

Left to Cope Alone

The unmet support needs after a dementia diagnosis



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For a full list of thanks, see the Appendix.

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Executive Summary

Dementia is a complex condition crossing primary, secondary, community, acute and social care. This complexity inevitably leads to a lack of ownership of the condition within the health and care system, which creates variation in the quality and type of support people receive. Funding for dementia services is also often limited by cost and staff capacity meaning services cannot consistently offer people with dementia the support they want and need.

This report has sought the views and experiences of over 2,000 people affected by dementia to understand what support they need after diagnosis. It shows that people's needs are holistic and wide-ranging, encompassing support for medical, emotional and social wellbeing. Yet these needs are often not being met.

We found people are regularly missing out on care that is timely and appropriate. This failure is having a negative impact on the wider system as well as on the quality of life of those living with the condition. For example, Hospital Episode Statistics for 2021-22 show that almost one third of people with dementia admitted to hospital stayed for a day or less.

This suggests that better community support would be able to treat many of these admissions in the community, relieving pressure on NHS acute services. One system case study in our report projected it could save £2 million by reducing crises and costly admissions through improved community support for people affected by dementia.

People with dementia have been hardest hit by the pandemic, yet gaps in support were evident long before Covid-19 with the pandemic acting to further widen these gaps. A key theme from our evidence collection is that people struggle to access care and support when they need it, largely because services are so fragmented.

One person with dementia told us:



Different parts of the system do not seem to talk to each other. The memory clinic tells you to contact your GP and then the GP tells you to contact the memory clinic. Social workers say that your relative should be entitled to a review, but then you can't get a referral, and so on. It is like banging your head against a brick wall.

There are national metrics, although limited, in England to assess earlier parts of the pathway such as diagnosis. These diagnosis metrics are not centrally collected in Wales and Northern Ireland, meaning the experience of people with dementia also varies across the United Kingdom. Yet apart from annual dementia reviews, there are no other performance metrics in England that look at the effectiveness of the care and support offered after diagnosis. Perversely, the diagnosis rate metrics often force local health and care systems to shift attention toward the start of the dementia pathway, leaving fewer resources for providing support after diagnosis.



This report shows that a diagnosis without sufficient post-diagnostic support leaves people living with a complex and potentially devastating condition with limited understanding, capability or tools to cope with or manage its symptoms. One person caring for someone with dementia told us:

“

It is a lonely place to be because at every turn you are dealing with professionals who mean well to support, but they exist in a system that is busy and understaffed. I felt exhausted mentally and physically and was rejected many times when all I wanted was my father to be looked at as a person with complex needs.

The complexity of dementia also means that when support needs go unmet, people deteriorate quicker and are more likely to experience a crisis. Our overarching recommendation is for everyone to have access to a dementia support worker or similar service. These roles should be recruited in every primary care network to act as the initial lead professional and first point of contact. This would facilitate a smoother transition between the memory service and primary care and reduce the pressure on general practice. It would also ensure people living with dementia have a single point of access to connect with wider care and support services as their needs change and become more complex. This should be planned as the first step for integrated care systems to develop an overall ‘stepped’ model of care where people can easily access specialist intervention within the community to reduce crises.

Given health inequalities have been exacerbated by Covid-19, areas with high ethnic minority populations should also consider a community link worker component to these roles to reduce the disparities in support this report also highlights for ethnic minority communities.

With the introduction of integrated care systems, combined with a new national dementia strategy, there is now a real opportunity to improve the post-diagnostic support offered to people living with this potentially devastating condition. Dementia must be recognised as a priority and given the resources it requires.

What needs to change?

The general post-diagnostic support pathway for people with dementia is that they will be diagnosed by a specialist – usually a memory assessment service – who may also provide immediate support after diagnosis. After some time, depending on the type of dementia diagnosed, people will then be discharged from the memory assessment service to their GP, who will take over their ongoing care and support.¹

However, a lack of guidance around this stage of the pathway often leads to a postcode lottery of access to effective care and support.^{2,3} The complexity of dementia also requires a multidisciplinary approach to support, including both health and care providers, which is frequently lacking in primary care.⁴

This report looks at what people affected by dementia want from support after diagnosis and the outcomes that are important to them. It finds that many people struggle to access appropriate care and support for themselves and their families.

A consistent theme of people's experiences was fragmentation, in terms of both access to, and quality and timing of, support. This inevitably leads to people and their families being unsupported, left to manage a complex, degenerative condition with little help. Recent research studies have shown similar findings.^{5,6,7}

The recently established integrated care systems are best placed to take ownership of local areas' post-diagnostic support for people affected by dementia. Yet there is also a need for national action to provide direction for improving dementia care locally.



Recommendations

Main recommendation

- Ensure everyone diagnosed with dementia has access to a dementia support worker or similar service. These roles should be featured as the first point of contact in every primary care network, with automatic referral from memory services. To reduce crises, the service should be delivered as part of an overall, integrated 'stepped' model of care where people can easily access more specialist intervention within the community as their needs become more complex. These roles should include a community link worker component in areas with a high ethnic minority population.

Annual dementia review

National

- National health systems in England, Wales and Northern Ireland should undertake a review of the Quality and Outcomes Framework (QOF), or its equivalent funding mechanism, in collaboration with people affected by dementia. They should consider additional indicators to support a more comprehensive, high-quality annual dementia review.
- National health systems in England, Wales and Northern Ireland must publish a plan for Covid-19 annual boosters to ensure that primary care need never again pause QOF, or its equivalent funding mechanism, activity as happened between 2020-22.

Regional

- Local health systems should support primary care to return care plan reviews to pre-pandemic levels, such as 75% in England, by April 2023.
- Local health systems should ensure that a system is in place to identify those with dementia who are most vulnerable and at risk of crisis, who can then be offered more frequent care plan reviews if needed.
- Local health systems should undertake a multidisciplinary team approach to annual reviews and stagger reviews throughout the year to improve quality and increase primary care capacity.

Wider post-diagnostic support

National

- National health systems in England, Wales and Northern Ireland should assess social prescribing provision for people with dementia, including workforce support and training. They must ensure people with dementia are offered equitable support compared with other long-term health conditions.
- NHS England must undertake a review of capacity of urgent community response services. It must also commit to a timeline to bring in the second phase of the service – providing reablement packages within two days of a crisis to prevent it reoccurring.

Regional

Dementia pathways should be commissioned to:

- Achieve the Memory Services National Accreditation Programme standard, which states everyone diagnosed with dementia should be offered a post-diagnostic meeting. This should be offered at an interval after diagnosis that suits the individual's needs.
- Provide post-diagnostic information and education support in relevant community languages other than English, as well as in non-written resources, to reduce health disparities.
- Offer equitable access to non-pharmacological interventions as per national guidance, such as cognitive stimulation therapy (CST), and ensure all memory services have access to CST by April 2024.
- Ensure occupational therapists, psychologists and other allied health professionals have protected time to carry out post-diagnostic support at memory service level alongside their diagnostic responsibilities, including home visits if appropriate, in line with patient need and symptom deterioration.
- Ensure all memory assessment services are designed to provide an equal offer of support for all subtypes of dementia, including appropriately timed discharge and provision of interventions, and that the needs of ethnic minorities are catered for.
- Ensure that all carers are offered a psychoeducation course as per national guidance to support them in their caring role and that carer information and support groups are available locally.
- Ensure services under the Improving Access to Psychological Therapies (IAPT) programme do not reject referrals based on a diagnosis of a cognitive disorder and are designed to accommodate the needs and symptoms of people with dementia and their carers, with staff appropriately trained to offer this support.

Introduction

The need to diagnose dementia and support people affected to live well will only become greater as the number of those with the condition increases and new treatments become available.

There are currently around 900,000 people with dementia in the UK and this is projected to rise to over 1 million by 2025 and 1.6 million by 2040.⁸ New treatments and diagnostic tools for the diseases that cause dementia are expected to be available within the next two to five years.



Dementia is a complex progressive neurological condition, and its symptoms are unpredictable. It occurs when the brain is damaged by diseases (such as Alzheimer's disease) or by a series of strokes.

The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function. The rate of progression also varies from person to person. The specific symptoms that someone experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia.



After diagnosis, **three out of five people (61%) of people told us that they did not feel supported by the health and care system** to cope with their diagnosis and manage their condition.

Post-diagnostic support is wide ranging, as this report will show, but can be categorised overall as a 'a system of holistic, integrated continuing care in the context of declining function and increasing needs of family carers' from diagnosis to end of life.⁹

The importance of effective and appropriate post-diagnostic care and support is outlined in the Dementia Statements, which are grounded in human rights law, and directly reflect the needs of people living with dementia:

- **We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.**
- **We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.**

Are people's post-diagnostic support needs being met?

Annual dementia review

An annual dementia review is an essential part of the care a person with dementia receives – it should recognise the needs of people living with the condition and develop a plan to address them. This review should be conducted at least annually,¹⁰ most often by a GP. It should comprise of a review of medication, a check for new symptoms or behaviour changes and a discussion of planning ahead as well as support for carers.¹¹

Research suggests that structured management of long-term conditions like dementia through an annual review can delay the point at which people experience complications and deterioration in their health.¹² A care management approach to dementia – co-ordinating treatment and care within the community – is a cost-effective approach, reducing adverse outcomes such as hospitalisation and premature institutionalisation.^{13,14}

However, we know that people aren't getting the right care for their needs. Research suggests that just 38% of people with dementia report that they are receiving dementia services.¹⁵ It is therefore clear that annual dementia reviews are not working as effectively as they should be in addressing and signposting the necessary support to meet people's needs.¹⁶



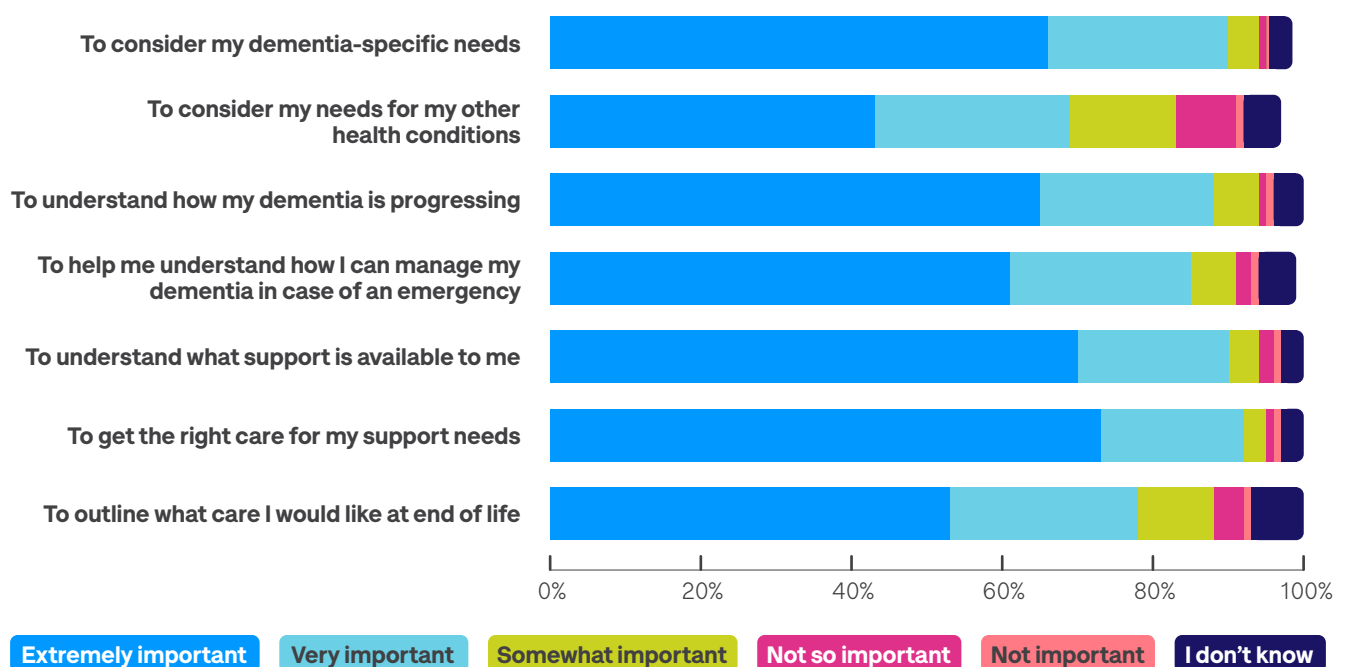
An annual review is that ticket into further support.

Person living with dementia

Based on an extensive literature review, we have identified seven key needs that people living with dementia require from annual dementia reviews. We then used a survey of 914 people affected by dementia to rank their importance.

The following graph shows the seven needs identified for annual dementia reviews.

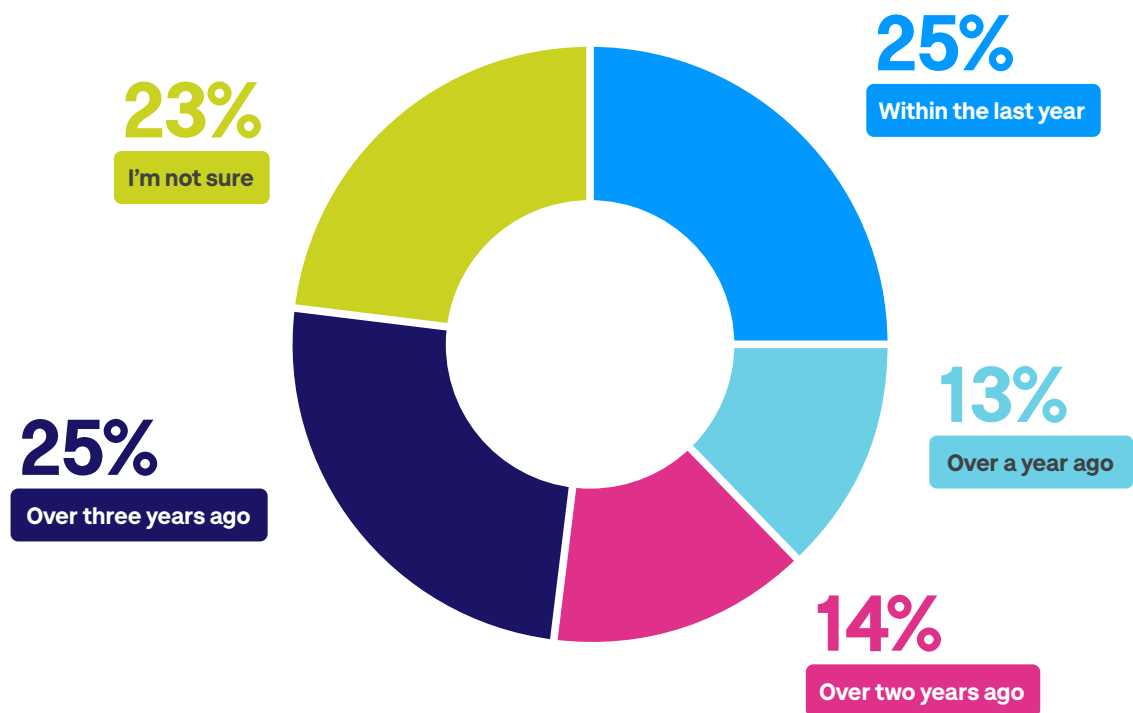
Thinking about the annual dementia review, how important are the following to you?



Access to annual dementia review

Both people with dementia and professionals suggest annual dementia reviews are not happening as often as they should, if at all, echoing recent research.¹⁷ Despite guidance stating that people should be offered a review at least annually, our survey found just one in four people (25%) reported they or their loved one had had their dementia review within the past year. Two out of five (39%) said it was at least two years ago.

When was the last time you have, or the person you care for, had an annual dementia review?



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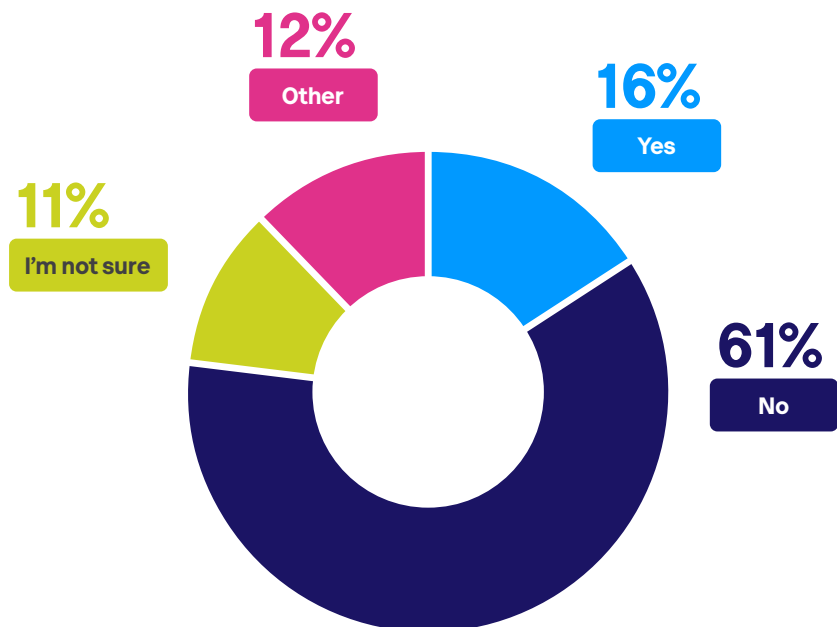
‘I wasn’t even aware that we should have an annual review about dementia. I should have known about this so why wasn’t I aware – has there been [a] breakdown somewhere?’

Person living with dementia

Many people we spoke to told us they have rarely or never had a review. Some spoke of being let down by their GP practice and felt as if they were left ‘to get on with it’ – left to manage the condition without appropriate care and support. An impact of this is that people received care and support much later than they would have done via their GP, if at all, as they were left to arrange access to interventions and services themselves.

Just 16% of our survey respondents said they had received enough support from local services and organisations – such as their memory clinic, GP or voluntary organisations – to help manage their or their loved one’s condition.

In the previous 12 months, have you or your loved one received enough support from local services and organisations, such as your local memory service, your GP or voluntary organisations, to help you manage dementia?



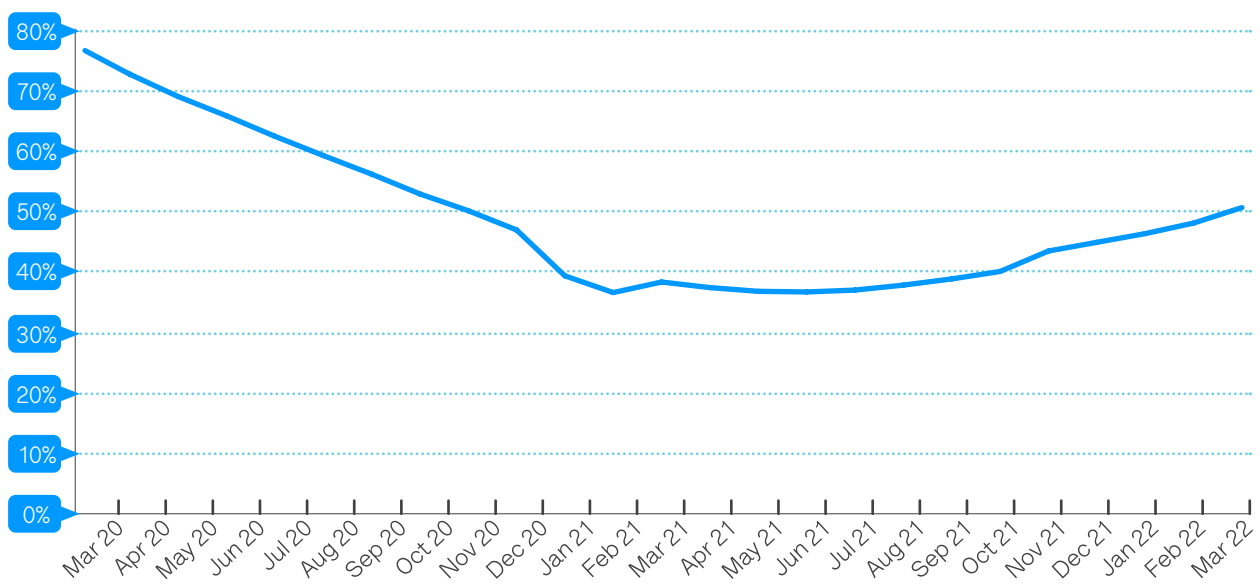
“

It’s been three years since I was diagnosed, and I have never had a review specifically for my dementia... I think it should be compulsory to have an annual review, as it would be good to have the chance to talk about the whole of your well-being, not just one particular issue or problem.

Person living with dementia

The pandemic has further entrenched a lack of access. The following graph shows the proportion of people with dementia receiving a care plan review during the pandemic.

Monthly proportion of people with dementia receiving a care plan review during the pandemic





Research suggests that the remote delivery of healthcare by GP practices may have deterred some people from accessing an annual dementia review, given people with dementia are likely to be older and therefore less likely to engage in technological solutions.¹⁸ Changes to national guidance will also have played a significant part in this reduction.

Annual dementia reviews are contained under the QOF, a pay-for-performance scheme aiming to improve the quality of care patients receive by rewarding practices for the care they provide.¹⁹ In July 2020, NHS England agreed to suspend QOF until the end of the 2020/21 financial year to free up capacity and resources to respond to the challenges of Covid-19. Yet income protection was guaranteed on those care activities that were no longer required to be undertaken by primary care.²⁰ In December 2021, NHS England again suspended QOF to free up capacity for the Covid-19 vaccination programme, similarly protecting income on certain care activities for GP practices.²¹

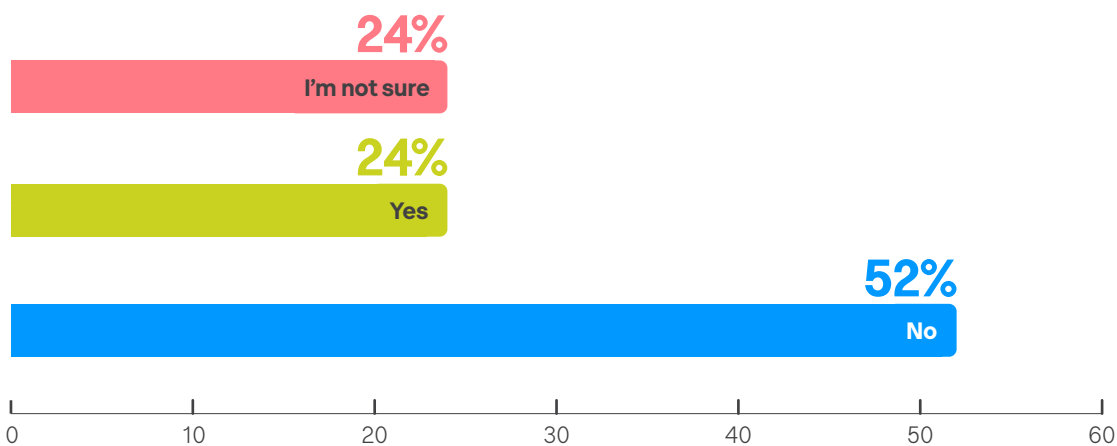
We believe that the challenges of primary care, alongside the income protection on suspended QOF care activities, led to the drastic drop in the proportion of people receiving an annual dementia review during the pandemic. It's essential that people with dementia are prioritised as we emerge from the pandemic, particularly since we have seen a significant increase in people's needs.^{22,23} Restoring annual dementia reviews to pre-pandemic levels must be a key focus of local health systems.

Quality of annual dementia review

Previous research has found the quality of annual dementia reviews to be variable.²⁴ In response to our survey, almost one in four (23%) said they were not sure when they or their loved one last had an annual dementia review. If people are unaware of whether they have received one, this raises concerns over the quality of the annual dementia reviews that are conducted.

Further, just 24% of people said their or their loved one's annual dementia review helped them manage the condition, with over half (52%) saying it did not.

If you or the person you care for has had an annual dementia review, did you feel it helped manage the condition?



A local survey of annual dementia reviews in Shropshire found many people had not had a review and that out of 23 people who did, just two people reported their support measures changed as a result.²⁵

“

[I was] initially impressed that we got a call out of the blue... Unbelievable. It was a tick box exercise. The call lasted about five minutes and I'm not sure he listened to me. He was clearly going through his list.

Person living with dementia

People told us that their annual dementia review too often narrowly focused on their medical needs with less attention being paid to their wider dementia-specific needs. This meant that people weren't receiving the person-centred care necessary to direct them to appropriate care and support services.

Professionals we spoke to also saw annual dementia reviews as insufficient. One reason given for this is the lack of a standardised and structured approach to conducting these reviews under QOF which leads to variation in quality.



To receive payment for annual dementia reviews under QOF, professionals simply need to ‘tick’ that they’ve completed a review. There are no additional indicators in place to understand whether a high-quality review has taken place. As a consequence, professionals reported to us that delivery of care under QOF has become too rigid, placing focus on the process, not on patient outcomes.

For example, a key part of an annual dementia review is that it allows regular conversations around advance care planning and future wishes. But the local Shropshire survey found that advance care planning was not discussed once in 23 reviews.²⁶

“

It [QOF] lets dementia patients down spectacularly... at the minute, we’re getting the money for naff all for dementia patients. QOF was set up to improve quality and outcome measures for patients, but it does the complete opposite. It isn’t fulfilling its intended use.

GP

Professionals particularly value the importance of annual dementia reviews as a ‘safety net’ and a mechanism to proactively put in place support measures to reduce crises.²⁷ Research suggests that a community-delivered dementia management care programme to co-ordinate treatment and care has the potential to reduce avoidable healthcare costs, mainly through fewer hospitalisations and delayed institutionalisation.²⁸

“

I would want to run through how they’re generally coping, any decline in cognition or behaviour, or falls and things like that – trying to identify possible things that might contribute to crisis.

GP



I always say to patients that if there's something we can do to keep you at home, then outcomes are better because a hospital admission has really adverse health outcomes. A lot of the annual review is about providing advice and educating patients about what may lie ahead in the future.

GP

Some primary care professionals believe that easily accessible, standardised templates would reduce inconsistency and enable patients to receive a better quality review.²⁹ While it is positive that NHS England provides a best-practice resource on dementia care planning for primary care professionals,³⁰ little is known about its uptake. One solution would be to make QOF requirements more comprehensive by providing additional indicators, such as a review of carer health and wellbeing as well as advance care planning.

Holistic annual dementia review

People with dementia often have one or more accompanying conditions; 77% of patients with dementia experience at least one of either hypertension, diabetes, stroke, coronary heart disease or depression.³¹ They are also more likely to have multiple conditions in comparison to people without dementia; over one in five people with dementia (22%) have three or more conditions and almost one in ten (8%) have four or more. This is compared to just 11% and 3% respectively for all patients.³²

These conditions may impact how well their dementia is managed, so it's important that additional health conditions are considered when conducting an annual dementia review. Previous research has shown that having other conditions was associated with a decreasing quality of life for people with dementia.³³



I take all the info regarding the changes, but discussion is always around medication which does very little for quality of life and my husband is reluctant to take [it].

Carer of person living with dementia

However, QOF's reimbursement structure perversely incentivises GPs to conduct separate reviews for each long-term condition a single patient has as funding can be claimed for each review.³⁴ Health systems should explore a multidisciplinary approach to annual dementia reviews to improve the time given to each one, which people with dementia often say is much too short. Research has shown that people with dementia would prefer reviews to be conducted by a professional with more time, with greater skills and knowledge of the condition. Professionals also report benefits of sharing this across different roles.^{35,36}

International research has shown a shared care approach between different professionals within primary care improves care and outcomes.^{37,38} In practice this could mean involving a healthcare assistant to complete physical health checks, a social prescriber to focus on activities and a GP to focus on medication. Alternatively, a dementia specialist could complete the whole review.

Frequency of annual dementia review

Research suggests that both people with dementia and their GPs value flexibility over the timing of their reviews, as opposed to rigid annual provision.³⁹

Professionals also point out that, while valuable, annual reviews address the needs and support at just a single point in time.



The issue with annual review is that it is an assessment of needs at a single point of time. At one annual review everything can be fine, then two weeks later they have a fall, get delirium in hospital, discharged, go back into hospital – have all these crises – and the care plan that was done just a few weeks ago becomes meaningless.

GP



People we spoke to also cited the fact that challenges and crises requiring formal support can arise unexpectedly and throughout the year.



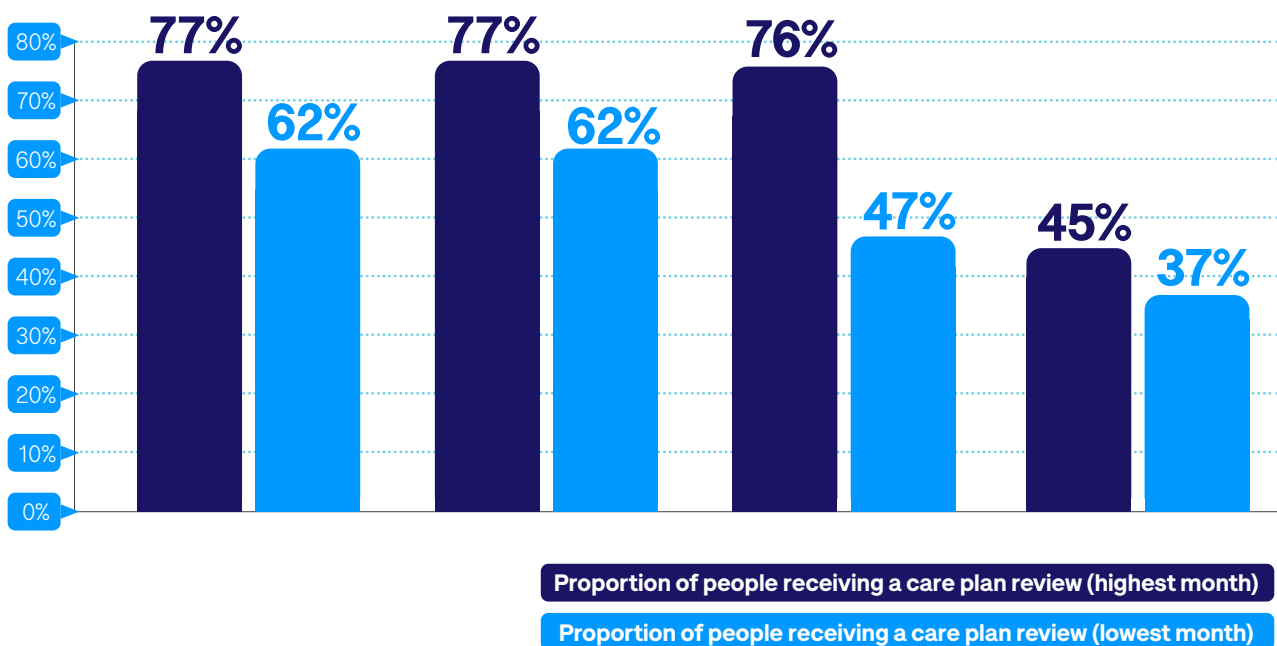
I have an issue with “annual”... that isn’t enough with all the twists and turns throughout the year. I never really felt supported anyway, not from my doctor anyway... I had to be proactive. I wanted mum to have as active a life as possible and to look at my wellbeing.

Carer of person with dementia

Additional formal reviews may be particularly necessary in moderate and advanced stages of the illness, given the complexity of people’s needs.⁴⁰ QOF reimbursement should not dictate the timing of these reviews, yet too often GPs conduct reviews in March ahead of the financial year end to ensure they receive funding. This timing also coincides with winter pressures, adding stress to the primary care workforce.⁴¹

The graph below outlines the proportion of people receiving a care plan review between 2018 and 2021, in the best and lowest performing months each year.

Monthly variation in the proportion of people receiving an annual dementia review from 2018 to 2021

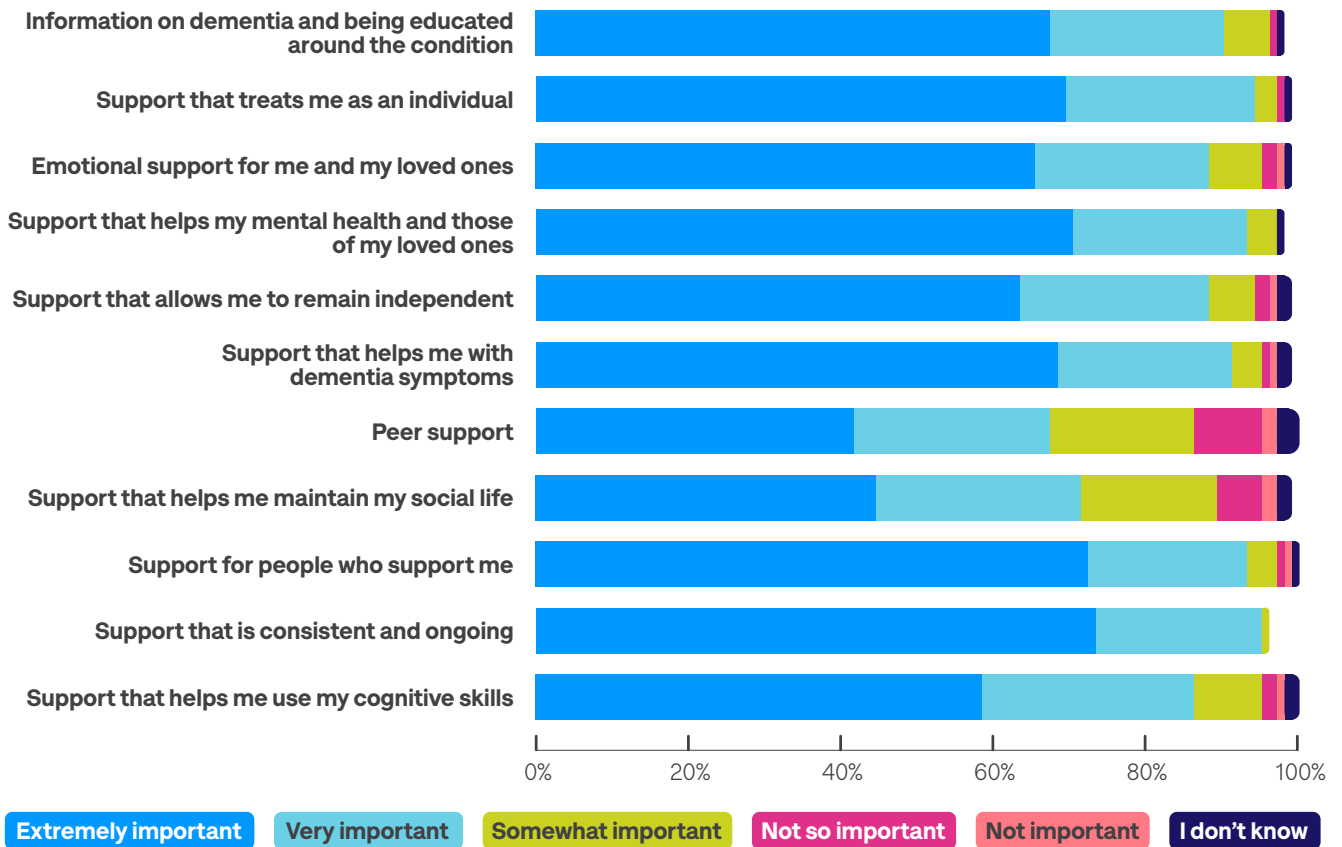


Post-diagnostic support

We have identified 11 support needs that people living with dementia require from post-diagnostic support based on an extensive literature review.

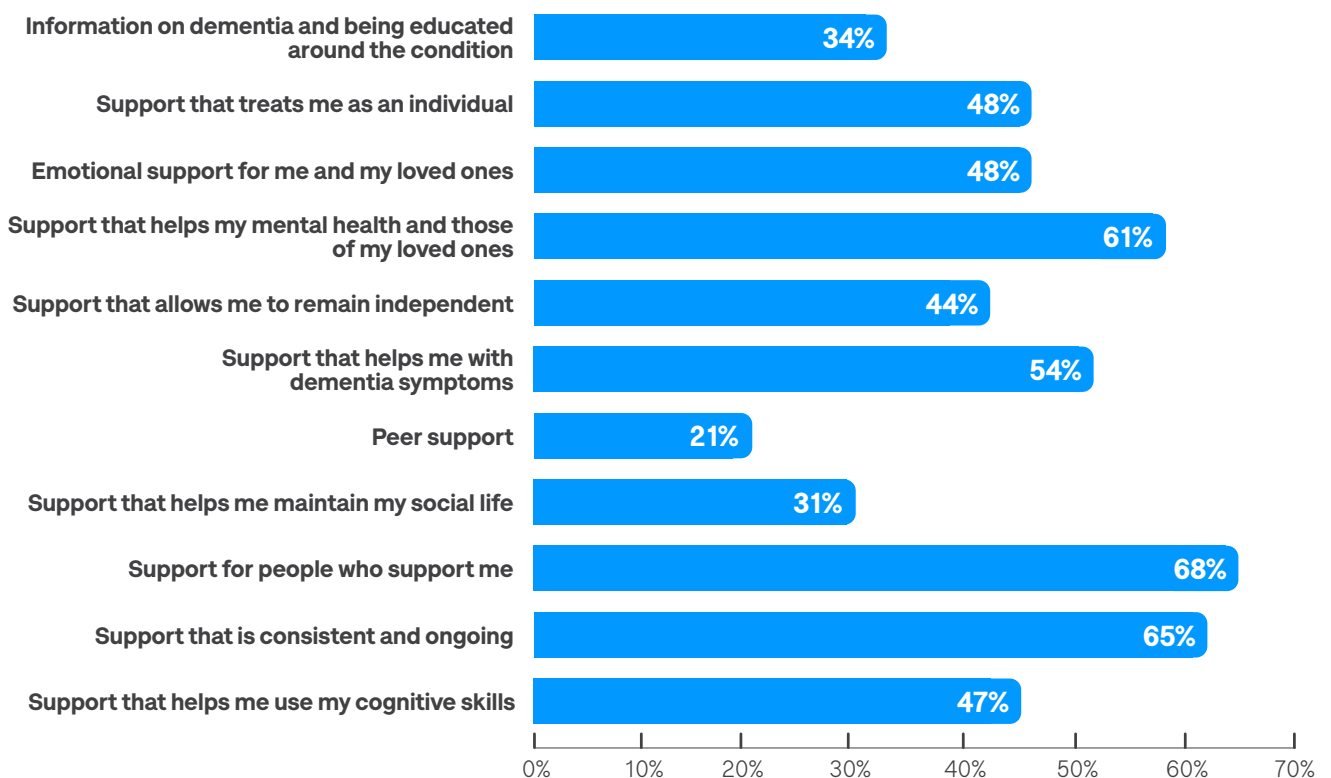
These were categorised as nine outcomes, which were then ranked by their importance in a survey of 914 people affected by dementia.

Thinking about support after diagnosis, how important are the following to you?



Yet, despite the importance people affected by dementia place on these outcomes, many people are not receiving the care they want and need.

What support do you feel you need now to help you manage your dementia that you are not currently receiving?



Information and dementia education

Despite information provision being a key component of post-diagnostic support,^{42,43} research suggests that people are not having their needs met in this area.⁴⁴ Our survey found that one in three people are not currently receiving sufficient information around dementia (34%).

An audit of post-diagnostic support showed that, while medication was discussed with 82% of people with dementia, driving was only discussed with 64% of patients and lasting power of attorney with 63%.⁴⁵ The information needs of carers of people with dementia are also going unmet, especially in regard to respite care and carers' assessment.^{46,47}



When I was diagnosed, I was just told I had dementia; I got no information. I had to look it up on the internet and it wasn't an easy read – the internet can make things so much worse.

Person living with dementia



I would have liked information about where to find out more about dementia itself. Get a handle on what my wife was going to face and what I could do to support her.

Carer of person who lived with dementia

People from South Asian communities expressed an unmet need in information provision, particularly for people in the earlier stages of dementia and in a first language that is not English. This meant people had to manage dementia with little guidance, and source support through non-formal avenues such as family members who worked in healthcare.⁴⁸ Information in alternative languages or formats, such as educational videos, needs to be developed to support people who struggle with English language literacy. This may help reduce inequities in dementia outcomes.



I don't know what there is, so how can I know where to go for support?

Person living with dementia

It is also important that information is personalised to each individual and given to people when they want and need it.^{49,50}



The support is exceptionally inconsistent – I had a multitude of boxes of information, but after reading the front page of one you're totally bored out of your mind.

Person living with dementia

Research also shows that due to the impact on the individual of receiving a diagnosis, a single diagnostic consultation is insufficient to both explain the diagnosis and offer follow-up support.⁵¹

It's important that the commissioning of diagnostic services does not inhibit opportunities for follow-up discussions to take place. Yet, worryingly, some memory services told us that their commissioned model of discharging a patient soon after diagnosis means people do not get the chance to ask questions once they have come to terms with their new diagnosis.



One of the challenges with post-diagnostic support is information provision. People are different and process information at different points and to different degrees. For some, information doesn't get processed there and then.

Memory service professional

Services should be designed to achieve the Memory Services National Accreditation Programme standard, which states all people diagnosed with dementia should be offered a post-diagnostic meeting.⁵² Information for ethnic minorities should be provided in community languages as well as in non-written resources.

Person-centred support

Person-centred interventions bring many benefits. For carers, they can decrease burden, improve quality of life and enable them to provide care for longer periods before the person with dementia might need admitting to a care home.⁵³ For people with dementia, person-centred interventions can reduce agitation, depression and improve quality of life.⁵⁴

However, a recent study found that only 29% of people living with dementia and 33% of carers said they received psychosocial interventions. When carers were asked the same question, 33% said the person they care for had received a psychosocial intervention.⁵⁵ **Our own survey found that almost half of people (48%) currently lack person-centred support.**

Psychosocial interventions include nationally recommended interventions such as reminiscence therapy – shown to enhance cognition and reduce depressive symptoms⁵⁶ – and cognitive rehabilitation, among others.⁵⁷ An audit into memory services in 2015 found that while the majority offered pharmacological interventions, the availability of non-pharmacological interventions varied, with half providing none or only one intervention.⁵⁸

The variability of access may be dependent on the type of dementia and care arrangements. Those diagnosed with mixed vascular dementia and Alzheimer's disease were more likely to receive psychosocial interventions. People cared for by a partner were more likely to receive psychosocial support than those with no carer.⁵⁹

People from South Asian communities also expressed a lack of person-centred support, particularly for earlier stages of dementia. They reported a lack of culturally accessible, non-pharmacological interventions supporting cognitive function, independence and wellbeing.⁶⁰

“

It's about igniting that spark in her brain to get her to do stuff, you know, cultural things that she enjoys.

Carer of person living with dementia

Memory services told us that the inability to provide psychosocial interventions meant risking over-medicalising dementia and ignoring the importance of psychological and social support that enables people to live well with the condition. This is pertinent given research shows the majority of unmet needs of people with dementia are non-medical.⁶¹

“

What's the point of medication to help reduce impact of cognitive decline without the social interaction and stimulation to support that medical intervention?

Allied health professional

Access to psychosocial interventions should be a core part of local areas' post-diagnostic support offer, and services should be designed to enable access to these interventions. However, little is currently known about provision and access to psychosocial therapies. We are pleased to note the next iteration of the national memory service audit will look at how often these therapies are offered, but commissioners must act to include these interventions if they are not already available to services. There is a need to enhance access to non-pharmacological interventions,⁶² and it is important services are designed to offer access to a range of these interventions.



Emotional and mental health support

Depression and anxiety are highly prevalent in people with dementia; 38% of people with mild dementia have depression, as do 41% of people with moderate dementia and 37% of people with severe dementia.⁶³

Similarly, 38% of people with mild dementia have anxiety, along with 41% of people with moderate dementia and 37% with severe dementia.⁶⁴ Over the past year, 33% of carers reported to us they experienced anxiety and 22% experienced depression.⁶⁵ This is considerably more than the general population – around one in six people in the UK report experiencing a common mental health condition like anxiety and depression.⁶⁶

Older people who experience depression are at an increased risk of frailty, functional decline, cognitive decline and reduced quality of life.⁶⁷ Despite the impact of mental health conditions, people affected by dementia reported to us that they are not receiving adequate mental health support, if at all. The 2021 Community Mental Health Survey found that people with dementia were less likely to have seen an NHS mental health service often enough for their needs compared to the general population.⁶⁸

Our own survey found that

60% of people affected by dementia are currently in need of emotional support

61% of people are currently in need of mental health support, for them and their loved ones.

Over half of people affected by dementia (57%) who had been signposted to mental health services report having to wait up to 12 months or more to receive the support they needed.⁶⁹

Improving Access to Psychological Therapies (IAPT) is a free-to-access NHS service providing evidence-based psychological treatments for common problems such as depression and anxiety.⁷⁰ Evidence shows these therapies, such as cognitive behavioural therapy (CBT), problem-solving therapy and life review, can be effective in treating later-life depression and anxiety disorders.⁷¹ Further evidence shows that CBT is effective in reducing psychological distress in carers of people with dementia.⁷²

However, people with dementia do not appear to be accessing these services. Unpublished data provided by NHS Digital for the Alzheimer's Society-funded study MODIFY shows there were over 1 million referrals for IAPT services (1,125,815) in 2018, but just 0.2% (2,277) had a record of dementia.⁷³ This is substantially lower than would be expected given prevalence of dementia in the adult population: one in 14 people over the age of 65 and one in six people over 80 have dementia.⁷⁴ Poor access to IAPT services is concerning given the high rates of dementia and associated mental health conditions. The data also does not show whether these referrals entered or completed the therapy.

Research has shown that the structure of some IAPT services, and the demands it places on staff, means they are not flexible enough to meet the needs of people with dementia, with cost-effectiveness and patient care priorities often in opposition.⁷⁵ These pressures mean that some services may reject referrals of people living with dementia. Services also reported to us that the lack of dementia expertise in primary care may mean people with dementia are less likely to be referred to IAPT services.



While IAPT can be accessed in primary care via GPs, people with dementia may often need mental health support at the point of diagnosis, particularly emotional support to help them manage the impact of receiving a diagnosis. However, psychologists told us that given local pressure to diagnose dementia, much of their clinical time and input was too focused on diagnostic work, leaving little room for support after diagnosis, such as post-diagnostic counselling.

Workforce capacity may compound the issue further. In a survey in 2020, 57% of mental health services reported a shortage of one or more clinical psychologist and 44% of psychologists reported their workload to be either unmanageable or mostly unmanageable.⁷⁶

“

You can give me a million pounds and I couldn't do anything with it – it's just so difficult to recruit.

Memory service professional

“

Even if you have pots of money, workforce is a challenge. Particularly for us, it's difficult to recruit and it takes longer to find that skillset for that specific role.

Commissioner

It is important that all memory services have access to psychologist input and professionals should have protected time for post-diagnostic support. IAPT services should not reject referrals based on a diagnosis of a cognitive disorder and should be designed to accommodate people with dementia, and their carers.

“

I can't find the time for counselling because I'm forever chasing people to get support for Mum.

Carer of person living with dementia.



Maintaining independence

Maintaining independence is important for people affected by dementia.⁷⁷ However, our survey found 44% of respondents do not currently receive sufficient support that enables them to remain independent.

Occupational therapy is key to enabling people with dementia to live well by remaining independent in their homes. The intervention works by using environmental modifications, behaviour management, physical activity and emotional support as active components.⁷⁸



Most of the support is about reassurance and the ability to self-manage and stay as independent as possible, whatever support we give it's tailored to making them independent.

Memory service professional

Occupational therapy has been shown to be successful and cost-effective.^{79,80} One study finds that £1,280 can be saved per patient over three months via an occupational therapy training service for carers.⁸¹ Occupational therapy can also help to reduce falls, which are the most common reason for hospital admissions in people with dementia, accounting for 17% of admissions in 2021.⁸² The average length of stay in hospital following a hip fracture is seven days. However, over 85% of dementia patients with this injury stay for up to 14 days and 34% for over a month. The extra cost is estimated as £5,950 per patient.⁸³

However, our research found that not all people accessed an occupational therapist, despite research showing that almost three-quarters (73.2%) of people with dementia living in the community have unmet needs relating to daily activities.⁸⁴ We found that a quarter of people affected by dementia (25%) waited up to 12 months for occupational therapy support after being signposted.⁸⁵

One specific intervention occupational therapists, as well as other professionals, can employ is cognitive rehabilitation, a nationally recommended intervention for people with dementia.⁸⁶ Cognitive rehabilitation is a goal-orientated and solutions-focused intervention which addresses the impact of cognitive impairment on everyday activities and independence and has been shown to have significant positive effects on people affected by dementia.⁸⁷ Yet despite its benefits, services lack the resources to provide the intervention in the community.⁸⁸

Occupational therapists can provide functional assessments during diagnosis as well as post-diagnostic support such as cognitive rehabilitation. However, occupational therapists told us the limited diagnostic capacity of memory services meant much of their time was spent on diagnosis, with less time spent supporting patients after their diagnosis. It's important that services can access occupational therapists and that they have protected time to carry out post-diagnostic support like cognitive rehabilitation.

Symptom management

Research suggests people value managing the symptoms of dementia,⁸⁹ yet our survey found that over half of people (54%) currently lack support that helps them manage their or their loved one's symptoms.

A key theme from our engagement with people affected by dementia and with health professionals who support them was the disparity between the expectations of what memory services offer and what they actually provide. Many people expected to remain with their memory service for longer and for the service to oversee their ongoing care.

This may be because the availability of treatments determines how clinical pathways are designed. Currently, there are only symptom-modifying pharmacological interventions for Alzheimer's disease dementia, which requires follow-up from a specialist (memory service) to ensure there are no adverse effects. This ultimately leads to more contact time with the service.

There are no pharmacological interventions for other dementia subtypes yet. This creates an inequity of service provision for people that do not have Alzheimer's disease dementia and are likely to be discharged from memory services sooner as a result.

Previous research shows that those with a vascular dementia diagnosis say they feel abandoned when they are offered no ongoing support.^{90,91} This supports other research that suggests people receiving antidementia drugs reported greater improvement in their quality of life.⁹²

In the absence of treatment, discharging non-Alzheimer's disease dementia patients and their families too soon can be hazardous. Services told us that discharging those with Lewy body or frontotemporal dementia (where there may be significant symptoms concerning behaviour) without appropriate, specialist support can risk crisis. This is important given research has shown that a higher number of behavioural and psychological symptoms was found to be a predictor of higher unmet needs in people with dementia and therefore a lower quality of life.⁹³

People from South Asian communities may also be adversely affected in comparison to the wider population, as they are often referred to inappropriate support that does not recognise their cultural needs and places too much focus on drug approaches to dementia.⁹⁴



We have access to support through the GP and memory service, but the latter offers short-term intervention at crisis points then signs us off once a more stable position is reached. We can get referred back but support that is consistent and ongoing would be far more useful as the improvements after each intervention are only short lived.

Carer of person living with dementia

It is important that all services are designed to provide an equal offer of support for all subtypes, including appropriately timed discharge and provision of interventions, and that the needs of ethnic minorities are not forgotten.

Peer support and social contact

People affected by dementia value peer support and social contact,⁹⁵ yet research shows there is a clear unmet need in this domain.^{96,97,98}

One study exploring the needs of people affected by dementia found 50.7% and 39.5% of people reported an unmet need in daytime activities and company, respectively.⁹⁹ This consequently contributed to a higher level of unmet need, with a resulting negative impact on quality of life.¹⁰⁰ **Our own survey found that one in five (21%) said they currently lack receiving peer support and almost one in three (31%) lack receiving support to maintain their social life.**



One study evaluating peer support groups in London found these groups produce a social value greater than the cost of investment, providing a return on investment of up to 400% by reducing loneliness and isolation as well as reducing stress and care burden for carers.¹⁰¹

Those from South Asian communities reported a specific benefit of peer support, particularly knowing others from the same community – in which dementia may not be explicitly recognised – are going through similar experiences.¹⁰²

Social prescribing can facilitate access to peer support groups and activities that enable people to live well with dementia. Delivered within primary care networks, social prescribing was brought in to support more personalised care and reduce the burden on primary care. Around one in five GP appointments focus on non-health needs (an implied cost of nearly £400 million to the health service) and 80% to 90% of health outcomes are linked to social determinants.^{103,104} Six out of ten GPs (59%) believe that social prescribing reduces their workload,¹⁰⁵ and research has shown that following referral, the intervention can reduce demand on GP services by 28%.¹⁰⁶ Additional research suggests this could be as high as 70%.¹⁰⁷

Service users report that the intervention brought a personalised provision of care and enabled the setting of goals and priorities that focus on gradual and holistic changes beyond ‘health’.¹⁰⁸ Other positive outcomes include improved quality of life and emotional wellbeing.¹⁰⁹

Around 30% of social prescribing work is with people with long-term conditions.¹¹⁰ However, speaking with commissioners, we found that people with dementia may be routinely missing out on a social prescribing intervention, with local delivery focusing more on other patient cohorts.



You go into a GP practice for a few hours, look at the people there, it’s mostly older people – so why have they been left out of this type of support? Our GP lead said he’s seeing such isolation in older patient cohorts – for some people, a GP would be the only person they would see as they have no family or friends and that’s where social prescribers can really help.

Commissioner

Furthermore, specific patient groups may be particularly disadvantaged from accessing social prescribing – referrals were at least 1.4 times lower for people from non-white ethnic backgrounds.¹¹¹

People with dementia missing out on social prescribing interventions is likely due to the lack of guidance within the national primary care network contractual arrangements for social prescribing link workers.¹¹² We have heard of some local service delivery examples that aimed to mitigate this by having memory services automatically refer people with dementia to social prescribing link workers. Additional guidance by NHS England on delivery of social prescribing link workers may be necessary. This will also support NHS England to meet its own internal target to introduce 4,500 link workers by 2023/24. At the end of the second quarter of 2021/22, there were just 436 of these workers, where there should have been at least 2,000.¹¹³

Care continuity

Research shows that people value continuity when receiving post-diagnostic support,¹¹⁴ yet our survey found that two-thirds (65%) are not getting support that is consistent and ongoing.

National guidance recommends that following diagnosis people with dementia are provided with a single named health or social care professional who is responsible for co-ordinating their care.¹¹⁵ This is important given that the complexity of dementia requires the involvement of many services and professionals. It may also have other benefits; research suggests a care management approach means 18% fewer people needing residential care after two years.¹¹⁶ In most instances, GPs will be the professional responsible for co-ordinating a person's care.



For mum's care it was the lack of continuity. Mum had suffered with psychosis and when the mental health team got involved, I thought mum would be under their care forever, but they said she's been signed off. I don't understand as dementia isn't going to get better. Every time she had a fall, we phoned an ambulance and sent her off to hospital. Even though we felt bad for doing it, we did it just to get her back in the system.

Carer of person with dementia

The 2021 GP Patient Survey found that people with dementia are 20 percentage points more likely to report having a particular GP they usually prefer to see or speak to in comparison to all patients.¹¹⁷ This is welcome data as we know people value seeing the same GP consistently and doing so has many benefits.

A higher continuity of GP care is associated with safer prescribing as well as reduced risk of delirium and incontinence.¹¹⁸ Having a named and regular GP is associated with lower use of out-of-hours services, fewer hospitalisations and lower mortality.¹¹⁹



However, pressures at primary care level can mean that people may not be able to see the same GP as often as they'd like or need. A recent study found that just 29% of people with dementia and 39% of carers said they had a health professional to contact should they need support at any time.¹²⁰ Moreover, GPs have previously reported low confidence in providing care for patients with dementia, particularly in the post-diagnostic stage.¹²¹ Throughout our engagement, carers reflected that the onus was often on them to co-ordinate their loved one's care.

A dementia support worker role (also known as Dementia Advisers or dementia navigators) can address support gaps that may exist within primary care. They could act, as per national guidance, as the nominated lead professional following diagnosis, ensuring a smoother transition from specialist care to primary care. Dementia support workers have knowledge of a range of available local services, providing advice and information for people with dementia and their carers, and ensure people can access wider care and support services as needs change and become more complex.

Importantly, they have been shown to create positive outcomes such as a reduction in carer burden and improved quality of life.¹²² Dementia support workers are also cost-effective – every £1 invested in these roles results in almost £4 worth of benefits, primarily through reduced pressure on mental health services due to carer breakdown, increased information and knowledge for carers and improved peer support.¹²³ Better links to a navigator-type role can also address information and social engagement needs.¹²⁴



Support should be ongoing with one professional to be a point of contact. We need to build relationships with those that support us and, in doing so, build trust. With trust comes openness and honesty when things are not so good.

Person living with dementia

Professionals we spoke to highlighted the benefit of dementia support workers, primarily through providing dementia expertise and addressing low-level support needs that may be unable to be fulfilled within primary care.



We offer a lot of support right at the start because we're commissioned to do so but the cohorts we're diagnosing are fairly early on in their disease progression. So, what you get is people not wanting support because they don't need it and then when they finally need it, they're not with our service. We need a system where we can keep people on the books – then you can drip feed support as and when people require it.

Memory service professional

People from South Asian communities reported benefits of a dementia support worker service, particularly if they are enabled to link in with communities and access culturally appropriate care through informal community networks. This in turn facilitates a person-centred approach to dementia care.¹²⁵

Given the importance and benefits of dementia support worker services it's important that local areas reduce barriers to accessing the service. They should consider automatic referral from secondary care (where referral is typically lower than from memory services) and integration of the service within primary care networks.

Areas should also consider community link worker elements as part of this role in areas of high ethnic minority populations.

Cognitive stimulation and managing cognitive decline

Our survey found that nearly half (47%) of respondents lack support that helps them to use their cognitive skills. We also found that 53% of carers reported a worsening of their loved one's memory over the last year, and 28% reported a worsening of their loved one's orientation.¹²⁶

Managing cognitive decline can help with the functional ability of people with dementia and research suggests those who have greater functional impairment are less likely to live well with the condition.¹²⁷ National guidance prescribes that people affected by dementia should be assessed for emerging dementia-related needs at primary care appointments and be asked if they need additional support.¹²⁸ However, people affected by dementia told us this was not routinely happening, with lack of knowledge of available community services within primary care noted as a particular barrier.

Cognitive stimulation therapy (CST), a recommended treatment in national guidance, is not widely available in England. A recent national audit of memory services found that a quarter (25%) of services did not provide it or were unable to refer to another service for the therapy. However, of the patients offered CST (46%), just half (54%) accepted the treatment.¹²⁹

CST is one of only a few recommended treatments nationally, so it is important that the intervention is a core part of the post-diagnostic support offer locally. It is also important that the benefits of the treatment are explained to people with dementia to promote take-up when it is offered.

Carer support

People affected by dementia value carer support after diagnosis,¹³⁰ but over two-thirds (68%) of our survey respondents told us they are not receiving carer support.

The burden of caring for someone with dementia primarily falls on unpaid, family members. Despite the immeasurable support that carers provide to people living with dementia, our engagement found that they could not routinely access care and support in a timely way.



I found it very hard to come to terms with the fact that I was now a full-time carer. It really is a 24/7 job. I feel stressed every waking minute.

Carer of person with dementia

The complexity of the health and care system means carers routinely miss out on support for themselves, and the support they are offered can often be unsuitable.¹³¹ Carers told us of often having to research information by themselves, which consequently limited their ability to provide care for their loved one or look after themselves. Particular support gaps included information on benefits, lasting power of attorney, home and respite care services, social care support such as a carers' assessment, as well as information on available emergency support when crises arise. One in four carers (26%) reported that the health and social care support for their loved one has got worse over the past year.¹³²



As the carer, I feel at sea, trying to find answers that must be there. My husband feels fine I am fine – but there should be clear pathways to help and support and readily available information on how the illness progresses... Currently the wellbeing of my husband and I depends 100% on how well I'm doing my homework.

Carer of person living with dementia

While Covid-19 inevitably had a significant impact on the provision and availability of support groups for carers, people told us they wanted a consistent provision of support as opposed to intermittent support that often occurs right after the point of diagnosis.



I feel it would have been of great help for someone to sit with me as a new, elderly carer and explain what is involved and what my needs might be. Someone to point me towards help or make actual links instead of lists on an email.

Carer of person with dementia

Interventions that enable carers to cope are cost-effective.¹³³ Evidence includes work that shows a £14,000 reduction in costs of residential care if psychosocial care is given to carers (through a 200-day delay in need for residential care).¹³⁴

However, an audit of memory services found over a quarter (26%) of services were unable to provide or refer on for carer psychoeducation and, of the services that could, in 45% of cases it was deemed inappropriate.¹³⁵ As per national guidance,¹³⁶ areas should ensure that carer support – including information, interventions and support groups – is a key pillar of the post-diagnostic offer locally.

Case study

My husband, David, was diagnosed right at the beginning of the pandemic in March 2020. Previously we had been away for Christmas with family, but he was asking where we were going when we left the house. My sister, her husband and my son mentioned that he was becoming forgetful. There was one time when he was driving on a motorway; I told him we had to get off at a certain junction and he started to panic and indicated the wrong way. I think that really shook him as the next morning he said he wasn't going to drive again, so I think he noticed himself that something wasn't quite right.

We booked an appointment with our GP who did some memory tests, but he scored well on it. We were then referred to the memory service who did some more tests and they showed us the brain scan which looked like mixed dementia – Alzheimer's and vascular dementia. We were told about medication and the memory service called us four weeks later to see how he was coping on it. After that, nothing. That was it, no support, no referrals to anywhere, no information. That was 15 months ago.

There was a time when David was seen in A&E and had got a UTI from a catheter while in there. At hospital a doctor asked me, 'what care package do you have?' I didn't know what they were talking about. Eventually, he was discharged but experienced delirium whilst I was looking after him at home. The surgery sent out a paramedic to help and again I was asked, 'what care package do you have?' It was at that point I was finally told what care was available to me and David. But why wasn't I told about this earlier? Why did I have to struggle by myself for 15 months alone and without support?

We eventually had a care package put in place, which was an absolute life saver. I can now get some respite to just focus on things I can't do when looking after David.

But it shouldn't take an A&E admission to find out about and access the support we're entitled to. Overall, it took two years to get the social care support I and David need, and I had to battle to get every last thing. That's not even to mention the cost of care, which is continually hanging over me. David's GP has been excellent, however, as he always pushed for the extra care and support we've needed but there's only so much he can do.

What would've been useful at diagnosis is information on dementia and what's available locally to support us. At that point I needed to know about progression; what could I expect? What did I need to plan? Knowing is half the battle.

I think someone to speak to face to face would've been really helpful – someone with experience of dementia to help me prepare for what's in store.

David's short-term memory is really bad now. He's forgotten his motor functions, basic things like sitting down or lifting his leg. That's what people need to prepare for because it's incredibly difficult to support someone. All of these things I wouldn't have imagined would be a problem and they came as a terrible shock. But I just got through it because I had to; we spent our lives together so I want to ensure he's as safe and well as he can possibly be.

Caring for someone with dementia takes a terrible toll. At points, I've cried and been at the end of my tether. You hear about people with dementia, but until you go through it yourself, you just don't know.

What is the impact of support needs not being met?

Hospital and mental health admission – ‘the avoidance of unnecessary hospital admissions should be a pillar of living well with dementia’

What was clear throughout our engagement with people and professionals was that people’s support needs were not being met, with a postcode lottery in the provision of support across the country. In our survey, just one in ten respondents (12%) said they are receiving all the support they want or need.

GPs, commissioners and memory, community and acute services overwhelmingly reported that the risk of crisis increases when support needs go unmet, particularly hospitalisation. Addressing support needs within the community is especially important given almost nine in 10 hospital admissions of people with dementia (88%) in 2020/21 were of people who lived in their own homes.¹³⁷

People with dementia experience worse outcomes when admitted to hospital than those without the condition.¹³⁸ Research shows that, in comparison to those without cognitive spectrum disorders, people have a higher 30-day mortality rate (13.6% v 9.0%), one-year mortality rate (40% v 26%) and readmission rate (62.4% v 51.5%).¹³⁹

Professionals spoke of the overwhelming need to prevent admissions given the adverse outcomes people can experience, particularly if they are admitted for longer than two days. Data for 2020/21 shows that almost one-third (31%) of all admissions of people with dementia were between two and seven days, 19% between eight and 14 days, 13% between 15 and 30 days and 4% over 31 days.¹⁴⁰ **A third of admissions (32%) were for one day or less, suggesting better community care could have prevented admissions altogether, reducing system pressures and improving patient experience.**



I’ve rarely seen people go into hospital and come out better than when they came in – they might have their pneumonia sorted but really come out worse in terms of their functional ability. The ones who stay longer than a few days, universally come out worse... The avoidance of unnecessary hospital admissions should be a pillar of living well with dementia.

Consultant

Evidence suggests that hospital admission of people with dementia is strongly associated with multimorbidity (having two or more health conditions), polypharmacy (being on multiple medications), lower functional ability, unintentional weight loss and falls.^{141,142} Urinary tract infections, pneumonia/chest infections and delirium as well as falls – common reasons for admission – are potentially preventable admissions.^{143,144}

The Hospital Episode Statistics dataset shows that between 2015 and 2020, there were:

137,235 admissions for chest infection/pneumonia

26,791 admissions for delirium

106,684 admissions for falls

85,971 admissions for urinary tract infections¹⁴⁵

356,681 admissions in total for people living with dementia for just these four conditions

Professionals told us, given the complexity of dementia, the costs of hospital admissions for people with dementia are often more expensive than for those without the condition. This is backed up by research suggesting hospital costs are 15% higher among patients with dementia compared to those without.¹⁴⁶ Our analysis of Hospital Episode Statistic data for admissions of people with dementia shows a stark economic cost to local health systems and the NHS.

Using the National Schedule of NHS Costs in 2019/20, we calculate the six-year cost (2015 to 2020) of these admissions to be almost £1 billion (£987,966,865). As discussed, one-third of admissions are short stay (0-1 days), which suggests that these people did not need acute health support but could rather be kept out of hospital through provision of better community care. **Preventing these short stays would have meant a saving of around £326 million for the NHS between 2015 and 2020.**

“

Personally, it's the out of hours which is the problem. My dad had really bad sundowning and when you're trying to get that sorted at seven or eight o'clock at night, people just palm you off on 111 or say go to A&E. It seems like you can only have dementia Monday to Friday, nine to five.

Carer of person living with dementia

Similarly, commissioners and acute services told us they increasingly see avoidable mental health admissions of people with dementia. The complexity of dementia means people are likely to experience increased behavioural and psychological symptoms – up to 90% of all people with dementia experience such symptoms over the course of their illness.¹⁴⁷ **The 2021 GP Patient Survey found people with dementia were 35 percentage points less confident managing any issues arising from their condition in comparison to the general population.¹⁴⁸ Similarly, our survey found 41% of people said they were not at all confident managing their or their loved one's dementia.**

Carer breakdown – ‘there is no area of my life that hasn’t been affected’

Our engagement found carers regularly reaching breaking point, stressed and unable to cope with the demands of caring. Carers’ mental, physical and emotional wellbeing deteriorated as a direct result. Despite this impact, carers still experienced feelings of guilt when they could no longer safely care for their loved one and consequently moved them into residential care.

Research suggests that more severe caregiver burden was associated with higher rates of hospital admission.¹⁴⁹ The impact of Covid-19 has certainly exacerbated caregiver burden, with carers spending 92 million hours caring for loved ones with dementia in just the 20 weeks between the start of the first lockdown and August 2020.¹⁵⁰

“

I’m exhausted, worried, angry, frustrated and nobody seems too interested. In the middle of the night, struggling to get my wife, in pain, partially incontinent, out of bed and to the toilet I feel desperate, utterly shattered and alone.

Carer of person living with dementia

“

We know a lot of people didn’t get the right support during Covid when they should’ve. What we found was carers turning up at Accident and Emergency saying they couldn’t cope.

Commissioner

During our engagement, we found that voluntary, community and mental health services were cut or reduced due to the pandemic. **54% of carers reported to us reaching crisis point over the last year due to a lack of necessary support, with 22% reporting this was due to their loved one being admitted to A&E with a crisis in their healthcare. Additionally, 18% reported having to call family and friends for emergency help because they could not cope and 13% needing emergency social care intervention.**¹⁵¹ This meant carers struggled to access appropriate support, particularly at point of crisis. Research suggests that the complexity of post-diagnostic support pathways means carers routinely miss out on support for themselves, with the diverse range of services providing support contributing to this complexity.¹⁵²

“

There is no area of my life that hasn’t been affected.

Carer of person living with dementia



Inevitably, this leads to carers being admitted to either hospital or mental health services. Strikingly, we heard that when carers were admitted to hospital, the person with dementia was also admitted despite having no clinical reason for being there as there were no alternative community support measures available.

“

The pressure I feel under to keep everything ticking along like medication, appointments, making sure that my husband is safe, cared for and maintaining some quality of life is exhausting.

Carer of person living with dementia

Carers of people from South Asian communities reported the wide-ranging impacts of caring for a person with dementia without appropriate cultural support, which included mental, physical, social and financial impacts. Despite being resilient, many carers reported feelings of isolation, loneliness, anxiety and depression. Some reported a double impact of not receiving cultural support from formal services or support from their own faith communities, many of which do not recognise dementia as a condition.¹⁵³

“

Services can't help us because they don't have the resources or understand our needs. The community aren't educated enough to provide us with any support.

Carer of person with dementia

As previously discussed, dementia adviser support roles help reduce carer burnout – a return on investment of almost £4 for every £1 spent is primarily gained by the reduction of carer breakdown.

Deterioration – ‘He has survived Covid, but no longer knows me, and makes little sense’

While dementia is a progressive condition, people told us they believed their loved one’s condition had deteriorated at a quicker rate during the Covid-19 pandemic. Our survey found 84% of carers reported a decline in the health and wellbeing of their loved one in the past year, with one in four (27%) describing this decline as unmanageable.¹⁵⁴

This supports recent research that found people with dementia experienced perceived negative impacts due to the pandemic, including on their functional skills and ability to engage in self-care and manage everyday activities.¹⁵⁵

The median time to someone with a dementia needing to be admitted to a care home or similar is 47 months after diagnosis.¹⁵⁶ Predictors of people needing care home support more rapidly include severity of dementia, greater functional impairment, greater unmet needs in activities of daily living, severity of behavioural and psychological symptoms, fewer caregiving hours and higher caregiver stress.^{157,158}

People with dementia who are cared for by their partner move into a care home around two and a half years later, emphasising the importance of carers in enabling people to remain independent in the community.¹⁵⁹ Additional research suggests having a spousal carer makes care home admission 20 times less likely over a one-year period.¹⁶⁰



Covid-19 has played an instrumental role in finding our new normality. The impact has been a clear deterioration in my mum’s mental and general health. Isolation has played an awful role.

Carer of person living with dementia

Carers reported to us that they believe the inability to access care and support during Covid-19 contributed to their loved one moving into a care home quicker than they would have if they had had support. This was particularly the case when physical and cognitive needs went unmet. They also saw their inability to source care for themselves had a negative impact on the care they could provide to their loved one. Research shows that many carers were caring beyond capacity.¹⁶¹

This view was supported by commissioners, GPs and community services, who said they saw faster deterioration of people with dementia during Covid-19. Academic research also found people with dementia were particularly vulnerable during Covid-19 to losing the benefits of support, such as socialisation, keeping active and peer support, with a resulting impact in terms of loss of cognition and memory and increased confusion.¹⁶²

“

I think if people do get the right support, it would delay institutionalisation. We've noticed this in the pandemic – people's support systems have been taken away from them, and now they've deteriorated at a quicker rate.

Commissioner

Outside the context of Covid-19, people from South Asian communities expressed a lack of culturally accessible support, which meant they were unable to access services to help manage the decline of dementia, with some expressing this directly contributed to the deterioration of their loved ones.¹⁶³

“

She's suffering so much. Her decline is rapid because of the lack of support she has had... My mum has worked in this country, she's paid her taxes and now she's old and in need of care, there's nothing for her.

Carer of person living with dementia

How can crises be reduced?

People and their families can often cope and live well with dementia, meaning they will present with low-level needs. However, the progressive nature of dementia means people's needs will increase over time and the majority of people with the condition will need more specialist support and intervention at some point.

Yet the fragmentation of services means specialist support is often difficult to access, particularly in a timely manner. This can result in a reactive approach to dementia care with support provided only at crisis point. Similarly, co-ordination at primary care level currently lacks dementia specialist input, preventing people with dementia being offered ongoing, crisis-preventing support.

In terms of providing targeted, timely and proactive support to people affected by dementia in the community, we found a stepped model of post-diagnostic support was effective. This echoes findings from recent research.¹⁶⁴ Models of post-diagnostic support incorporating a stepped model of care were found to improve care co-ordination, delay transitions into residential and nursing care, reduce inappropriate hospital admissions (both acute and mental) and improve the physical, emotional and mental wellbeing of people with dementia and their carers.^{165,166}

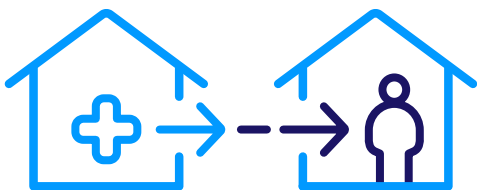
A recent systematic review found that a specialist nurse-led case management approach (that bridges the interface between primary and secondary care) was the most promising primary care model of dementia support, in terms of both person-centred outcomes and care costs.¹⁶⁷



A dementia support worker service can be the first point of contact for people, offering low-level support for the ongoing management of their needs, such as information provision and signposting. More intensive support could then be offered when needed through specialist roles such as an Admiral Nurse or advanced nurse practitioner. These health professionals can co-ordinate care between primary and secondary services and manage care transitions such as hospital admissions and discharge.¹⁶⁸ Once intensive support is no longer required a person would then be ‘stepped down’ back to the dementia adviser.

‘Stepped’ care should be developed as a core offer of post-diagnostic support locally and be delivered within primary care networks to support primary care management of people living with dementia. They would ensure that people experience co-ordinated care, accessing community services and interventions as seamlessly as possible.

Such models would also reduce carer breakdown, ease current system pressures on hospital discharge and support people to remain in their own home.



This is important given **75% of all people with dementia who were discharged from hospital between 2018/19 and 2019/20 returned to their own homes.**¹⁶⁹

When crises do arise, there is a need for local areas to provide intermediate and rapid response crisis teams, filling a support gap between the community and acute care setting. This would reduce unnecessary carer breakdowns and hospital and mental health admissions, as well as premature admissions to care homes.



Under the NHS Long Term Plan, urgent community response teams are designed to deliver emergency intervention to support community care in the event of an individual health crisis. The aim is to provide immediate support at a person's home or care home to reduce unnecessary emergency admissions to hospitals. It's important that NHS England commit to a review of provision of the service to ensure that all people are able to access the service if needed.

We recommend urgent community response teams have geriatrician input, with appropriate dementia training, to support those with dementia living in the community. We also urge NHS England to commit to a timeline to bring in the second phase of the urgent community response service, namely reablement packages offered within two days of the crisis occurring, to ensure that people with dementia receive longer-term support to recover from a crisis episode. Without this, emergency admissions are at risk of being merely deferred, not prevented.

Conclusion

The voices of 2,000 people affected by dementia sit at the centre of this report. Their experiences show that people are struggling to access the right post-diagnostic support to meet their medical, social and emotional needs.



The main driver for a dementia diagnosis is that it facilitates access to care and support that enables people to manage and live well with a complex condition. Driving up diagnostic rates without investing in post-diagnosis support results in people with dementia feeling unsupported after their diagnosis.

This report makes a clear set of recommendations that span the scale of post-diagnostic support, from the vital annual dementia review and the innovative post of a dementia support worker through to support from allied health and mental health professionals.

We believe that if integrated care systems work to commission care that meets these recommendations at the level of 'place' or primary care network, people affected by dementia will have a much greater quality of life. In addition, systems are likely to see significant pressure lifted from current bottlenecks such as in GP and acute care capacity.

With the advent of integrated care systems, along with the upcoming Department of Health and Social Care's new national dementia strategy, we now have a genuine opportunity to bring together all post-diagnostic support services and provide people living with dementia with the integrated support they both need and deserve.

Appendix

Best practice

Bristol Dementia Wellbeing Service

The Bristol Dementia Wellbeing Service provides post-diagnostic support to people affected by dementia in Bristol. It is a primary care-led, 'stepped' model of post-diagnostic support for people affected by dementia until end of life.

Every GP practice has a named dementia practitioner and dementia navigator. All people receiving the service are allocated a navigator, who acts as a support worker and named point of contact for the service. The navigator:

- Provides guidance and flexible, tailored practical and emotional support
- Explores service user's changing needs and supports advance care planning
- 'Checks in' with people every six months, meaning they can receive information that is tailored in its timing and content
- Facilitates access to local groups and activities in the community as a way of enhancing connection and quality of life, alongside signposting to other agencies
- Co-produces a 'wellbeing plan' with the person and their carer(s) and families
- Helps people to access carers' assessment to recognise the individual needs of carers.

If people's needs exacerbate or become more complex, they are then 'stepped up' to a practitioner (a qualified health and social care professional), who:

- Supports people's care network and manages changing needs
- Reviews the medical aspects of a person's care plan
- Supports care transitions such as hospital discharge
- Where necessary, will work jointly with psychiatry to provide further assessment and treatment.

The service also has access to psychology staff who can provide targeted one-to-one or family-based interventions. An additional post-diagnostic team provides one-to-one or group interventions such as cognitive stimulation therapy. The service has also built up good working relationships with local social care and a small team of navigators are also trusted assessors for the local authority. Similarly, the majority of people's needs are assessed in a home setting, enabling the service to get a detailed understanding of how people are coping in their own surroundings. This enables people to access social care support in a timely way.

The stepped model of care, as well as integration of services between health and social care, means people are supported in a person-centred way by maintaining their independence and supporting their quality of life. The service also actively engages in outreach work with seldom-heard communities to break down stigma associated with dementia and to better understand the needs of communities and adapt service provision accordingly.

The seamless, stepped model of care means that the service can proactively identify needs as they arise, which has many patient and system benefits. Despite an increasing caseload since 2015, there has been a reduction in the average number of monthly admissions to mental health inpatient beds. This suggests that people are being kept well for longer in their own homes.

When people do reach crisis requiring an acute or mental health admission, the service has access to two social care 'flexi-beds' which are used to prevent inappropriate admissions due to breakdown in social care provision. The service jointly manages these beds alongside local social care and actively supports people to access them.

Best practice

Islington Memory and Dementia Navigation Service

The Memory and Dementia Navigation Service is Islington's pre- and post-diagnostic support provision for people affected by dementia. The London borough offers a 'stepped' model of post-diagnostic support, with the local NHS trust providing both dementia navigators and nurse-level intervention. The service is supported by a multidisciplinary team of doctors, nurses, dementia navigators, psychologists and psychology assistants. It currently has over three-quarters (77%) of the estimated number of people with dementia in the area on its books.

After diagnosis, people will be offered a post-diagnostic review, which usually occurs around four to six weeks after diagnosis. They are given a signposting pack about available community support in the local area. In the initial stages after diagnosis, carers are offered STRategies for RelaTives (START) by the psychology team. This is a psychoeducation intervention that aims to develop coping strategies for carers of people with dementia and has been shown to reduce anxiety and depression in carers. People are also offered one-to-one psychology support, as well as cognitive stimulation therapy. The service offers equity in its support provision, with all people affected by dementia being offered these interventions regardless of their subtype.

People can be referred into the service by their GP, hospitals and by self-referrals. People who have lower levels of need are allocated a dementia navigator who provides advice and guidance and facilitates access to community support and groups. People always remain under the caseload of the same navigator, improving the continuity of care as well as quality of support. Navigators work in primary care network localities, meaning they can liaise well with GP practices and support primary care provision of dementia care. If people's needs exacerbate, they can be 'stepped up' to a nurse, who can manage more complex needs.

Following this, people are, on average, reviewed every six months but the service offers flexibility on the timing of reviews according to patient need. During the review, people's needs are assessed, and appropriate support measures are put in place, including advance care discussions. These reviews, and the overall involvement of the service, will continue until people either move into a care home, move out of the borough, or die.

As well as regularly reviewing people, the service runs a duty system during working hours. Patients and their carers are encouraged to call for support if there are any changes or queries regarding their dementia care and people are visited at home outside of the planned reviews as needed. This supports people to continue to live well in the community.

The service operates a biopsychosocial model of dementia support, undertaking a holistic assessment of people's medical, emotional and social needs, which contributes to a more person-centred provision of care. It currently evaluates the impact of the service through patient feedback, though aims to develop an outcome measure to monitor people's quality of life.

The service has forged good working relationships with the rest of the local NHS trust, such as with community mental health teams and the home treatment team, meaning people are able to access wrap-around care according to their level of need. It also has access to the emergency response team within the local trust, which helps reduce mental health and acute admissions in case of crisis.

Lastly, the service also plans to work with seldom-heard communities to improve awareness and understanding of dementia and reduce barriers to diagnosis and post-diagnostic support. This work, conducted by the whole of the multidisciplinary team, will involve providing outreach to different community groups.

Best practice

Doncaster Accountable Care Partnership

The Accountable Care Partnership provides post-diagnostic support for people diagnosed with dementia in Doncaster. It brings together all partners and services delivering support across the area, sitting under an alliance agreement. This includes Rotherham, Doncaster and South Humber NHS Foundation Trust, Age UK, Alzheimer's Society, Royal Voluntary Service, Choices for Doncaster and Making Space.

All people diagnosed with dementia locally are offered a referral to the post-diagnostic support service and people are only discharged if they move into a care home, move borough or die. Anyone can refer into the service including local memory services and community mental health teams as well as GPs and self-referrals. The local offer of support is a tiered and 'stepped' model of care with a single point of access. People's support needs are assessed and, depending on their level of need, they are then allocated an Admiral Nurse or a dementia adviser. They are also able to access a befriending service, cognitive resilience intervention, young-onset dementia support and peer support groups. The service also has access to psychology input, which can provide support such as counselling for people and their family, helping people to deal with the immediate impact of receiving a diagnosis as well as supporting the challenging behaviours of dementia.

People with lower-level needs are allocated a dementia adviser, who provides information and guidance and enables access to community support. If people's needs increase, they can be 'stepped up' to an Admiral Nurse who, for example, manages more complex needs such as liaising with local community mental health teams and co-ordinating care transitions such as a hospital admission.

The service has four whole-time equivalent Admiral Nurses as well as an additional Admiral Nurse who provides clinical leadership. Four dementia advisers work on a locality basis supporting the Admiral Nurses.

The service is jointly commissioned by the local authority and the NHS. This makes it easier for system commissioning and patients experience more co-ordinated care, with services and organisations working in collaboration. Admiral Nurses are co-located within the community mental health team, liaising with other mental health and support teams. This helps mitigate crises and ensures people receive appropriate care and support in a timely way. The service also has access to occupational therapists who support people to remain as independent as possible.

Best practice

Dorset Clinical Commissioning Group (CCG)

Dorset CCG undertook a full review of dementia services from prevention to end-of-life. This was co-produced through a series of workshops with service users, service providers, statutory organisations and voluntary organisations. Participants identified where improvements can be made in the dementia pathway and how to improve the quality of services and the local dementia support offer.

A key theme resulting from the workshops was that service users required more continuity of care and for service providers to work more collaboratively. There was also a need to support more community-based resources for people affected by dementia and reduce the impact on costly acute and specialist dementia bed admissions.

The area established dementia co-ordinators with dedicated young onset co-ordinators who are aligned to primary care networks. Each primary care network has a named dementia co-ordinator whose time allocation is based on the number of people on the dementia register in that area. These professionals provide lower-level support such as advice and guidance but can also facilitate access to clinical support by working closely with other services, such as community mental health. This is particularly beneficial given people with dementia are likely to experience behavioural and psychological symptoms.

Dementia co-ordinators will make contact within 10 working days of diagnosis, but GPs are also able to refer people to the service who have come from out of area. To support quick access to social care support, dementia co-ordinators can also make direct referrals for social care packages.

The CCG identified a need for rapid, crisis care which was the result of slow access into services other than through people's local GP or A&E services. It noted that threshold requirements for crisis services often meant people did not access crisis support in a timely way. To reduce this, the CCG established a 24/7 crisis telephone helpline, providing support and guidance to people who can then be referred onto and receive appropriate services such as the dementia co-ordinators, mental health services or social services.

There was an overall decline of 18% in specialist dementia inpatient admissions between 2015/16 and 2018/19, which has been linked to the positive impact of the Intensive Care Service for Dementia (ICSD), designed to enable people to remain at home where possible. Intensive support is offered to patients in their own homes for up to six weeks to try to maintain them in their home environment, where possible. The ICSD works closely with the acute dementia ward meaning the team can manage patients' needs better as well as supporting the discharge process. It is a cost-effective service and is estimated to reduce inpatient admissions by around 400 people per year.

Together, these service changes lead to projected cost savings of around £2 million per year, much of which could be reinvested into the health and care system. Most savings come from reduced inpatient admissions, across both acute and specialist dementia beds, as well as fewer Mental Health Act detentions, reducing the money spent on Section 117.

Methodology

Literature review

We undertook a thorough literature review of over 100 resources including research papers, existing pathways and key documents relating to post-diagnostic dementia support to identify key outcomes people value from support after diagnosis.

Engagement with people affected by dementia

Following the literature review, we identified nine outcomes people affected by dementia value from support after diagnosis, as well as seven outcomes health professionals value from annual dementia review.

Between 14 December 2021 and 19 April 2022, we ran an online survey of people affected by dementia. We asked respondents to rank the importance of these outcomes as well as asking about their experiences of accessing care and support after diagnosis.

The survey had 914 responses:

- 66 (7.24%) were people with a diagnosis of dementia
- 711 (78.05%) were a family member and/or carer of someone with dementia
- 134 (14.71%) were 'Other', such as former carer.

We also conducted a further survey via the agency Yonder in April 2021 to carers of people with dementia, looking at their and their loved one's experiences of health and care during the pandemic. The survey had 1,041 responses.

We also conducted a survey of 89 of our staff working in our support services. The fieldwork for our staff survey took place across the whole of April and hosted on SmartSurvey.

Focus groups

Between December 2021 and March 2022, we ran a series of focus groups through our Dementia Voice team with people affected by dementia to explore their experiences of care and support. In total, we engaged with 11 focus groups, speaking to 72 people affected by dementia.

We also conducted interviews with an additional seven people affected by dementia.

In total, over 2,000 people affected by dementia contributed their views and experiences to this report.

External commissioning

In June 2021, we commissioned Dr Karan Jutla to undertake qualitative research exploring the experiences of support after diagnosis within the South Asian community. Her methods included using a social media campaign to recruit research participants and a recorded, structured interview to gather evidence. This resulted in a final report of 13 detailed case studies of people's experience of care and support (12 carers and one person living with dementia).

We commissioned research on South Asian groups due to this demographic being one of the largest minority ethnic groups with dementia in the UK, with previous research showing significant unmet needs within this group.

Engagement with healthcare professionals

To supplement our understanding of issues within the post-diagnostic support pathway, we conducted semi-structured interviews with a range of health service professionals. These included commissioners and professionals involved in providing dementia care, including GPs, neurologists, psychiatrists, psychologists, occupational therapists, hospital nurses and geriatricians. In total, we engaged with eight commissioners, six GPs and 25 professionals from memory, community or acute services.

We also surveyed our own support service staff including Dementia Advisers/Dementia Support Workers and Dementia Connect Local Service Managers.

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