THE TIVERTON AND MINEHEAD DEMENTIA REPORT

A report to examine the current levels of clinical and community care and support for individuals living with dementia in the Tiverton and Minehead Constituency, and to make recommendations for improvements.

Published By

The Office of

Rachel Gilmour MP

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Author: Emre Demir; Editors: Rhys Wallis and Ruth Giles.

With Contributions From: Rachel Gilmour MP, Alex Chowdhury, Jack Dean, Jason Berry, Sam Thomson, Rebecca Clements, Lisa Nagle, Philip Durban, Gordon Czapiewski, Brendan Almqvist, Professor Sube Banerjee, and others as listed.

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A Foreword by Rachel Gilmour MP: Commissioner of the Tiverton and Minehead Dementia Report

I am privileged to represent the constituency of Tiverton and Minehead.

I have a disproportionately large number of elderly constituents, and a disproportionate number of those find themselves in very difficult circumstances. Those with dementia, or who fear they might have it, are some of the most vulnerable of all.

I commissioned this report because I wanted to shine a light on what is happening to my constituents, and to tell government exactly what they need. In particular, I would like to pay tribute to Emre Demir, for his hard work in researching and authoring this report whilst interning in my office.

It is also why I applied to bring forward a Ten-Minute Rule Bill on Dementia Specialist Support – to turn this into action in Parliament.

I am incredibly grateful to Professor Sube Banerjee for his insights, which can be found in the video accompanying this report, as well as Appendix 8, and for the time he has given my staff and me in producing the video.

Despite being a politician, I am a human being first. I dedicate this report to my mother, who lives with dementia.

Section 1 - Introduction

This report has been created to explore the growing dementia challenge within Tiverton and Minehead, and to understand the concerns of those most affected by the condition. The report also addresses what is going well within the Tiverton & Minehead Parliamentary constituency. The report will explore suggestions for how concerns could be addressed in a best-case scenario, alongside key recommendations that would improve the lives of people living with dementia, whilst supporting carers.

The main elements of this report – items 4 through 8 – are made up of the following sections listed below. Each section discusses both concerns raised, and areas of work which appear successful. There are also, within each section, areas of improvement, framed as ‘how to improve’, which are based around an ideal scenario.

The conclusion of this report – section 9 – contains key recommendations, which are more practical in nature.

Following the compilation of the first draft of this report, stakeholders were approached for comment on the contents. Those comments have informed any amendments made to the report, and, as such, are contained, in full, in Appendices 3 through 7.

Special comments from Professor Sube Banerjee, and video testimonials from contributors to the report, have been included as Appendix 8, and also appear as part of the material surrounding this report’s publication.

Section 2 - Key data on Constituency Dementia Prevalence, and Support:

As part of the producing of this report, **we reached out to Dementia UK[1] to ask for a statistical analysis on those living with dementia within the constituency, and for diagnosis rates.**

Their response states that data from NHS Digital[i] indicates that 849 individuals in Tiverton and Minehead area are currently recorded on the dementia register, 834 of whom are aged over 65. Despite this, based on the demographics within the constituency, it is expected that dementia prevalence is significantly higher. Current estimates from the 'For A Cure' Website[ii] suggest the true number to be closer to 1,877 within the constituency.

We also asked how many Admiral Nurses are in the area:

There are currently 29 Admiral Nurses across the South West region[2]. Within Tiverton and Minehead specifically, provision is more limited. At present, the only dedicated service in the area is delivered in partnership with the Royal British Legion, supporting those who have a connection to the Armed Forces.

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[1] See Appendix 1 for the response from Dementia UK in full.

[2] Appendix 1.

Section 3 - Key data provided by the Alzheimer’s Society[3]:

We also reached out to the Alzheimer’s Society to ask **how many people have dementia or memory loss within the area of West Somerset:**

In March 2026, the most recent month for which we have data, there were an estimated 10,268 people with dementia in the Somerset Council area[4]. Of these people, only 5,755 had a formal diagnosis. This means that 4,513 people in Somerset are without a diagnosis and are therefore less likely to be accessing appropriate support services.

Somerset Council’s diagnosis rate of 56.1% is below the rate for the wider South West region (61.8%) and England’s rate (66.3%). The national ambition is two thirds, or 66.7%. According to the Alzheimer’s Society, Somerset Council’s dementia diagnosis rate has decreased slightly in the last six months and has only risen 1.3% in the last year[5].

These statistics are sourced from the NHS’s Primary Care Data[iii]. The lowest level of geographic granularity in this data is the local authority level, meaning data for West Somerset has not been included due to Somerset’s reorganisation into Unitary Authority status in 2023.

The impact of this memory loss on day-to-day life (West Somerset):

Dementia impacts the lives of both those living with the condition and their support network. This can vary for all individuals due to the complexity and severity of the condition.

Whilst there are the four "common" types of dementia (Alzheimers, Lewy Bodies, Mixed and Vascular) there are several other types of dementia which can be caused by a range of factors. These factors include personal circumstance such as alcohol-related dementia, and disease in the brain, which can lead to frontotemporal dementia (FTD). Due to the number of

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[3] See Appendix 2 for the response from Alzheimer’s Society in full.

[4] No data was provided for the Devon County Council Area, as the areas of Tiverton and Minehead with the highest prevalence of individuals living with dementia are in West Somerset, which focussed the author’s question to the Alzheimer’s Society.

[5] Appendix 2.

different types of dementia and the progression of the condition, the impact it can have varies but it does have a life altering impact, no matter the severity.[iv]

In West Somerset, transport is a major issue facing those living with dementia. Access to services and amenities is better within towns like Minehead, Wiveliscombe and Watchet, but for those living outside the towns, particularly across Exmoor, travel is very difficult. The Alzheimer's Society report that, in their experience, the fear of losing driving licences based on a dementia diagnosis often leads to people being reluctant to pursue said diagnosis[6]. This reluctance can also create issues for carers and lead to knock on challenges, including accessing support services or medical appointments.

The Minehead Medical Centre received a 'requires improvement' CQC rating in 2022[v], which the Alzheimer's Society report still leaves a legacy. Part of that rating demonstrated that it was extremely difficult for people to get medical appointments. This can lead to delays in receiving a diagnosis, accessing clinical trials, receiving treatments for symptoms, and understanding and accessing the support available. Whilst the rating for Minehead Medical Centre is now 'Good' across the board, this testimony from the Alzheimer's Society speaks to a lasting impact of a service rating of 'Requires Improvement'.

Additionally, hospital stays are often in Taunton - about an hour and a half away on public transport, with more complex travel routes. This is particularly hard for those needing routine appointments or visiting loved ones, and for those living with dementia whose condition has declined markedly, this can be a near-impossible task, even with family support.

There is a "shortage of micro providers in general"[7], with many not willing to travel across the more remote areas, particularly during the winter months. Many people retire to West Somerset, and their family networks are miles away - family support can therefore be limited, leading to isolation for some with dementia.

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[6] Appendix 2.

[7] Appendix 2. This is a direct quote from the Alzheimer's Society, which references a general shortage of micro providers across the country (UK), and does not pass comment on the status of those micro providers.

Section 4 – The First Deep Dive: Dementia support within the community, and activities:

What is going well:

Across Tiverton and Minehead, grassroots initiatives – such as memory cafés, peer support groups and what they identify as dementia-friendly activities[8] – are playing a vital role in reducing isolation and supporting both individuals and carers. Local organisations like Unite Carers in Mid Devon and groups linked to Age UK provide safe, welcoming spaces where people can socialise, share experiences and access informal support. Activities such as creative workshops, singing groups and light exercise classes can help to improve mood and wellbeing, reduce isolation, provide routine and support social connection. This helps to support both the person living with dementia and their carers.

A local charity based in Tiverton, Unite Carers in Mid Devon, does valuable work not only to support those with dementia, but also those who care for them. They currently offer a wide range of services, including specialised groups for dementia carers and those for whom they care, providing face-to-face support groups across Mid Devon. They also support individuals with form-filling at all levels and provide a free counselling service for carers of those with dementia.

A dementia action group based in Watchet, Watchet Dementia Action Alliance, holds fortnightly meetings and Forget Me Not events for carers and people living with dementia. I visited a Forget Me Not event hosted at the Sanctuary in Watchet. The team of volunteers provided hot drinks alongside activities. From speaking with people living with dementia and their carers, they explained this was a positive way to reduce the isolation

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[8] These activities include reminiscence activities, and creative activities – ranging from music to art and dance, as outlined in the Dementia and Cognitive Decline Evidence Review Oct 2014 (Sujata Ray and Dr Susan Davidson, Age UK Research) – and are intended to be designed around activities which can be cognitively stimulating, without being emotionally or physically taxing. Ideally, these activities would also be able to provide parallel respite for the carer, although it is noted that, where a conflict between the needs of the carer, and the needs of the individual living with dementia, come into conflict, that the needs of the individual living with dementia should take primacy.

barrier. Based on my experience of visiting Unite carers in Mid Devon Carers and Watchet Dementia Action Alliance, it is clear there are some cross-county opportunities for people living with dementia, and their carers.

I also met with Libby Price, CEO of The Filo Project. The Filo Project's purpose is to provide a day care service with high aspirations for what can be achieved for people with dementia. The Filo Project serves parts of the constituency, most notably Tiverton and the surrounding areas, with a further hub in Wellington, Somerset. Although Wellington is just outside of the constituency, this hub serves people from the West Deane section of Tiverton and Minehead. The concept surrounding a 'Filo Day' is that dementia-trained hosts collect a person living with dementia from their home and host them in a small group setting. The team at Filo aim to create a friendly atmosphere; by limiting sessions to small groups, it has a similar feeling to friends visiting one another.

The people living with dementia guide each Filo Day and can choose what activities they wish to take part in. From the information provided by the Filo Project, they explained that these interactions support those living with dementia and promotes independence and respite for those providing care, which many carers who engage with the Filo Project feel is much needed.

This model is particularly relevant to the issues raised throughout this report because it supports both the person living with dementia and their carer. The small-group setting helps to reduce isolation, provide a sense of routine and build confidence for the person living with dementia, while the collection element and hosted day care offer carers a meaningful period of respite. This makes The Filo Project an important example of community-based dementia support already operating within parts of the constituency.

An Exeter based home care provider, Home Instead, which received an 'Outstanding' CQC rating in 2018[vi], also operates within the constituency. For this report, we met with the Exeter and East Devon Branch, which operate in the Tiverton end of the Tiverton and Minehead constituency, however, the Taunton and West Somerset branch of Home Instead operates in the Minehead area, and is the 'only CQC Outstanding provider in the area, offering compassionate, personalised visiting and live-in home care'[vii]

Home Instead provide essential home care services to people living with dementia, as well as people with a variety of other needs. As part of compiling this report, I met with Kirsty Cambridge (Managing Director of Home Instead Exeter and East Devon). Kirsty outlined Home Instead's vision of empowering the people within their care. Providing good quality community care like Home Instead helps identify changing needs sooner, implement plans and deliver for clients, with the aim of preventing unnecessary hospitalisations where they can be avoided. Home Instead cover large parts of the Tiverton & Minehead constituency, but not beyond the Somerset boundary, which is run under a different franchise operated by the same group.

Key Concerns:

Awareness and Visibility:

From conversations with providers and micro providers in the constituency, it has become clear that many families appear to be unaware of the support which exists locally. This lack of awareness is reported to be particularly the present amongst those living with dementia and their carers in the time immediately following a diagnosis.

Services are often fragmented and not centrally promoted, and diagnosis does not always lead to clear signposting. These factors can result in people only accessing support at crisis point.

Geographical Barriers (rurality):

There is limited public transport across rural parts of Tiverton and Minehead. Given the difficulty in attending regular activities, there is a clear reliance on carers for transport. As a result, these barriers disproportionately affect people living with dementia who live alone, along with older carers and low-income households.

Capacity, Sustainability, and Financial Viability:

Groups such as those mentioned earlier in this report rely on volunteers or short-term funding. This risks burnout amongst organisers and can limit the ability of services to scale or expand to meet the changing needs of those with dementia. Dementia prevalence is expected to continue rising, with national estimates suggesting that around one million people in the UK are living with dementia, rising to 1.4 million by 2040. Therefore, if services do not expand, more people living with dementia and carers may be left without timely support.

After speaking with Unite Carers in Mid Devon, they explained that due to a lack of centralised funding for groups like themselves, they have had to stop some levels of support that they were previously able to offer. They outlined that they used to provide a home care service to people living with dementia, allowing their carers to take time for respite. They were previously paid £5 per visit by Devon County Council, as part of the 'Time for You' visiting scheme[viii], which supplemented a £5 charge per visit which was paid by the carer, or person living with dementia. Once the initial setup funding "ran out"[9], Unite Carers Mid Devon were unable to continue the provision of this service, as they could no longer meet the cost of a staff member conducting a safety visit in advance of the sessions, plus the cost of mileage for volunteers across a rural area. Unite Carers in Mid Devon believe this was a critical part of their service.

Inclusivity gaps:

It was also observed that there are fewer tailored activities for younger people living with dementia, particularly those with early-onset dementia, as well as those from diverse communities and those with more advanced needs.

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[9] See Appendix 3 for the full comments made by Sharron Trerise, of Unite Mid Devon Carers.

How to improve:

Improve awareness and signposting:

Create a single, easy-to-access directory of dementia support in the constituency, managed, maintained, and operated by the local Integrated Care Board, to contain clinical advice, and a local 'directory' of community and charitable organisations which work in this field. This could be achieved by the ICB, or clinical team providing information at diagnosis, and the General Practitioner providing a more detailed, in person, outline of support at a follow up session, subsequent to the diagnosis being delivered by a clinical professional. This in-person pathway explanation would come alongside printed guides in the GP surgery/ at the hospital for ease of access, an online hub[10] and partnership working with local organisations such as Alzheimer's Society.

Expand community-based activities:

Increase the availability and variety of dementia-friendly sessions[11], building on the work of community groups, and using their training models to expand the number of practitioners able to provide this type of session. This could be achieved through small grants for community groups. Other avenues which could be explored, could be use of existing venues such as churches, libraries and community centres, and stronger partnerships between charities and local councils. Whilst this report recognises the stretched nature of local government finance, these grants would ideally originate from local councils, to allow for local decision making to direct the funding to where it is most needed. It is also argued that, whilst the up-front costs of such a scheme could prove burdensome for councils, the savings generated from improved community care, as well as avoiding more

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[10] The NHS already operates an 'online hub' of sorts (Dementia - NHS), however, this is not specific to the local area in which an individual living with dementia lives. It is recommended, therefore, that individual ICBs would operate their own online hubs, with links to the entire spectrum of support available for individuals living with dementia within the local area, including community or charity groups.

[11] As outlined in Footnote 8.

acute care spending on individuals living with dementia, would out way such costs.

Address transport barriers:

Improve access to activities for rural residents by supporting community transport schemes, volunteer driver networks and coordinated lift-sharing through local groups. This should remain aligned with the needs of people living with dementia.

Support carers alongside activities:

Ensure activities provide respite as well as engagement by having parallel carer support groups, flexible drop-in sessions and expanded respite-linked activities.

Target early-onset dementia:

Develop age-appropriate support and activities, including evening or weekend sessions, work-focused or skills-based activities and peer networks for younger individuals. This would be especially useful for those with early-onset dementia who may have other responsibilities or lifestyles compared with older retired individuals with the condition. More focus should be placed on flexible, age-appropriate and inclusive provision.

Section 5 – The Second Deep Dive: Geographical divisions within Tiverton and Minehead Constituency

What is going well:

Groups and charities are already set up and are travelling within the area. Unite Carers in Mid Devon run 14 groups within Tiverton and Mid Devon.

In Watchet, I met with Margaret Tatham, organiser of the Watchet Dementia Action Alliance, who explained there is a community car scheme available locally which can be used to support people with transport. I also spoke to a carer of a person with dementia who explained that community bus schemes exist in the area, and that her husband, who has dementia, uses buses to attend social activities.

Overall, this shows that in some areas of the constituency, community transport schemes do exist and are making a positive difference. There are also established community transport schemes in both Somerset and Devon. Somerset Council states that community transport schemes can offer individual transport, group hire and door-to-door services[ix]. In Devon, Mid Devon Mobility also provides a 'Ring & Ride' service in the Tiverton area[x], including accessible transport for people who struggle to use conventional public transport.

The Filo Project, by collecting people living with dementia and bringing them to the host's home, also contributes towards addressing rural access issues for its clients. It is also clear that, through expansion of the project and more hosts within the constituency, this could have a further positive impact on people living with dementia and their outcomes.

Key Concerns:

Lack of Public Transport:

Within Tiverton and Minehead, public transport is not always far-reaching. This disproportionately affects people living with dementia, as many cannot drive or may lose confidence using public transport independently as their condition progresses. For people living with dementia who need to attend hospital appointments, GP appointments, dementia support groups or social activities, poor transport links can mean they are left relying on family members, carers, community schemes or expensive taxis. This can be particularly difficult for low-income households and older carers.

This concern is supported through wider public guidance. The NHS states that, for non-emergency hospital visits, people living with dementia, or any other non-emergency care need, are normally expected to make their own way to hospital[xi]. NHS Somerset similarly states that people going to hospital will normally be expected to make their own way there[xii], although does include on its website a list of alternative options which may be used – should qualifying criteria be met, and there be sufficient availability to arrange such a trip. This guidance creates clear difficulties for people living with dementia and carers living in rural communities without reliable transport. From Winsford to Musgrove Hospital, for example, it is a 46-minute drive in a private vehicle, but if you need to use public transport it takes 3 buses and 2.5 hours.

> *Note: In a rural area such as Tiverton and Minehead, ineffective public transport is a widely experienced issue, and as such, this section will appear in many sections of this report. Whilst efforts have been made to ensure that unnecessary duplication of this section has been avoided, where that is not the case, attention will be drawn to fact that the relevant section is a substantive repetition – although different emphases may be included, depending on the nature of the relevant section.*

Geographic divisions within the constituency:

There are clear geographic divisions across the constituency. Some communities have access to voluntary transport, local groups or community buses, whilst others are much more isolated. These disparities are most notable in parts of Exmoor and West Somerset, including communities around Wootton Courtenay and parts of Exmoor. Accessing services such as Musgrove Park Hospital can involve long journeys, winding roads and reliance on private transport or carers. This concern is not new, with evidence previously given to Parliament[xiii] noting that public transport provision to and within Exmoor was inadequate for the needs of residents.

Demographical Understanding, Including Digital Exclusion:

Digital exclusion is also relevant to how dementia support is offered, both to carers, and to those living with dementia. In an overwhelmingly rural area, digital connectivity is at a premium. The House of Commons Library reports that the availability of superfast broadband in Tiverton and Minehead is 8 percentage points lower than the UK average, and the availability of gigabit broadband is 39.2 percentage points lower than the UK average. The proportion of households receiving under 10Mbps download speed is 7.6 percentage points higher than the UK average and the proportion of households receiving speeds of over 30Mbps is 16.2 percentage points lower than the UK average. Finally, the average download speed in Tiverton and Minehead is under 50% of the UK average download speed (measured in Mbps), and the proportion of properties unable to receive 'decent' broadband is 5 times the UK average[xiv]. Much of the constituency's 'small areas'[12]

With such paucity of connection, it is unsurprising that digital connectivity regularly occupies a prominent place within the constituency activities of the Office of Rachel Gilmour MP. There are geographical barriers to better digital connectivity, which must be overcome to allow constituents within Tiverton and Minehead to access an increasingly online only, or at the very least online-first, world.

The demography of Tiverton and Minehead is also a relevant consideration when contending with the issue of digital exclusion. 30% of constituents within the boundaries of Tiverton and Minehead are over the age of 65, with a further 23% between the ages of 50 and 64 (mid-2024 estimate, House of Commons Library)[xv]. This is an age group which we know struggle more with technological solutions, and digital platforms, than others, as has been shown through Age UK research, which found that 31% of over-60s

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[12] As defined by the breakdown contained in table 2 of the House of Commons Library Constituency Dashboard for connectivity – see endnote xiv.

say life is harder than five years ago because more services are now online[xvi].

Given that the statistics used in the opening of this report, from NHS Digital, show that 834 of the 849 individuals living with a formal diagnosis of dementia in Tiverton and Minehead are over 65, digital exclusion – whether for demographic or geographic reasons – is a highly pertinent example of what has not been working effectively within dementia care pathways in Tiverton and Minehead.

Pressure on Carers:

Where public transport is poor, carers are often expected to fill the gap. This can mean driving long distances, taking time off work, waiting during appointments, or paying for taxis when they are unable to transport someone themselves; all of these examples have been provided through conversations with carers, and organisations otherwise listed in this report. This is more difficult for older carers, those with health conditions, or carers who do not drive. Poor transport therefore does not only affect the person living with dementia; it also increases stress and practical pressure on the carer.

In addition, digital exclusion and poor connectivity can have an impact on the ability of a carer to readily access areas of support, both for themselves, and also advice and support in how to care for an individual living with dementia. This can be particularly prescient for older carers, or carers living in isolated, rural communities

How we could Improve:

Improve Awareness of Existing Transport Schemes:

There should be clearer signposting to existing community transport schemes across Tiverton, Minehead, Watchet, Exmoor and surrounding villages. This signposting would be done in a collaborative effort between the local council, ICB, and charities and community groups who provide these transport options. Such platforms do exist on both the Devon County

Council, and Somerset Council, websites – but more could and should be done to promote these schemes.

This could be achieved by giving every person living with dementia and their carer a transport information leaflet, provided by the Council based on the web page already operational, with key points of contact to aid those with transport needs. These points of contact would include, but not necessarily be limited to, community and charity schemes which run transport options, and Council run schemes.

Strengthen Community Transport Capacity:

Community transport schemes are already doing valuable work, but they need to be more sustainable. It could be worth exploring additional funding or small grants to support volunteer driver recruitment, fuel costs and accessible vehicles. An increase in transport options would support greater geographical mobility. Whilst this is anticipated to incur further costs, these costs would, in the opinion of this report, be balanced out by the savings made through decreased acute care need, arising from more regular ability to engage with early interventions in clinical and non-clinical settings.

Dementia-Friendly Transport Training:

Drivers and volunteers working across community transport schemes should have access to basic dementia awareness training. This would spread awareness, and the training could be delivered online through a proposed dementia hub. Further information about the hub proposal is contained in the later sections of this report.

Explore a Subsidised Taxi or Travel Voucher Scheme:

For the most rural areas, especially Exmoor and isolated villages, traditional bus routes may not always be practical or cost-effective. The Government, local authorities, or NHS partners could explore a targeted, subsidised taxi scheme for people living with dementia and carers needing to attend appointments and social events designed for people living with dementia and carers. This would be valuable for those who cannot use ordinary buses due to dementia symptoms or rurality.

Section 6 – The Third Deep Dive: NHS GP Support

What is going well:

The NHS provides a recognised pathway for dementia assessment, diagnosis and initial support.

In Somerset, the Dementia Assessment and Support Service is the point of contact for assessment, diagnosis, initial treatment, information and family support.

The Devon Memory Service assesses memory problems through memory clinics, while older people's community mental health teams can support people who cannot attend memory services and provide short-term post-diagnostic support.

Key Concerns:

Post Diagnosis Gaps:

Following a two-hour meeting with Unite Carers in Mid Devon, one of the clearest concerns raised was the gap in support after diagnosis. Families reported that support can drop off once a diagnosis has been received, leaving people unsure of whom to contact, what support exists locally, or how to access social care, carer support, respite, benefits advice and community activities.

Diagnosis:

Data shows that around one in three people aged 65+ who are estimated to have dementia still do not have a recorded diagnosis. This is a key issue and can prevent people from accessing support that is available.

GP Pressures:

GPs are often the first point of contact, but short appointments can make it difficult to explore memory changes and carer stress, reducing the likelihood that respite provisions or wider support options are discussed.

This can also limit the time available to explore community support provision.

NHS Care Plans:

NHS England data for January 2026 showed that 348,685 people, or 68.3% of those with a recorded dementia diagnosis, had received a recorded dementia care plan or care plan review within the previous 12 months[xvii]. This means almost one in three still did not have a recent recorded care plan or review.

How we could improve:

Improve GP Signposting:

Every individual given a formal diagnosis of dementia, as well as every individual for who an age-related cognitive impairment, or mild cognitive impairment, is identified, should leave the GP surgery, or other clinical setting where their care need is identified, with an information pack. If an individual is given their formal diagnosis, either for dementia, or either of the other cognitive impairments listed above, then the diagnosing clinical specialist, or the patient's GP practice should have the option to "refer" people directly to charities or support agencies so they can follow up and provide support. A "referral" of this nature would not be a clinical referral to an outside body – which would sit outside what is currently able to occur from within the NHS when the body to which an individual is being referred is not a privately registered healthcare setting – but a kind of warm transfer, with the consent and knowledge of the individual living with dementia.

From the conversations undertaken in the compilation of this report, it is my understanding that this would be particularly beneficial for people living with dementia and carers who struggle with modern technology.

Strengthen post-diagnosis follow-up:

Introduce a routine follow-up call or appointment after diagnosis from a clinical professional, ideally within 6-12 weeks of diagnosis. This phone consultation should check medication, carer strain, safety at home, driving, finances, and access to community support.

Create a clearer local Dementia Pathway:

The local Integrated Care Board should produce a one-page ‘what happens next’ guide for people living with dementia and carers, along with a wider NHS-wide guide, similar to the NHS Online page about dementia, but including more specific details of support. These details should include GP referral options, memory clinic, diagnosis, care planning, social care assessment, and voluntary sector support.

Address rural appointment barriers:

There is a clear need to expand phone or video follow-ups where clinically appropriate, but it is right to acknowledge that this is a challenge given the lack of digital connectivity in the area, as well as digital literacy amongst the age demographic. These digital/ phone sessions should be seen as a way in which the NHS can expand capacity for increased appointments but must be accompanied by expanded access to *safeguarded* face to face sessions for those digitally excluded.

It is also crucial to improve links between the NHS, local council, and more generally the public, and community transport schemes. It would also be recommended to explore outreach clinics, run by the NHS but in collaboration with community groups and charities who can provide direct support, or community-based dementia advice sessions within the constituency. A potential model for these outreach clinics is how the old Willand GP surgery was run; this was a ‘spoke’ of the main ‘hub’ practice in Cullompton, but allowed people local to Willand to access their healthcare needs closer to home – breaking down one of the main barriers to healthcare in a rural area.

Better integrate NHS & community support:

Memory services and GP practices should routinely refer into local groups such as Unite Carers in Mid Devon, memory cafés, carer groups, and dementia-friendly activities. In addition, community organisations should be treated as a reliable and regular complement to the clinical dementia support pathway, rather than as an optional extra.

NHS Care Plans:

By improving NHS digital tracking and reminder systems, this could help reduce the risk of reviews not taking place due to workload pressures. These systems do already exist within the NHS, but reviews are still missed, therefore it is clear that work in this area needs to move further and faster, to close the gaps in the safety net. It would be useful to introduce automatic reminders, central tracking systems and digital dashboards for dementia reviews within the NHS. This could help ensure annual care plans are not overlooked, ensuring the correct package is in place to support the person living with dementia and, simultaneously, their carer. If these systems are a success internally, then it is hoped that they would be able to be made available to individuals with dementia and their carers, in a similar fashion to how other health information can be provided and stored on an individual's NHS App – although this must be done in a manner which is mindful of the previously raised concerns regarding digital exclusion.

Key summary:

NHS dementia support exists, but the main issue is not simply whether services are available. The bigger challenge is whether people can access them quickly, understand the pathway, and receive practical support after diagnosis. For Tiverton and Minehead, improved signposting, rural access, and post-diagnosis follow-up would have a positive impact on people living with dementia and carers.

Section 7 – The Fourth Deep Dive: Support for Carers/Social Care:

What is going well:

Local organisations and charities such as Unite Carers in Mid Devon are providing valuable levels of support to carers of those with dementia. This includes free counselling, telephone outreach, signposting and referrals. This work is alongside the breadth of workshops and their approach to a ‘different journey’, where both the person living with dementia and their carer are supported through the process. The overriding point is that social and support grassroots groups such as Unite Carers in Mid Devon help to reduce isolation.

One carer described the support from Unite Carers in Mid Devon in the following terms: “Unite Carers in Mid Devon have made such a difference to us. Without it, we would have had no positive contact since the diagnosis. So, thank you from both of us for all you do.”

Testimonials such as this show the impact and importance of support groups for those living with dementia but especially highlights the need for supporting the carers as well as the person living with dementia. These charities are making a substantial positive contribution, even with limited funds and resources.

The Filo Project also provides a relevant example of support for carers because its day care model gives carers time away from caring responsibilities while ensuring the person living with dementia is supported in a small, familiar, and dementia-aware setting. This is particularly important where carers are experiencing exhaustion, isolation or difficulty accessing conventional respite options.

Key Concerns:

Carer burnout and emotional exhaustion:

Based on key information and surveys from Unite Carers in Mid Devon, certain key phrases have been far too common. Carers describe feeling 'burnt out', 'exhausted', 'relentless', 'lonely' and 'imprisoned'. One carer described caring for someone with dementia as "doing a nursing role without any training. I am making decisions I think are right, but if I get it wrong, I feel dreadful and guilty."

Financial pressure:

Carers often face financial strain due to a variety of factors, including reducing working hours, leaving employment and rising household costs. It is also clear that, due to the rural nature of the constituency, travel costs for appointments can be high. It is worth noting that unpaid carers in the UK provide care valued at £184.3 billion per year in 2021/2022[xviii]. Stakeholders also raised concerns that existing support, including Carer's Allowance, does not adequately reflect the intensity of dementia care or the number of hours many carers provide. From my time speaking to Unite Carers in Mid Devon, many carers – but also people living with an early dementia diagnosis – arrive at their offices unaware of benefit eligibility, lacking understanding around social care assessments, and struggling to navigate the wider system.

Social care staffing shortages:

The social care sector is struggling to recruit and retain staff. According to the Adult Social Care Workforce Survey, the South West had the highest percentage of respondents within the region (of England) reporting recruitment for their workforce as 'more challenging', at 74.7%[xix]. As a result of recruitment and retention pressures, additional pressure is placed on existing care workers, as well as unpaid carers. Stakeholders raised concerns that this can lead to reduced continuity of care, missed visits, and inconsistency in the level of support provided. This is particularly concerning for people living with dementia, who often rely on familiar routines, trusted relationships, and consistent communication. Evidence given to the House of Commons Health and Social Care Committee has previously warned that continuity of care can be undermined when people experience a 'revolving door'[xx] of carers, limiting staff ability to understand individuals properly and identify changes in their condition over time.

Lack of specialist dementia training:

Both charities and carers raised concerns that many frontline staff do not receive the relevant training specific to supporting those who suffer with dementia. Stakeholders within the constituency felt this lack of training can affect the support staff provide to people living with dementia, including a lack of awareness around issues, such as appropriate plates on which to serve food, and understanding certain triggers. The lack of training can also result in staff misinterpreting behavioural symptoms and lacking confidence to support people in distress; this was brought to my attention by the team at Unite Carers in Mid Devon. Research commissioned by Alzheimer's Society found that only 55% of care staff in England reported receiving any dementia-specific training[xxi].

The misinterpretation of behavioural symptoms has also been found in research[xxii] as a key challenge in practice. There is also a challenge found in the severe to extreme behavioural and psychological symptoms which can sometimes present amongst individuals living with advanced dementia. With these symptoms can come the risk of increased aggression – both physical and verbal – as well as the risk of individuals living with dementia leaving their homes, or location in which they are provided care, unaware of their locations. Without adequate training, this report contends that those symptoms are near-impossible to deal with in a manner which is sensitive to the disorientation of an individual living with dementia, but also in a manner which maintains the safety of said individual, and those around them.

Rural Isolation and access barriers:

In the most rural areas within the constituency, due to the lack of public transport and the distance between services, carers can feel isolated. Older carers without access to transport may struggle to attend support groups and services. They may feel too isolated to access respite services and struggle to accompany loved ones to essential appointments. This rural isolation and high access barriers do not only affect the person living with dementia, but also the mental health of carers, many of whom are at breaking point.

Admiral Nurses & Specialist Support:

Admiral Nurses are specialist dementia nurses supported by Dementia UK. They provide specialist dementia advice, emotional support, crisis prevention, care coordination, and guidance for families navigating health and social care systems. Stakeholders spoke highly of Admiral Nurses and felt that greater access to this type of specialist support would help carers managing complex dementia needs. Dementia UK's 2024/25 Annual Report states that there were 476 dementia specialist Admiral Nurses in post in July 2025[xxiii].

How we could improve:

Improve Respite Provision:

There needs to be an increase in access to flexible respite provision, regardless of income levels, to support fairness within society. It is also clear, from hearing the direct testimony of individuals living with dementia, carers of those individuals, and community groups which support both the carer, and the individual, that day services could make a real difference to both people living with dementia, and their carers. Government funding to subsidise these day services would make access easier for more people living with dementia and reduce the prevalence of acute spending – either on care for the individual living with dementia, or their carer – further down the line, which would equate to a cost saving. In recognition of some carers being in crisis, emergency respite options should be more widely available to carers. An international study sourced through the University of Birmingham found that 4.7% of dementia caregivers reported suicidal thinking during the study period[xxiv]. Combining this with the experiences I have heard from Unite Carers in Mid Devon, this is something that must be addressed, and emergency respite would help aid this. Given that the prevalence and risk factors of suicidal behaviours have also been shown to increase amongst caregivers[xxv], and potentially increase amongst individuals living with dementia, more support for the caregiver and individual living with dementia would be of benefit.

Models such as The Filo Project show how community-based day care can support both people living with dementia and their carers. Providing the necessary capital and man-hours to expand access to similar small-group, dementia-aware day care provision across Tiverton and Minehead could help provide regular respite, reduce isolation and support people to remain in the community for longer. This expansion could be supported either through public or private finance.

Strengthen support for carers:

Simple methods such as clearer signposting would make a real difference to carers. One way this could be achieved is by having GP referrals to support groups such as Unite Carers in Mid Devon or other services, either at the discretion of GPs or where a carer or a person living with dementia has specifically requested extra support. It is also crucial for carers to be treated as key partners in care planning.

Increase workforce capacity:

Support recruitment and retention within social care, making social care more attractive to those seeking employment. This could be achieved through better pay, improved incentives, changes in working hours or by having more care delivered within the community. It is also important to explore local workforce initiatives, training and support alongside access to dementia-specific training.

Expand Admiral Nurse Provision:

Explore opportunities to increase Admiral Nurse coverage. Central government funding or an NHS scheme could be one option to support expansion. It is also important to embed specialist dementia nurses within

GP practices or community teams and improve support for carers managing complex needs. It is suggested that a potential ‘levy’ on profits generated from taking care of individuals living with dementia could be collected, in order to fund this increased provision of Admiral Nurses, as well as allowing for a wider range of specialist training to be delivered for workers in the social care space.

Tackling rural accessibility:

Notwithstanding the already documented issues with public transport in rural areas which, in an ideal world, would be rectified to provide a functional rural public transport network, the Government should consider a subsidised taxi scheme to take people living with dementia to appointments. Alternatively, increased outreach support and improved transport options, including more frequent buses, could be explored. Overall, private hire transport options may be more appropriate in some cases due to the nature of dementia and could be more cost-effective than expanding bus routes to areas with lower levels of demand.

Section 8 – The Final Deep Dive: Financial support

What is going well:

Financial support schemes are available. Attendance Allowance, although it remains too low to meaningfully match the ever-increasing cost of living pressures – particularly for individuals living with dementia and their carers, provides important financial support to many families affected by dementia and helps individuals manage additional care costs. Some carers of those with dementia may also be entitled to Carer's Allowance, although this depends on their working pattern and eligibility. The Better Care Fund also exists to encourage closer working between NHS services, local authorities and social care providers.

Key Concerns:

Complexity of the application process:

When I spoke with Unite Carers in Mid Devon, who help many carers and people living with dementia complete the essential paperwork needed to access Carer's Allowance and Attendance Allowance, they explained that many found these applications too lengthy, difficult and emotionally draining. Therefore, a more streamlined process would make a real difference and be hugely beneficial. It was also clear that digital poverty and digital skills gaps mean some people are not aware of the support available simply by virtue of the fact that they are not able to access the online services.

Financial Pressures on Social Care Funding:

Stakeholders highlighted concerns that demand for dementia and social care support is increasing faster than the resources available or planned. This has a knock-on effect, leading to delays in support, limited respite provision, workforce shortages, and undue pressure being placed on unpaid carers.

The Better Care Fund aims to reduce hospital admissions, allow more capacity within the wider NHS, improve community support and help vulnerable individuals remain independent for longer. This fund, whilst there are elements of good practice within it[13], has not been utilised effectively enough to provide the necessary levels of support within Social Care for individuals living with dementia. Dementia is not one of the Better Care Fund's targets/ key milestones, and therefore, the fund cannot be leveraged to properly engage with improvements in the dementia care space.

Baroness Casey's review of Adult Social Care may well provide recommendations on the nature of the future of the Better Care Fund, therefore this report has not turned to the BCF as a funding source in detail – although the mechanisms for allocation of this funding could be considerably improved.

How We Could Improve:

Streamline referrals for benefit applications:

A key way to improve the simplicity of benefit applications would be to create a clear 'warm referral'[14] route from GP practices, memory services and dementia hubs into welfare rights support. It is proposed that the Department for Work and Pensions would be the home of this 'warm referral', after having received information from an individual living with dementia's clinical team. The DWP would then be in a position to start the process of onboarding an individual living with dementia to the correct level of welfare support, as per the law, without needing to run their own application process, as this would be handled by a clinical professional passing the relevant information to the DWP. This would mean that, after diagnosis, people living with dementia and their carers could be directly referred for help with Attendance Allowance, Carer's Allowance, Council Tax reductions and other relevant support. This would help streamline applications while ensuring eligibility decisions remain with the relevant statutory body.

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[13] Such as home adaptation funding, which is in part positive where effective.

[14] This is a term coined by the author of this report for this process, and is not intended as a clinical or technical term in and of itself.

Strengthen Support for Unpaid Carers:

From discussions with individuals living with dementia, and their carers, it has become clear to be that increasing Carer’s Allowance and expanding eligibility for it would make a stark difference right across the country and within the constituency. In addition, funding to support more respite provision would be beneficial to carers and would support their overall wellbeing. Stakeholders made it clear that carers should be treated as key partners within dementia care planning.

It is important to restate that, whilst this recommendation is to treat carers as key partners in this care planning, the primacy of the wishes of the individual living with dementia must be respected, and protected. Where they have a clear wish for their carer to be involved in the planning of their care, then carers should be consulted as key partners, and be intimately involved, acting in the best interests of the individual living with dementia, to provide the best support.

Improve transparency around the Better Care Fund:

Throughout my research and meetings within the community, it has become clear that there must be better communication about local funding priorities. We also need to ensure that stronger public engagement takes place regarding the Better Care Fund, with more visibility around how dementia and carers’ support is funded locally.

Invest in early intervention and crisis prevention:

Stakeholders repeatedly highlighted that earlier community support can reduce long-term pressure on NHS and social care services. While dementia itself cannot currently be prevented, investment in respite care, community activities, carers’ support groups and dementia outreach services could help prevent avoidable crisis situations, carer burnout, social isolation, unnecessary hospital admissions, and poorly planned moves into residential care. This investment could be a partnership funding action between the local council and Integrated Care Board, and should be focussed around early interventions in care for individuals living with dementia, with a goal of preventing or reducing emergency or urgent care requirements, and the need for increased levels of domiciliary support. This should therefore be seen as a long-term saving made over the lifespan of these interventions.

Section 9 – Concluding Recommendation for Future Actions:

Recommendation 1: Dementia Community Hubs:

From my time spent researching dementia within the community, one thing has become a common theme: the need for localised community dementia hubs. These would be run by a Dementia Care Navigator[15], and could be funded through a combination of local council, central Government, and local ICB funding. Alternatively, the Better Care Fund[xxvi] would seem to be an ideal place for this funding to be found, should Dementia be refocussed as one of the BCF's priorities.

As shown throughout this report, there is a lack of knowledge around where to go for support and what funding options are available. A localised dementia hub, or hubs, within Tiverton and Minehead would bring together all aspects of support required. GPs could signpost people living with dementia to this hub after diagnosis, allowing it to act as a central point of support for dementia advice, signposting, activities, carers' support and links into NHS and social care services.

A localised hub could bring together:

Dementia advice and signposting, carers' support, social activities, welfare and benefits advice, respite information, mental health support, and direct links into NHS and social care services for those who are identified as requiring more input from these services. Some potential services could include dementia or Forget Me Not cafés, like what I saw first-hand in Watchet. In addition, carers' drop-in sessions could provide wellbeing support and bespoke advice, alongside regular Admiral Nurse or specialist dementia nurse clinics delivered through a hub-and-spoke model where required.

This service would help to address the concerns consistently raised by groups such as Unite Carers in Mid Devon. For people living with dementia,

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[15] See Recommendation 3.

it would allow easier access to support from key partners such as social services or specialist dementia nurses. Hubs would help to combat loneliness and isolation. Through social activities, they could improve routines and social engagement. For carers, a dementia hub would provide emotional support and peer networks to support wellbeing. In addition, a hub would provide easier access to advice and respite services, aiming to reduce stress and reports of burnout amongst carers. For NHS and social care services, a hub could support earlier intervention and crisis prevention by helping people access advice, respite, carer support and care coordination before problems escalate. It could also help identify changing needs earlier and support better-planned transitions into social care or residential care where required.

Suggested Delivery Model:

Key partnerships would be needed between local councils, NHS services, charities, carers' organisations and community volunteers to ensure the effective running of a dementia hub. In 2012, the Government introduced a £50 million Dementia Capital Investment Programme, which supported the establishment of the Merton Council and CCG joint Merton Dementia Hub with £357,000 of capital funding. While there does not appear to be a publicly available full cost-benefit evaluation of the Merton model, local evidence suggests dementia support services in Merton have contributed to positive case studies, carer feedback and wider dementia strategy development. This suggests that a similar capital funding route could be explored to support localised dementia hub provision within the constituency. In terms of location, the hub could be set up in existing premises to ensure the best value for money.

Recommendation 2: Increase the number of Admiral Nurses, and Specialist Training

From discussions with groups such as Watchet Dementia Action Alliance and the team at Unite Carers in Mid Devon Carers, it is clear that Admiral Nurses are held in high regard. Admiral Nurses are specialist dementia nurses supported by Dementia UK. These nurses give specialist dementia advice and help families understand the type and stage of dementia, symptoms and changes in behaviour, medication and treatment issues, communication difficulties, safety at home and what to expect as the condition progresses. Admiral Nurses also provide support for carers, including emotional support, practical advice, coping strategies, help managing stress and burnout, guidance around complex decisions and support when caring becomes overwhelming. These nurses also aid people living with dementia, carers, and wider support networks with crisis prevention, care coordination, behavioural and psychological support, and end-of-life and advanced dementia support. Admiral Nurses are valuable because they fill a gap between NHS, social care and voluntary support. For many families, they provide a named specialist professional who understands dementia and can stay involved when needs become complicated. Dementia UK's 2024/25 Annual Report states that there were 476 Admiral Nurses in post in July 2025.

Suggested Action:

Dementia UK has set a clear ambition to increase the number of Admiral Nurses to 1,000 by 2030, as set out in its 2025-2030 strategy. The Office of Rachel Gilmour MP will engage in written communication with Dementia UK to offer help in raising awareness. Admiral Nurses are not funded through a single ring-fenced government programme. Instead, they are developed through local commissioning and partnership arrangements between Dementia UK and host organisations such as NHS bodies, Integrated Care Boards, local authorities, charities or care providers. The Office of Rachel Gilmour MP will be asking NHS Somerset and NHS Devon to assess the case for commissioning additional Admiral Nurse provision across Tiverton and Minehead, particularly given the rurality, post-diagnosis support gaps, and carer burnout identified throughout this report.

Recommendation 3: Introduction of Named Dementia Care Navigators

A consistent concern throughout this report is that people living with dementia and their carers can be left to navigate a complicated system after diagnosis. Families often need to deal separately with GP practices, memory services, social care, benefits advice, transport schemes, community groups, and voluntary organisations. This can be particularly difficult for older carers, people experiencing digital exclusion, and families living in rural parts of the constituency.

A named Dementia Care Navigator would provide a single point of contact for people living with dementia and carers after diagnosis. This role would not replace GPs, memory services, social care or charities. Instead, it would help connect people to the right support at the right time, including local dementia groups, welfare rights advice, transport information, care-plan reviews, respite options and community activities. Currently, 2 nurses operate across Somerset with a similar, but distinctly different, purpose. These nurses complete the memory evaluations which are currently referred to by General Practitioners in Somerset, which has a massively positive impact – according to workers in the care sector – on how this system can be administered. Widening the role of a Dementia Care Navigator to provide that point of contact for all avenues of care for an individual living with dementia could make a significant difference for individuals living with dementia and their carers, particularly when combined with recommendation 1.

This recommendation would sit alongside the proposed dementia community hubs and increased Admiral Nurse provision. A hub would provide the main place of support, Admiral Nurses would provide specialist dementia expertise, and a care navigator would help ensure people living with dementia and carers are not left to find services by themselves.

In the previously cited NICE report into 3 pilot ‘named care coordinator’ roles, cost analysis was conducted on the introduction of a named care coordinator. In each case, the introduction of such a role reduced the cost to the NHS of care, and was not shown to have any negative impact on the quality of care on offer – in fact, it would be argued that the quality of care was increased. In the Oxleas Advanced Dementia Service – a saving of £10,983 per patient was calculated, for each emergency hospital admission avoided; this was in addition to estimated savings of £177,200-£310,100 for patients receiving palliative care at home – from a 2009 audit.[xxvii] In the Care Home Pilor Scheme from Sutton Vanguard, there were no firm costings, but the project saw an expected reduction in unnecessary hospital admissions, ambulance conveyances, and reduced spending on medication, thanks to the work of partners alongside the named care coordinator.[xxviii] And in the Midhurst Macmillan Palliative Care Service: the overall service (not specific to the named care coordinator) was shown to reduce the total cost of care in the last years of an individual living with dementia's life by 20%.[xxix]

Suggested Action:

The Office of Rachel Gilmour MP will ask NHS Somerset, NHS Devon, Somerset Council and Devon County Council whether a named dementia care coordinator or equivalent role is currently available to people living with dementia and carers across Tiverton and Minehead. If provision is found to be inconsistent, The Office of Rachel Gilmour MP will ask both Integrated Care Boards to assess the case for a Dementia Care Navigator pilot across the constituency, with a particular focus on newly diagnosed people living with dementia, carers at risk of burnout, rural communities and those struggling to access benefits, respite or social care support.

Afterword: Emre Demir, Report Author

I wrote this report because dementia is not only a national health and social care challenge, but something that has touched my own family. My Grandfather, Alan Spivey, sadly passed away from dementia at the age of 75. I saw firsthand the challenges presented by this condition; alongside the devastation it can cause to the family of the individual living with dementia. His experience has stayed with me throughout this work. Through this report, commissioned by Rachel Gilmour MP, I wanted to understand what life can really be like for people living with dementia, their carers, and the community organisations supporting them across Tiverton and Minehead.

My findings are based on conversations with local charities, care providers, dementia support groups and stakeholders, alongside data from organisations including Dementia UK, Alzheimer's Society and NHS sources. I visited and spoke with groups working directly with people affected by dementia, including Unite Carers in Mid Devon, Watchet Dementia Action Alliance, The Filo Project and Home Instead. These conversations helped me understand not only what support exists, but also where families are being left to struggle.

What I found was a picture of strong local commitment, but uneven and often fragile support. Across the constituency, dedicated volunteers, charities and care providers are doing vital work to reduce isolation, support carers and help people living with dementia remain connected to their communities. However, I also found serious challenges around rural transport, post diagnosis support, low diagnosis rates, carer burnout, social care pressures, financial strain and the difficulty many families face knowing where to turn.

These findings sit within a wider dementia care landscape where sadly demand is rising, unpaid carers are under growing pressure, and health and social care services are struggling to meet need. It became clear throughout my detailed look at the situation that the lack of guard rails, around funding are having a marked negative impact on the lives of those living with dementia and their carers. Pressures are also intensified in rural areas due to distance, poor transport links and digital exclusions.

The cornerstone recommendations of this report are the creation of local dementia community hubs, which would be a one stop shop for support, where different support groups can come together to support those living with dementia and carers. This would help to coordinate access to an admiral nurse, welfare advisors~~,~~ support groups. This would help to address the clear gap in post diagnosis support identified within this report. I also recommend the introduction of a named Dementia Care Navigator to organise support within the area, to be that point of contact for families but also support groups, enabling there understanding to be developed so they can provide the best and most up to date support available.

Together, these recommendations would help make support more visible coordinated and accessible. My hope is that this report helps bring the experiences of people living with dementia and their carers to the centre of local and national decision making.

Emre Demir

Appendices:

Appendix 1 – Full Email from Dementia UK

Good afternoon

Thank you both for your emails on behalf of Rachel Gilmour MP about dementia and Dementia UK support within the constituency of Tiverton and Minehead.

Please find below the information requested, which I hope is helpful.

- Data from NHS Digital indicates that 849 individuals in the Tiverton and Minehead area are currently recorded on the dementia register, of whom 834 are aged over 65.

- However, based on local demographics and the age profile of the population, we would expect the prevalence to be significantly higher. Current estimates suggest the true number of people living with dementia in this area may be closer to 1,877.

- Memory problems may not be obvious in the early stages of some types of dementia, like frontotemporal dementia – changes in behaviour and personality may develop first. People with young onset dementia (where symptoms develop before the age of 65) are also less likely to experience memory loss as an early symptom.

- People with dementia may experience day to challenges with memory, which can impact them with:
    - difficulty retaining information
    - getting lost in places that used to be familiar

  - difficulty remembering names and recognising faces
  - difficulty remembering where things are; misplacing things frequently or putting them in the wrong place

- For any constituent who is concerned about themselves or a family member, they should speak to their GP. **To speak to one of Dementia UK's specialist Admiral Nurses about dementia, they can contact our free Helpline on 0800 888 6678 (Monday-Friday 9am-9pm; Saturday, Sunday and bank holidays 9am-5pm, every day except 25th December.**

- There are currently 29 Admiral Nurses across the South West region. Within Tiverton and Minehead specifically, provision is more limited. At present, the only dedicated service in this area is delivered in partnership with the Royal British Legion, supporting carers who have a connection to the armed forces.

- These figures are not fixed and may fluctuate over time, as provision is dependent on local funding arrangements, commissioning decisions, and changes in service delivery, including potential closures or developments.

Please do let me know if you have any questions or would like further information.

Appendix 2 – Full Email from the Alzheimer's Society

Thanks for getting in touch, and thanks again to Rachel for coming along to our event last week.

Happy to share the below, I've also looped in Freddie from our Local Systems Influencing Team who would be happy to chat further and provide some more information:

1. How many people have dementia or memory loss within the area of West Somerset?

In March 2026, the most recent month we have data for, there were an **estimated 10,268 people with dementia in the Somerset Council area**. Of these people**, only 5,755 had a formal diagnosis**. This means that 4,513 people in Somerset are without a diagnosis, and are therefore less likely to be accessing appropriate support services.

Somerset Council's diagnosis rate of 56.1% is below the rate for the wider South West region (61.8%) and England's rate (66.3%). The national ambition is two thirds, or 66.7%. Somerset Council's diagnosis rate has declined slightly in the last six months, and has only risen 1.3% in the last year.

These stats are sourced from the NHS's Primary Care Data. The lowest level of geographic granularity in this data is the local authority level, so data for West Somerset has not been included since Somerset became a unitary authority in 2023.

2. What is the impact of this memory loss on their day-to-day life (West Somerset)?

Dementia can impact the lives of those living with the condition and their loved ones in a number of ways. These impacts are similar across the country**, however some areas, such as rural areas like West Somerset, feel these more acutely.**

In West Somerset for example, **transport is a major issue facing those living with dementia.** Access to services and amenities is better within towns like Minehead, Wiveliscombe, and Watchet. However, for those living outside the towns, particularly across Exmoor, travel is very difficult and the fear of losing driving licences often leads to people being reluctant to get a diagnosis. This also creates issues for carers and can then have knock on problems including accessing support services or medical appointments.

The Minehead Medical Centre received a 'requires improvement' CQC rating - **it's extremely difficult for people to get medical appointments**. This can lead to delays in getting a diagnosis, accessing clinical trials, receiving treatments for symptoms, and understanding and accessing the support available. Additionally, hospital stays are often in Taunton - about an hour and a half away, with more complex travel routes. This is particularly hard for those needing routine appointments or visiting loved ones, and often impossible for people living with dementia.

There is a shortage of micro providers in general, with many not willing to travel across the more remote areas particularly during the winter months. Many people retire to West Somerset, and their family networks are miles away - **family support can therefore be limited, leading to isolation for those with dementia.**

We believe a new dementia community/support hub is opening on the 12th of June in the village of Porlock, providing much needed support for those in the area.

I hope the above information is helpful. As always, we are happy to chat further and support you and Rachel in raising the profile of dementia and taking action both on a national and local level.

Appendix 3 – Stakeholder Feedback from Sharon Trerise, Unite Carers Mid Devon:

Sharron Trerise – Unite Mid Devon Carers:

‘ I would like to add my thanks for all the hard work you have put into your research.

As well as agreeing with Fiona’s comments[16], I also note that there is no mention of the enormous amount of funding Devon County Council pay to commission Devon Carers/Westbank to support unpaid carers in the whole of Mid Devon.

For your information it was Devon Carers that did the “Time For You” visiting scheme funded by DCC. We got an initial set up amount and then were able to charge £10 per visit - £5 paid by the carer and £5 paid by “Time For You”. Once the initial “set up” money ran out and although we are a “not for profit” charity, we were unable to meet the cost of a member of staff doing a “safety visit” and then the mileage payment to our carers, although we have many volunteers that are happy to travel to carer’s homes. The cost is obviously exacerbated by the rural locations and lack of public transport to the remote parts of Mid Devon.

Our “group sitting service” which we set up after Age UK closed in lockdown also had to close due to lack of attendance mainly due to transport issues. We had plenty of volunteers to support the group, but lots of community transport services are for one off appointments and cannot be used for regular attendances to groups – especially when the cared-for person is travelling on their own.

I would like to add that ALL of the services we offer are free of charge – including the counselling and that we rely solely on grants and donations. The Filo Project is a fantastic, but it is a paid-for service which I believe costs more for a day than a whole week’s attendance allowance. Please feel free to contact us again if you have any further questions.’

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[16] Appendix 4

Appendix 4 – Stakeholder Feedback from Fiona Bladon, Trustee, Unite Mid Devon Carers:

Fiona Bladon – Trustee Unite Mid Devon Carers:

Dear Emre and Jason

Sharon has forwarded to me a copy of your report, “Dementia Project”, which I have been delighted to read. Obviously, you have put a great deal of thought and work into this report and should be congratulated for it. Some of the facts and figures are really concerning, and for people who live in cities, it is difficult to grasp the reality of “rurality”!

I hope sincerely that you do not mind me commenting as below:

You mention micro-providers - many of whom are absolutely amazing in the support they give. However, they are not monitored or regulated routinely, so care must be taken in selecting a micro-provider. This is not always something of which carers are aware.

Would you be able to alter our name from Unite MD (or Unite MD Carers) to Unite Carers in mid-Devon? (several entries) (I want carers to be able to find us!)

Page 6 – Section 2 Geographical division

Unite Carers provides support in several areas, but we can’t claim to visit 14 areas yet! We may have confused you at this point – we run 14 groups within Tiverton and around mid-Devon.

I believe Somerset has a Dementia Strategy, but it is something that Devon has been slow – even reluctant to deliver. It is only now, after several years of work and a huge outcry from interested parties that the Devon ICB has ratified the Devon Dementia Strategy. Work is progressing to show how important the strategy is, and how it will impact the numbers of people requiring hospital stays and how much money could be saved!

I have been working on a document showing what we do at Unite Carers and I attach a draft copy which may be useful to you.

Thank you for bringing these issues to light and raising awareness of the needs of people with dementia, their journey partners and also the challenges faced by the charities who are doing their best to support them. As more responsibility is moving from the hospital services to the community and the “neighbourhood” schemes, so more responsibility is falling on the carers and charities.

Appendix 5 – Stakeholder Feedback from Margaret Tatham, Watchet Dementia Action:

Response From Margaret Tatham – Watchet Dementia Action:
Dear Emre

Many thanks for this.

On p.3 you record your visit to the Forget me not café. In line 4 it should read
wordsearches
not
crosswords.

More generally, the accepted terminology is
people living with dementia and their carers
not
carers and patients.

Apart from these two points, this seems to me to be a good and helpful summary of the situation.

Thank you,
Best wishes
Margaret

Appendix 6 – Stakeholder Feedback from Libby Price, CEO and Director, the FILO Project CIC:

Response From Libby Price – Filo Project:

Hi Emre,

Apologies for the delay, I have been away.

I am happy with your report.

Thanks

Libby

Appendix 7 – Stakeholder Feedback from Kirsty Cambridge, Owner/ Director of Home Instead Exeter and East Devon:

Response From Kirsty Cambridge – Home Instead Exeter and East Devon:
I am happy with our mention, and will be meeting 2 of the MPs you mentioned in the next few weeks

Kirsty

Kirsty Cambridge

Appendix 8 – Video Testimonials from Professor Sube Banerjee, and Stakeholders Involved in the Report

Following the conclusion of this report, it was presented to Professor Sube Bannerjee (MBE, MBBS, MSc, MBA, MD, FRCPsych), Old Age Psychiatrist, Professor of Dementia at the University of Nottingham, , Co-Director of the National Institute for Health and Care Research's Policy Research Unit on Dementia and Neurodegenerative Diseases. Prior to his time at the University of Nottingham, where Prof. Banerjee also serves as Pro-Vice-Chancellor for the Faculty of Medicine and Health Sciences, he was the Executive Dean of the Faculty of Health at the University of Plymouth, Associate Dean for Strategy and Deputy Dean at Brighton and Sussex Medical School and Professor of Mental Health and Ageing at King's College London. He has been awarded national and international awards for policy and research in dementia. He is also a Trustee of Alzheimer's Society, a Non-Executive Director of Somerset NHS Foundation Trust, and an elected member of the Executive of the Medical Schools Council.

Below, is a video testimonial from Professor Banerjee.

Click Here to See what Sube Banerjee had to say

The author of this report also approached the stakeholders listed in appendices 3 through 7, two of whom responded with a video testimonial – which can be found below:

Click Here to listen to the testimonials of two individuals who work in the dementia care sector

REPORT END

Sources Used – As Referenced through Endnotes:

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[i] Primary Care Dementia Data, March 2026 - NHS England Digital Published 30th April 2026. Next set of figures due for publication 30th July 2026 covering the period to June 2026.

[ii] Dementia Prevalence by UK Constituency 2024 The 'For A Cure' Website is run by Alzheimer's Research UK, and estimates Tiverton and Minehead to have 1,877 individuals living with dementia

[iii] Primary Care Dementia Data, March 2026 - NHS England Digital

[iv] Types of dementia | Alzheimer's Society

[v] All inspections: Minehead Medical Centre - Care Quality Commission – 4th November 2022 Report found MMC Required Improvement across 3 elements of inspection – 'Safe', 'Well Led', and 'Effective' – with a rating of Good attained for the areas of 'Caring' and 'Responsive', with an 'Overall' of 'Requires Improvement'.

[vi] Home Instead - Care Quality Commission Home Instead Exeter and East Devon registered again with the CQC on 25th November 2022, but their previously registered address received an Overall Outstanding CQC rating across all 6 areas (including Overall) in 2018.

[vii] Home Instead Taunton & West Somerset - Care Quality Commission Home Instead Taunton and West Somerset received an Overall Outstanding CQC Rating in July 2019, with 5 out of 6 areas (including Overall) deemed as Outstanding. The only 'Good' rating was for the category of 'Safe'. In 2023, a review of the provider's rating was undertaken, and the status of all points categories were maintained.

[viii] Time For You sitting service - Devon Carers at Westbank Run through Devon Carers, a funded, Devon County Council Commissioned service, this service was previously supplemented by a match-funded contribution from Devon Carers, which ran alongside the payment by the carer or person living with dementia, but is now voluntary

[ix] Community transport in Somerset

[x] Ring & Ride Tiverton | Mid Devon Mobility

[xi] How to organise transport to and from hospital - NHS

[xii] Patient Transport - NHS Somerset ICB

[xiii] committees.parliament.uk/writtenevidence/25846/pdf/ Evidence Given to the Health and Social Care Select Committee, April 2021, by Age UK; committees.parliament.uk/writtenevidence/127755/pdf/ Evidence submitted to the Health and Social Care Select Committee, January 2024, by Age UK.

[xiv] Constituency data: broadband coverage and speeds

[xv] Headline statistics for your constituency

[xvi] One in three (31%) over 60s say life is harder than five years ago because more services are now online

[xvii] Primary Care Dementia Data, January 2026 - NHS England Digital

[xviii] Valuing Carers 2021/22: the value of unpaid care in the UK – Report commissioned by the Centre for Care, and Carers UK, published November 2024, authored by Dr Maria Petrillo, Dr Jingwen Zhang and Professor Matt Bennett.

[xix] Adult social care workforce survey: April 2025 report - GOV.UK

[xx] committees.parliament.uk/writtenevidence/25846/pdf/ Evidence Given to the Health and Social Care Select Committee, April 2021, by Age UK; committees.parliament.uk/writtenevidence/127755/pdf/ Evidence submitted to the Health and Social Care Select Committee, January 2024, by Age UK.

[xxi] Baristas are better trained than dementia staff | Alzheimer's Society

[xxii] Palliative Care for People With Very Severe to Extreme Behavioural and Psychological Symptoms of Dementia (BPSD): A Scoping Review - PMC

[xxiii] dementia-uk-annual-report-2024-2025.pdf Page 4 – Chair and Chief Admiral Nurse/ Chief Executive Officer's Report.

[xxiv] The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over 2 years - University of Birmingham Karlin Joling, Siobhan O'Dwyer, Cees Hertogh, Hein van Hout, published in the International Journal of Geriatric Psychiatry, Feb 2018; Vol 33, Issue 2.

[xxv] Similarities and differences in the prevalence and risk factors of suicidal behavior between caregivers and people with dementia: a systematic review | BMC Geriatrics | Springer Nature Link Mohamad, M.A., Leong Bin Abdullah, M.F.I. & Shari, N.I. Similarities and differences in the prevalence and risk factors of suicidal behavior between caregivers and people with dementia: a systematic review. *BMC Geriatr* **24**, 254 (2024). https://doi.org/10.1186/s12877-024-04753-4

[xxvi] Tailored resource: The named care coordinator role from the perspective of older people – Using the Oxleas Advanced Dementia Service as a model, this type of innovation was funded through the Better Care Fund, p18. Published by NICE.

[xxvii] Tailored resource: The named care coordinator role from the perspective of older people page 9.

[xxviii] Tailored resource: The named care coordinator role from the perspective of older people page 14

[xxix] Tailored resource: The named care coordinator role from the perspective of older people page 16