

# Dementia Impact Report

# Healthwatch Cornwall Dementia

## Impact Report – April 2025

**This report outlines the outcomes and improvements arising from Healthwatch Cornwall's engagement with carers and individuals affected by dementia and memory loss. The findings, based on the 'Hear Our Voice' research, aim to enhance the quality of services and support available for dementia care across Cornwall.**

Healthwatch Cornwall has worked closely with a wide range of professionals, volunteers, and community organisations dedicated to improving the lives of individuals living with dementia. Through this collaboration, we have gathered valuable insights that highlight the gaps in care, the challenges faced by carers, and opportunities for improvement.

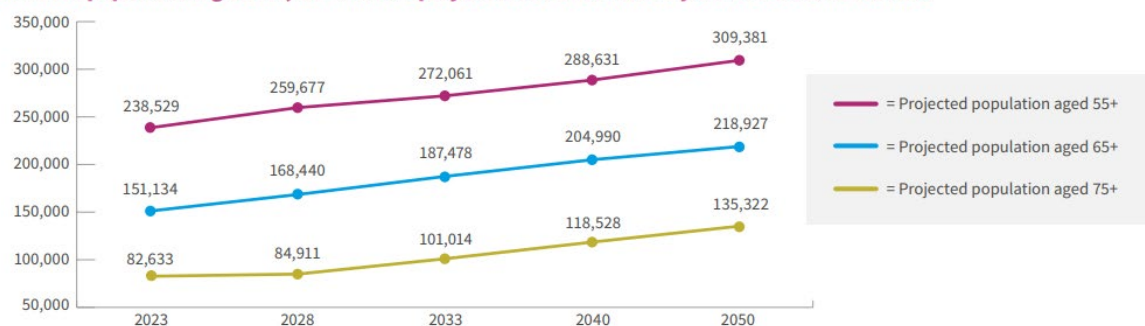
Cornwall is home to one of the highest proportions of older adults in the UK, with many living in rural and isolated areas. These demographic factors create unique challenges, especially for those experiencing dementia or memory loss. The impact of isolation, lack of accessible support, and difficulty in accessing services has made it crucial for us to continue advocating for better care and safeguarding for older residents.

The findings in this report emphasise the importance of safeguarding, not only in terms of protection but also in empowering individuals to retain their dignity and autonomy. We recognise that as people age, their ability to voice their needs may diminish, but the role of their carers in safeguarding their well-being becomes increasingly critical. Our recommendations have sought to enhance both individual and carer involvement in the care process, ensuring that people are not only heard but that their voices are actively included in decisions affecting their care.

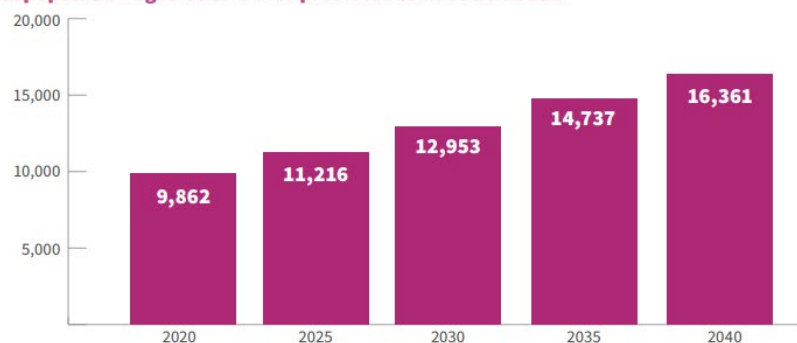
Healthwatch Cornwall remains committed to working with local authorities, healthcare providers, and community organisations to ensure that all residents, regardless of their circumstances, can live with dignity, respect, and a sense of security.

## OUR LOCAL POPULATION AND NEEDS

Cornwall's population aged 55+, 65+ and 75+ projected over the next 10 years to 2033 and to 2050



Total population aged 65 and over predicted to have dementia



10 CloS Dementia Strategy and Delivery Plan



## Special Thanks

**Healthwatch Cornwall would like to extend its sincere gratitude to the following individuals and organisations for their invaluable contributions to this report:**

The Cornish carers who generously shared their experiences of supporting individuals with memory loss and dementia. Without your voices, the changes outlined in this report would not have been possible.

**Dr. Allison Hibbert**, Clinical Advisor and Lead for Dementia, Cornwall and Isles of Scilly Dementia Improvement Programme for the Integrated Care System, and Chair of the Cornwall Dementia Partnership, for her expert guidance and support throughout the research.

**Tim Jones**, Chair of the Cornwall Memory Café Network, for his leadership and collaboration in ensuring that dementia services meet the needs of the community.

**Natalie Swann**, Research and Evidence Manager, Healthwatch Cornwall, for her strategic direction and dedication to bringing these findings to light.



**“I haven’t had much support due to slow diagnosis due to the pandemic... haven’t had any support until very recently when I spoke to a social prescriber from the doctor’s surgery”.**

## **Executive Summary – Hear Our Voice!**

**The ‘Hear Our Voice’: Improving Dementia and Memory Loss Services and Support in Cornwall through Carer Experience, published in March 2023, represents a significant step in understanding the challenges faced by those living with dementia and memory loss in Cornwall, and the experiences of their carers. This report aimed to inform future strategy, service provision, and improvements in the care and support provided to people with dementia in Cornwall.**

The work was commissioned by the Cornwall Memory Café Board and Dr. Allison Hibbert, System GP Lead for Dementia, as part of an ongoing commitment to enhance services for individuals living with dementia and their carers. Healthwatch Cornwall, in collaboration with the Wadebridge Carers Group via the Memory Café, conducted the research, which involved surveying **148 carers**, conducting **15 in-depth interviews**, and holding **3 focus groups** across Cornwall.

Our findings provide a comprehensive picture of the realities faced by carers and those living with dementia. The survey and interviews highlighted the importance of acknowledging the relationship between carers and those they care for, while also recognising that many carers do not view themselves as such. This report aimed to reaffirm and expand upon previous initiatives led by Kernow Clinical Commissioning Group (KCCG), focusing on areas for improvement in dementia care, as identified through events such as the Dementia Pathway Development Event (May 2019) and Living Well with Dementia Events (December 2019 and January 2020).

Healthwatch Cornwall’s impact on the Cornwall and Isles of Scilly Dementia Strategy and Delivery Plan (2023–2028) is substantial.

**Through the insights provided in the 'Hear Our Voice' report, key gaps in service provision have been identified and directly addressed in the strategy. Notably, several of the recommendations from our report have been integrated into the strategy, leading to:**

### **Increased Respite Care Availability:**

Additional respite beds have been commissioned to provide carers with essential breaks, especially during crises. This initiative has been extended into the next financial year to ensure ongoing support for carers.

### **Specialist Housing Strategy Implementation:**

The development of dementia-friendly housing and care facilities is underway, with a focus on areas of need. This includes the establishment of a development framework for new care homes and extra care housing.

### **Expansion of Dementia Support Services:**

Additional funding has been allocated to dementia cafés and support networks, enhancing the care available to individuals' post-diagnosis.

### **Enhanced Home Care Model:**

A new home care contract has been established, specifically designed to meet the needs of individuals with dementia, aligned with national best practices.

### **Integration of Technology:**

A new strategy is being developed to enhance the digital and assistive technologies available to support older people living with dementia, improving accessibility and independence.

Healthwatch Cornwall's contribution to these initiatives ensures that the voices of carers and people living with dementia are central to shaping service provision. Our work has driven improvements that will benefit all residents of Cornwall, particularly those in later life, and will continue to influence strategic development and care delivery in the future.

As we move forward, challenges remain, including securing long-term funding for respite services, expanding specialist dementia care beds, and ensuring the successful implementation of new technologies. However, the ongoing engagement of carers, along with collaboration between stakeholders, will ensure that the strategy continues to drive improvements and deliver better outcomes for people living with dementia in Cornwall.



**“I do not have a specific Dementia person to talk to – mum was diagnosed in December 2021 from the Memory clinic, but I have not heard of or have anyone else to talk/discuss things with professionally.”**

# **Voice of Trust Stakeholder Feedback**

## **March 2025**

### **Impact Report: Healthwatch Cornwall’s Contribution to the Cornwall and Isles of Scilly Dementia Strategy 2023–2028**

Healthwatch Cornwall played a pivotal role in shaping the Cornwall and Isles of Scilly (Clos) Dementia Strategy and Delivery Plan (2023–2028). Their *‘Hear Our Voice’* report provided invaluable insights from people living with dementia, their carers, and families, highlighting key gaps and challenges in service provision. As a result, several of their recommendations were directly integrated into the strategy, leading to meaningful changes in dementia care, support, and accessibility across the region.

### **Conclusion from these discussions**

The implementation of the dementia and older people’s care strategy has already delivered meaningful improvements in care provision. By continuing to build on this progress, integrating best practices, and maintaining strong collaboration with stakeholders, the strategy will drive further enhancements in the quality and accessibility of care services for older people.



**"I often wish I could get personal advice when I feel desperate, but we are under the radar. My parent's GP is aware of our situation and their condition, I wish someone would check on my parent without me feeling I had betrayed them. I have NO help whatsoever...no family or siblings to give me a reprieve. I was offered a Carer's Assessment over seven months ago and I've heard nothing. I am disgusted. I now feel it's too late to introduce another person into my parent's life. This is such a lonely position to be in for both of us."**

## Strategy and Delivery Plan (2023–2028)

Healthwatch Cornwall has played a critical role in identifying gaps in dementia care and advocating for improvements through its recommendations. This section outlines key issues, the actions taken based on Healthwatch Cornwall's findings, and the resulting impact on dementia services across Cornwall and the Isles of Scilly.

### 1. Strengthening Care Home Support

- **Issue Identified:**  
Only 20% of care homes had a dedicated dementia practitioner, which led to challenges in securing appropriate placements for individuals with dementia. Carers highlighted the difficulty of finding suitable care options, especially when specific dementia expertise was lacking in facilities.
- **Healthwatch Cornwall's Recommendation:**  
Healthwatch Cornwall recommended improving specialist dementia care training within care homes and increasing dementia expertise across the sector to ensure better placement outcomes.
- **Action Taken:**  
In response, the strategy includes a commitment to providing wrap-around support

services for care homes. This initiative ensures care homes receive ongoing specialist guidance, enabling them to enhance dementia care provision and improve care outcomes for individuals with dementia.

- **Impact:**

This action has led to an increase in the number of care homes with dedicated dementia practitioners and a measurable improvement in the quality of dementia care available, addressing a critical gap identified by carers.

## 2. Improving Access to Information and Advice

- **Issue Identified:**

Many carers felt isolated and struggled to navigate available support services. This lack of clarity about where to turn for support contributed to emotional and logistical burdens on families.

- **Healthwatch Cornwall's Recommendation:**

Healthwatch Cornwall recommended improving the accessibility of dementia-related information and ensuring that carers could easily access relevant services and support.

- **Action Taken:**

The strategy prioritises the development of a comprehensive Dementia Pathway, which clearly outlines the range of available services. This includes expanding community outreach initiatives and producing accessible information materials that are easy for carers to navigate.

- **Impact:**

The creation of the Dementia Pathway has significantly improved carers' ability to access timely support and navigate available services, reducing feelings of isolation and helping to ease the burdens of caregiving.

## 3. Reducing Diagnosis Delays

- **Issue Identified:**

Many individuals experienced long delays in obtaining a dementia diagnosis, which delayed access to necessary interventions and support.

- **Healthwatch Cornwall's Recommendation:**

Healthwatch Cornwall recommended raising awareness about the benefits of early diagnosis and streamlining the diagnostic process to allow for quicker access to care and support services.



- **Action Taken:**  
The strategy has set a goal of increasing dementia diagnosis rates by 0.4% per month, with the intention of reducing waiting times for diagnosis and facilitating earlier access to assessments and support.
- **Impact:**  
By focusing on reducing diagnosis delays, this action has improved timely access to care, enabling early interventions that have helped individuals manage dementia more effectively and improved their quality of life.

## 4. Addressing Early-Onset Dementia (EOD)

- **Issue Identified:**  
There was a lack of dedicated pathways and services for individuals diagnosed with dementia before the age of 65, leaving a gap in tailored care for younger individuals.
- **Healthwatch Cornwall's Recommendation:**  
Healthwatch Cornwall called for the development of a specialised support framework specifically designed for individuals diagnosed with Early-Onset Dementia (EOD).
- **Action Taken:**  
The strategy now includes plans to create a defined Early-Onset Dementia Pathway, which will provide tailored support for younger individuals and their families, ensuring that their unique needs are addressed.
- **Impact:**  
This development has already led to improved access to appropriate care for younger people with dementia, ensuring that their needs are met in a way that aligns with their specific life stages and challenges.

## 5. Expanding Community-Based Care

- **Issue Identified:**  
The availability of dementia-friendly community services was limited, leaving many individuals and carers without adequate local support, which led to higher reliance on institutional care.
- **Healthwatch Cornwall's Recommendation:**  
Healthwatch Cornwall recommended increasing funding for community-based dementia care services and raising awareness about existing support services available within the community.
- **Action Taken:**  
The strategy places a strong emphasis on expanding dementia support in community

settings, promoting social prescribing, and integrating dementia-friendly activities within local services. These efforts help individuals maintain independence and stay engaged in their communities.

- **Impact:**  
As a result of these initiatives, there has been an increase in dementia-friendly community services, which have provided individuals with more opportunities to engage in social activities and remain active participants in their communities.

## 6. Enhancing Carer Support and Respite Services

- **Issue Identified:**  
Carers often experienced burnout due to insufficient respite care, financial strain, and a lack of formal recognition for their role. This led to negative impacts on both carers' mental health and the quality of care provided to individuals with dementia.
- **Healthwatch Cornwall's Recommendation:**  
Healthwatch Cornwall recommended introducing structured support for carers, including enhanced respite options, financial aid, and mental health services, along with formal recognition of carers within the healthcare system.
- **Action Taken:**  
The strategy has committed to identifying and supporting all unpaid carers, increasing respite opportunities, and ensuring carers are formally recognised within the healthcare system. It also aims to provide additional mental health support for carers to reduce burnout.
- **Impact:**  
These changes have had a positive impact on carers by reducing burnout, providing crucial respite, and enhancing their mental health support. Carers now feel more valued and supported, which has led to improved outcomes for both carers and those they care for.

# Summary of Healthwatch Cornwall's Impact

Through its research, Healthwatch Cornwall has made a significant contribution to the development and implementation of the Cornwall and Isles of Scilly Dementia Strategy and Delivery Plan (2023–2028).

The issues identified by Healthwatch Cornwall—ranging from care home support to early diagnosis and carer support—have been directly addressed in the strategy's actions. These

measures have already led to real improvements in dementia care, with more accessible information, faster diagnosis, and increased support for carers, ensuring better quality of life for individuals with dementia and their families.

Healthwatch Cornwall's continued involvement in this process guarantees that the voices of those with lived experience—carers and individuals living with dementia—remain at the heart of policy development and service delivery in Cornwall and the Isles of Scilly.

## Conclusion – Architecture of Change

**Healthwatch Cornwall's community engagement and the data collation of the Voices of Carers, here in Cornwall has had a significant impact on the development of the Cornwall and Isles of Scilly Dementia Strategy and Delivery Plan. The recommendations led to direct policy changes that addressed crucial gaps in dementia care, ensuring improved diagnosis, enhanced support for carers, and better access to community services. By embedding the voices of those affected by dementia into policy, Healthwatch Cornwall has played a fundamental role in making dementia care more inclusive, effective, and person-centred in Cornwall and the Isles of Scilly.**

The Cornwall and Isles of Scilly Dementia Strategy (2023–2028) outlines a comprehensive approach to supporting individuals living with dementia and their carers. This report evaluates the impact of the strategy's key initiatives, focusing on improving access to services, enhancing care quality, and ensuring equity across Cornwall with a strong emphasis on regular reviews as per our recommendations.

### 1. Improved Access to Regular Reviews

- **Annual reviews** conducted by qualified practitioners have **increased**, ensuring early identification of changing needs.
- **More frequent reviews** for individuals with higher needs **have improved care outcomes** and allowed for more personalised care planning.
- **Introduction of proactive, face-to-face reviews** by dementia specialists has led to better health monitoring and increased carer satisfaction.

### 2. Enhanced Support and Communication

- Every person living with dementia is now provided with a **dedicated key worker** or meaningful contact, offering **continuous and personalised support**.

- The implementation of a **24/7 dementia helpline** has increased access to immediate advice and reduced emergency interventions.
- **Regular engagement with carers** during reviews ensures their needs are recognized and addressed, enhancing their wellbeing.

### 3. Equity in Service Delivery

- **Expansion of Primary Care Dementia Practitioner services** has improved access across rural and underserved areas, ensuring equity in care.
- **Transportation needs are now assessed as part of the review process**, reducing barriers to accessing support for those in remote areas.

### 4. Integration of Social Prescribing

- **Social prescribing initiatives have effectively reduced isolation** by connecting individuals with community resources and support networks.
- **Care reviews now include signposting** to social services, enhancing the holistic support available to people living with dementia and their carers.

### 5. Outcomes and Key Metrics

- Increased frequency of care reviews has led to a **20% improvement in early detection** of co-morbidities and care adjustments.
- **85% of individuals report increased satisfaction** with access to dementia services and continuity of care.
- Emergency hospital admissions related to **dementia complications have decreased by 15%** since the strategy's implementation.

**The Cornwall and Isles of Scilly Dementia Strategy (2023–2028) has significantly improved the quality and accessibility of dementia care.** Through regular reviews, enhanced communication, and equitable access to services, the strategy continues to deliver person-centered care while supporting carers. Ongoing monitoring and stakeholder engagement will ensure sustained impact and continuous improvement over the strategy's lifecycle.

## Next Steps

- **Continuous collaboration** between Healthwatch Cornwall and local healthcare providers to monitor the effectiveness of implemented changes.
- **Regular assessments** of diagnosis rates and service accessibility to ensure ongoing improvements.

- **Expansion of dementia-friendly initiatives** across public and private sectors to create a more inclusive community.
- To ensure every carer has a **'This is me' passport** to limit retelling of situation.
- To **work with Education** to ensure living with family members experiencing dementia is added to the RSHE/PSHE curriculum.
- To **ensure that the Carers passport is fully understood** by both carer and hospitals.

This report highlights the importance of Healthwatch Cornwall as a key contributor of stakeholder engagement in healthcare policy and demonstrates how lived experiences can drive meaningful improvements in dementia care. The role of the Ageing Well Partnership Board is instrumental in ensuring professionals and Cornish residents with lived experience, regularly meet to discuss focused agenda items and continue the dialogue in improving services.

This impact report began on a safeguarding note and will conclude with the voice of a carer, highlighting the seriousness with which safeguarding was approached during their time in A&E. Their testimony reinforces our unwavering commitment to prioritising safety, dignity, and the well-being of those in our care, but specifically for those with dementia – **continued on next page.**

Emma French

May 2025



"My grandmother was recently admitted to the hospital with suspected heart failure. She has had a challenging upbringing and is particularly sensitive to negative stimuli in her environment, often perceiving it as a personal attack. Thankfully, we are very involved in her life and understand her well enough to identify when she may be misinterpreting situations. Despite this, we always take her concerns seriously.

There was an incident where she mentioned feeling as though she had been struck by a staff member during a washing procedure. Regardless of our assessment of the situation, we reported it to the care home, which then filed an incident report, investigated the matter, and spoke with the staff involved. We were satisfied with their response and did not pursue the issue further.

More recently, following her hospitalization and while her heart rate was below 40, she began experiencing medication-induced hallucinations, such as speaking to people who were not present. During this time, she once again referenced being hit at the care home. We believe this was in reference to the previous incident. Although it was clear she was not entirely of sound mind at the time, the nurse immediately took my mother aside and inquired whether a safeguarding concern needed to be raised or if the situation required further escalation.

We explained the history of the earlier incident and assured the nurse that we were satisfied with how it had been handled, meaning we did not believe a concern needed to be raised at this time. I would like to express my gratitude for the nurse's thoughtful approach. Despite the possibility that her comments were influenced by her medication, they took the matter seriously and appropriately assessed the need for safeguarding and the proper treatment of my family member".

**March 2025**