

# CARING FOR SOMEONE LIVING WITH DEMENTIA



**Wiltshire Council, BSW ICB and Carer Support  
Wiltshire Dementia Strategy Engagement  
Summer 2023**

## About us

Carer Support Wiltshire is a registered charity that supports all unpaid carers, including young carers and young adult carers, across Wiltshire and Dorset. We help them to access services, information, education and training, respite, and breaks from their caring role.

We ensure unpaid carers have a voice that is heard and work with health and social care professionals and employers to raise carer awareness and develop best practice.

A carer is anyone who cares, unpaid, for a family member or friend who could not always manage without their support. They might look after someone with a physical disability, learning disability, autistic spectrum disorder, long-term health condition, mental health issue, or a problem with substance misuse.

Find out more at [www.carersupportwiltshire.co.uk](http://www.carersupportwiltshire.co.uk) and [www.carersupportdorset.co.uk](http://www.carersupportdorset.co.uk)

## Foreword

In Dorset and Wiltshire one of our goals is to ensure that the views and experiences of unpaid carers are heard in the development of strategy and service developments that impact them. Over 200 carers have recently contributed to a series of engagement activities specifically looking at the support for some who is looking after someone living with dementia in Wiltshire. They told us what they felt was most important to them in terms of the support they needed from diagnosis to end of life. Our report highlights the things that matter most to carers in terms of the support they receive to live their lives well. A big thank-you to all the carers who took part in these activities.

Liz Brown - Chair of Trustees Carer Support Wiltshire and carer

## Summary

A core part of our mission is to ensure that carers' voices are heard when developing our services and so that we can feedback carers' needs to our key local partners. As part of the development of Wiltshire Council's and BSW ICB's new dementia strategy, we were asked to help facilitate three focus groups with carers and issue an online survey to ensure that the draft strategy accurately reflects their support needs.

We carried out the following engagement activity:

- An online survey completed by 186 carers
- Three focus groups held in Corsham, Trowbridge and Salisbury

The aim was to investigate, across four themes, what support carers looking after someone living with dementia value when carrying out their caring role. The four themes were:

- Diagnosis and support
- Wellbeing
- Dementia-friendly communities
- Dying well

The findings were quite clear:

- As with other carers we've spoken to, it is the inconsistency in support that frustrates many. What one person is told, another may not be.
- Many professionals don't seem to know enough about dementia and its many symptoms, and often ignore or dismiss the huge amount of knowledge that the carers themselves have. This causes a lot of anxiety for carers as they worry that their loved one isn't being looked after properly.
- Again, as we've heard at our other carer engagement events, more liaison/signposting between services is needed so that people don't fall through the gaps.
- There were several services that were very highly praised by those that had been offered them including Alzheimer's Support's dementia advisors and introductory training course.

This piece of work will be shared with Wiltshire Council and BSW ICB who will use it to inform their new dementia strategy document. We will also use the feedback provided to inform our future planning for services for unpaid carers and on continuing to develop our plans for a carer friendly Wiltshire.

## Introduction

Many dementia carers go on a journey that is uniquely rewarding but sometimes incredibly frustrating. Their experiences may reflect that of others, but the diversity of carers and the progression of this terrible disease means that one size does not fit all when it comes to finding solutions. So many people do not realise they are carers; they do what they do because they love those they care for. They need our recognition, creativity, and tangible action so they feel confident, supported, and able to cope with the often-tough demands they face daily.

**The 2021 census revealed there were approximately 43,860 unpaid carers in Wiltshire. Most of us are likely to experience caring at some point in our lives; indeed 3 in 5 of us will be carers in our lifetimes and many of us will also need care.**

With 1 in 2 of us likely to be affected by dementia in our lifetime (either by caring for someone or developing it ourselves, or both)\*, it's been important carers voices are heard as Wiltshire Council and BSW ICB develops their new dementia strategy.

**There were close to 1 million people living with dementia in the UK in 2021. This number is expected to rise to 1.6 million by 2050.**

Source: Luengo-Fernandez, R. & Landeiro, F. (in preparation). The Economic Burden of Dementia in the UK.

The stark reality for many dementia carers is that the system seems disproportionately unfair. Dementia is one of the few medical conditions that doesn't receive ongoing support from the NHS so carers are left to navigate the complicated and underfunded social care system.

We also know that carers are facing unprecedented pressures on their finances during the cost of living crisis. Dementia care costs are often significantly higher than those of standard social care which places additional pressures on those families. Many may take on additional caring needs as they simply don't have the long-term funds to pay for specialist dementia care. This can result in their own health declining and lead to them needing care of their own.

And when families do access care, many find that staff lack the knowledge and understanding of dementia and the impact it has on both the person living with the disease and the person caring for them. This results in poor quality care and increased anxiety on the part of the carer.

This was the purpose of the recent engagement work we did in Wiltshire. It was an opportunity to look at what has been working well and look ahead to identify local long-term solutions. We welcome the opportunity to work with our partners in Wiltshire to make the county truly dementia carer friendly.

\*Office of Health Economics for Alzheimer's Research UK

## Method

To help Wiltshire Council and BSW ICB ensure that their new dementia strategy accurately reflects the support needs of unpaid carers we used a variety of engagement methods, including an online survey and three focus groups held across the county.

We invited unpaid carers from across Wiltshire from our carer register. We received 186 responses to our online survey and 23 people attended the focus groups.

The online survey focused on four key areas:

- Diagnosis and support
- Wellbeing
- Dementia-friendly communities
- Dying well

Each attendee at the focus groups had the opportunity to feed in their views on their experiences of caring for someone living with dementia in Wiltshire.

## Findings

These findings are a summary of the online survey responses and comments and suggestions from the three focus groups that were carried out during May to July 2023.

## Diagnosis

Of those people who responded to our dementia survey, 97% have received an official dementia diagnosis. For nearly a third of respondents, the diagnosis took more than twelve months.

Feedback from the focus groups would suggest that, due to the progression of the disease, this can have a significant effect on the support needs of the person with the disease and therefore the impact on the carer. Several carers said that they'd noticed things weren't quite right several years before diagnosis. This is backed up by research from the Alzheimer's Society in 2016 that showed that 1 in 4 people wait for 2 years before getting help for dementia symptoms.

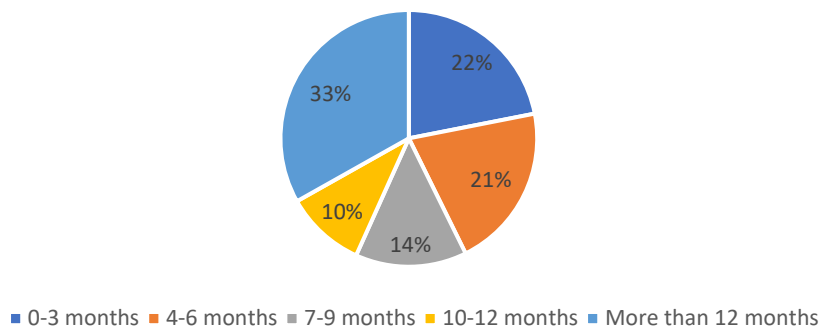
### I WISH I'D KNOWN

How long it takes to get any kind of diagnosis or assistance and that I'd had a realistic understanding of the pathway and what diagnosis meant for my mum.

### CARER FRIENDLY TAKEAWAY

Better awareness of the symptoms of mild cognitive impairment, and how it can be a sign of dementia, would help those living with the disease maintain their independence for longer.

If yes, how long did it take to get a diagnosis?



Some of those we spoke to at the focus groups questioned what getting an official diagnosis gave them other than a label. They weren't initially convinced that it achieved anything. However, there were those that said that without it they wouldn't have got the support they now have.

### I WISH I'D KNOWN

An official dementia diagnosis is critical to accessing support for both the carer and cared for.

However, an official diagnosis isn't always that simple to get. Some at the focus groups found that the results of the various tests can be talked about in quite vague terms. Some had to ask if the official diagnosis was dementia.

The memory clinic is a critical part of the diagnosis pathway. For many carers who attended the memory clinic, there seemed to be inconsistencies as to how much information was given at diagnosis, with some carers being left to find things out for themselves. Once in the care of their GP it can also be pot luck as to how much information and support is offered.

Many said that a diagram of how the system works would have been useful as it was noted that you can't care 24/7 and be able to navigate the system. Someone at the focus group described the system as a labyrinth.

#### CARER FRIENDLY TAKEAWAY

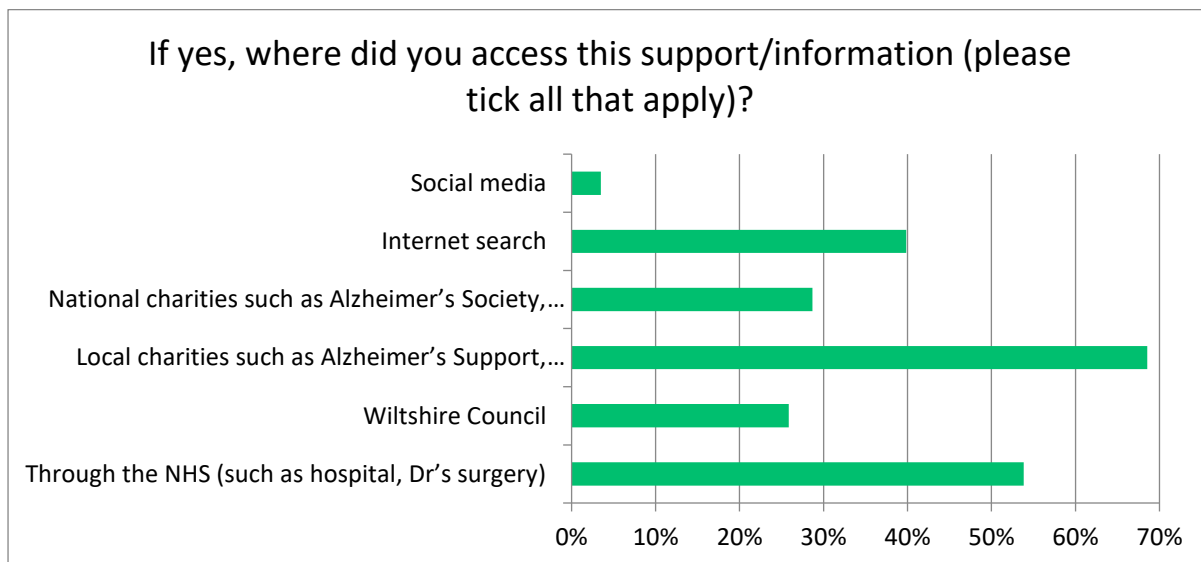
The consistency of information given at diagnosis is critical for carers so as they aren't left to fend for themselves at a time when they have a lot to deal with.

## Support

Once someone received their diagnosis, it was about 50:50 as to whether they were given the support and information they needed about the condition.

*"I didn't know what I didn't know" Husband caring for his wife*

70% of people felt they knew where to get support from. The majority of respondents sourced their information from local charities such as Alzheimer's Support and the NHS.



In terms of other support or information that would have been helpful at diagnosis the most common comments in the survey and at the focus groups were:

- A booklet with information about the support available both to carer and cared for as the disease progresses
- Information on the diagnosis timeline so as to help manage expectations ie when to expect an appointment with the memory clinic, time to diagnosis after the appointment, progression of the disease

- Access to face-to-face support wherever you are in the county
- Better promotion of Alzheimer's Support's introductory dementia course
- More proactive follow-up from post diagnostic services
- More liaison between services as system doesn't feel very joined up
- A single point of contact. So much to think about when you've had the diagnosis and can be difficult to remember who to contact for what.
- A buddy system would allow someone to talk to someone with lived experience
- Help with form filling as they can be long and complicated
- Everyone's journey is different, so support needs to be personalised

There were several mentions in the survey responses of cross border issues, where the carer lives in one county but the GP is in another. These carers seem to often fall through the cracks.

#### **CARER FRIENDLY TAKEAWAY**

A single source of information about the support available would be extremely useful. Ideally this would be a booklet.

#### **I WISH I'D KNOWN**

How to deal with the changes in the person with dementia.

Within the focus groups, there seemed to be mixed awareness of Admiral Nurses, specialist dementia nurses provided by Dementia UK. It was felt that there clearly weren't enough of them but that as they were expensive to train and support, perhaps there should be more of a focus on specialist dementia carers within the community.

This also linked into concerns from several carers that all too often they come across health and social care professionals that didn't seem to understand dementia and often lacked empathy. This can lead to huge anxiety amongst carers that their cared for isn't being looked after properly. It was doubly frustrating for them when their own expert knowledge was ignored or dismissed. This seemed to often result in carers not being able to take the breaks they need, impacting on their own health and wellbeing.

#### **CARER FRIENDLY TAKEAWAY**

Should there be an Admiral equivalent for paid carers? At the very least a minimum standard of dementia knowledge?

At the focus groups there were several sources of information and support that had been found to be really useful:

- Alzheimer's Support - dementia advisors, introductory training course
- Music therapy
- Peer support groups have been helpful for info exchange (Alzheimer's Support groups and Carer Support Wiltshire ones)
- Contented Dementia book a really useful read
- Age UK Wiltshire
- Tell us once - service when someone passes

### I WISH I'D KNOWN

That I could get a 25% discount on my council tax with a diagnosis of dementia. And that I could use a prescription as proof of address.

### I WISH I'D KNOWN

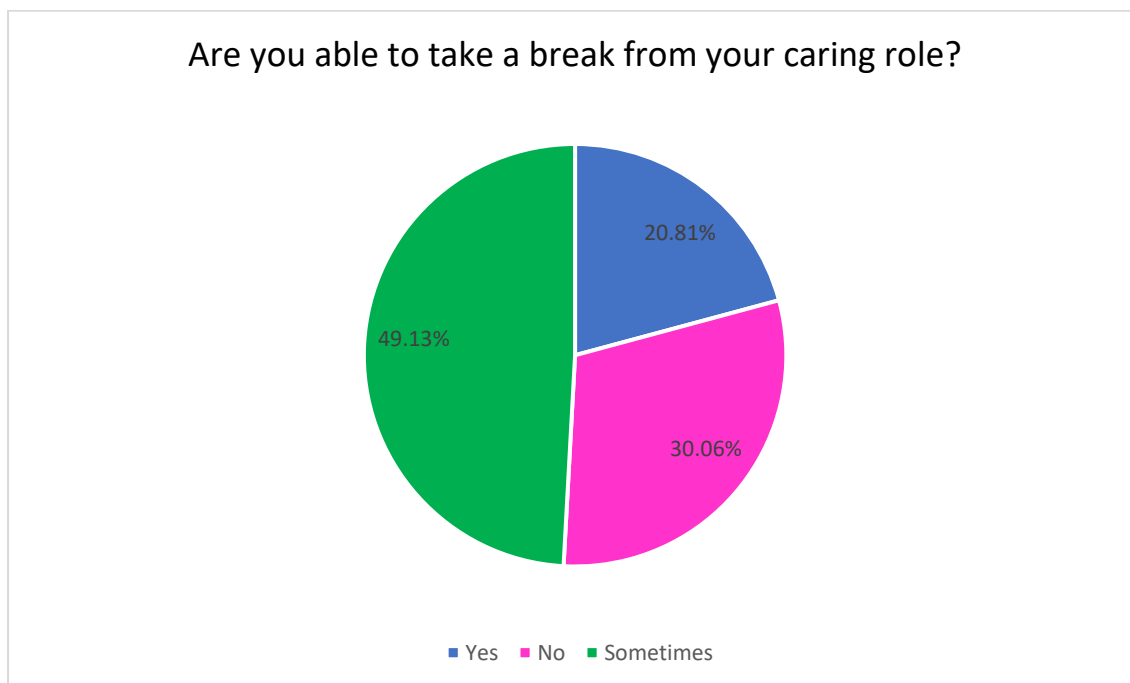
Don't leave asking for support until you've reached crisis point. Dementia can progress very quickly and services can take time to set up.

“You have to have patience and humour to get through the day”

Male carer looking after his wife

## Managing your wellbeing

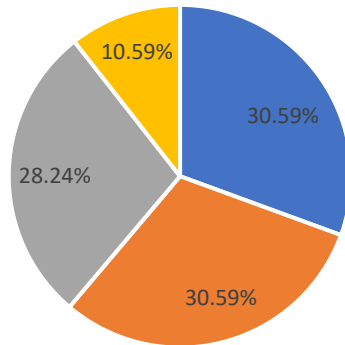
Nearly a third (30%) of carers said they are unable to take a break from their caring role. Just under half are only sometimes able to take a break.



When asked if they are able to meet up with other people caring for someone living with dementia at support groups etc, only 30% said yes. 31% said they aren't able to and 11% said specifically that they aren't able to access these sorts of groups.



Are you able to meet up with other people caring for someone living with dementia at support groups, cafes etc?



■ Yes ■ No ■ Don't want or need to ■ Aren't able to access

In terms of the wellbeing support that people have found the most useful, the most popular were:

- Carers groups run by organisations such as Carers Support Wiltshire and Alzheimer's Support
- Alzheimer's Support home support

Carers were asked what the barriers are to accessing support for them:

- Not knowing what's available so more communication
- A sitting service to allow carer to attend groups/funding to pay for that
- Groups not being at convenient times/sitting service not offered at times that match available groups - online and evening would help
- Transport
- Not being allowed to bring cared for with them

As being able to take a break from their caring role means having replacement care, we asked how many were currently accessing a sitting service. 62% said no.

There were mixed views from carers that are accessing a sitting service.

- A lack of dementia training amongst care staff was a common issue
- The cost
- Not enough hours offered to do anything really meaningful
- Others felt it was a lifeline, enabling them to do the shopping, manage their own appointments and meet friends

About half of carers (48%) said in our survey that they'd had a carers assessment. 14% said they'd not had a 12mth review, but an additional 29% said they didn't know.

57% of people who responded to our survey said they have had the opportunity to talk about the support they need and for this to change as and when their needs change.

Those that came to the focus groups, said that usually didn't have time to attend events for carers. The specific barriers they mentioned were a lack of options and that people needed

different things as they progressed along the dementia journey rather than a one size fits all approach. Transport was also cited as a barrier. Online options were welcomed but again it shouldn't be the only option.

## Planning for the future

73% of respondents to the survey said that they had made and registered a lasting power of attorney. Of those that said they hadn't, over 50% said they've interested in doing so. For those that have an LPA, the majority (74%) said they'd done so to help with both financial and care and support decisions.

## Dementia support in the community

The average response to the question of how friendly they find their local community on a scale of 1-10 was only six.

Those things that have helped to make the community more dementia friendly are:

- Carer Support Wiltshire and Alzheimer's Support services
- Neighbours, friends & family
- Shops, local services and GP being more understanding
- Local churches

Carers were also asked what difficulties or barriers they face within their community:

- Isolation - friends dropping off once diagnosis is made as there seems to be a stigma around dementia
- A lack of understanding about dementia in all settings - shops, care homes, carers, GP surgeries
- Some mentioned transport, in particular accessible wheelchair transport, and the state of the pavements.

At the Trowbridge focus group, Bradford on Avon was mentioned as a good example of a dementia friendly town. It was felt that there was good collaboration between the voluntary sector, the town council and private sector.

There was some support for continuing to be part of the wider community for people recently diagnosed rather than creating 'special' groups. It was felt important for maintaining a sense of independence for the cared for.

However, with lots of discussion at the groups about a lack of awareness about dementia there would perhaps be more dementia awareness training needed amongst key community services. This would avoid any misunderstandings or conflict.

### CARER FRIENDLY TAKEAWAY

Additional dementia awareness training needed amongst professionals and the local community in order to improve the quality of care.

This seemed to be a particular issue amongst paid carers, care homes and day centres. We were given many examples of paid carers not treating carer as an expert in the care of their loved one. They have often been doing it for years so know what works and what doesn't. Paid carers, either domiciliary or care home, often don't seem to have had dementia training. Don't seem to understand how to manage the care of someone with dementia. Family members have often been told they are interfering when making suggestions as to how to look after their cared for. Changes in carers also don't help with someone with dementia.

### CARER FRIENDLY TAKEAWAY

Professionals need to respect the knowledge that many carers have of their cared for's condition and see them as partners in their care.

There were several complaints about parking at Wiltshire Council car parks. Some carers are now struggling to be able to pay for parking as they don't use the MiPermit app and the machines are often broken and won't take cash. Many of the carers at the groups wanted the free blue badge parking back. It was also mentioned that payment machines are often not where disabled parking spaces are which, particularly when you are with someone with dementia, can be an issue. It is very easy for someone with more advanced dementia to disappear if you aren't focused on them.

### CARER FRIENDLY TAKEAWAY

There seems to be a strong case that there must be adequate provision maintained for those who cannot or do not wish to use online public services, often the most vulnerable, becoming more isolated.

## Conclusion

In conclusion, the five key areas that were raised consistently during this engagement work were:

- Inconsistencies - as with other carers we've spoken to, it is the inconsistency in support that frustrates many. What one person is told or offered; another may not be.
- More dementia training for professionals - many professionals don't seem to know enough about dementia and the affect it has on both on the person living with it and the carer
- Partners in care - professionals often ignore or dismiss the huge amount of knowledge that the carers themselves have about the condition.
- Better co-ordination between services - as we've heard at our other carer engagement events, more liaison/signposting between services is needed so that people don't fall through the gaps.

- Better promotion - There were several services that were very highly praised by those that had been offered them including Alzheimer's Support's dementia advisors and introductory training course but they weren't always that well promoted.

## Recommendations and next steps

We have identified the following recommendations to lead on as an organisation. We cannot do this alone and our priority will be to ensure that the voices of carers are at the forefront of all the work we do. We will seek to work with a range of organisations to embed these recommendations in Wiltshire.

- We will ensure that all dementia carers that come to us are made aware of the key support that is available to them in the community.
- We will also look to strengthen our links with organisations such as Alzheimer's Support and the Alzheimer's Society and look for opportunities to jointly provide additional services for dementia carers.
- We will ensure that all of our support staff and volunteers have completed the Alzheimer's Society's dementia awareness training.

## Acknowledgement

Thank you to all that attended and contributed to the online survey and focus groups about the Wiltshire Council and BSW ICB dementia strategy. We look forward to working with our partners in Wiltshire on making the county more carer friendly.