

Hear Our Voice

Improving dementia and memory loss services and support in Cornwall through carer experience

March 2023

Executive Summary and Key Findings





I watch as she continues to decline weekly and feel sad that even as a person who understands the health sector, I am not able to get her access to services that would mean that she and her family that care for her have the quality of life they deserve. The comment that I am sure will haunt me from my mum... "It feels like nobody really cares and I have been left to die." This makes me cry every time I write this, but I will continue to try and make sure she lives well with dementia. What is so hard to see, is the withdrawal of services in our county compared to the investment in services that ensure our ageing population can indeed live well with dementia.

I feel very isolated. In mid-Cornwall, there is a dearth of Memory Cafes.

I had to search out one which is held twice a month and is a 30-minute drive from our home. I need advice e.g. on ways to talk to my (spouse) who is very argumentative and is in denial about their own physical and mental capacity... has multiple health problems so attending courses or even participating in online events is out of the question as I have to be around them 24/7. There must be others like me so support would be much appreciated.

I feel like I was left to figure everything out by myself. Adult social care seemed to think throwing money at us for 'care' was the limit of their responsibility. Money is only useful if you can find services/carers/respite to spend it on. I needed different kinds of help.

(Experiences of services and support)



I feel there should be more regular contact with someone about the patient and the carer. I have been looking after X for more than two-and-a-half years and find it difficult to obtain help. It is not just the patient suffering this terrible illness but the carers who

need more assistance to get better breaks and respite. I have been unable to obtain either.

Most important to us was the role of our Primary Care Dementia Support Worker who was very supportive at all times and always on the end of phone or email should we require it.

Local voluntary groups are fantastic...Memory Cafe, Memory Matters, Sensory Trust, Carers Group. Can't imagine how I would have coped without them.

(What's working Well?)



If there were a way of having regular contact with someone who could keep track of my wife's progress and give information on how things are going and the likely next steps, that would be good. Although I've seen it in other people I've not been 'close' so it is still like I'm walking in the dark.

Help to navigate the system - a directory of services and support provided at diagnosis, so you know what to apply for and when.

Faster diagnosis that enables earlier intervention with preventative services. Better services that focus on preventing the decline of cognition/memory and provide respite for carers. A central hub for information that shows me all the support groups my mum could access...A care plan that focuses on what is important to my mum that I can help her with versus a very medical-focused plan. Clear guidance on what I should look for as a carer regarding safety risks and a single point of access to alert people to my concerns. Care coordinator in place, before the person with dementia and their carer, hit crisis.

(What additional support or new service?)



About Healthwatch Cornwall

At Healthwatch Cornwall, we have a statutory remit to gather people's views and experiences of publicly funded health and social care services locally. We are an independent, publicly funded organisation with the purpose to make sure health and social care services in Cornwall are the best they can be for people, now and in the future.

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Foreword

David Gregory, Cornwall Memory Cafe Network Board, and carer with lived experience

Dementia is a devastating illness that is more than just memory loss. It is a degenerative and life-limiting condition that impacts every level of an individual's physical, cognitive, emotional, and social functioning. The impact of dementia upon individuals, those they care for – and their wider families is almost impossible to imagine.

That is why we must listen to the voices of the people who generously shared their lives through this work and highlight the significant variations across Cornwall. They told us that they need to be listened to and for their needs as individuals to be recognised by professionals and services and wider society. They highlighted the difficulties they have in accessing the information, support, and services that can make a big difference to their lives, often feeling alone at the most difficult times.

This report gives a voice to people living with dementia and those that care for and care about them. It provides an opportunity for us to reflect on where we are now in Cornwall. It has messages for the whole of society and should be used as a challenge to ourselves, to not only build upon what we have already done but also to build upon this in a way that delivers a better quality of life for people living with dementia and their carers.

For too many people living with dementia, the consequences of this disease lead to a withdrawal from wider society and the things, often the smallest of things, that give them pleasure and bring value, meaning, and purpose to their lives. But it is important that as a society we support people with dementia to be included for as long as possible, that we focus on the skills that they still have or can still learn, and that through our actions, we ensure they have the best quality of life for as long as possible.

We need to do more, both within our public services and as a county, to support people in its widest sense to stay included, stay within their own homes and the communities that matter to them, and ensure that our carers have all of the support they need to continue to care for as long as possible. This is good both for individuals with dementia and the public purse. Within Cornwall, we should have a strong focus on well-being and people with dementia must not be excluded from this agenda.

Dementia is a clinical illness. Whilst it is right that we focus on its prevention, diagnosis, and symptoms, we must focus just as much on ensuring that people with dementia are able to have the very best possible lives they can. We must make sure that they feel safe and listened to, valued and respected, can get the help that they need, can do the things that matter to them, and live in a place that suits them and their lives. There will be other things that need to be done,

but the issues raised in this report are the things that people have spoken to Healthwatch Cornwall about and, if implemented, would go a long way towards ensuring that people living with dementia and their carers maximise their quality of life for as long as possible and that they are no longer excluded and unseen, but rather have the best possible quality of life.

Introduction

There are a wide range of health, social care and voluntary sector services in Cornwall which support those affected by dementia and memory loss. These include GPs, memory services, specialist nurses, dementia practitioners and support workers, physio and occupational therapists, social workers, assessments, carers, charities, and local support groups etc. People may have accessed them through their GP surgery, social care services, a hospital, in the home or community, online, or over the phone.

With the aim of informing future strategy, service provision and improvement, Cornwall Memory Cafe Board colleagues and Dr Allison Hibbert – system GP Lead for Dementia, asked Healthwatch Cornwall to conduct this work to gather the experiences of carers of people living with dementia or memory loss (suspected dementia). This was a collaborative approach with aspects of survey co-production supported by the Wadebridge Carers Group via the Memory Cafe.

The survey ran between 29 April and 4 July 2022. We conducted 15 in-depth interviews and spoke with 21 carers in three focus groups held at Memory Cafes across Cornwall.

We report on people's experiences of services and support through the lens of the carer, acknowledging the relationship between the carer and cared for – seeing them as one. While we know many carers do not necessarily see themselves as such, by carer we mean anyone providing unpaid care and support to a family member or friend who needs help because of their illness, frailty, disability or mental health.

This report may serve to both reaffirm and build on the numerous activities undertaken prior to the pandemic coordinated by Kernow Clinical Commissioning Group (KCCG) to identify improvements to better support people and carers of those living with dementia and memory loss: the Dementia Pathway Development Event, 15 May 2019, and Living Well with Dementia Events, 10 and 12 December 2019 and January 2020. These activities identified aspects of what works well, and what needs to improve, which was summarised in the following statement:

“The current provision of post-diagnostic support is well received but is felt to be limited and inconsistent in its delivery across Cornwall. Work is needed to develop a clear minimum offer by developing collaborative approaches with primary care, the voluntary community sector and by engaging with secondary and acute care.”

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 Cornwall Dementia Partnership.

Every day people, family and friends across Cornwall and the Isles of Scilly are living with dementia and every year that number will increase dramatically. Dementia is becoming a common long-term condition.

With this in mind, it is vital that we develop and improve the dementia services we provide, learning from the experiences of local people every step of the way.

It was hearing the story of a carer from a Memory Cafe expressing their concerns at a meeting of the Dementia Partnership Board that led to the suggestion of undertaking this research project.

Having been a carer myself, I know how busy and precious your time is, so I'd like to thank you for taking the time to feedback on your views, experiences and ideas and assure you that your feedback will be used to develop the way we support those living with Dementia.

It is thanks to Healthwatch Cornwall and the Memory Cafe Network that we have been able to gather this vital feedback that is already shaping the way we want to deliver services in the future. There is still further work to do to gather feedback from those living in care homes and care home staff which we will continue to collate in the year ahead.

Recognising that our services need to keep pace with the increasing numbers of people now living with dementia in Cornwall, I am delighted to say that Cornwall and the Isles of Scilly Integrated Care Board have named dementia as one of their five key priority areas for service improvement and development. This means we are prioritising dementia, and we will continue to listen, respond, and act upon your feedback to shape our future services.

You will see from the research report and recommendations that we need to address a wide variety of areas to improve services, including access to useful information, recognition of carers, social care, and health services for older adults living with dementia, but also for those with young onset dementia.

Your feedback also demonstrates the importance of dementia awareness, dementia-friendly environments and inclusive activities, and shows the findings are relevant not only to health and social care settings but all local communities.

We must also acknowledge the challenges for our staff who experience constraints on their time and services that can sometimes prevent them from providing the support that they know is needed. It is clear from this research that we need more staff skilled in dementia care, and this is a key priority for us to deliver on.

Your feedback is an important call to action for our commissioners and service providers who are committed to making sure that people living with dementia can feel safe and supported across Cornwall and the Isles of Scilly.

These recommendations are going to support our ongoing dementia improvement work and the development of local strategies and action plans within the local NHS and Cornwall Council.

I hope the discussion generated by this report inspires, raises awareness in local communities and makes sure we make 'dementia everyone's business'.

On behalf of my colleagues across Cornwall and Isles of Scilly Integrated Care System I would like to thank all who have supported this project, especially carers and people living with dementia, the team at Healthwatch Cornwall, Cornwall Memory Cafe Network and carer group volunteers.

Thank you

Tim Jones, Chair, Cornwall Memory Cafe Network

The Cornwall Memory Cafe Network thanks Healthwatch Cornwall for taking forward this work. The Network, which exists to support the growing number of determined teams of volunteers who run Memory Cafes in Cornwall, frequently hears the anguished words of carers seeking solutions to the challenges they face in accessing sources of help and support.

The Network raised these concerns at the Cornwall Dementia Partnership Board where other members echoed the same experiences. This provided the stimulus for the Chairs of that Board to approach Healthwatch Cornwall for this report. The Network will now wait with anticipation that decision-makers in our new, integrated health and social care system will respond to this report with compassion and action that brings about system change - placing the person living with memory loss and their care partners at the centre of service provision enabling the most appropriate support in its many forms. This being at home, at day resources, and in short-stay settings to provide essential, restorative care and respite that sustains well-being and maintains independence.

We hope that the wait will not be a long one, not least as we are keen to support the development of more memory cafes to fit around the other essential resources that are necessary to provide joined-up care.

Natalie Swann, Research and Evidence Manager, Healthwatch Cornwall

On behalf of Healthwatch Cornwall, we feel privileged to have been involved in this work and remain immensely grateful to all who have contributed to this project and shared their views, experiences, and valuable time.

Special thanks to our colleagues and collaborators at the Cornwall Memory Cafe Network, particularly Chair and Board Members Tim Jones and David Gregory, and to the Network's carers and members who helped to shape the survey.

We also extend our thanks to Dr Allison Hibbert, GP System Lead for Dementia, Cornwall and Isles of Scilly, who has been instrumental in this work.

Most importantly, we would like to thank all the carers who completed our survey, participated in focus groups, and spoke with us during interviews. We fully appreciate how precious your time is. Your experiences, whether captured fully in this report, will remain at the forefront of our hearts and minds. It will continue to shape our work at Healthwatch Cornwall, our scrutiny of the health and social care system locally, and its response to this report. **Thank you.**

A contextual literature review

Tim Jones, Chair Cornwall Memory Cafe Network

To put this Healthwatch Cornwall survey in context it may be helpful to consider the extensive background of guidance, standards, strategies and independent reports relating to carers, in particular carers of people living with dementia. Between 1998 to 2020, 2,376 papers have been published relating to the impact of dementia on informal care givers.¹

A natural place to begin to consider official guidance is the “National Service Framework for Older People” in 2001², which set in Standard 7 emphasis on supporting the independence of older people with mental health problems and their carers. This was followed five years later with the National Institute for Health and Care Excellence guidance: “Dementia: supporting people with dementia and their carers in health and social care Clinical guideline [CG42]”³. This made recommendations for the identification, treatment and care of people with dementia and the support of carers. Three years later saw the publishing of “Living Well with Dementia – A National Dementia Strategy”⁴ with strategies for Scotland published in 2010, for Wales and Northern Ireland in 2011. A common thread is provision of carers breaks, support, and personal budgets for carers as well as for people with dementia.

The apparent absence of change experienced by Carers of People Living with Dementia was emphasised in research commissioned from the University of York by the Carers Trust⁵. Entitled “A Road Less Rocky – supporting carers of people with dementia” the report was informed by a national survey that collected responses from 325 carers. Considerable variance in the experience of carers was found. Ten critical points during

¹ Lindeza P, Rodrigues M, Costa J. 2020. “Impact of dementia on informal care: a systematic review of family caregivers’ perceptions”. (BMJ Supportive & Palliative Care, 2020).

² “National service framework for all the people” (Department of Health, 2001).

³ “Dementia: Supporting people with dementia and their carers in health and social care” (NICE, 2006).


⁴ “Living well with dementia: A National Dementia Strategy” (Department of Health, 2009).

⁵ Newbronner L, Chamberlain R, Borthwick R, Baxter M, Glendinning C. 2013. “A Road Less Rocky – Supporting Carers of People with Dementia” (Carers Trust).

the caring journey were identified when carer support is essential. Best practice recommendations were made around these ten critical points.

UK Prime Minister's Challenges on Dementia were published in 2013 and 2018,⁶ reinforcing commitments for positive change. Despite many years of such initiatives a recent report by The Health and Social Care Committee⁷ raises concerns describing:

 Instead of receiving integrated care across the health and social care system, those living with dementia and their carers are required to navigate complex and uncoordinated care pathways. The most vulnerable in our society are left at risk of falling through the gaps after receiving a diagnosis of dementia and their families and carers are left to grapple with burdensome bureaucracy in a system 'set up to ration'.



These concerns are echoed in three independent reports published this year "State of Caring 2022 report" by Carers UK,⁸ "Why can't I get care? Older people's experiences of care and support" by Age UK⁹ and "Dementia Carers Count Survey 2022".¹⁰

In summary, there is a trend in the literature mentioned here that guidance is consistent in describing the approaches that are helpful to carers, that Government directives make reference to shortcomings and set strategies for improvement, while independent reports highlight the value of carers and the gaps between expectations and lived experience.

This short contextual overview may leave the reader with a sense that the needs of carers of people living with dementia have been researched, understood, and verified, resulting in standards of support being defined and published. It may be fair for the reader to assume that this body of understanding, available to commissioners, managers of health and social care organisations, as well as practitioners will have impacted positively on carers of people living with dementia in Cornwall. The reality will become clear to the reader as they progress through this report.

*For the full review – please see **Appendix 2: Contextual literature review.**

⁶ ["Prime Ministers Dementia Challenge 2020" \(Department of Health, 2016\).](#)

⁷ ["Health and Social Care Committee Supporting people with dementia and their carers, Seventh Report of Session 2021–22" \(House of Commons, 2021\).](#)

⁸ ["State of Caring 2022 Report – A snapshot of unpaid care in the UK" \(Carers UK, 2022\).](#)

⁹ ["Why can't I get care? Older people's experiences of care and support" \(Age UK, 2022\).](#)

¹⁰ ["Dementia Carers Count Survey 2022" \(Dementia Carers Count, 2022\).](#)

Executive Summary

Dementia is a term used to describe a progressive condition that can affect thinking, behaviour, personality, and people's ability to carry out day-to-day activities. It is a complex, degenerative condition that impacts the physical and mental well-being of people living with the disease, and consequently, their carers and families. There are currently just over 5,000 people in Cornwall (5,181) with a diagnosis of dementia out of an expected prevalence of 9,460 (54.8%). In the UK, the number of people with dementia aged over 65 is predicted to grow by over 80% (2019–2040)¹¹. While it isn't a normal part of ageing, prevalence of dementia increases with age. Cornwall has a higher than average older population and as such, this presents a significant challenge for the health and care system locally, and its communities.

Public feedback locally tells us that carers and people living with memory loss (suspected dementia) and dementia often struggle to access the care and support they need, yet we know unpaid care saves the NHS around £11 billion pounds each year¹².

We have collaborated with Cornwall Memory Cafe Network and colleagues to hear from carers of people living with memory loss and dementia in Cornwall. We gathered the views of 148 carers through a survey, spoke with 21 carers in focus groups and conducted 15 in-depth interviews.

Experiences of diagnosis, accessing and receiving different kinds of memory loss and dementia services and support in Cornwall varied:

- across areas of Cornwall
- between carers, such as carers of spouses/partners and carers of parents – who were very often working carers
- by age of people living with dementia

Carers described **positive** experiences of accessing care and support, particularly from **dementia-specific roles** and where regular, planned reviews were in place. Having a professional who was accessible – especially when concerned or during a **crisis**, provided much-needed reassurance and support. The **voluntary sector and local support groups and services** were a valued source of information and advice. They provide meaningful activities, training, and advocacy (whether formally or informally) in local communities. **Connecting with other carers** was important to people, and carers welcomed **continuity** of staff when connecting with health and care professionals.

¹¹ Care Policy and Evaluation Centre, London School of Economics and Political Science Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040, Working Paper 5, Raphael Wittenberg, Bo Hu, Luis Barraza-Araiza, Amritpal Rehill: https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

¹² [Supporting carers of people with dementia \(nihr.ac.uk\)](https://www.nihr.ac.uk)

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Despite this, many carers also described **negative** experiences of feeling **lonely** and **isolated**. Some told us they felt **abandoned** or that access to services and support was **patchy** or **inconsistent**. **Navigating** the health and social care system to access a range of services and support was often a **struggle**: information, advice, assessments and financial support were not always volunteered proactively, routinely, or when needed most. Services were not always connected.

Carers wanted practical **information** and **advice** that was relevant to them as individuals and their caring circumstances. Access to **meaningful activities** enhanced the well-being of both the carer and the cared for. There is a variety of great services providing this in Cornwall, most often through the voluntary sector. However, not all carers were made aware of these services or information proactively or were able to access them for reasons including, transport, online/digital access, juggling work and caring, and being able to leave those they cared for.

Having access to **respite services** to support carers to take a break from their caring role when needed is vital to **maintaining carer health and well-being** and preventing **a crisis**. However, this was one of the things carers told us they most wanted to see improved.

While the number of respondents caring for people with **early onset dementia** (those diagnosed under the age of 65) was small, there was a **clear gap** in service provision for those with this diagnosis and their carers.

Healthwatch Cornwall has outlined a number of **recommendations** in this report that, if implemented, could ensure experiences of dementia diagnosis and diagnosis rates locally will improve, and that care and support provided in Cornwall meets the needs of people living with memory loss or dementia, and those who care for them. Cornwall and Isles of Scilly have a newly formed health and care system known as the Integrated Care System (ICS), in which **dementia** was deemed one of the **five priorities**. The **vision** for the ICS is for Cornwall and the Isles of Scilly to be: **'A great place to; be born, live and thrive, and to grow old'**.

With the system's focus on dementia and this vision in mind, we recommend it provides a **timely** and **clear pathway** of **diagnosis, services, and support**, that is **accessible** and **local** to people. It must place the person living with memory loss or dementia and those close to them at its heart. Understanding individuals' needs and preferences and providing **person-centred** care through **regular review** should be a key priority. To support those who are providing two-fifths of the total health and care costs of dementia¹, we must ensure carers have the right **services** and **respite** in place to ensure they too can live well and do not reach crisis point. Carers should not have to fight to uncover support that should be available to them, nor should they be further burdened by the difficulties people have outlined in navigating the system of health and care. It is clear that while each person and their carer's needs, experiences, and preferences are unique, there are critical points at which people need to know that our Integrated Care System is there for them, providing regular, proactive advice and support when needed, throughout this distressing and unpredictable journey – and beyond.

- Carers wanted to remain included and involved as carers, and supported by networks, when the person they care for goes into care, or they are bereaved.

Regular review and support

- Experiences of access to support through general practice varied, with working carers finding access to GPs particularly difficult.
- Knowing what to expect from services; having regular scheduled reviews and assessments (how is the person I care for doing/are they declining) was important to people. However, experiences of accessing regular ongoing reviews and support following diagnosis were mixed. This varied across the county and across different groups of carers (carers of spouses/partners, carers of parents and working carers).
- Many carers described support from health and social care services as patchy and inconsistent, or that they felt left to manage alone.
- Vacancies across different teams and pressures on staffing led to a variation in access to support and poorer experiences for some.



I don't know how far into this we are... it would be good to see somebody, have a check and see if its 'normal progression'.



I did see the (dementia practitioner) they are lovely but burnt out... would describe the hell they are going through, all are firefighting and have extraordinary caseloads. I just had to take that. They said to phone any time, but I never did until I was desperate.



I was number 24 in the queue and had to phone back 3 times in the same day to get a prescription of urgent medication for (parent)...The anxiety and stress...Why have you made this so difficult? It's not speaking to the same person, the lack of understanding...It's like 58 pages. I just couldn't face it (attendance allowance forms)...Despite all this and a diagnosis of dementia, (plus multiple chronic diseases). We haven't seen a GP face-to-face in five years...You haven't got five minutes to sit there and be sad. My brain is full. (working carer)



Praise for services and support

- Dementia-specific roles were often highly praised by those able to access them.
- We also heard about the difference paid carers could make to the lives of people living with dementia and their carers.

Navigating the health and social care system was challenging:

- People described the challenges they often faced in trying to access help, assessments, and financial support and were too often having to chase or push for care and support – all while caring.
- Carers felt help was often provided by other carers and helpers in the community through word of mouth, and volunteer-led informal groups, rather than proactive signposting and support from public services.
- Many carers had not had a carer's assessment or were not aware of the assessment, and some carers were struggling to access a timely assessment.



I feel isolated and ignored, to sum it up.



The support can be really good. More recently as needs increased, but communication between different health disciplines does not always happen and I have had to liaise between the teams to get mum the treatment she needs.



Respite

- Respite and taking a break from a caring role is essential to supporting carers' health and well-being. For some, it is essential to prevent a crisis and carer breakdown. However, there were clear challenges in accessing respite including access to day care, longer periods of respite, and respite in an emergency. Carers most wanted to see improvements in services to support them to take a break from their caring role.



Support through the days and nights allowing the carer to have time out or to sleep.





Someone to sit with my partner for an hour or two to give me a break. Someone to call in the middle of the night.



Continuity of Care

- Carers value continuity of care from healthcare professionals and services. Building trust with professionals who know and understand their situation is important to carers and those they care for.

Voluntary and third-sector support

- Support from the voluntary and charitable sectors was highly valued by carers. The types of support provided include:
 - groups that provide support and/or therapy such as the Memory Cafes, Memory Matters groups and carer groups
 - meaningful activities for carers and those they care for
 - essential information and advice (including help with filling in forms)
 - telephone-based support, including advocacy and advice
 - training online and in-person
 - companions
- Some of this help was provided informally in communities, such as help to fill in complex forms, advocacy, and advice. Support from this sector and being able to connect with other carers through these networks was especially important, given many found it hard to navigate the health and social care system and/or felt abandoned or alone.

Access to meaningful activities

- Carers want those they care for to live well with dementia and to have improved access to meaningful activities. However, there were gaps in opportunities for this in some areas, and for some carers.
- Carers described how having something in the calendar to look forward to that could provide structure to the day, help people to keep active, socialise, maintain skills or provide enjoyment and enrichment was significant to them, and the person they care for. Much of this support is currently provided by the voluntary sector.

Additional information and advice

- Carers wanted practical and accessible advice, knowledge, and information to help them in their caring role, provided locally to them, and in different formats. The types of information and advice carers want differed depending on different groups, localities, and demographics. It is important to understand individual preferences and needs and to provide information and advice proactively.
- Top responses included:
 - How to recognise what to do if the person I am caring for has **unsettled behaviour** (51%)

- **The type of dementia** the person I care for has and the **changes to expect as the condition progresses** (50%)
- **Advice to support** the person I am caring for **to live well and keep them safe** (38%)
- **Local services and support groups available** (34%)
- **Advice on how to communicate** with the person I care for (30%)
- **Dementia-friendly activities we can engage in** (30%)



The best thing I heard of is a YouTube site called 'Dementia Careblazers'...Very practical help and short manageable videos with many individual topics and how to address your own anger. This is what dementia services should offer.



What's important to you and the person you care for 'personalised care'

- Carers were not consistently being given the opportunity to discuss what matters most to them and the person they care for, or involved as much as they wanted to be in decisions being made about planning the care and support they, or the person they care for may need.
- Experiences of 'personalised care' differed across different groups of carers (e.g. carers of spouses/partners, carers of parents and working carers).



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.



Early onset dementia

- We heard from eight carers of people living with early onset dementia within the survey and interviews. Interview participants all experienced 'negative' and protracted diagnoses.
- Carers felt there was little relevant support or services for people living with early onset dementia and their carers in the county, and had often had to access support from outside of Cornwall.

Recommendations

The recommendations from this report should inform the dementia and memory loss strategy for Cornwall and the Isles of Scilly.

Dementia pathway

- Develop a clear, dementia care pathway of services and support so that people experience timely, evidence-based care and treatment along with access to information and advice that is personalised, flexible and meets the needs of the person living with dementia and memory loss and those who care for them.
- This should be based on the NHSE Well Pathway for Dementia¹³, should be co-produced with all agencies and ratified by the Integrated Care System.
- The dementia care pathway should take into account carer roles and responsibilities, and their personal and work situations in order to ensure equity of access to advice, information and support for all, across all areas of Cornwall.
- The dementia care pathway will be auditable, scrutinised and comply with the current NICE guidance (Dementia: assessment, management and support for people living with dementia and their carers (NG97)).¹⁴

Diagnosis

- Monitor waiting times for diagnosis and ensure there is equitable access to a diagnosis across Cornwall.
- Monitor local diagnosis rates.
- Ensure that the diagnosis is added to the person's medical record and GP dementia register.
- Ensure the diagnosis is the key to accessing the dementia pathway of support, yet ensure those who choose not to access a diagnosis are not denied advice and access to services.

Education

- Promote information and advice about memory loss and dementia in local communities, GP surgeries and other health and social care settings. This should include advice on how to raise concerns about someone with memory loss, and how to manage consent, as well as signposting for advice and support.
- Provide education and training, and raise awareness among health and care staff to ensure they can recognise the symptoms of dementia and know who is at risk.
- Ensure all staff know how to recognise and identify carers and can help carers to recognise this.
- Consider what education and information wider professions may also need i.e. police, voluntary sector, etc.

¹³ [dementia-well-pathway.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/well-pathway/dementia/)

¹⁴ [Overview | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE](#)
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Carer identification

- Routinely identify carers and use current NHSE coding guidance¹⁵.
- As a minimum, ensure carers are identified and recorded on a GP practice carer register, along with a contingency plan – should they be unable to provide care.
- GP practices to adopt the principles and practice set out in the NHS England and NHS Improvement ‘Supporting carers in general practice: a framework of quality markers’.¹⁶
- There should be better communication and connectivity between services to ensure continuity of care, information, and care plans. This could help to ensure that people do not have to repeat their stories and could be facilitated through carer identification, carer passports, shared care records and ‘This is me’ documentation, etc.

Regular review

- Provide all people living with dementia with an annual review by an appropriately qualified practitioner as a minimum, ensuring more frequent reviews for those with greater need – as identified through effective care planning.
- Provide all people living with dementia with a key worker or meaningful contact for support, recognising continuity is important to people, over the long term.
- For people living with dementia and their carers to have a telephone number they can call when they need help and advice, which is responded to in a timely way.
- Build on the positive experiences of the services provided by Primary Care Dementia Practitioners and ensure equity in access to the service across Cornwall.
- Regular, face-to-face reviews should be offered proactively to people living with dementia and their carers by staff with specialist dementia training and expertise.
- Reviews should address the needs of carers as well as those living with dementia and involve signposting to other services and support, as appropriate.
- Reinforce the role of social prescribing in signposting to services, managing complex needs and reducing isolation.
- Ensure people who cannot access transport are not limited in their access to services and support. This should be considered as part of the review process.

Carer’s assessments, benefits, and financial support

- At the time of diagnosis, carers should be informed about the carer’s assessment, how and where to apply, and how this might be of benefit to them.
- Monitor waiting times for carer’s assessments and address any delays in accessing them. Inform carers of any delays and timelines to assessment. Signpost carers to support while they are waiting for an assessment.

¹⁵ [NHS England » Coding Unpaid Carers: SNOMED CT](#)

¹⁶ [NHS England » Supporting carers in general practice: a framework of quality markers](#)

- Any carer who appears to have needs for support should be offered an assessment in the most appropriate way that allows them to easily express their needs (face-to-face, phone, online).¹⁷
- Advice about funding available to people living with dementia or memory loss and their carers, (rights under the Care Act 2014) and how to apply for it should be more widely promoted within local communities and health and care settings. Appropriate support should be provided to make the application process easier for all.

Support

- Support groups and activities through non-statutory services such as Memory Cafes, Sensory Trust etc, were highly valued by carers where they existed or were commissioned. They should be supported to continue and expand in areas of Cornwall where provision is limited.
- The integrated Care System should support the development of more dementia-friendly activities, particularly for younger people living with dementia and their carers. Activities do not have to target people living with dementia specifically – people would like to see a range of activities which are inclusive for people living with dementia and those close to them.
- Develop opportunities for peer support, particularly for younger, working carers.

Respite

- Discuss opportunities for respite as part of the annual review and through carer's assessments. Address issues which make taking a break from caring more difficult.

The integrated Care System should urgently prioritise provision for:

- A range of opportunities for respite which includes helping carers to take a break for a few hours in the day or to sleep at night, as well as residential respite care for longer periods of time.
- Increase daytime engagement opportunities for people living with dementia, including for people living with advanced-stage dementia who have physical health needs.

Information and advice

- Promote practical and financial information and advice in a range of formats based on individual needs, through different avenues. This should include at diagnosis, during reviews, through local community spaces and activities, in health, care and voluntary sector settings, and online.

¹⁷ [assessments-england_april-2022-23.pdf \(carersuk.org\)](#)

Personalised Care

- Regular reviews and carer assessments should provide opportunities to deliver personalised care:
 - o Valuing people as active participants and experts in the planning and management of their own health.
 - o Completing a personalised care and support plan which discusses what matters most to the person living with dementia, considers the wider family in care planning, pays attention to their and their carers' needs, and their wider health and wellbeing.
 - o Give families a copy of the care plan so they can refer back to it and share plans with other health and care services.
- Monitor how this is being implemented.
- Raise awareness and promote the personalised care approach among health and care staff.

Early onset dementia

- Improve the experiences of diagnosis of people with early onset dementia, their carers and families.
- Clear gaps in service provision should be addressed to ensure there are:
 - o more opportunities for carers of people living with early onset dementia to connect or 'buddy up' with other carers.
 - o More day care, respite care, activities and support that is tailored for younger people living with early onset dementia.

Thank you for your interest in this important work. For further advice and support, **please contact any of the organisations below:**

- www.cornwallcarers.org.uk Phone 01736 756655
Adult carers in Cornwall are supported to self-manage via an Adviceline run by disability Cornwall, where there is enhanced support when you need it. There is a dedicated Team available to answer Carer calls and queries, text-to-chat options, support to access a Carers Emergency Card, Carers Passport, Carers Register and Carers Newsletter.
- www.ageuk.org.uk/cornwall Phone 01872 266383
Age UK CIOS have Carer's Coaches and Community Support available to help carers to connect with their communities and to improve their wellbeing.
- www.alzheimers.org.uk Phone 0333 150 3456
- Dementia UK (staffed by Admiral Nurses): Phone 0800 888 6678 or email: direct@dementiauk.org
- Mind (for mental health information and support): Phone 0300 123 3393
- To find your local memory cafe: www.cornwallmemorycafes.co.uk or phone Cornwall Memory Cafe Network Coordinator on: [01736 697459](tel:01736697459)

For any other information, advice or support about health and social care in Cornwall, please contact us at Healthwatch Cornwall: Email: enquiries@healthwatchcornwall.co.uk
Tel: [0800 0381 281](tel:08000381281) or <https://www.healthwatchcornwall.co.uk/share-your-views>



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