

Hear Our Voice

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

March 2023





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 their home, 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"

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 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 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 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)

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/publications/dementia-well-pathway-pdf/)

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

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.

Main Findings:

Carer experience of services and support

Experiences shared through the survey, interviews and focus groups have been themed and summarised under the headings below. Survey results broken down by participant characteristics for each question are provided in Appendix 1.

Diagnosis

Seeking a diagnosis

More information and guidance could help encourage and enable people to seek a dementia diagnosis

The Alzheimer's Society encourages people to discuss symptoms and concerns about memory loss, stating: "Getting a diagnosis of dementia can give you a better understanding of the condition and what to expect. Timely diagnosis can help you make important decisions about treatment, support and care." As outlined earlier, rates of diagnosis in Cornwall are currently lower than predicted at 54.8% of predicted figures.

Of the small number of people who had not yet seen a GP or healthcare professional about their symptoms, their reasons varied from the person with memory loss or their carer not being aware of the need to seek a diagnosis, or not being concerned, feeling concerns were not urgent or feeling afraid of what a diagnosis might mean. We heard in one interview that knowing how to ask for an appointment with a GP to discuss concerns for a loved one would be helpful, as they didn't know what their rights were, or how to navigate the issue of consent. Adding to this challenge, was that the person with memory loss did not accept they had such symptoms.

Carers shared how lack of awareness or acceptance of symptoms could be challenging for them when trying to support someone to access a diagnosis, and/or ongoing care and support.



It's an age thing; mum isn't too bad at the moment, she just gets a bit forgetful sometimes.



We didn't know we had to see a GP to get parent assessed.



Place of diagnosis

People were diagnosed with dementia by a range of healthcare professionals in general practice, hospitals, and specialist services

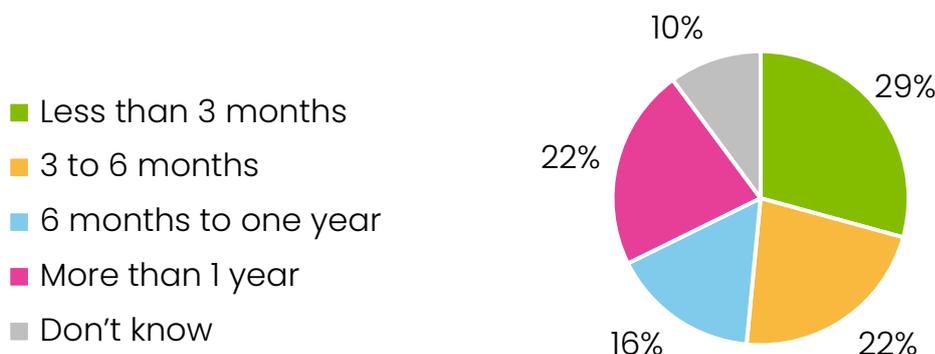
Nine in ten people cared for by those responding to the survey had received a diagnosis of dementia. Carers told us a memory clinic or other specialist service was where most diagnoses were given (61%). Being informed by a GP accounted for 41% of diagnoses, and 12% were diagnosed in another healthcare setting. This meant some people received a diagnosis from more than one setting. Around a fifth (21%) selected 'Yes, by a GP' and no other option. However, it would be difficult to completely rule out whether this is because the GP gave them the diagnosis following tests elsewhere.

Time to diagnosis

There were mixed experiences of accessing a diagnosis of dementia with waits for a diagnosis being longer than expected. This varied across the county

Half (51%) received a diagnosis within six months of first discussing concerns with a healthcare professional to receiving the diagnosis. Two-thirds (67%) were diagnosed within a year.

Time until diagnosis



However, waits varied across the county, with carers of people living with dementia in the West of Cornwall having waited longer for a diagnosis compared to other areas: Nearly two-thirds (62%) of carers in the West waited six months or more for a diagnosis compared to less than a third (29%) in Central Cornwall and under a half (44%) in North & East.

(N.B It is important to note, we did not ask people how long ago the person they care for received their diagnosis. Data as of October 2022 supplied via Cornwall Dementia Partnership Board demonstrated a high proportion of people are now diagnosed within 3 months of being referred. The ambition to improve diagnosis rates locally remains and should remain a focus for the ICS.)

Carer feedback relating to the referral to diagnostic services, or to the assessment process demonstrated mixed experiences, with some receiving a swift diagnosis and feeling supported throughout the process. Where there were negative comments, these related to the length of wait and/or to the diagnostic assessment process, or to negative interactions with staff. These included:

- the assessment not being tailored to the individual (for example, being asked to spell a word where the carer explained they would struggle due to dyslexia)
- involved negative interactions with staff
- for a small number, having to chase a follow-up review beyond an initial diagnosis of cognitive impairment.

Experiences of diagnosis

Several people sought a diagnosis out of the county for reasons including wanting a second opinion, or not being satisfied with the speed or quality of the diagnosis. Several negative experiences related to their GP being dismissive, or putting symptoms down to old age. Some were told to go away and come back in a few months if still concerned, leaving it to those affected by dementia to organise a follow-up.



My mother was diagnosed with dementia earlier this year. Her GP was excellent with her - and me in listening to mine/my family's observations. She was then referred to the Memory Clinic. The appointment was within three weeks.



It took in excess of two years for my mother's diagnosis to be completed and we had to travel out of county multiple times to find the support she required.





I live in a small village, do not drive and have my own health problems; services seem to be in towns I cannot get to.



Once seen you tend to be forgotten about unless you make an effort to find someone. You are just a number to add to their list so they can get finances for their department. If Mum had no family I dread to think the state she would be in.



My experience as a carer has been mainly during the pandemic so I acknowledge that some of my experiences have been clouded by that. Nevertheless, I often felt completely alone and not listened to. I always had to chase people to get anything done. I felt the GP wasn't interested because my wife's care was under a consultant at the hospital. I asked several times to see the consultant without success.



General Practice

GPs were a source of support throughout people's caring journey – and at the point of crisis. Some described their GP as helpful and were able to access them, but this was not the case for all. Continuity of care was important to carers who often preferred in-person consultations (depending on the carer) rather than phone or video consultations. Not all carers had digital access and found new systems for booking an appointment very difficult to access.

For some, the GP is the first point of contact for advice, signposting, and support. Carers turned to their GP with concerns about the mental and physical health of the person they cared for, including changes in medication, or for referral to other services (such as social care, physiotherapists and occupational therapists, nurses, district nurses, etc).

Access to a GP appointment is one of the most common areas of concern the public tells Healthwatch Cornwall about. The unprecedented pressures on general practice have been evident for a number of years both locally and nationally. The pandemic has understandably exacerbated this further.

Experiences of access to support through general practice varied with some carers finding access particularly difficult

Working carers found it more difficult to access a GP: only one-third of carers who were in full, or part-time work said they were able to access the GP when they needed to, compared to just over half (51%) of retired carers. Some working carers described the challenges of getting through on the phone or accessing support through the GP, such as for medication for the person they cared for. In addition, two-fifths (40%) of carers had additional caring responsibilities making juggling their caring role and accessing support, complex.

GP access is still difficult. We now have to fill in Klinik online to be triaged to see if we need to be seen. As an unpaid carer the work we do daily saves the council and government £1000s and access to a GP when we need to see one for our cared for, or ourselves, should be easier not harder.

GP has said call if I need to and has been great. They have asked how I am.

Carers were not routinely identified in general practice

Only half of the carers taking our survey (49%) told us they were recognised by their GP as a carer. Identifying carers and recording this in general practice (and in all services) at the earliest opportunity is key to ensuring carers are: 'recognised as partners in the care of the person they are supporting and can access any advice and support they may need'.¹⁸ Doing so can have a positive impact on carer well-being; reduces crisis and carer breakdown; ensures more equitable support, and helps to better manage the demand for the service.¹⁹

Identification is a complex and often sensitive issue, as carers do not always see themselves as such, with many feeling caring for their spouse/partner or relative as their duty. It often takes around two years before a carer acknowledges themselves as such²⁰. Carers often experience poor physical and mental health and also may have unmet care needs themselves. There is mounting evidence that unpaid care should be considered a social determinant of health²¹.

Just over three-quarters (77%) of people being cared for were over the age of 75, and 57% of carers were aged over 65 years: increasing age is associated with

¹⁸ <https://www.nice.org.uk/guidance/qs200/chapter/Quality-statement-1-Identifying-carers>

¹⁹ [supporting-carers-in-general-practice-a-framework-of-quality-markers-v2.docx \(live.com\)](#)

²⁰ [Social care and support guide - NHS \(www.nhs.uk\)](#)

²¹ [Caring as a social determinant of health: review of evidence - GOV.UK \(www.gov.uk\)](#)

increasing health needs. Two in five (40%) of carers stated their day-to-day activities were limited because of a health problem or disability. Therefore, identifying carers in general practice, and other health and social services, is not only essential for enabling carers to support and care for people living with dementia but also for identifying and anticipating any health and care needs of carers.

Carers need to remain included and involved as carers, and supported by networks and services when bereaved or the person they care for goes into care

Carers of people who have moved into a care setting remain advocates for those they care for and made clear their need to be treated as such. Identifying as a carer in these instances, or when bereaved, did not mean people no longer saw themselves as carers. For example, a bereaved carer we spoke with was concerned when wanting to access local support in case they were no longer viewed as a carer. Many carers were still keen to remain connected through carer groups and seek support from other carers and often carried on providing valuable help and advice to other carers. Maintaining the identity of a carer was important to some and should be supported.



Better communication and information sharing between carers and care homes, as your carer role and responsibilities still continue.



There was limited evidence of access to social prescribers in primary care

Carers seldom mentioned social prescribing. When prompted in some interviews, carers had little knowledge and minimal experience of this, yet felt it would be useful to know more or to speak with a social prescriber.

GP surgeries in Cornwall should have access to a social prescriber who can signpost to and recommend people to local support. The aim of social prescribing is to support people and carers to manage long-term or complex conditions which may help people to feel less isolated. We signposted several carers to social prescribing.



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.



Regular Review and Support

Knowing what to expect from services and having regular scheduled reviews and assessments (how is the person I care for doing/are they declining) was important to people.

Having a named professional or care coordinator leading on the person's care and treatment and for when the carer or patient needs advice is a recommendation within the National Dementia Care Pathway²². It states,



Access to dementia care can be greatly facilitated by a named coordinator of care who has a good understanding of the person and their needs along with how to navigate the health and social care system.



Experiences of accessing regular ongoing reviews and support following diagnosis were mixed

Some experienced regular reviews and support from a dementia-specific practitioner, were able to contact them if needed and were clear about the regularity of reviews. However, some carers said they did not have access to this type of professional or felt they were not clear as to when the person they cared for would have a review. Some carers expressed their concerns about the decline in the person they cared for and as such, a review was important to them. Some simply felt they were left to manage alone.

While 47% of survey respondents answered ('What works well'), 'I have a phone number I can call for information and advice, over a quarter of carers (26%) would like to have 'easier access to help and advice when need' and 'to have a phone number they can call for help and advice when needed'. (select three) 'Which three things would you most like to see improved'.

Carers of parents compared to carers of spouses/partners were even more likely to want support and easier access to help and advice: over a third (36%) compared to one in five (20%) carers of spouses/partners. These issues were also reflected by carers in full and part-time work who were mostly caring for parents '(select three) Which three things...'



We have no support from any key staff or other professionals, only the 12-month assessment for mum to receive the allowance.



²² National Collaborating Centre for Mental Health. The Dementia Care Pathway. Full implementation guidance. London: National Collaborating Centre for Mental Health; 2018.



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.



A regular (say annual) progress assessment to see how quickly dementia is progressing and what support may be needed.



I would not call even if I needed something as I do not feel they would be helpful. Which is a shame. I have worked with other teams (that do not cover my area) and have been truly inspired by how caring and compassionate they are. It's such a shame that the consistency falls below par between different regions.



Vacancies across different teams and pressures on staffing led to a variation in access to support and poorer experiences for some

Many carers were aware of caseload pressures, and staff vacancies and some told us their awareness of this meant they did not want to burden staff by contacting them for support. They were concerned others might take priority or indicated they were accepting of less support. One carer told us how a paramedic expressed concerns for colleagues at high risk of suicide (due to work related stress). Carers conveyed their awareness of high caseloads, vacancies, and limited availability. These examples are an unfair burden for carers to shoulder. Pressures in the system being communicated by staff have been evidenced recently in other aspects of Healthwatch Cornwall's work, such as the 'Carer experience of hospital discharge' project with NHS England and Improvement.



Our dementia support person works only X hours per week and has not contacted us for eight months in which time there has been a large deterioration such that we are now looking for a care home. This may be partly my fault because we are quite independent.



Trained staff in the community exist but are hopelessly overloaded. One Dementia Nurse, who works part-time, has over XX patients (and carers) to support.. and this is regarded as completely inadequate by their patients and their carers.

I feel it is important to have services fully staffed to be able to attend to carers' appeals for help when needed and promptly. A returned call if made can possibly be too late to help."

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.

Praise for Services and Support

Carers particularly valued the support provided by some services and staff

There were predominantly positive experiences relating to support from carers whether funded through Adult Social Care (ASC), NHS or privately funded. Having carers to support with providing care, or to sit with the cared-for provided much-needed support and help. It also meant carers were afforded some independence or could take a break from caring.

Praise for the support received from a range of dementia-specific roles

Dementia-specific roles were often highly praised by those able to access them. One very clear example of this which stood out, related to those who had frequent and planned support from a Primary Care Dementia Practitioner (PCDP). This was reiterated in one focus group in particular, where all participants from the same locality told us just how significant the PCDP role was to carers and the cared-for, with carers in this group feeling particularly well supported by their PCDP. The PCDP provides a vital link to secondary care mental health teams and for when medication changes are required (such as dementia-specific treatment therapies or medication for anxiety and depression). All comments about Admiral nurses were also positive, despite awareness of or access to these seeming limited.



Alzheimer's team/Alexandra House has been very helpful.



The Admiral Nurse used to come to our home. She was very experienced and would listen, as well as offer advice.



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



Found out through a friend that can self-refer to the [Admiral Nurse] service. The CPN (Community Psychiatric Nurse) is helpful.



PCDP helpful albeit they realised they had left x off list. No clear plan in place for regular review but they can be accessed by phone and it is helpful when speaking to them. [PCDP] has visited once.



Navigating the Health and Social Care System

Carers found navigating the health and social care system difficult and services didn't always communicate with each other.

In addition to the challenging role of caring, carers described difficulties trying to 'navigate' the health and social care system to access care and support. Carers were often trying to understand which health or social care service they should reach out to, and what support was available to them. People described the challenges they often faced in trying to access help, having to chase or push for care and support – all while caring.



Listen when asking for help and provide it. Call back with support when you say you will. Ensure systems and processes can communicate (i.e. share test results).



For medical professionals to be able to share clinical notes from different services about my parent, as none of them know that he is being seen by other services.



Some carers shared concerns about navigating other assessments to access support and financial assistance with care. This included assessing the needs of the person living with dementia, for financial support such as Personal Independence Payments (PIP) and Attendance Allowance, and for accessing Continuing Healthcare (CHC) – where nursing care needs are complex it is paid for through the NHS. Some carers told us charities and advisory services supporting carers through the process of appealing for funding for PIP and CHC stated having to appeal for funding was now “a normal part of the application process”.

Where funding to access carers or personal assistants was granted, or for self-funded support, maintaining employment of suitable carers and personal assistants required further navigation of the system – and as employers of carers. This brought new challenges that carers felt they were often left to navigate alone.



So they were good at giving me a budget. It took nearly a year to get PIP and it went to an appeal. Citizens Advice say this is the usual process – they always refuse people in the beginning, and you have to go through months of trials and tribulations trying to prove that you need this support and all these things make you very jaded and angry.”



They just make an assessment – call you their liaison coordinator – but they just give you an assessment and a budget and leave you to it – they think they’ve done their job. They have no idea how hard it is to spend that money and to get help get the appropriate people to help your situation and how difficult it is to introduce help into somebody’s life especially when they don’t think they need it. X wouldn’t accept help in the early stages, thought it was intrusive...

I got help from a charity to appeal again. The whole experience was so complex and even I, an intelligent person struggled and guidance. It’s notoriously difficult to appeal. Why have it [Continuing Health Care funding] if they are never going to give it to anyone?

Help with attendance allowance forms and what you’re entitled to. No one told me about the carers support service.

Carers felt help was often provided by other carers and helpers in the community through word of mouth, rather than proactive signposting and support from public services

Many felt they were left to find out information for themselves, including how to access support through Local Authority assessments, and how to fill in essential forms for accessing financial support, which people found to be very complex and off-putting. Suggestions carers might find helpful included information hubs and directories, helping them to know which services and information could be accessed and where from.

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



Carers haven't a lot of energy to navigate, and also battle on and then give up. Everything ends up being difficult. A one-stop shop would help.



I would like information on any benefits available to my wife and I. It seems I only get information from people in the same position as me.



It has been very difficult to access help. My father had dementia and without me actively pursuing support and help for him and my mother there would have been little support. The only reason I was able to do this is that I was a nurse and able to navigate the very complex system."



Adult Social Care and the managers say I will hold your hand through this but never come up with anything (I just take with a pinch of salt now). I'm now more experienced and say if you don't help, you will have a crisis on your hands.



Many carers had not had a carer's assessment and some carers were struggling to access a timely assessment

A carer assessment should be undertaken for any carer with an appearance of need for support to see what help could be provided to support people in their caring roles. Recommendations could be made for support, such as: advice about benefits, help to find a carer so carers can take a break, accessing support groups, help with taxi fares if a carer doesn't have transport, etc.

Just over a third (38%) of carers had undergone a formal carer's assessment either over the phone (21%), or in person (17%). There is a high proportion of carers (26%) who were recognised as such by their GP but have not had either a formal carer's assessment undertaken by either their local council or carers service. One in five carers stated that health and social care services were not aware of their caring responsibilities or identified them as a carer, meaning some eligible carers weren't being assessed.

Carer assessments are usually carried out once a year, following an initial assessment. However, some carers were concerned these were not happening regularly enough, that timescales had slipped, and they were having to chase for an assessment. Some carers told us they were still waiting for an assessment more than 6 months after their initial enquiry, others were unaware of the carer's assessment. Not knowing how long people would wait for an assessment could be stressful and managing people's expectations about timescales was important.

Some carers felt it was important to have a face-to-face assessment (rather than by phone) to be able to best understand their needs and caring situation – particularly where the needs of the person being cared for had become more complex. A small number of carers mentioned carer's grants were no longer available, stating there was confusion about this and the assessment.

Whenever a carer has an assessment, you are always chasing to get it done. They are now saying you don't need an assessment every year. How do they know that you don't need an assessment? Lots of new carers coming in are being told we don't need an assessment but your loved one might change and have three dips in a year.

Have stopped the carers grant...They have taken this away and are offering different groups to go to like 'Promas'. I know they are saying the groups are free, but if you need someone or to pay someone to come and sit with your loved one so you can attend... Some carers think it's still available, but we hear conflicting stories. You need to know there is help out there when you need it.

Good experience of carers assessment - it only took two weeks to get one and I now have the support I need.



Primary care dementia practitioner said I should get a carer's assessment. I did, but it's a battle to get a regular carer's assessment ...and it's not on a regular timescale... Sometimes took six months to process ... phoned last autumn. Told it doesn't look like you need anything (over the phone not by assessment) to spend money on or for grants so I didn't get one... I felt put in my place like it was a gate keeping exercise.



Face to Face essential.



Respite

Carers most wanted to see improvements in services to support them take a break from their caring role.

Respite and taking a break from a caring role is essential to supporting carer health and well-being. For some it is essential in preventing a crisis.

Listed as the top response to the question: (select three) 'Which three things would you most like to see improved', over a third of people (34%) felt they would like more opportunities to take a break from their caring role. Nearly twice as many carers of spouses/partners than carers of parents said they would like more opportunities to take a break from their caring role (44% of carers of a spouse/partner compared to 23% of carers of a parent).

Carers described different types of respite they felt could help them, from being able to leave the house for short periods of time; accessing day care; to longer periods of respite; and respite in an emergency. Providing respite for some may also have helped them to access in-person training for carers or simply to take time to do something for themselves.

However, there were clear challenges in accessing respite. While some of this remains a legacy of the pandemic and service closures, the complexities of accessing the right information, support, assessments, and regular review is likely to compound this issue.



Would like more opportunities to take a break from my caring role but a healthcare person from the council gave me a form to choose a carer. Cost me £300.





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.



Day care for people with more severe dementia that provide safe environments and support to go to the toilet etc.



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



Complete lack of help when we needed respite care in an emergency; support only offered once or twice a year.



Continuity of Care

Carers value continuity of care from healthcare professionals and services

Carers frequently talked about the need for greater continuity of care, accessing people who knew them and the person they cared for. Building trust with professionals who knew and understood their situation was important to carers and those they cared for.

For some, in-person appointments were more important than over the phone. In the question (select three) 'Which three things would you most like to see improved' over a quarter (26%) wanted to be able to see health and care staff face-to-face – joint third highest response.



We tended to see people once or twice to do their bit. It's really hard to understand... telling your whole story again... not a lot of coordination.





Greater continuity of person i.e. GP or other person they can talk to about their care – even an email/someone they can pose questions.



Voluntary, Community and Social Enterprise Sector Support

Support from the third sector is highly valued

There was a wealth of evidence in the surveys, focus groups, and interviews which demonstrated carers and people living with memory loss and dementia greatly valued the support they received from organisations within these sectors – some of which are commissioned locally by the public sector. The types of support provided include:

- groups that provide support and/or therapy such as Memory Cafes and Memory Matters, Sensory Trust, etc
- 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 also provided informally in communities, such as help to fill in complex forms, advocacy and advice. Support from this sector was especially important, given many found it hard to navigate the health and social care system and/or felt abandoned or alone.



If it wasn't for the volunteer organisations like the Memory Cafe and the Memory Matters sessions, there would be little cheer for sufferers of this cruel condition. The authorities appear to give scant regard to the psychological impact of isolation which they do little about.



Connecting with other carers is important to many carers, but opportunities for this varied from person to person and across the county

It is highly important for carers to have opportunities to connect with other carers. This has been made possible through an extensive network of carer, memory loss and dementia support groups and activities, such as the Memory Cafe network, Memory Matters (providing NICE Guideline cognitive stimulation therapy), the Sensory Trust, Cornwall Carers advice and support line.

Opportunities to connect with others varied across the county and across different groups: More carers in the North & East area said, 'I am able to meet with other carers and share experiences' (34% in N&E compared to 20% in Central and 10% in West).

Being able to meet with other carers is working well for more older carers and carers of spouses/partners, compared to younger, working carers, caring for parents. For example, only 5% of 25 to 49-year-olds are able to meet with other carers compared to 30% of 65 to 79-year-olds and 33% of those over 80.

As an observation of the focus groups, it was evident that when carers were given the opportunity to meet and connect with other carers, they valued this greatly. Furthermore, when they were able to do so away from the person they cared for, there was a further change in the dynamic. We observed this provided carers respite and an opportunity to share thoughts, experiences, tips, and ideas to help manage their own wellbeing and that of the person they care for. While interviewing carers in this work, there was a sense of a therapeutic conversation and exchange, which several carers expressed had been helpful to them, sensing they valued the opportunity to be listened to and to offload. Several carers felt a buddy system could also be a helpful service for them.

 Talking to people at the Memory Cafe at Fowey has helped make me realise how things may progress in the future. I feel I have made friends. It helps to talk. 

 To be able to openly discuss the condition with other carers, to see how they are coping with day-to-day living. My only advice came from another lady carer... she shared some of her experiences and solutions with me. 

 Memory Cafe to have a separate meeting for carers while partners are in the Memory Cafe. To give carers time to share experiences. 

 Being able to meet up with other carers and clients who are at a similar stage to my husband and me for a coffee or walk. I do not know how to contact such folks. 



Carers support groups locally or respite care we can access so I can have a rest to keep on top of my own health issues.



Access to Meaningful Activities

Carers want those they care for to live well with dementia and to have improved access to meaningful activities.

Meaningful activities include a range of social and physical activities that are important to the person living with dementia or memory loss but also their carer. Access to meaningful activities was the second most popular response to the (select three) 'Which three things would you like to see improved' question (28%), after respite (34%).

Carers described how having something in the calendar to look forward to that could provide structure to the day, help people to keep active, maintain skills, socialise; provide enjoyment and enrichment, were significant to them and the person they cared for. Much of this support is currently provided by the voluntary sector. While dementia and memory loss-related activities and groups were welcomed by many, they were not right for all, or at all times in people's journey with dementia. We also heard how activities benefiting people living with dementia should not always be labelled as such. Activities such as those provided by the Sensory Trust, for example, were inviting to both carers and those they care for. Other examples were tea dances at a local hotel and venues that hosted seasonal lunches and parties at local venues, etc. Having choices and a range of activities available, was helpful to people.

However, there were gaps in opportunities for this in some areas, and for some groups

It is possible that opportunities for meaningful activities varied in different areas of the county. Responses to the question 'the person that I care for has access to meaningful activities they enjoy' varied: 42% in N&E, compared to 22% in Central and 20% in the West.



Meaningful activities that provide steppingstones throughout the year... Something to look forward to.



Activities that focus on what people can do, not what they can't.





Services tailored to the carer and person living with dementia - like the sensory trust or Hayle day centre, or the events at a hotel that are inclusive and not just dementia-related with people sitting in circles.



Additional Information and Advice

Carers wanted practical, accessible advice and information to help them in their caring role, provided locally and in different formats.

When asked 'is there any additional information and advice that would help you in your caring role?', the 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%)

Information and advice needs differed somewhat, depending on different groups and demographics

Some topics of information and advice were more often requested by carers with particular characteristics or depending on the age of the person they were caring for. The table below shows some examples of topics which were more often requested by specific carer 'groups', along with the percentage of the group requesting the topic. See pages 22 to 24 of Appendix 1, for all group comparisons.

Carer characteristics:	Topic of information and advice (% of group requesting it):
Carers of people under 65	<ul style="list-style-type: none"> • Supporting mobility issues (63%) • The type of dementia the person I care for has and the changes to expect as the condition progresses (63%)
Carers of people aged 65 to 74	<ul style="list-style-type: none"> • Dementia-friendly activities we can engage in (46%)
Carers of people aged 75 and over	<ul style="list-style-type: none"> • The type of dementia the person I care for has and the changes to expect as the condition progresses (55%)
Carers with no spare income	<ul style="list-style-type: none"> • Supporting mobility issues (42%) • Medical matters, such as medication and other physical health needs (27%) • Financial affairs, such as lasting power of attorney (24%)
Carers of parents/parents-in-law	<ul style="list-style-type: none"> • Financial affairs, such as lasting power of attorney (25%)
Female carers	<ul style="list-style-type: none"> • Local services and support groups available (40%)

Understanding what information and advice would be most helpful to carers and how they might prefer to access it is key

This variation shows just how important it is to understand people's personal preferences and circumstances and to ensure they have access to information that is meaningful and relevant to them. It also demonstrates a possible gap in the types of information being provided and/or made accessible to carers and what they would value most.

Carers described the need for proactive (not reactive) information, advice, phone numbers and signposting to be made accessible to the carer, through a variety of sources and formats, both off and online. Carers would like transparency about the care pathway and the breadth of local support available that could be available to them, as the disease progresses. Carers told us information about financial aid and what people are entitled to should be provided proactively, be well publicised, and

regularly discussed with carers, including attendance allowance; carers assessments; bursaries, etc, - regardless of people's financial status.

One explanation for the above might be attributed to a lack of regular contact and review, particularly with known professionals beyond the point of diagnosis reported by some carers, and carers often feeling alone and abandoned, as described earlier.

More than a quarter (27%) of carers wanted information about advance care planning and planning for end-of-life. Improving end-of-life care planning through the promotion of personal end-of-life plans and supporting individuals to make plans in advance has been a key priority identified in Healthwatch Cornwall's end-of-life research in 2018 and is identified within the Cornwall and Isles of Scilly End of Life Strategy²³.

Some carers were able to access training provided in person or online. However, some were not able to access learning online. For others, they were unable, or found it very difficult to leave the person they cared for to attend training in person, as they did not have someone to help provide respite care for them - or were unaware of how to access a carer to provide this service. Just under one in two carers (47%) felt they were able to help themselves by looking up information and advice online. This dropped to less than one in three (29%) for carers over 80. Carers often expressed their views that services should not work on the assumption that all carers were digitally enabled.



Provide [support] in local community hubs, not just online, don't assume digital accessibility or use of text.



Availability of care home places that are local.



Transparency about care pathway and local support as [the] disease progresses. Need training that is more accessible, local, digital/non, support i.e. transport or carers to help access it... Out-of-county ideas like Memory Matters hub in Plymouth.



More advertisements in the press to promote awareness of attendance allowance and how to claim it.



²³ <https://www.healthwatchcornwall.co.uk/report/2018-05-13/end-life-care-report>



Crib sheet of practical tips and advice on how to care, practical tips for around the home...



Support and guidance for people with finances, not just for people without.



Resource with information with phone numbers of who to contact for what.



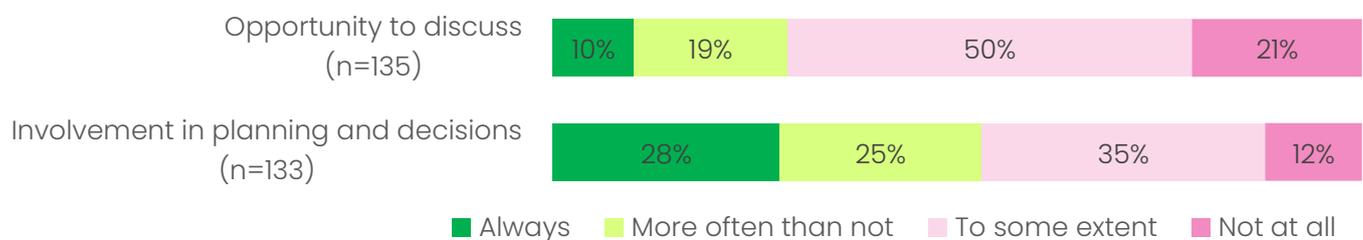
How to help manage when wife thinks she needs to go home to see her parents.



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

In the survey we asked two questions:

- When accessing services and support, have you been given the opportunity to discuss what matters most to you and the person you care for in managing their health and well-being?
- Were you involved as much as you wanted to be in decisions being made about the person you care for and in planning the care and support you/they may need?



We formulated these two questions based broadly on the NHS principles of personalised care, and refer to it as 'personalised care' in this report.

Personalised care offers an opportunity to improve the approach to the identification, assessment and support of carers and to coordinate and integrate support around the whole family through:

- The **early identification** of carers (including young carers) and **providing information, advice and social prescribing**.
- Ensuring carers are able to **access assessments and personalised support planning** in their own right.
- Personalised care planning that includes a **whole family approach** involves carers as expert care partners and **supports carers to maintain their independence, physical health and emotional well-being**.
- Use of **personal budgets** for carers to give them choice in how they meet their own needs or take a break from caring.
- Empowering and supporting carers to make **choices** about their caring role.

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/the person they care for may need**

Less than a third of carers (29%) for whom the question was relevant say that when accessing services and support, they have always or 'more often than not' been given the opportunity to discuss what matters most to them and the person they care for in helping to manage their health and wellbeing. One in five (21%) did not have the opportunity at all.

Just over half (53%) say that they have been involved as much as they wanted to be in decisions being made about the person they care for and in planning the care and support needed.

There were differences in experiences of 'personalised care' across different groups

Carers of parents were less likely to have opportunities to discuss what matters most to them and the person they care for compared to carers of spouses/partners. For example, twice as many carers of spouses/partners (34%) said they 'always' or 'more often than not' had the opportunity to discuss what matters most to them than carers of parents (17%). There was a very strong correlation between those caring for parents and those in employment, with 91% of carers in full or part-time work caring for a parent or parent-in-law, which may be one explanation for this.

Carers with no spare income for extras or leisure also tended to have fewer opportunities to discuss what matters most to them and the person they care for compared to carers with spare income for extras and leisure. One in seven (14%) carers with no spare income said they have 'always' or 'more often than not'

been given the opportunity to discuss what matters most to them compared to over a third (38%) of carers with spare income.

Feeling listened to and receiving support that is tailored to people's needs is an area for improvement

In our focus groups and interviews, we discussed a 'personalised care' approach and there were similar, mixed responses in that very few people mentioned a care plan or knew about a care plan when prompted, and there was limited knowledge or evidence of access to social prescribing, for example. While this does not give a conclusive answer to the question: did people living with dementia and their carers receive personalised care, it does signal that personalised care may be more of an ambition than a reality. This is further underpinned in the wider evidence within the report in feedback about access to support from health and social care, social prescribers, carers assessments, respite for carers, information provision and advice, etc, and also in regularity and continuity of support.

Without consistently and regularly creating the opportunity to have conversations with all carers, which enable care planning and support to be personalised, it makes providing tailored information, care planning, and support less possible. Some face-to-face contact is important in this context to better understand personal and family situations. Furthermore, annual dementia reviews with a GP (included in the Quality Outcome Framework (QoF)) stopped during the pandemic. This continued in the effort to allow General Practice to deliver the Covid-19 vaccine rollout. This means that the opportunities to discuss and plan care with a GP in a regular and planned way have also been reduced. A clear recommendation is to restart annual dementia reviews in the 2022 Alzheimer's Society report: *Left to cope alone*²⁴).

 I don't feel I've been consulted about what's best for mother, I'm just getting on with it. I asked the care agency to print off a rota so I can see who is going in. There's a care plan online I could access if needed, but I think there might be one on paper. I would have to look online to see what they have done and it's one step extra to go through. 

²⁴ [Left to Cope Alone: The unmet support needs after a dementia diagnosis | Alzheimer's Society \(alzheimers.org.uk\)](https://www.alzheimers.org.uk)

For further consideration

While we did not focus specifically on the following issues raised, or there were a smaller number of comments, there were several other aspects of feedback about services we feel are worthy of further consideration, monitoring and potential research. Some relate to issues Healthwatch Cornwall is aware of through our public feedback and statutory role within the health and social care system.

Early onset dementia

Early onset dementia, when a person develops dementia under the age of 65, is much less common – about one in twenty people living with dementia in the UK has 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 and services for early onset dementia in the county and had often had to access support from outside of Cornwall.

Responses of those caring for people diagnosed with early onset dementia to the 'use three words to describe memory loss and dementia services and support in Cornwall' question, were negative: with the exception of one comment:



The top two improvements these carers would like were 'more opportunities to take a break from my caring role' (50%) and 'For the person I care for to have opportunities to access meaningful activities they enjoy' (38%). Access to respite care and day care, and more activities and services tailored for younger people with dementia were also suggested in response to 'what additional or new service would help you?':

Activities and services for younger people with dementia - those I have found are aimed at older people and are not appropriate for a XX-year-old.

Respite for younger adults 40+ is non-existent. Our local memory cafe has been our rock throughout the pandemic.

Day care, including weekends, with the option of transport and some overnight stays.

Asked if they could connect us with another couple but they can't due to confidentiality...so just pottering on our own. A buddy system and connecting with others of similar age/diagnosis would be helpful.

Provide services that are geared towards early onset dementia, so appropriate activities for people living with dementia who are younger; and carer support for early onset carers and their families.

Five of eight carers (63%) would like more information and advice on:

- The **type of dementia** the person I care for has and the **changes to expect as the condition progresses**
- Advice to **support the person I am caring for to live well and keep them safe**
- How to recognise and what to do if the person I am caring for **has unsettled behaviour**
- Supporting **mobility issues**

Carers were using online sources to seek out information and advice relevant to their personal circumstances - three quarters (75%) of carers of people with

early onset dementia said 'I can help myself by looking up information and advice online'. One carer described a positive impact of the pandemic as more support groups moved online and so they were able to access national support groups. Being able to connect with other carers with experience, who are able to offer advice, was discussed by two interview participants, both suggesting a buddy system would be helpful.

Hospital care

A small number of carers shared their experiences of hospital care. Although this was not asked about explicitly within the survey or interview questions, some carers described poor experiences of hospital admissions, including known concerns such as noise and long stays in emergency departments, poor communication with carers and families during hospital stays and at the point of discharge. These issues arose in other work Healthwatch Cornwall have undertaken, including in a recent project with NHS England and NHS Improvement to understand carer experience of hospital discharge 2021/22.

Care homes

We did not specifically ask about carer experiences of people living with dementia in care homes, but several issues were raised by carers. Carers mentioned a lack of availability of local care homes, especially for young people living with dementia, for respite care and for longer-term complex care. Carers also spoke about their continuing, active caring role when their spouse/partner or relative had moved into a care home, and the importance of effective communication between the carer and the care home to support this – as mentioned earlier in this report.

End-of-Life Care

In one interview we heard about the challenges a carer faced when having to coordinate end-of-life care with GPs, community nurses and in accessing and coordinating medication. This resonated with other work Healthwatch Cornwall conducted, outlined in the 'My Life My Death', 2018 report, and in the Carer experience of hospital discharge 2021/22 research mentioned above. This showed carers are playing a significant role in coordinating care and support at a time when they should be focused on being with their loved ones. This also highlighted poor experiences of hospital discharge, accessing domiciliary care and of not being able to fulfil wishes in respect of the preferred place of death, due to these challenges.

Experiences of changes to services during the pandemic

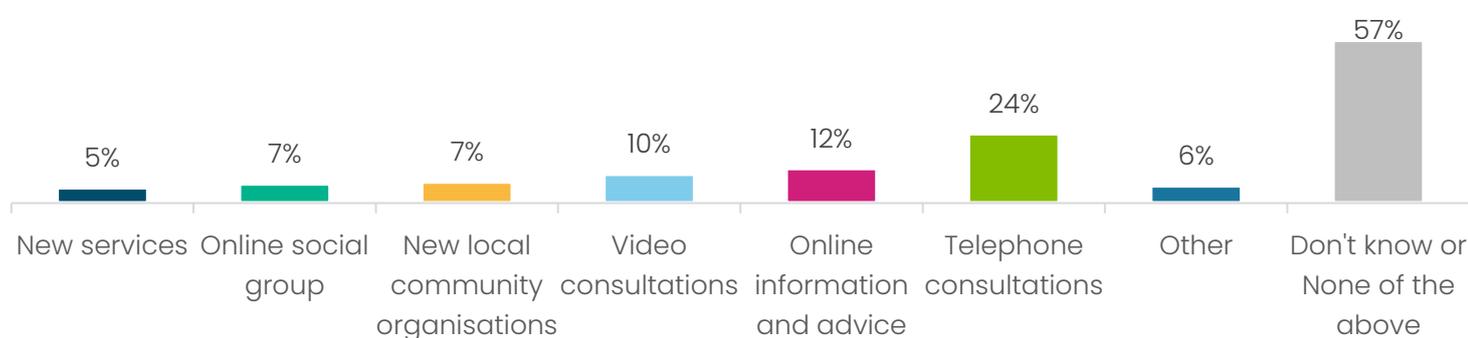
We know there has been a significant, ongoing impact of social restrictions and staffing pressures on health and care services because of the pandemic, which has directly affected people living with dementia and memory loss, and their carers.

Through the survey, we were interested to know if there have been any positive changes to service provision, that can be built upon for the future. For example,

there have been changes to the way health care and support is delivered, such as online and telephone consultations; increased use of video technology for social groups; and local community innovations.

Respondents were asked to describe the positive changes to services and support that they would like to see continue.

43% of respondents had a view. Carers would most like to see telephone consultations continue (24% of all respondents), online information and advice (12%) and video consultations (10%). Online information and advice were helpful for younger carers in particular (60% of carers aged 25 to 49 were able to help themselves by looking up information and advice online compared to 29% of carers over 80), possibly because they are more likely to be juggling their work and caring responsibilities and have easier, more convenient digital access.



ICARE IMOVE now do an NHS-funded Zoom falls prevention course. We have been able to access this from our own living room which has been brilliant. Previously this took place at a village hall. My mother would have found it too exhausting to travel and attend.

To have easy access to GP via phone and video. To have easy ways of collecting medicines/ local delivery.

 During the pandemic, Memory Cafe ran Zoom sessions on Tuesday mornings and Thursday afternoons which helped a lot during lockdown in addition to their normal Saturday afternoon sessions. 

It is important to note that although some carers would like to see telephone consultations continue and online information and advice expand, these have not been helpful for everyone. Over half of respondents said 'don't know or none of the above' and some carers provided negative feedback about changes introduced in the free text response option. Carers talked about the importance of face-to-face contact with health and care staff, including GPs and carers assessments, and emphasised the importance of providing information and advice through different avenues as online information and advice is not accessible to everyone.

 We cannot use a computer. 

 Carers need support from actually being able to meet with healthcare workers rather than online which is very impersonal. 

 Telephone consultation during the pandemic was stressful – my husband was told over the phone about his dementia. 

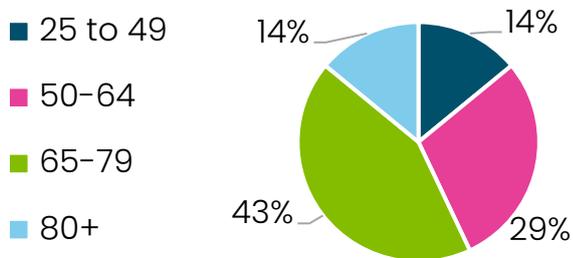
Who took part in the survey

In this section, we report on the demographics of people specifically related to those who took part in the online and paper survey only. Full demographic information for all survey, interview and focus group participants is in Appendix 1: Participants and Survey Results.

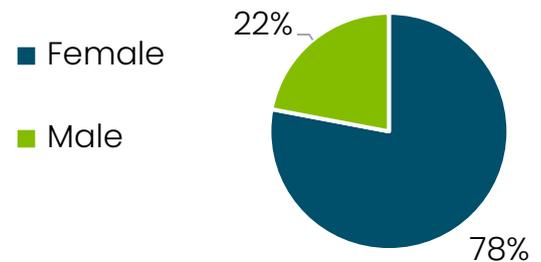
148 people aged 25 years and above took part in the survey. The majority of carers who responded to the survey were:

- over the age of 50 (43% aged 65 to 79)
- women (78%)
- white British or Cornish (98%)

Age of Carer

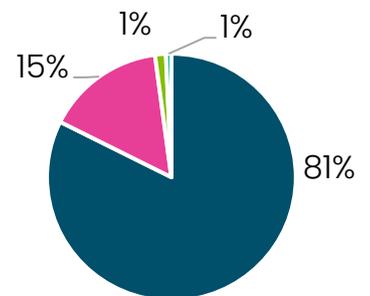


Gender of Carer

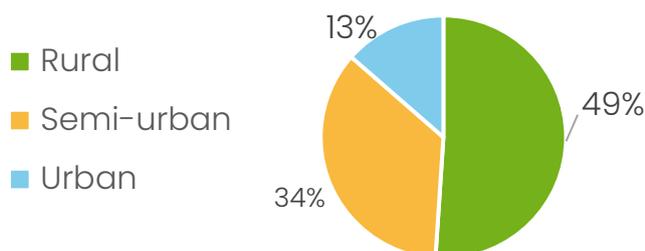


Ethnicity

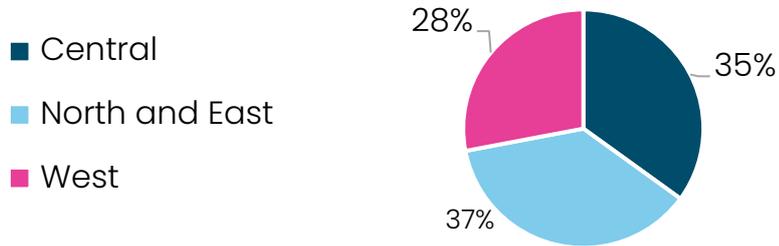
- White: British / English / Northern Irish / Scottish / Welsh
- White: Cornish
- Any other White
- Mixed / Multiple ethnic groups: Black Caribbean and White



Just under half of the 137 carers who told us what type of area they lived in, lived in a rural area.

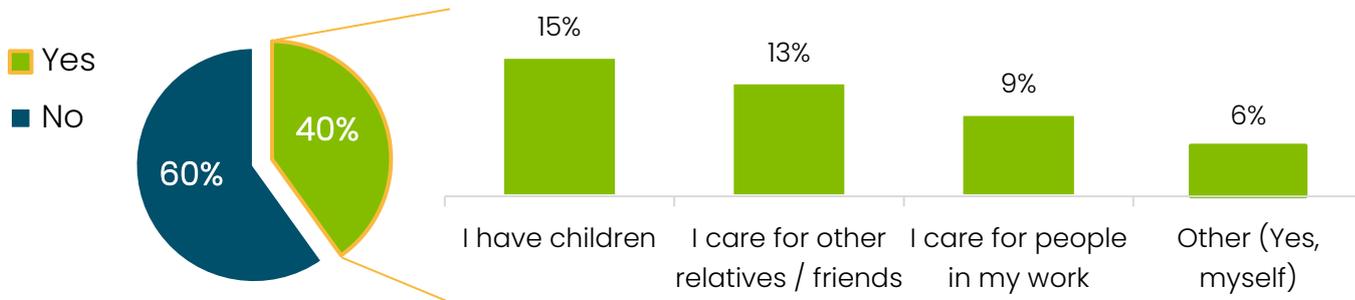


Respondents were asked to provide their postcode, which allowed them to be categorised by Integrated Care Area (ICA). 143 of the 148 responding provided a postal district or full postcode. All ICAs were represented, with the North and East area being the most represented. One carer was from the Isles of Scilly.



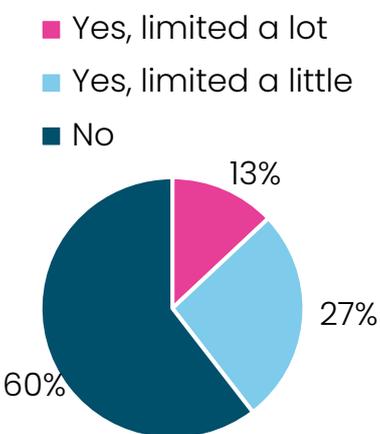
Two-fifths (40%, 57) of the carers completing the survey had additional caring responsibilities, which included their children, other relatives/friends, and people in work.

Do you have other caring responsibilities?

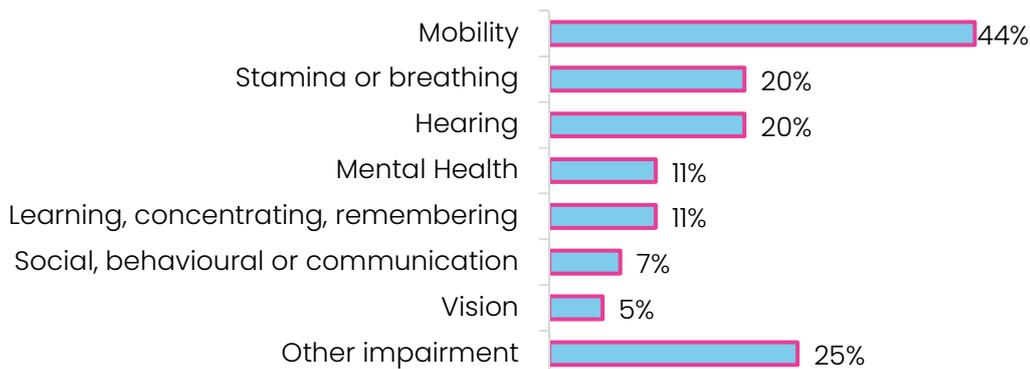


In addition to any additional caring responsibilities, 40% of the carers stated that their day-to-day activities are limited either a little or a lot because of their own health problem or disability. Nearly half of those stated that their disability was related to mobility. This may be linked to the high proportion of older carers and highlights the additional pressures and limitations which carers face.

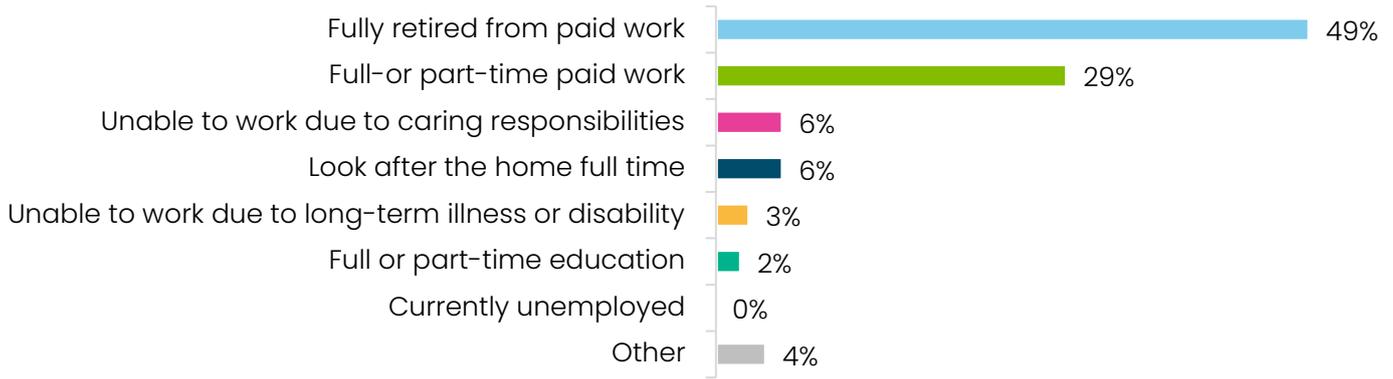
Are your day-to-day activities limited by a health condition or disability?



% of 55 carers who said "yes", I am limited "a lot" or "a little" with specific health conditions or disabilities:

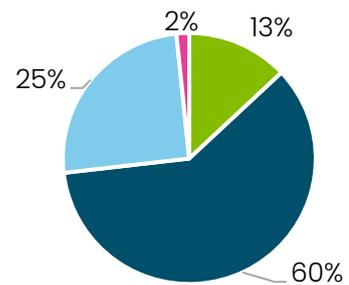


Approximately half of the carers were fully retired from paid work, further highlighting the older age profile of our carers.



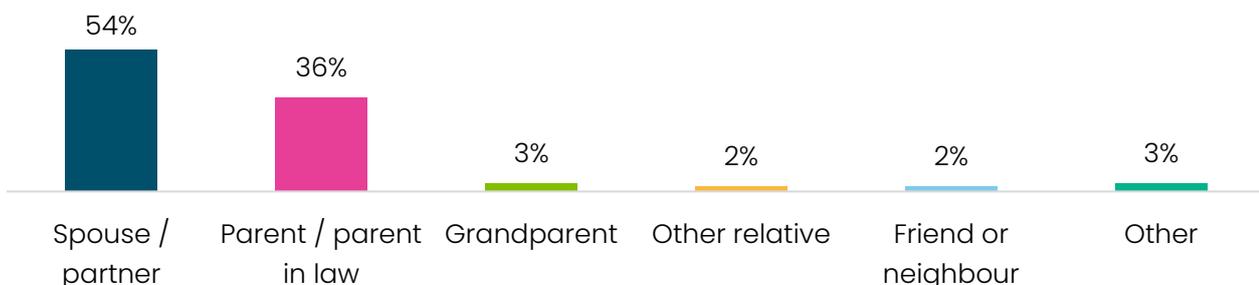
Carers were also asked about their financial situation. Over a quarter of carers (27%) indicated financial restrictions stating that they have just enough for basic necessities and little else and 2% do not have enough. The majority of carers (60%) have a little spare to spend on extras or additional leisure activities with the person they care for. The survey was completed in June 2022 and so does not reflect recent increases in the cost of living.

- I have more than enough for basic necessities, and a lot spare that I can save or spend on extras or leisure
- I have more than enough for basic necessities, and a little spare that I can save or spend on extras or leisure
- I have just enough for basic necessities and little else
- I don't have enough for basic necessities and sometimes or often run out of money

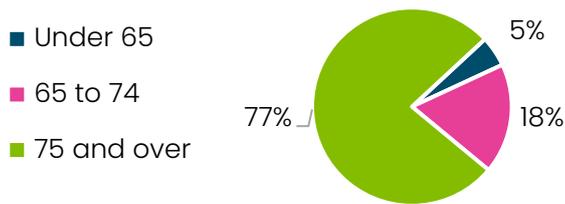


Who is being cared for?

Just over half of all the carers who responded to the survey were caring for their spouse/partner (54%). Just over a third were caring for a parent or parent-in-law (36%).



Linked to the above, over three-quarters (77%) of those being cared for were age 75 or over.



Respondents from the West area were also more likely to be caring for a parent (53% v 30%/28%) and less likely to be caring for a spouse/partner (33% v 62%/62%) than those from the other two areas.

Full details of participant characteristics are provided in the Appendix 1.

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**

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 or <https://www.healthwatchcornwall.co.uk/share-your-views>



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