recorded on the death certificate has increased from 6.6% to 12.0% in England. Dementia North West guidance <sup>20</sup>. Despite this a dementia diagnosis is not always recognised as a life limiting condition and therefore palliative and end of life care approach to care isn't always considered. The North West Model for Life Limiting Conditions below suggests that personalised care and support (PCSP) or advance care planning (ACP) should be considered at the point an incurable and progressive life limiting condition is diagnosed.

#### North West Model for Life Limiting Conditions



We want people living with dementia and their carers to have access to assistive technology and digital tools, which will enable them to live well in their own homes for as long as possible.

Lancashire TEC is available for those who want reassurance that they will receive help quickly and easily in an emergency<sup>21</sup>. The service is available to all, regardless of Care Act eligibility, however you must live within the Lancashire County Council boundary. There are different levels of monitoring technology to choose from. Note there is a weekly charge for this service.

<sup>20</sup> [palliative-care-guidelines-in-dementia.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/palliative-care-guidelines-in-dementia.pdf)

<sup>21</sup> [Telecare services - Lancashire County Council](https://www.lancashire.gov.uk/leisure-and-culture/telecare-services-lancashire-county-council)

## **Dementia diagnosis**

Dementia is frequently not recognised as a life-limiting condition nor considered suitable for palliative care. Getting a diagnosis removes uncertainty for people and families and is an essential first step in enabling them to make sense of symptoms. A timely and accurate diagnosis opens the door to care and support, empowering people to play an active role in managing their condition and enabling them to plan for their future. This can be more challenging for some populations e.g., people with a learning disability due to communication barriers, reliance on second hand reporting from families/paid carers, risks around diagnostic overshadowing, alongside assessments not being standardised for this population. Initial clinical PDS provided by the memory assessment service will support the person and families/carer working to understand the implications of the diagnosis and any treatment which may be available to them, dependent on the type of dementia. A referral to non-clinical PDS available across Lancashire and South Cumbria providing access to ongoing support for the person and family/carer working providing bespoke, person-centred support, working out problems and producing together a forward support plan with contact available as frequently as required.

## **The health and care experience of those living with dementia and their carers**

Personalisation is at the heart of the Department for Health and Social Care's reform agenda, empowering patients to have a say in the way their care and support is delivered.

Following a dementia diagnosis, the way the health and care system works, including its support to people who might care for people living with dementia, is critical.

Integrated and person-centred health and care is vital in improving all aspects of dementia care from the point of identification of symptoms to end of life. However, there is still too much variation in the health of people living with dementia and their carers receive. As an ICS consideration should be given to the establishment of dementia friendly communities and related activities. With a commitment to changing perceptions and educating communities. Enabling people with dementia to access the support they want and require.

When thinking about health and care it is important to avoid a one size fits all approach, especially for people with dementia. The help and support available should correspond to the needs and wishes of people from a wide range of ethnic groups reflective of the patient population across Lancashire and South Cumbria. Instead, the focus should be on personalised care that meets the specific needs of the person.

Most people with dementia will need or would benefit from professional support and care at some point. It is widely accepted that care and support for people with dementia should be person-centred. This means providing services adapted to the needs and wishes of each person with dementia. These will usually be linked, to some extent, to their cultural, religious, and linguistic backgrounds. Ensuring every person is considered unique, valued, and is treated with respect and dignity.

## **Unpaid carers**

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. Unpaid carers play a huge role in the care of those living with dementia and it is important that they get a chance to access the support available to them.

Information should be offered to carers to ensure they understand the changes they may witness in the individual they are caring for and the availability of counselling for carers and family members, struggling to come to terms with the diagnosis and the decline of the person they are caring for.

All carers are legally entitled to a carer's assessment of their needs independent of the person they care for - yearly or when circumstances change. Young carers are entitled to a young carer's assessment. No thresholds need to be met ahead of the assessment. Local carer organisations provide information and advice to all carers. Carers will be entitled for financial support if they meet the national eligibility criteria. The Lancashire and South Cumbria Integrated Care Partnership has a Carers Charter which sets out what carers can expect from services across Lancashire and South Cumbria. (See details and link at end of the strategy document)

As part of the strategy the ICS will ensure that carers are recognised, valued, and respected in their caring role and treated as experts by experience. We will listen to carers and share relevant and meaningful information in relation to the person they care for. We will ensure that health and care services are aware of the support available to unpaid carers across the whole of LSC and know how carers can access it, so they can successfully link carers to adequate support.

Identifying of carers and promotion of the carers assessment will be part of the PDS offer commissioned.

Primary Care Networks will also be assisted to identify carers and consideration will be given to carers when ensuring they receive support to access GP appointments and health care.

## **Coordinated approach to safeguarding**

People living with dementia can be additionally vulnerable to health, wellbeing, and safety concerns. Memory loss symptoms can particularly cause rise to inadvertent self-harm concerns, such as under- or over-taking medications or missing meals and drinks; while symptoms, changing behaviours or how we respond to information and our needs can put our personal safety at risk (such as night-time walking while disorientated) or risk to others (threats and physical abuse). These can also bring about or be a sign of carer breakdown. We know demands on health and social care (and people sometimes hesitating to ask for help from health professionals) and the continuing impact of covid delays has meant more people having fewer and less timely contacts with professionals who might have intervened on signs of risks at earlier stages.

People in these situations will also continue to increase as the number of people living with dementia does.

This means an opportunity to help people better by identifying best practice for a measured, informed, coordinated response where anyone in and around the dementia care pathway encounters people living with increasing risks. Detail on how this can be done to ensure individuals with dementia/learning difficulties are supported are covered by the Mental Capacity Act and Best Interest process.<sup>22</sup>

### **Greater use of technology enabled care**

Technology has so much to offer people living with dementia and their carers: access to information, advice, and entertainment as well as reassurance for a carer who does not live near a loved one. Used sensitively and thoughtfully, technology enhances rather than replaces human relationships and interactions.

TEC can:

- Support diagnosis, assessment, and monitoring.
- Provide an array of communication methods so people with dementia can maintain important relationships.
- Bring the world of entertainment into someone's life, offering a wealth of opportunities for the person with dementia to learn, laugh and enjoy.
- Provide an array of methods so people with dementia can be informed, stimulated, and engaged; and
- Help people to remain independent providing support without compromising care.

As the generation of people living with dementia become more tech savvy, harnessing everyday technologies to support care could enable remote and virtual preventative care and support the first steps on the care continuum. The shift from reactive to more proactive and less obtrusive technology, such as passive sensors, will also drive in-home monitoring as a support tool that should particularly be used to monitor (the risk of) falls, day and night rhythm, personal hygiene, nocturnal restlessness, and eating and drinking behaviour.

There are a multitude of benefits technology, machine learning and Artificial Intelligence (AI) can bring in the health, care and leisure for people living with dementia and their caregivers. However, issues such as privacy and consent, information overload and ethical concerns related to dehumanising care, need careful consideration with the person's safety and best interests at the centre of any decisions made.

The pace of TEC development requires urgent policy, funding, and practice change, away from a narrow medical approach to a holistic model that facilitates future risk reduction and prevention strategies, enables earlier detection, and supports implementation at scale for a meaningful and fulfilling life with dementia.

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<sup>22</sup> [Mental Capacity Act - Social care and support guide - NHS \(www.nhs.uk\)](https://www.nhs.uk/conditions/mental-capacity-act-social-care-and-support-guide/)

Too many people are diagnosed late meaning they often do not receive appropriate or timely access to technology. Early intervention is necessary and offers an excellent opportunity to enhance the quality of life of both the individual with dementia and their carer. Getting the right support in place early may mean that an individual can continue to live in an environment of their choice with independence and dignity and help to ensure that the appropriate assistive technology package is provided to them. Across Lancashire and South Cumbria, we will ensure that access to technology and TEC monitoring services will not require a formal diagnosis.

Advance care planning and technology assessments are at the very core of future technology provision.

### **Training of the health and care workforce**

Evidence suggests that people with dementia occupy at least a quarter of hospital beds and up to two thirds of homecare and care home places ([Dementia the true cost](#), 2018). This means that most health and social care professionals will support someone with the condition at during their career.

This includes carers awareness training for health and social care professionals, so they know how to identify carers, involve them in decision making and signpost them to support available.

We know that receiving good quality care improves the lives of people living with dementia, as well as the lives of their carers. It is crucial that we equip the health and social care workforce with the skills they need for providing high quality care and support for those living with dementia and support to their carers.

We have good foundations in place to build from. In recognition of the need to improve dementia training standards, the [Dementia Training Standards Framework](#) was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care in 2015. The framework was designed to help support the development and delivery of appropriate and consistent dementia training and education for the health and care workforce as well as wider workforce groups within settings which support individuals with dementia and carers. The framework covers 14 subjects and is split into 3 tiers that are described as:

- Tier 1: dementia awareness raising, in terms of knowledge, skills and attitudes for all those working in health and care settings and taking into consideration awareness around at-risk populations, e.g., people with learning disabilities.
- Tier 2: knowledge, skills and attitudes for roles that have regular contact with people living with dementia.
- Tier 3: enhancing the knowledge, skills, and attitudes for key staff (experts) working with people living with dementia as well as training to raise awareness of carers and the roles they play.

The Challenge on Dementia 2020<sup>23</sup> aimed for all NHS staff to receive dementia training appropriate to their role, for new healthcare assistants and social care support staff to undergo training as part of the Care Certificate, and for the Care Quality Commission to ask for evidence of compliance as part of their inspection.

The ICS is committed to ensuring the health and social care workforce can deliver personalised support that recognises the individual needs of people affected by dementia, from the point of diagnosis until they die, so that people are receiving the care and support they want and need regardless of the individual's ethnicity or setting they are in. Collaborative health and social care staff training should reiterate dementia as a life-limiting condition and embed dementia palliative and end-of-life care into core competencies. Training for the health and social care workforce regarding the importance of engaging in sensitive conversations around needs and desires for individuals with dementia early in the dementia pathway – Advance Care Plans and Ceilings of Treatment personal views, whilst the individual still has capacity. The ICS also wants to ensure that health and care professionals support carers so that they feel able to provide the care they want to. Involving carers in decision making and listening to what matters to them is especially important in all aspects of transfer of care between settings.

Care homes across Lancashire and South Cumbria provide care for residents living with dementia and for many of those they will be in the last year of their life and therefore will have PEOLC needs. The ICS needs to ensure that the care home workforce has dementia and PEOLC training as part of their overall standard training. This will not only ensure that residents receive the best quality of care, but it will also ensure that the care home workforce feels equipped to deliver the care required for residents.

Particular attention should be paid to those people with young-onset dementia and their families, who often have complex diagnostic management and personal needs. It is important that these needs are met in a timely and effective way ([Young-onset dementia in mental health services](#), 2018). We will assess how we can ensure staff have the right combination of expertise and training that will ensure that people with young-onset dementia, as well as children and young adults identified with dementia and people with dementia from ethnic minorities and learning disabilities, are able to have their needs considered and met.

Through the development and delivery of a high-quality dementia training programme that all health and social care professionals can benefit from, we can set a standard of care across the board.

### **3. Improved performance against the national diagnosis rate target**

By the end of this 5 year strategy we want to ensure that receiving a timely and accurate diagnosis of dementia is the norm so that individuals can access the advice, information, care and support that can help them to live well with the condition and remain independent for as long as possible.

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<sup>23</sup> [Prime Minister's challenge on dementia 2020 - GOV.UK \(www.gov.uk\)](#)

The ICB will support Lancashire Care Foundation Trust with the delivery of the memory assessment services, monitoring the dementia diagnosis rates across Lancashire and South Cumbria to improve the experience of individuals who are referred to memory assessment services with a suspected dementia, and that all memory assessment service teams achieve the national dementia diagnosis rate target of 66.7%. With the aim to continually increase the diagnosis rate achieved each year.

#### **4. Championing innovation and participation in research**

One of the major difficulties dementia researchers continue to face is recruiting the most appropriate participants for their studies. At the same time, many people are looking for studies to contribute to and take part in, but don't know how to find out about them.

In Lancashire and South Cumbria we will ensure that services (Memory Assessment services and Post Diagnostic Support providers) are aware of the opportunities available to individuals wanting to participate in research studies and how to access them as part of the post diagnostic offer.

## Chapter 4: Delivery of enablers for this strategy

This five-year strategy will only be successful if the right infrastructure is there to support it. To ensure this is in place, the ICS has identified three key cross cutting enablers, where we feel, activities are needed to support delivery of the above proposals and our overall strategic vision for the next 5 years. Scoping and making progress in these areas will be a key focus initially to help lay the foundation for delivering on the commitments within this Lancashire and South Cumbria strategy.

### Appropriate governance processes and structures

For this five-year strategy to be a success, we need to ensure that we have tangible and ambitious targets that are measurable. To ensure the actions set out in this and subsequent implementation plans are delivered on time and make a real difference to people living with dementia and their carers. The ICS will need to ensure it can monitor progress against measures of success through a strong overarching governance structure which is fit for purpose.

To achieve this, we will:

1. Establish a clear implementation plan for the five-year plan including identifying who is responsible for delivery, how success will be measured and when we expect to see change.
2. Introduce a governance structure: an implementation group of delivery partners who are accountable to the Lancashire and South Cumbria ICS for monitoring overall progress and themed subgroups focussing on key aspects of the plan that ensure broad and inclusive representation.

### Improved collection and utilisation of data

Data can help us in many ways, including understanding the impact of health inequalities, targeting advice to at-risk groups, and measuring variations in the provision and effectiveness of post-diagnostic support.

In June 2022, the government published *Data Saves Lives: Reshaping Health and Social Care with data*<sup>24</sup>, following an engagement period and public survey. The strategy sets out three key priorities around how data can be used to improve care for individuals in Lancashire and South Cumbria living with dementia and their carers:

1. Increase transparency, understanding and trust in how data can be used to improve health and care services.
2. Making appropriate data access the norm and not the exception across health, social care, and public health

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<sup>24</sup> [www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data](https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data)

### 3. Building the right foundations – technical, legal, cultural, regulatory to make that possible

As the dementia strategy is implemented each organisation will need to review any relevant data being collected and whether it enables us to measure the impact the changes have had on the services provided for people diagnosed with dementia and their carers. Collaborative system wide dashboard development is necessary to triangulate available data from the point of diagnosis until death, which focuses on outcomes, quality of care and identifies inequalities. This will provide meaningful data which will support service improvement priorities.

### **Greater engagement of people affected by dementia**

For this strategy to result in meaningful change for people living with dementia and their carers across Lancashire and South Cumbria, the ICS must ensure that there are processes in place that allow them to feed in their views and feedback on the progress. It is important that this strategy is grounded in the experiences of those living with dementia and their carers throughout the course of the 5 years, so that we can measure the impacts across Lancashire and South Cumbria.

## **Chapter 5: Next steps**

An ICS dementia action plan has been developed as part of the overall five-year strategy. This will be monitored by members of the strategy group and assurance provided through agreed governance structures for each of the organisations signed up to deliver this work.

As the strategy is delivered feedback will be obtained from people with dementia and their carers on the impact the work is having on the quality of care received and to identify any areas which require further work to improve the experience of individuals living with dementia and their carers. This will be carried out throughout the five-year period and will be a vital part of the assurance that the strategy is achieving what it set out to achieve.

As part of the ongoing review of the impact the strategy is having on the quality and consistency of services for individuals living with dementia and their carers, engagement with the groups listed in the Appendices will take place. This will assist in the review and identification of any further work required to ensure the population of Lancashire and South Cumbria receive good quality services and support when required.

## Appendices

### Appendix 1 – Carers information and groups

- 1.1 **Lancashire Carers Service** – Do you have a relative, friend or neighbour who cannot manage without your support. The Lancashire Carers Service may be able to help. They can provide specialised 1-2-1 and group support; carers assessments; chat lines etc. For North and Central Lancashire, Telephone 0345 688 7113 Option 2. For East Lancashire it is Option 1.
- 1.2 **North and Central Lancashire - N-Compass** (Lancashire Carers Service) [Advocacy, Carers, Well Being & Young People | n-compass](#) Tel: 0345 688 7113 Email: [enquiries@lancscarers.co.uk](mailto:enquiries@lancscarers.co.uk)
- 1.3 **Blackpool Carers** [www.blackpoolcarers.org](http://www.blackpoolcarers.org)
- 1.4 **Blackburn with Darwen** [www.bwdcarers.org.uk](http://www.bwdcarers.org.uk)
- 1.5 Carer Support **Cumbria** All Age Carers Support Services for both Cumberland and Westmorland and Furness Council's: [Carers Support Cumbria](#) Tel: 08443 843230
- 1.6 Carer Support **Furness** All Age Carers Support Services. Adult Carers (including Parent Carers) and Young Carers [Carer Support Furness](#) Tel: 01229 822822 Email: [admin@carersupportfurness.co.uk](mailto:admin@carersupportfurness.co.uk)
- 1.7 Carer Support **South Lakes** All Age Carer Support Services. Adult Carers (including Parent Carers) and Young Carers [Carer Support South Lakes - Improving the lives of carers](#) Tel: 01539 815970 Email: [admin@carersupportsouthlakes.org.uk](mailto:admin@carersupportsouthlakes.org.uk)
- 1.8 Carer Support **West Cumbria** All Age Carer Support. Adult Carers (including Parent Carers), Young Carers across the West Cumbria area (including Millom): [Carer Support | Carer Support West Cumbria | England](#) Tel: 01900 821976 Email: [general@carersupportwestcumbria.co.uk](mailto:general@carersupportwestcumbria.co.uk)
- 1.9 Carer Support **Carlisle & Eden**, Carlisle Office Tel: 01228 580214, Penrith Office Tel: 01768 890280 Email: [enquiries@carlisle-eden-carers.org.uk](mailto:enquiries@carlisle-eden-carers.org.uk)
- 1.10 **East Lancashire** [Home | carers-link-01 \(carerslinklancashire.co.uk\)](#) Tel 01254 387444 Email: [info@carerslinklancashire.co.uk](mailto:info@carerslinklancashire.co.uk)
- 1.11 Rethink **Mental Illness** Carers Advocacy Service [lancscarersgroup@rethink.org](mailto:lancscarersgroup@rethink.org)
- 1.12 Child Action Northwest for **Young Carers** (Blackburn with Darwen) <https://canw.org.uk/what-we-do/support-children-and-young-people/young-carers/>
- 1.13 Barnardo's **Young Carer Support** (LCC) [www.barnardos.org.uk/what-we-do/services/lancashire-young-carers](http://www.barnardos.org.uk/what-we-do/services/lancashire-young-carers)

## Appendix 2 – Glossary

<b>ACP</b>	Advance care planning
<b>AI</b>	Artificial intelligence
<b>CHL</b>	Care Home Liaison
<b>CPEC</b>	Care Policy and Evaluation Centre
<b>CMHT</b>	Community Mental Health Team
<b>ICB</b>	Integrated Care Board
<b>ICS</b>	Integrated Care System
<b>LSC</b>	Lancashire and South Cumbria
<b>LSCFT</b>	Lancashire and South Cumbria NHS Foundation Trust
<b>LA</b>	Local authority
<b>MAS</b>	Memory Assessment Service
<b>OHID</b>	Office for Health Improvement and Disparities
<b>ONS</b>	Office for National Statistics
<b>OHE</b>	Office of Health Economics
<b>OA CMHT</b>	Older Adult Community Mental Health Team
<b>PEoLC</b>	Palliative and End of Life Care
<b>PHSE</b>	Personal, Health, Social, and Economic education
<b>PCAS</b>	Personalised Care and Support
<b>PDS</b>	Post Diagnostic Support
<b>QOF</b>	Quality and Outcomes Framework
<b>RITT</b>	Rapid Intervention and Treatment Teams
<b>TEC</b>	Technology enabled care
<b>VCFSE</b>	Voluntary, community, faith and social enterprise