Information & Support Available to People Living with Dementia and their Carers After Diagnosis

Report of Engagement

JULY 2024

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Acknowledgments

We would like to thank all of the individuals who have contributed to this Report, and all of the organisations who have supported this work.

Our particular thanks go to everyone who gave their time to be interviewed by us and to all the organisations who allowed us to attend their Group or meeting and run a Focus Group with the participants. Thanks to you all. You really helped to deepen our understanding.

Our thanks also to members of the Dementia Programme Board and Officers of Worcestershire County Council who offered their advice, support and expertise and helped us to find a clear focus for this project.

EXECUTIVE SUMMARY

ABOUT HEALTHWATCH WORCESTERSHIRE

Healthwatch Worcestershire (HWW) gathers feedback about local publicly funded health and care services and makes recommendations to those who run them about how they could be improved from a patient, service user and carer perspective.

WHY THIS WORK

'My memory…. I remember the past but can't remember recent conversations …maybe I'll remember fractions of that …. I can't remember names but can remember things that have happened in the past… I'm just jogging along. I know what's coming down the line and I've just got to do my best' Person living with dementia, Interview

'Vascular dementia gives you a feeling of grief though no one has died, a feeling of having your heart ripped out every day, a feeling of, no matter how positive you try to be, something else happens' Carer, written submission

The National Institute for Clinical Excellence[1] describes dementia as:

'Dementia is a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and a reduction in a person's ability to carry out daily activities…. Dementia is a progressive condition, which means that the symptoms will gradually get worse.'

Worcestershire has a higher than average older population and as such, dementia presents a significant challenge for the health and care system locally, and its communities. The number of people with dementia in Worcestershire is set to increase to 11,257 by 2028, and 14,382 by 2038. The largest increase will be in those aged 85+, who are more likely to have increased care needs [2]

There are multiple ways in which people can receive a diagnosis of dementia in Worcestershire. Through engaging with people living with dementia and their carers we aimed to:

- Understand the information provided to people and carers on diagnosis
- Understand the experience of people with a diagnosis of Young Onset Dementia and their carers
- Understand the experience of support provided by health and social care
- Identify whether differences or inequalities exist in information and support provided across the diagnostic pathways

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[1] NICE Guidance: assessment, management and support for people living with dementia and their carers - Published: 20 June 2018 www.nice.org.uk/guidance/ng97

[2] Worcestershire Health and Wellbeing Board Dementia Joint Strategic Needs Assessment, March 2019

WHAT WE DID AND WHO WE HEARD FROM

The opportunity to participate in the project was promoted widely by HWW with an estimated reach of more than 12,700 potential contacts with the project.

We have heard the experiences of **217 people** over the course of this project through:

Survey – 131 Carers	**Survey – 38 People living with Dementia**	**7 Focus Groups**	**12 In-depth Interviews**
Female (67%), aged 65 + (85%) and White British (95%)	Female (72%), aged 65 + (67%) and White British (97%)	36 people Female (87%) Age 57-84yrs	10 Carers & 2 People with Dementia Male (66%) Age 48-91 years

Further information about who we heard from is available in the main Report

WHAT WE FOUND OUT

Diagnosis - Information and Support

'We were given a big envelope with loads of leaflets. I couldn't read all of this! I had to deal with my husband and my emotions, that was far more important. I hadn't got any capacity to take in other things - I just needed someone to talk to', Carer, Interview

'A named point of contact who is allocated to support us throughout. Someone who can advise, reassure and signpost, someone who can also advocate for us when needed. I feel very alone. I live in a constant state of anxiety and stress. Any support that came our way was time limited to 6 months. I've had enough' Carer, Survey respondent

People recognise that dementia is an individual experience, which will affect each person differently.

Information, or lack of it, was a theme that recurred frequently through our Survey and analysis of the content of our Focus Group and Interviews. These discussions revealed that providing people with the right level of information at the right time and in the right way is complex. When carers are provided with information they can feel overwhelmed, and do not always have the time or resources to be proactive and reach out for what they need.

People are often too tired/too focused on coping to follow-up or take the initiative in contacting a professional. They also don't know the questions to ask at this early stage, or are too shocked to take in all the relevant information.

Whilst there is a significant amount of information available, not everyone is aware of the resources which exist. Awareness of the Age UK H&W Dementia Services Directory is patchy. Our Survey and qualitative work provides guidance on the sorts of topics that people would find it useful to have information about.

A flow chart, or simple pictorial representation, of what might happen at each stage of the dementia journey and the main sources of information and support was frequently requested, along with tailored information, which is specific to the person and their condition, and to where people live.

The level of information provided to people differs across the diagnostic pathways. Patients and their carers requested a clear and consistent information offer, that provides them with access to the same level of training, information and support, regardless of the diagnosis pathway they experience.

Carers did not always feel that they had the support they needed at diagnosis, and this was influenced by the pathway through which they were diagnosed. The Early Intervention Dementia Service (EIDS) was described as most often providing the right amount of information and support at diagnosis, and GPs as least often providing this. However, the EIDS intervention is short term and can lead to people feeling 'dropped' and 'abandoned' once discharged.

Of most importance to the people we spoke with was easy access to someone with knowledge and understanding about dementia to talk to as needed, who is proactive about making contact, offers objective advice and signposting (specific to their particular situation). They also want ongoing emotional support and a 'listening ear' that helps people to prepare for the future – someone who will walk alongside people on their dementia journey.

Age UK Herefordshire & Worcestershire Dementia Wellbeing Service

Our findings suggest that for those in receipt of the Dementia Wellbeing Service most (70%) describe the support provided as good. More people had heard of the service than were actually using it; there could be multiple reasons for this. The Service is part of the Universal Offer for people living with dementia. 69% of respondents had either not been referred to the service, or did not know if they had been referred or not. Referrals to the service vary across the diagnostic pathways, which may result in carers and people living with dementia missing out on valuable support.

The Service needs to be embedded within the local health and care system with referrals made on diagnosis, with an aim of ensuring people are linked to support and advice at the earliest opportunity.

Care Planning

‘There was no joining up of services it was up to me to piece it together, it’s very fragmented’ Carer, Focus Group participant

Care Plans are an important tool for both professionals and people living with dementia and their carers. Our understanding is that Care Plans are part of the universal offer for people living with dementia. Despite this 83% of carers did not know if the person they cared for had a care plan or thought they did not.

Care Plans should form the basis for Annual Reviews[3], and can assist in ensuring that current and future needs are recognised and met.

Having a named professional or care coordinator leading on the person’s care and treatment and for when the carer or patient needs advice is a recommendation within the National Dementia Care Pathway[4]. 82% of carers reported that they did not know the name of the person responsible for co-ordinating their loved one’s care.

Carers wanted a more ‘joined up’ approach between services. There should be better communication and connectivity between services to ensure continuity of care, information, and care plans. This could help to ensure that people do not have to repeat their stories and could be facilitated through carer identification, Shared Care records and ‘This is me’ documentation.

Support from GP’s and other Health Services

‘GP doesn’t know I exist. GPs are like clouds, allocated as I make an appointment. I will see a GP once then never see them again’ Person with dementia, Interview

‘I told the GP of the diagnosis in advance and said you will need to read up on this. What we got was a 7 minute appointment. The GP went through a checklist and that was it. We were in and out. I left feeling really disgruntled’ Carer, Interview, describing their loved one’s Annual Review

General Practice

General Practice is one of the pathways through which people can be diagnosed with dementia. GPs’ connection to the rest of the health and care system as well as their base in the community make them well placed to take a leading role in care planning and care co-ordination for people with dementia[5]

GPs are required to maintain a register of people with a dementia diagnosis. It is important that this is kept up to date and that people living with dementia and their carers are appropriately coded on NHS records when a diagnosis is made. This would enable reasonable adjustments to be made, Annual Reviews to be programmed, and other services notified of the dementia diagnosis as appropriate.

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[3] D.E.M.E.N.T.I.A framework set out in NHS England Dementia: Good personalised care and support planning guide, 2020

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

[5] All-Party Parliamentary Group report, 2016 ‘Dementia rarely travels alone: Living with Dementia and other conditions’

Many carers appreciated and described the support offered by their GP practices, particularly those which had a designated dementia specialist role, such as a dementia nurse or dementia champion.

However, they also reported issues with booking appointments (including home visits); inconsistency of care; issues with medication and that some staff appeared to lack dementia awareness.

Annual Reviews carried out in a GP practice are a key part of a person's care[6]. However, 45% of respondents to our carers survey were not aware of them. Of those that had received an Annual Review satisfaction varied. Carers reported that they felt the Review could be a 'tick box' exercise and a missed opportunity for themselves and their loved one to access much needed support. For example, carers did not always feel able to discuss their own needs or to access input around medication or coping strategies.

Understanding individuals' needs and preferences and providing person-centred care through regular review should be a key priority. Reviews which follow the D.E.M.E.N.T.I.A. framework[7] have the potential to offer significant benefits to people living with dementia and their carers, and could address some of the issues about lack of care planning, support and co-ordination of services raised by carers through this work. At present however we cannot be confident that this is the case.

Our observation, from both the quantitative and qualitative work that we have undertaken, is that the understanding and support provided by GP practices is inconsistent and varies by practice, creating a 'postcode lottery' for people living with dementia and their carers.

Other Health Services

People living with dementia and their carers want the same access to health care as any citizen, but delivered with a recognition of the additional challenges which dementia can bring. For the Integrated Care System this means providing personalised care, which wraps around the person and their loved ones, and recognises the specifics of their circumstances.

For some carers the Admiral Nurse is the first point of call when help or support is required. The service was described by some as 'brilliant' and a 'lifeline'. Conversely we heard from Carers who had contacted the service but had not received the support they hoped for. We appreciate that responses from services are likely to be based on an assessment of individual circumstances, nevertheless from a carers' perspective a clear description of the assessment process and the service offer will be beneficial.

Although this was not a particular focus of our work carers also described their experience of hospital settings. Some had an excellent experience, whilst others

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[6] Annual Reviews are a component of the 2023/24 Quality Outcomes Framework – **Ongoing management** DEM004. The percentage of patients diagnosed with dementia whose care plan has been reviewed in the preceding 12 months

[7] D.E.M.E.N.T.I.A. framework set out in NHS England Dementia: Good personalised care and support planning guide, 2020

felt that some staff do not always have the time, skills or knowledge to deal with patients living with dementia.

Some carers wanted more information about clinical trials but were not always able to find this information.

We also heard of challenges to carers and people living with dementia to access services such as dentistry, eye and hearing checks, incontinence services and chiropody at home. Long waits for OT assessment were reported and Falls were not always quickly responded to.

These services are important to support people’s well-being and at times, prevent hospital admission.

Our Case Study highlighted potential lessons for the System in respect of raising awareness of the link between Learning Disability and dementia, using the Learning Disability Annual review as an opportunity to look for and discuss signs and symptoms of dementia. A clear pathway is needed for people with a learning disabilities who require a dementia diagnosis and ongoing support and review through their dementia journey.

Support from Social Care Services

‘If I start asking the wrong questions will it be taken the wrong way?’ Carer, Focus group participant

‘The relationship needs to be built to understand the individual and how their needs change over a period of time.’ Carer, Survey respondent

Dementia is a progressive disease and over time people living with dementia and their carers may need support to maintain their independence at home or assistance to plan for the future.

Not everyone we spoke with was aware of the role of Worcestershire County Council Adult Social Care Services (ASC), their legal responsibilities or what they could offer to people by way of information, advice and support. Some carers were concerned that approaching ASC may result in their loved one being taken away from them or the situation escalating beyond the carer’s control. A clear description of the role of ASC may alleviate this situation.

Of those who had contacted ASC (n64) the most frequent reasons were for support at home, for advice and information and for support in a crisis situation.

We heard positive comments about support received through ASC, and in particular a consistent allocated social worker was valued.

Of those receiving a service where ASC contributed to the cost the majority were satisfied with the quality of care provided. We asked only those who received a funded service how far they agreed or disagreed with a series of statements about the quality of care services. Respondents most frequently agreed that they were satisfied with the quality of the support, which was reliable and responsive to concerns. People were less confident they could get the response they required in a crisis situation

Other issues included frequent changes of social worker, and an apparent lack of understanding by social care workers about dementia. About 1 in 3 carers who receive a service funded by WCC felt that their needs as a carer were not understood by social care workers.

People who were self-funding (i.e. had savings above a financial threshold) felt particularly unsupported. Most self-funding carers reported they would have liked more support from Adult Social Care to organise care for their loved one.

We asked all Carer survey respondents, whether or not they had contacted ASC, about what care services they were using. We received comments about domiciliary care (reliability and consistency of care were greatly valued), respite and replacement care (carers had not always been able to find respite care that met their own and their loved ones' needs and which was flexible and affordable), day care services and residential care settings.

Support in the community for People Living with Dementia

'It saved my life, I thought I was going insane' Carer, Focus Group participant

Through focus groups and interviews, we heard how much people valued the support provided to them through local (District based) Age UK groups and activities, and by other local organisations and faith-based groups who are supporting carers and people living with dementia. Carers also praised the volunteers who ran or supported these activities.

These groups and organisations provided valuable opportunities for carers to find vital peer support and for their loved ones to continue to enjoy activities and relationships which are important to them.

Barriers to access included transport to activities, the appropriateness of the activity for the individual, timing (particularly a lack of activities in the evenings and weekends) and cost.

An identified gap in services was community support at the later stages of dementia, when some community-based services were no longer suitable for the person living with dementia due to changes in their behaviour or personal needs.

People also wanted one to one support and befriending services suitable for people unable to access community facilities.

There may be scope to better educate the public in general about dementia, and to further encourage communities to become dementia friendly.

Young Onset Dementia

'We were struggling to get incapacity benefits. So, then it was about, you know, trying to do the PIP and stuff like that. Luckily, I'm computer literate and have quite a senior job so I was able to put something together and word things … but yeah, it's a lot to have to take on board' Carer, Interview

Dementia is often described as 'young onset' when it is diagnosed before the age of 65. There are 122 people in Worcestershire who have received a diagnosis of young onset dementia.

The financial impact of a diagnosis at working age was significant and we heard that eligibility for benefits can vary according to age, therefore it is important that consistent and accurate advice is provided, and support is readily available to complete benefit applications.

Amongst the people who responded to our survey and those we spoke to; it is evident that knowledge of the Dementia Wellbeing Service is low and that referrals to it are even lower. This is a concern considering the additional needs and challenges carers of people with a diagnosis of Young Onset Dementia face.

The need for more age specific provision was evident for the benefit of both the person with a diagnosis and the person caring for them. The opportunity for peer support to develop is created via organised activities. We heard from carers how they often learned more from other carers than from any agency. Peer support was also identified as a key component in supporting the mental health of carers.

It is recognised that this community of people is a small proportion of Worcestershire's population, which may make justifying funding more challenging. However, the acuity of need makes it apparent that there is a real gap in provision. An opportunity exists to explore how some groups have created an inclusive provision for all ages.

Support For Carers

'When you've got somebody with dementia, then everything is on your shoulders.' Carer, Interview

'An understanding from all departments that caring can be extremely stressful, frustrating and exhausting and it's not a 9 - 5 role!' Carer, Survey respondent

Carers may experience poor physical and mental health and also may have unmet care needs themselves. There is mounting evidence that unpaid care should be considered a social determinant of health.[8]

The role of being an unpaid carer of someone living with dementia is a complex and demanding one, for many it is a 24/7 job, and carers feel they need support along the way. Many carers emphasised that the situation they were in was unknown, new to them and frequently challenging. They needed information, training, support, reassurance and sometimes, time to themselves and a break from it all.

Carers highlighted the challenges they face trying to balance caring and a working life.

Not everyone acknowledged or accepted the description of themselves as a Carer. Some felt that professionals and services made this assumption, sometimes to the detriment of the Carer.

Only 10% of Carer Survey respondents told us that they felt supported in their caring role.

The Worcestershire Association of Carers (WAC) provides a range of services for unpaid carers across Worcestershire. These include the Worcestershire Carers Hub.

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

The Hub is funded by Worcestershire County Council. 65% of respondents had heard of WAC and 35% had been in contact with the organisation. Of those who had been in contact with WAC satisfaction was varied, 62% reported that they were neither satisfied or dissatisfied with the support received, 26% were satisfied and 12% were dissatisfied.

Where provided, proactive support was welcomed, however some carers we spoke with reported a lack of awareness of the range of the services on offer or difficulties in accessing them. This was sometimes because they were unable to find replacement care.

Most carers (67%) had not been referred to WAC or did not know if they had been referred or not. It would appear that there is scope for NHS, ASC and other organisations to play a more proactive role in referring Carers to WAC.

Most Carer survey respondents (68%) were not aware of their entitlement to a Carers Needs Assessment, and only 8% have had such an assessment. Providing information about WAC and the Carers Needs Assessment is part of the universal service offer. This suggests that there is a need to promote this entitlement and highlight to them the potential benefits that this could bring.

CONCLUSION

A diagnosis of dementia is life changing for the person living with the condition and their family and friends.

As a County with a higher than average older population the challenge which dementia presents for the individual, their carers, our communities and for the health and care system locally is set to increase.

Through this work we have heard of both the positive aspects of care and support provided to people living with dementia and their loved ones and also some of the struggles and issues encountered.

There is a lack of consistency in the information and support that people living with dementia and their carers receive and this is influenced by the pathway through which they are diagnosed. They are not routinely offered referral to key services such as the Dementia Wellbeing Service and Worcestershire Association of Carers.

There is a lack of awareness of Care Plans and Annual Reviews. Implementation of these is patchy, yet they offer the potential to address some of the needs so clearly expressed by the voices that we have heard through our work.

There is some lack of understanding of the role of Adult Social Care, and how it can be of benefit in understanding and meeting people's existing needs and planning for the future. Carers require support in navigating an unfamiliar care system regardless of their financial circumstances.

People need health and care services where staff understand the challenges that dementia presents, and services will make reasonable adjustments to accommodate them.

Activities and support in the community is highly valued, yet barriers to access exist which need to be addressed.

For many caring is a 24/7 role, which can significantly impact on carers own quality of life. Carers should not have to fight, chase or push to uncover care and support that should be available to them. Nor should they be further burdened by the difficulties people have reported navigating the system of health and care.

It is clear that while each person and their carer's needs, experiences, and preferences are unique, they need to know that the Integrated Care System is there for them, providing regular, proactive advice and support when needed, throughout this unpredictable journey. As such it is critical that across the Integrated Care System, the issues that we have identified in this Report are addressed.

RECOMMENDATIONS

Diagnosis - information and support

1. Ensure that diagnosis is the key to accessing a clear pathway of consistent support for people living with dementia and their carers
2. Ensure those who choose not to access a diagnosis are not denied information, advice and access to services.
3. Introduce an 'opt out' approach for referrals to the Dementia Wellbeing Service and Worcestershire Association of Carers
4. Consider how the EIDS service manages discharge, and whether there is potential for people to move into and out of the service over time as needs change, to prevent feelings of invisibility and abandonment.
5. Ensure that people have access to a named individual contact who is knowledgeable about dementia and can provide proactive and ongoing information, advice, signposting and emotional support.
6. Develop a clear and consistent information and support offer at diagnosis, which provides people living with dementia and their carers with access to the same level of training, information and support, regardless of which pathway they are diagnosed through.
7. Consider how diagnosis, reviews, local community spaces and activities, health, care and voluntary sector settings, and online opportunities can be maximised to better promote the wide range of resources (particularly local resources) which are available to inform & support people living with dementia.
8. Ensure that information is accessible, and available in a range of formats to meet individual need including for people with additional communication needs or whose first language is not English
9. Develop a pictorial representation of what might happen at each stage of the dementia journey and identifies the main sources of information and support, including practical and financial information and advice

Age UK Herefordshire & Worcestershire (Age UK H&W) Dementia Wellbeing Service

10. Ensure that all diagnostic pathways are aware of the Dementia Wellbeing Service, and introduce an ‘opt out’ approach to referrals to the service.
11. Ensure that the Service is sufficiently resourced to deal with demand.
12. Ensure that the Service is able to offer a timely response and consistent offer to the people who contact it.
13. Develop a plan to increase the visibility of the service across relevant parts of the NHS, Adult Social Care (Front Door & ASC Teams) as well as Voluntary, Community and Social Enterprise organisations including dementia groups.

Care Planning

14. Provide all people living with dementia with a key worker or meaningful contact for support, recognising continuity is important to people, over the long term (see Recommendation 5)
15. Ensure that every person who is diagnosed with dementia has a personalised Care Plan, which is developed alongside an appropriately qualified practitioner.
16. Ensure the Plan identifies what matters most to the person living with dementia, considers the wider family in care planning, pays attention to their own and their carers’ needs, including their wider health and wellbeing.
17. Give families a copy of the Care Plan so they can refer back to it and share plans with other health and care services.
18. Monitor how this is being implemented.
19. Consider how connectivity between services to ensure continuity of care, information, and care plans can be facilitated and developed, including through the use of the Shared Care Record.

Support from GP’s and Other Health Services

GPs

20. Ensure that the diagnosis of dementia is added to the person’s medical record and GP dementia register, and that service users and carers where possible, are made aware of this addition to a medical record
21. As a minimum, ensure carers are identified and recorded on a GP practice carer register, along with a contingency plan - should they be unable to provide care
22. Consider how to build on people’s positive experience of dementia-specific roles in primary care, and ensure equity in access across the County. This could include consideration of how social prescribers could support people living with dementia and their carers.
23. Ask GP Surgeries to identify how they will make reasonable adjustments to ensure easy and consistent access to care and services within the practice for people living with dementia and their carers
24. Provide all people living with dementia with an annual review by an appropriately qualified practitioner, ensuring more frequent reviews for those with greater need – as identified through effective care planning.
25. Reviews should follow the D.E.M.E.N.T.I.A. framework set out in the 2023/24 Quality Outcomes Framework; addressing the needs of carers as well as those

living with dementia and signposting to other services and support, as appropriate.

Other Health Services

26. Raise awareness, and provide education and training, among health and care staff to ensure they can recognise the symptoms of dementia and know who is at risk.
27. Ensure health and care staff know how to recognise and identify carers and can help carers to recognise their caring role.
28. Consider what information, education, training and skills health and care staff may need to ensure that they can appropriately meet the needs of people living with dementia and their carers across a wide range of health and care settings.
29. Ensure that all health and care services make reasonable adjustments to meet the needs of people living with dementia and their carers so that services are accessible to them, including in the home setting where appropriate.
30. Ensure people are aware of the Admiral Nurse service offer and are clear about how to access this.
31. Ensure that health and care staff working with people with a learning disability are aware of the link between learning disability and dementia
32. Ensure that signs and symptoms of dementia are considered as part of the Annual Learning Disability Review
33. Set an age at which a baseline assessment is established, with which future assessments can be compared
34. Ensure there is a clear pathway for diagnosis, support and review of people with a Learning Disability who are diagnosed with dementia.

Support From Adult Social Care Services

35. Promote awareness of Adult Social Care and people's entitlements under the Care Act 2014 using a range of formats and channels (see Recommendations 7 & 8)
36. Explain the role of Adult Social Care and how the journey through Adult Social Care works using a range of formats and channels.
37. Ensure people who are self-funding feel supported, recognising that finding and organising high quality care will be unfamiliar to many people who contact the service.
38. Ensure that people in receipt of Adult Social Care services have access to an allocated social worker.
39. Ensure that Adult Front Door and Social Care staff have the necessary information, skills and training to engage effectively with people living with dementia and with their carers.
40. The Integrated Care System (ICS) should ensure that there are a range of opportunities for respite which includes helping carers to take a break for a few hours in the day or to sleep at night, as well as residential respite care for longer periods of time, and ensure that carers are aware of these opportunities.
41. The ICS to consider how the feedback we received about care services can be utilised effectively within the system.

Support In the Community for People Living with Dementia

The Integrated Care System should:

42. Continue and expand support groups and activities through non-statutory services in areas where provision is limited, including in the evenings and at weekends.
43. Increase opportunities for people living with advanced-stage dementia, who may also have physical health needs, to engage in meaningful activities.
44. Ensure that one to one and befriending support is available to those who need it
45. Consider how barriers to access such as transport to activities, the appropriateness of the activity for the individual, timing (particularly a lack of activities in the evenings and weekends) and cost can be addressed.
46. Support the development of more dementia-friendly or dementia inclusive activities and communities and consider what resources, information and advice may be required to do this

Young Onset Dementia

47. Ensure that consistent and accurate information and advice is provided, to people with young onset dementia and their carers, including financial advice and practical support where required (e.g. to complete benefit applications)
48. Introduce an ‘opt out approach for referrals to the Dementia Wellbeing Service and Worcestershire Association of Carers.
49. Consider how existing support groups might develop a more inclusive approach to accommodate all ages.

Support for Carers

50. On diagnosis make Carers aware of Worcestershire Association of Carers and introduce an ‘opt out’ approach to referrals to the service.
51. Ensure that the Service is sufficiently resourced to deal with demand.
52. Carers should be informed about the Carer’s Needs Assessment, and how this might be of benefit to them.
53. Develop opportunities for peer support, particularly for younger, working carers.

1. ABOUT HEALTHWATCH WORCESTERSHIRE

Healthwatch Worcestershire (HWW) gathers feedback about local publicly funded health and care services and makes recommendations to those who run them about how they could be improved from a patient, service user and carer perspective.

2. WHY THIS WORK

What is dementia?

The National Institute for Clinical Excellence[9] describes dementia as:

> *'Dementia is a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and a reduction in a person's ability to carry out daily activities, such as shopping, washing, dressing and cooking…. Dementia is a progressive condition, which means that the symptoms will gradually get worse. This progression will vary from person to person and each will experience dementia in a different way – people may often have some of the same general symptoms, but the degree to which these affect each person will vary'*

Prevalence of dementia increases with age. Worcestershire has a higher than average older population and as such, dementia presents a significant challenge for the health and care system locally, and its communities.

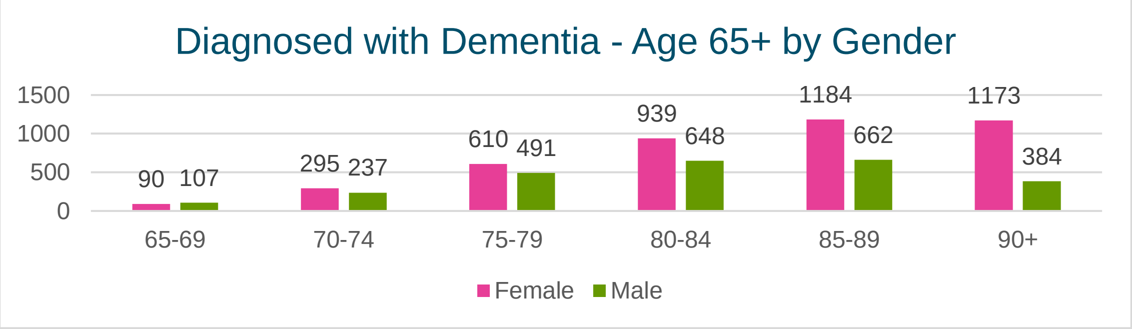
Numbers of people with dementia in Worcestershire

At September 2023 there were **6,820 people living with a diagnosis of Dementia**[10] in Worcestershire.

122 of these people have a diagnosis of **Young Onset Dementia** which means they received their diagnosis before the age of 65.

Of those with a diagnosis 4,291 are women and 2529 are men.

The age breakdown of those women and men aged over 65 with a diagnosis is shown below



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[9] NICE Guidance: assessment, management and support for people living with dementia and their carers - Published: 20 June 2018 www.nice.org.uk/guidance/ng97

[10] Figures supplied by Worcestershire Integrated Care Board, 24 October 2023

These figures are likely to be an underestimate, as not everyone living with dementia will have been diagnosed. Figures provided by the Herefordshire & Worcestershire Integrated Care Board (H&W ICB) estimate that a **more accurate estimate of the numbers of people with dementia in the County is 9,353.**

> **The number of people with dementia in Worcestershire is set to increase to 11,257 by 2028, and 14,382 by 2038. The largest increase will be in those aged 85+, who are more likely to have increased care needs [11]**

Obtaining a diagnosis of dementia in Worcestershire

There are multiple ways in which people can receive a diagnosis of dementia in Worcestershire. One of the aims of this project was to understand the different diagnosis pathways. These include:

- Diagnosis via GP
- Diagnosis via Early Intervention and Diagnostic Service (EIDS)
- Diagnosis via Older Adults Community Mental Health Team
- Diagnosis via Acute Hospital Departments – Neurology, Stroke and Geriatrics
- Diagnosis via Learning Disabilities Team
- Diagnosis via a clinical trial
- Diagnosis obtained privately

The ‘Universal Offer’ to people living with dementia

Regardless of where people receive their diagnosis in Worcestershire, we understand the following should be offered to everyone:

- Referral to Age UK Herefordshire and Worcestershire’s Dementia Wellbeing Service
- Information about Worcestershire Association of Carer’s and the Carer Needs Assessment
- Annual dementia health check with their GP and development of a care plan

Our aims in undertaking this project

Through engaging with people living with dementia and their carers we aimed to:

- Understand the information provided to people and carers on diagnosis
- Understand the experience of people with a diagnosis of Young Onset Dementia and their carers
- Understand the experience of support provided by health and social care to people living with dementia and their carers
- Identify whether differences or inequalities exist in information and support provided across the diagnostic pathways

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[11] Worcestershire Health and Wellbeing Board Dementia Joint Strategic Needs Assessment, March 2019

3. WHAT WE DID

Scoping

During the scoping phase for this project, we met with four senior clinicians from the Dementia Programme Board who provided valuable information about the diagnostic and post diagnostic support for people in Worcestershire.

In addition, we met with:

- ICB Dementia Lead
- Dementia Wellbeing Hub Manager - Age UK Herefordshire and Worcestershire
- Deputy CEO - Worcestershire Association of Carers
- Community Learning Disabilities Nurse
- Head of Service – Area Social Work

Their contributions were valuable in helping us identify the parameters for this piece of work.

Engagement Methods

Healthwatch Worcestershire reached more than 12,700 people with information about the project. Additional reach was achieved via local networks who shared the information. Engagement activity included:

- Social media – Facebook posts had a reach of 11,500
- Content on the Healthwatch Worcestershire website - 387 views of pages associated with the project
- Text messages sent out via two Primary Care Networks – 740 patients and carers
- Features in HWW newsletters and mailings sent to 462 individuals and organisations
- Information shared via district and community network meetings
- Community engagement activity by Healthwatch Worcestershire
- Communications shared through Age UK Wellbeing Hub, Worcestershire Association of Carers, Carers Careline and local (District based) Age UK organisations

Collecting people's experiences

People's experiences were collected in three ways, and these are outlined below.

Surveys

Surveys were created to gain insights from people living with dementia, and people caring for someone with dementia.

They were made available online and in hard copy. The survey for people living with a diagnosis was written in a format accessible to people with dementia, and following guidance issued by the Alzheimer's Society. People were asked to tell us about:

- Information and support received from health and care services **post** diagnosis

- Their experiences of accessing health and care services
- What sources of information and support they had found useful and what was missing
- What they would like people to know about living with dementia or caring for someone with dementia
- Carers were asked about the support they had received in their role as a carer

Focus Groups

We held focus groups in each district of the County, these were available to people with a diagnosis and people caring for someone with a diagnosis. Each Focus Group followed a structured guide to enable us to cover the same topics at each group.

Interviews

The opportunity to take part in an interview was made available so that it was as accessible as possible for people who wished to take part. Interviews were semi-structured and allowed us to capture in-depth, qualitative information about people’s experiences. Interviews were conducted in person, via MS Teams and by telephone in accordance with individual preference.

4. WHO WE HEARD FROM

We have heard the experiences of a total of **217 people** over the course of this project.

Survey – 131 Carers

Survey – 38 People living with Dementia

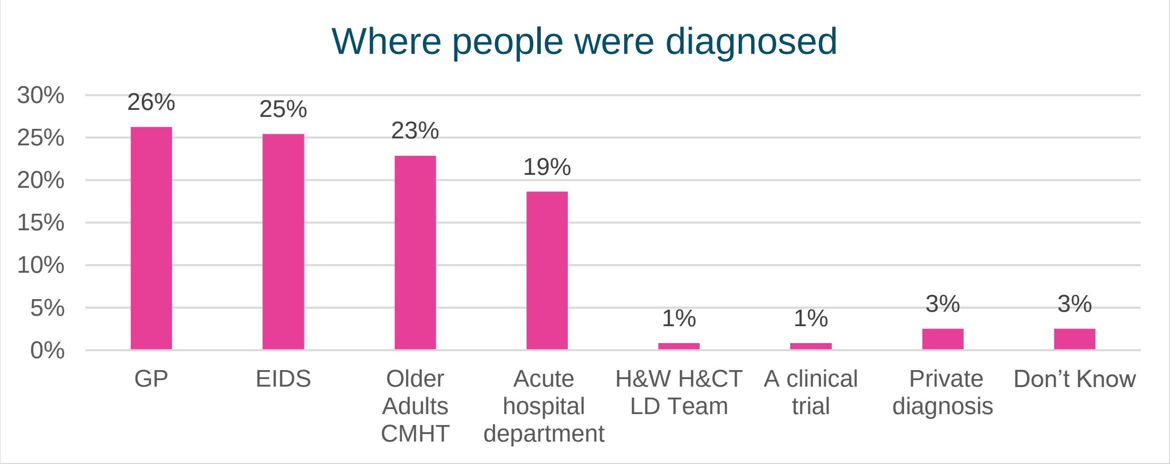
7 Focus Groups

12 In-depth Interviews

Carer Survey Respondents

One hundred and thirty-one people responded to our Carer’s Survey

- 72% were female and 27% were male
- 3% were aged under 44, 30% were aged 45 - 64, 63% were aged 65 - 84, and 4% were aged 85+
- 97% were White British, with 2% White Other and 1% Asian
- Respondents lived in Worcester City (35%), Bromsgrove (19%), Wyre Forest (13%), Wychavon (10%), Malvern Hills (8%), Redditch (5%) and Outside of Worcestershire (11%)
- The chart below shows where carers loved one’s received their diagnosis of dementia



People living with a diagnosis of dementia - Survey respondents

Thirty-eight people responded to our survey for people with a diagnosis of dementia.

- 67% were female and 33% were male
- 5% were aged 45 - 64, 85% were aged 65 - 84, and 10% were aged 85+
- 95% were White British, with 5% Caribbean
- Respondents lived in Worcester City (55%), Wyre Forest (40%),& Malvern Hills (5%)

Focus Groups

We held **seven focus groups around the county** and met thirty-six people including one person living with dementia.

- 83% were female and 17 % were male
- Ages ranged from 57 to 84

Interviews

Twelve people in total requested an interview and these were conducted either in person or via MS Teams or by telephone. Ten were with carers and two were with people with dementia.

One interview was held with someone caring for a person with a Learning Disability and a diagnosis of dementia.

- 66% were male and 33% were female
- Ages ranged from 48 - 91

Note

Not all Survey questions were answered by all respondents. When non-response is present, percentages are reported based on the numbers answering the question. Where numbers are small for clarity we have used numbers (n) rather than percentages.

We received 257 comments from people about their experience. We have themed these and reported on them where relevant in this Report. In some cases, the numbers reported for each theme or comment type may total more than the number of comments, due to feedback covering more than one issue.

To protect respondents' anonymity and confidentiality of information, all names have been removed and some information has been redacted. The gender of participants may also have been neutralised or changed.

We have used the term 'loved one' in this Report as a shorthand term to describe the relationship between the person living with dementia and their carer. We recognise that this may not be an appropriate description in all caring relationships.

5. DIAGNOSIS – INFORMATION AND SUPPORT

INFORMATION

Through our Focus Groups, Interviews and Survey responses it is clear that receiving a diagnosis of dementia is a life changing event for the person being diagnosed, and for their families and loved one's.

'My memory…. I remember the past but can't remember recent conversations …maybe I'll remember fractions of that …. I can't remember names but can remember things that have happened in the past… I'm just jogging along. I know what's coming down the line and I've just got to do my best' Person living with dementia, Interview

'Vascular dementia gives you a feeling of grief though no one has died, a feeling of having your heart ripped out every day, a feeling of, no matter how positive you try to be, something else happens' Carer, written submission

'At the beginning you think you will conquer it together, but you can't conquer it, you just can't. It just builds up and up and up' Carer, Focus group participant

The information and support that people receive at this time is critical to their understanding of the journey ahead, and the extent to which they feel equipped to undertake it.

Information at diagnosis

Our work has revealed that the information and support which people require at diagnosis is a complex issue.

Some people we spoke with wanted to know at the beginning as much as possible about the potential journey ahead. Others felt overwhelmed at the point of diagnosis, and unable to take in the information provided.

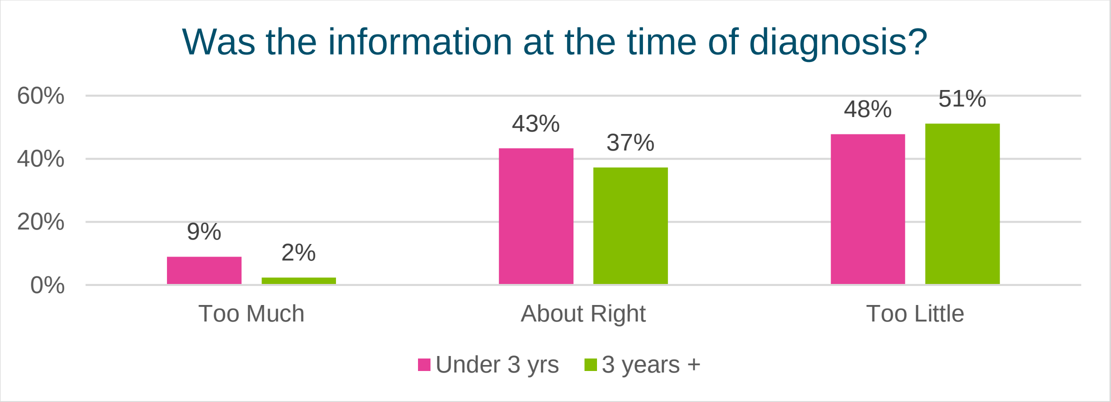
'When first diagnosed you're given loads of information, but you can't take it in due to needing time to come to terms with it, you feel a sense of shock and grief'. Carer, Survey response

'Once the diagnosis was given we were left as a family to try and find out any information. We were not aware of how it would impact X's life, the different stages of the disease, and the support that we could reach out for. This made caring for our loved one even harder, due to our little understanding of the disease' Carer, Survey response

We found that how much information is provided to people on diagnosis varied. These variations were influenced by how long ago people had been diagnosed, and the pathway through which they had been diagnosed.

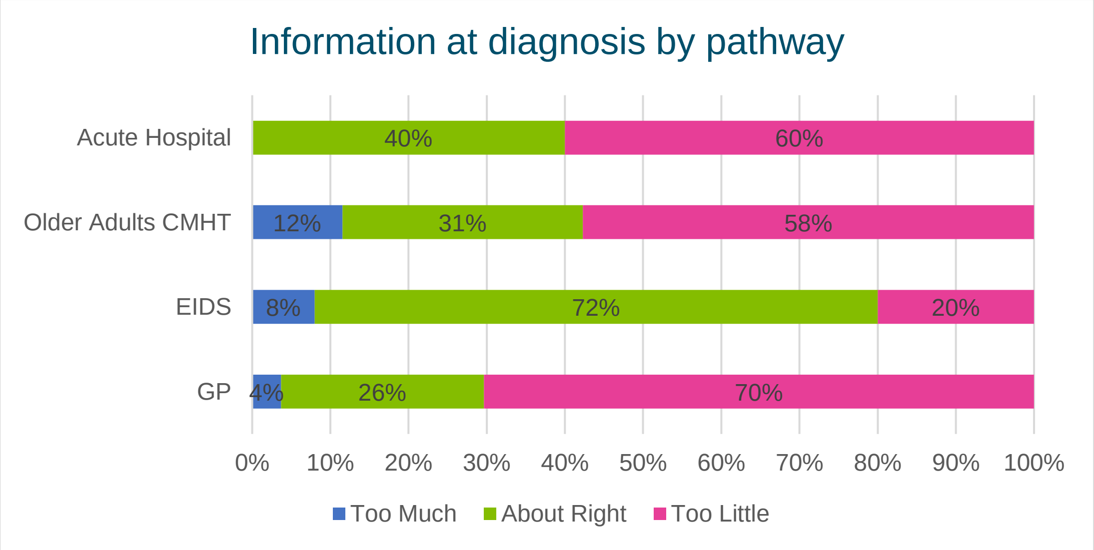
Respondents to our Survey of people living with dementia were more positive about the information provided to them than their carers. 62% said they had been given enough information about their condition. However, fewer people (50%) knew how to find information when they needed it.

We asked carers whether they were provided with the right amount of information when their loved one was diagnosed. We differentiated between those who had been diagnosed in the last three years and those diagnosed over three years ago.



The chart shows that, whilst information provision appears to have improved over the last three years, about half of respondents felt they were given too little information at the point of diagnosis.

Where people received their diagnosis made a difference to whether carers felt they had received the right amount of information. We looked at the information provided through the four main diagnostic pathways.



The chart shows that people diagnosed through the Early Intervention and Diagnostic Service (EIDS) most often felt that they had received the right amount of information. By contrast those diagnosed by their GP most often felt that they received too little information.

This finding was reinforced by discussions in our interviews and focus groups. We frequently heard praise for the EIDS service, and the visits, information, support and training provided. However this support only lasts for a relatively short period of time, after which people described feeling abandoned and alone.

‘I felt totally abandoned after being discharged from the Early Intervention Service’
Carer, Focus group participant

‘EIDS were great – they are the ones with the knowledge but once discharged we feel a nuisance or invisible’ Carer, Focus group participant

‘Once diagnosed and signed off by EIDS to the GP – that’s it – nothing’ Carer, Focus group participant

‘Absolutely no support provided, I had to research everything myself. Doctor diagnosed and I was basically left to get on with it’ Carer, Survey respondent

‘We were given the diagnosis and that was that – or so it seemed to us. I made several phone calls to find out what happens next to find out that nothing happened next.’ Carer, Survey respondent, diagnosed via GP practice

> **A clear message from our work is that people living with dementia and their carers, need a clear and consistent information offer, which provides them with access to the same level of training, information and support, regardless of the pathway through which they are diagnosed.**

What would carers like to receive information about?

Our Survey asked carers whose loved ones were diagnosed in the last three years what topics they had received information about. The table sets out the responses

Topic	**Yes**	**No**	**No, but it would have helped**
The type of Dementia and how it may affect the person you care for	61%	11%	20%
Other local or national organisations who could help	54%	9%	25%
Support for me as a carer	52%	21%	21%
Social activities, day care and community support for the person you care for	39%	20%	33%
The Worcestershire Directory of Dementia Services	39%	16%	28%
Aids, adaptations, equipment or assistive technology	38%	26%	25%
Worcestershire Care Services Directory	36%	14%	30%
Managing day to day life with a person living with dementia	35%	17%	39%
Early Intervention and Diagnostics Service Carers Information Guide	31%	22%	28%
Information about clinical trials	5%	59%	22%

Over half of carers had received information about the type of dementia their loved one had been diagnosed with, local and national organisation that could help and support for themselves as a carer.

The information that carers were **not supplied** with and **would have been most helpful** to them was:

- Managing day to day life with a person living with dementia
- Social activities, day care and community support for the person with dementia
- Directories - such as the Worcestershire Care Services Directory and the Directory of Dementia Services.

Discussions through our Focus Groups and interviews highlighted that carers would also appreciate information about **practical issues** such as:

- Finance and applying for benefits - e.g. PIP, Attendance Allowance, Carers Allowance, Council Tax rebate
- Legal frameworks – e.g. Power of Attorney
- Practical matters – e.g. advice about dementia friendly transport, applying for a Blue Badge

Much of this information is available, however people do not always know where to find it, or are not in a position to utilise it when they do.

Age UK Herefordshire & Worcestershire Directory of Dementia Services.

Age UK Herefordshire & Worcestershire produce a Directory of Dementia Services. This is not commissioned as part of the Dementia Wellbeing Service, but was produced in response to a recognised need for information. The Directory provides practical tips about living with dementia, as well as contact details for Dementia Cafes, Events and Activities, Dementia Meeting Centres, Dementia Day Care Centres and other useful information about organisations and initiatives which can provide help and support.

Through our Survey we asked people living with dementia whether they had heard of the Directory. 46% had not heard of it, and 17% did not know or could not remember.

In our Focus Groups we asked participants if they had seen the Directory. Only 7 people had seen the Directory.

‘I now realise there is plenty of information out there that no one knows about!’, Carer, Focus Group participant

Information tailored to the individual

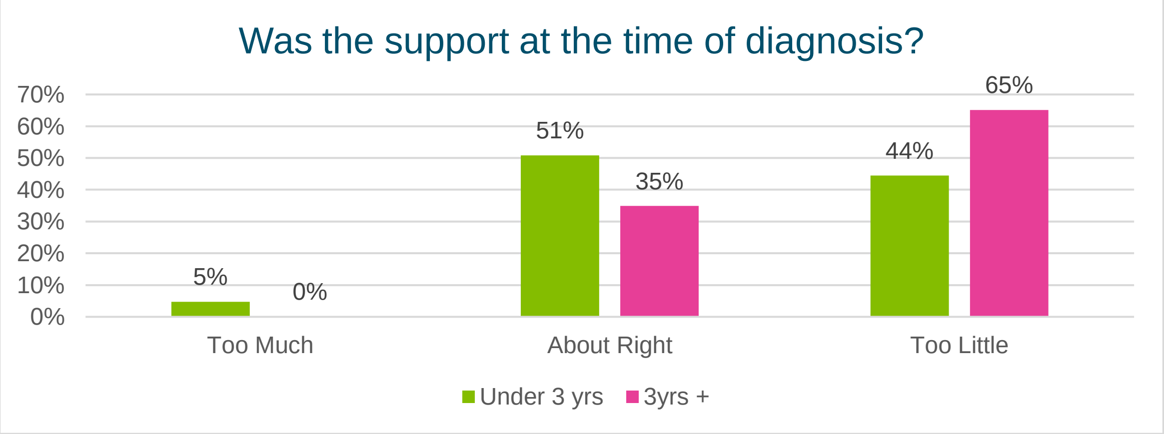
Another frequent message was that people wanted access to information which was specific to their loved one, or to their specific condition. For example carers who had found support groups for people with rarer forms of dementia described how valuable they had found this, to be able to learn from others and to feel that others could truly empathise with their situation. However this information was often found by happy accident, rather than being provided on diagnosis.

‘I came across a Facebook group called XXX support. It is aimed at carers of people with XXX and it's brilliant. You can learn from each other's experience; you get that virtual peer support and you can give other people information that you have learned as well’ Carer, Interview

SUPPORT

Support at the time of diagnosis

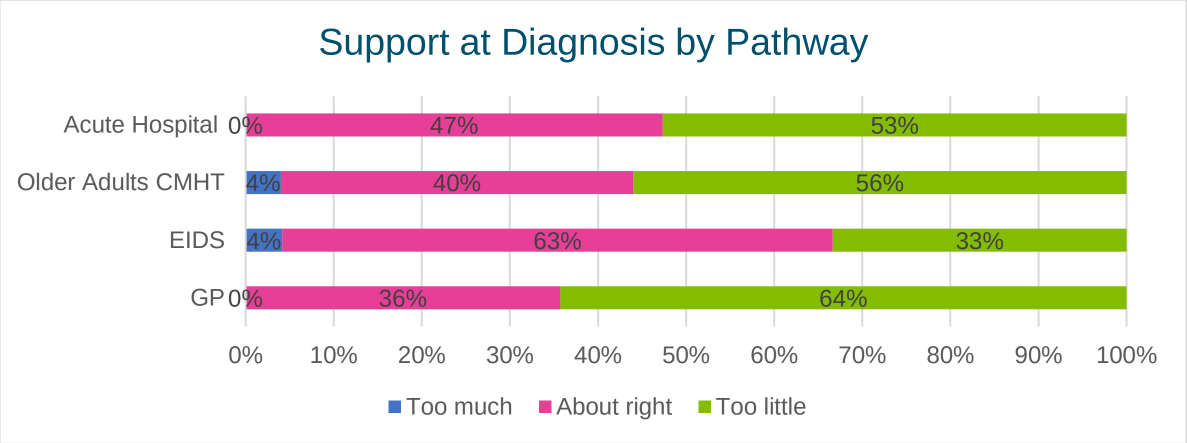
We asked carers whether they were provided with the right amount of support when their loved one was diagnosed. We differentiated between those who had been diagnosed in the last three years and those diagnosed over three years ago.



The chart shows that the situation has improved over time, but 44% of carers whose loved one's were diagnosed less than three years ago felt they had too little support at the time of diagnosis.

Looking at the relationship to the person they are caring for we found that respondents who were caring for a parent more often reported that they received too little information (57%), compared to other respondents.

Support by diagnostic pathway



There was also a difference in carers perception about the level of support they received dependent on the pathway through which the diagnosis was received. EIDS were described as most often providing the right amount of support at diagnosis, and GPs least often providing this.

How carers said they would like to receive information and support

Some carers described being provided with lots of leaflets and paper based information. Others had been sent links to online resources or PDF's which they were required to download or to print for themselves.

We also heard of a number of Dementia specialist organisations which provide short videos which contain practical information about how to live well with dementia and help carers to manage on a day to day basis. However, not everyone was aware of these resources.

While people recognised that there was a lot of useful information available, this could be overwhelming making it difficult to find the right advice for their specific situation.

A number of interviewees and focus group participants said that they would welcome a simple flow chart, or a pictorial guide, which followed the main stages of the dementia journey and signposted to main sources of advice and support at each stage.

Others described how the expectation placed on them to proactively reach out and follow up on information could feel overwhelming, and told us that they often had neither the time nor the emotional resources to do this.

It was clear from respondents that being handed a list of phone numbers, or a Directory of services was not enough.

'It's really hard to find the time when you've got caring duties to spend an hour on the phone finding things', Carer, Focus Group participant

'I was given a list of about 7 organisations I could get in touch with, but at that point I was just trying to cope. It's all down to you. There's no follow up', Carer, Focus Group participant

'We were given a big envelope with loads of leaflets. I couldn't read all of this! I had to deal with my husband and my emotions, that was far more important. I hadn't got any capacity to take in other things – I just needed someone to talk to', Carer, Interview

'In terms of the establishment I'm not confident that they do anything other than give you things to click and read. What I really need is someone to say 'can I come and spend half an hour with you', without you having to ask.. blokes… we're not very good at asking for help' Carer, Interview

Individualised personal support

The clearest message to emerge from our focus group and interview discussions was that people wanted easy access to someone with knowledge and understanding about dementia to talk to as needed, who will walk alongside people on their dementia journey.

'A named point of contact who is allocated to support us throughout. Someone who can advise, reassure and signpost, someone who can also advocate for us when needed. I feel very alone. I live in a constant state of anxiety and stress. Any support that came our way was time limited to 6 months. I've had enough' Carer, Survey respondent

'A nominated person allocated at time of diagnosis and continuation' Carer, Survey respondent

It was clear from the feedback received that what people wanted was individualised support. This included support that:

- **Is proactive in contacting families at regular intervals**
- **Could offer objective advice and signposting (specific to their particular situation)**
- **Offers ongoing emotional support and a 'listening ear'**
- **Helps people to prepare for the future**

6. AGE UK HEREFORDSHIRE & WORCESTERSHIRE DEMENTIA WELLBEING SERVICE

Age UK Herefordshire & Worcestershire (Age UK H&W) are commissioned to provide the Dementia Wellbeing Service. This is described on their website.

'The Dementia Wellbeing Service brings together a number of services and activities which offer support, information and guidance. These include Dementia Cafes, specialist support for families and people with Young Onset Dementia and help and advice from experienced Dementia Wellbeing Officers'[12]

The Dementia Wellbeing Support Advisor can offer support after a diagnosis of dementia has been made and throughout the different stages of living with dementia.

Age UK Herefordshire & Worcestershire (Age UK H&W) told us:

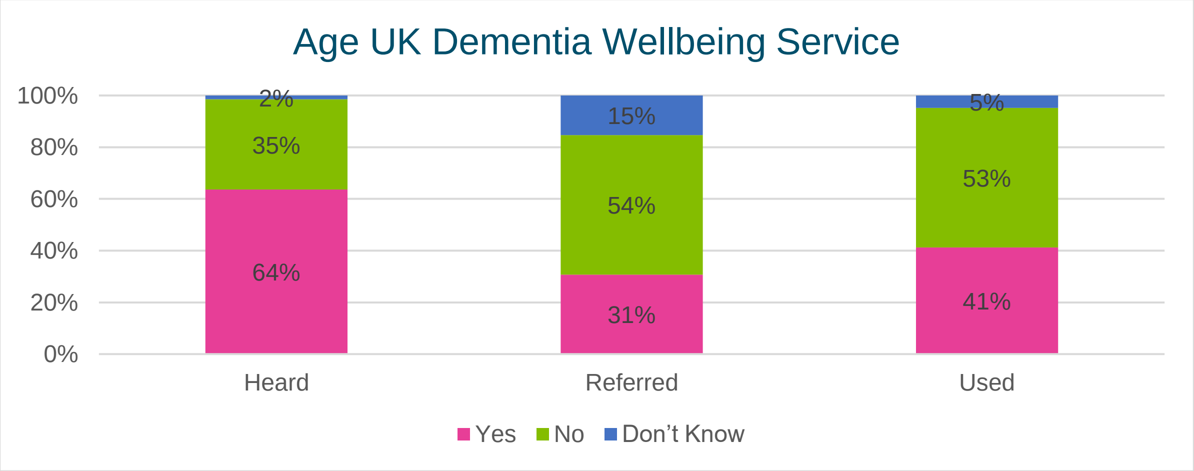
"The focus is to provide practical support to people living with dementia and enable them to live well with a diagnosis. We are required to raise awareness of, and provide connections to, local community based services. Whilst we do of course provide information and advice to the carers of people living with dementia, they are not the main beneficiaries of the service offer and are signposted to other agencies for emotional and wellbeing support."

Our understanding is that on diagnosis people with dementia should be offered a referral to the Age UK Dementia Wellbeing Service.

Awareness and use of the Dementia Wellbeing Service

In our Survey of carers we asked people whose loved one had been diagnosed in the last three years if they had:

- Heard of the Dementia Wellbeing Service
- Been referred to the Service by a health or care professional after diagnosis
- Used the Service



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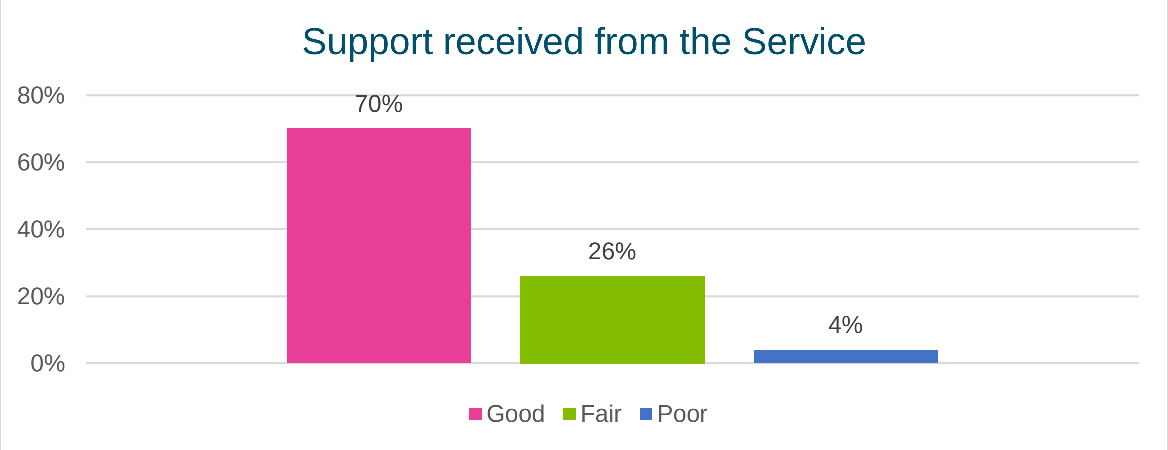
[12] Age UK H&W Directory of Dementia Services, 2023

The chart shows that 64% of respondents had heard of the service, and 41% had used it. Only 31% of respondents said they had been referred to the Service by a health or care professional.

For those who use the service we asked if they had been provided with a Dementia Wellbeing Support Advisor. 64% had been provided with an Advisor, 24% had not and 12% did not know.

We asked people who had used the Service how they would describe the support that they had received.

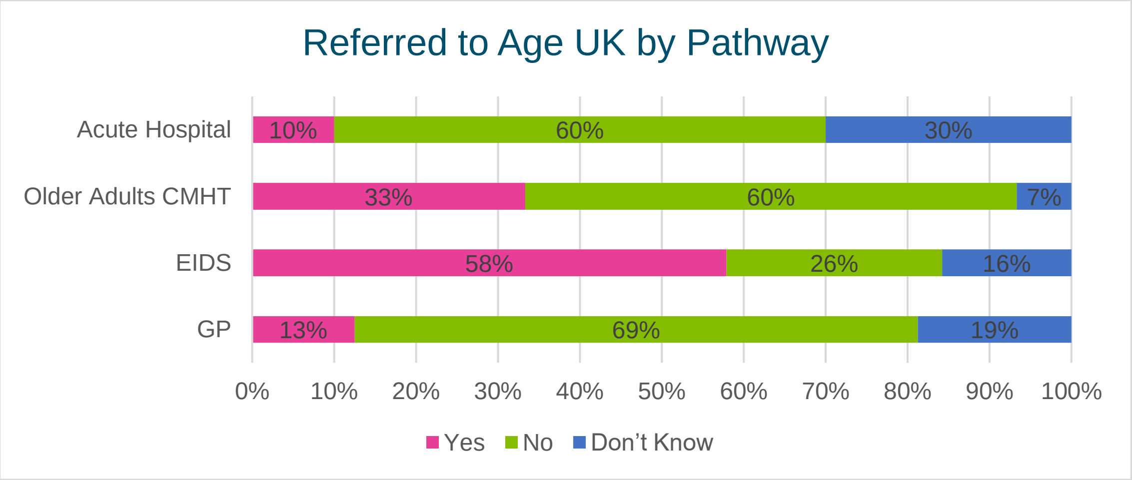


70% described the support as good, 26% as fair and 4% as poor.

Referrals to the Dementia Wellbeing Service by health and care professionals

In respect of referrals to the service by health and care professionals **69% of respondents had either not been referred to the service, or did not know if they had been referred or not.**

We looked at referrals to the service across the four main diagnostic pathways.



The Chart shows that the EIDS service most frequently referred people to the Age UK Dementia Wellbeing Service (58%), followed by Older Adults Community Mental Health Team (33%), GP's (13%) and the Acute Hospital (10%).

This indicates that despite the Service being part of the Universal support offer referrals to the service vary across the pathways. This may result in carers and people living with dementia missing out on valuable support.

7. CARE PLANNING

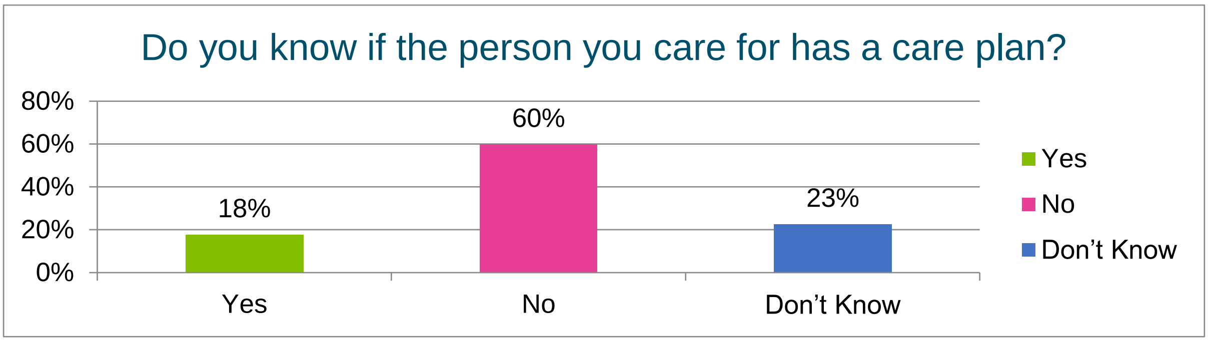
Part of the Universal Offer to people diagnosed with dementia is that they have a care plan. It is important that care plans are developed alongside people living with dementia and their carers and take a person centred approach, valuing people as active participants and experts in the planning and management of their own health.

The 2023/24 NHS Quality Outcomes Framework states:

'The NICE guideline for dementia recommends agreeing care plans with health and social services for people who have dementia, and having formal reviews at agreed frequencies.

Where a patient does not already have a care plan or an advanced care plan in place, it is expected that the [GP] practice will develop a care plan.' [our italics]

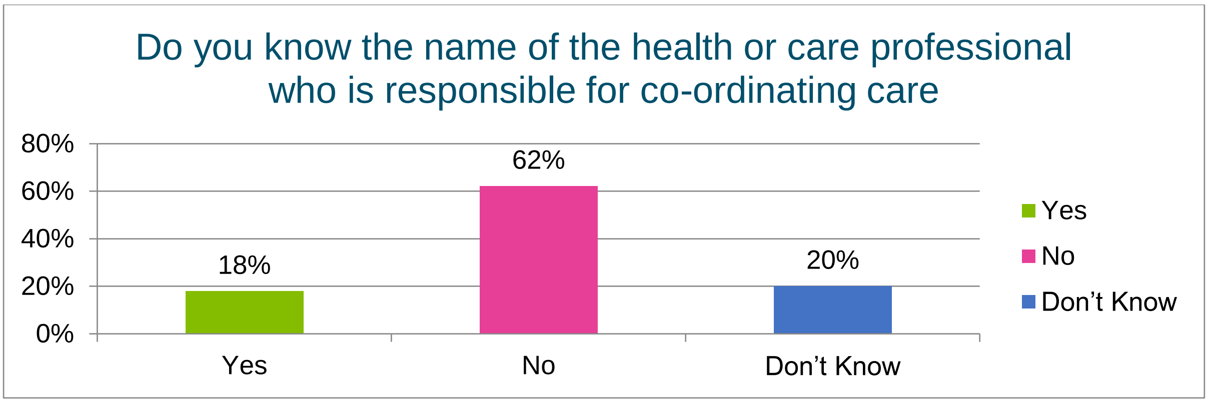
We asked carers if they knew if the person they cared for had a care plan.



The chart shows that 83% of carers did not know if the person they cared for had a care plan. Of these 60% thought they did not.

There was a similar lack of clarity about the person responsible for co-ordinating the care of their loved one.

82% of carers reported that they did not know the name of the person responsible for co-ordinating their loved ones care



Without this knowledge carers can be left feeling isolated and not knowing who they can turn to for help should they need it.

‘Joined Up’ services

In our Focus Groups and interviews we heard from carers how they felt concerned that no one had a clear picture of their loved one’s health and care needs. **Carers wanted a more ‘joined up’ approach between services.**

‘There was no joining up of services it was up to me to piece it together, it’s very fragmented’ Carer, Focus Group participant

‘Better communication between services. So when you ring them up you haven’t got to start all over again’ Carer, Focus group participant

‘A holistic approach, my husband has several health conditions, but separate appointments have to be made for everything. No one looks at the whole picture’ Carer, Survey respondent

8. SUPPORT FROM GP’s AND OTHER HEALTH SERVICES

GP’s

GPs’ connection to the rest of the health and care system as well as their base in the community make them well placed to take a leading role in care planning and care co-ordination for people with dementia[13]

Register of patients diagnosed with dementia.

Under the NHS Quality Outcomes Framework 2023/24 practices should establish and maintain a register of patients diagnosed with dementia[14].

Some carers we spoke with were unclear whether the Surgery had flagged on their records that their loved one was living with dementia, or that they were a carer.

For example in our Focus Groups we heard how a person living with dementia received text messages and letters from the GP practice that they were unable to deal with, even though the Carer had Power of Attorney.

We also heard how, even when the GP records were flagged this did not carry over to the hospital environment. One carer described visiting A&E with her husband, and feeling brushed aside and not listened to when she explained he had dementia.

It is important that dementia registers are maintained, and that GP records of people living with dementia and their carers are appropriately flagged to enable Annual Reviews to be programmed,

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[13] All-Party Parliamentary Group report, 2016 ‘Dementia rarely travels alone: Living with Dementia and other conditions’

[14] NHS QOF 2023/24: Records DEM001. The contractor establishes and maintains a register of patients diagnosed with dementia

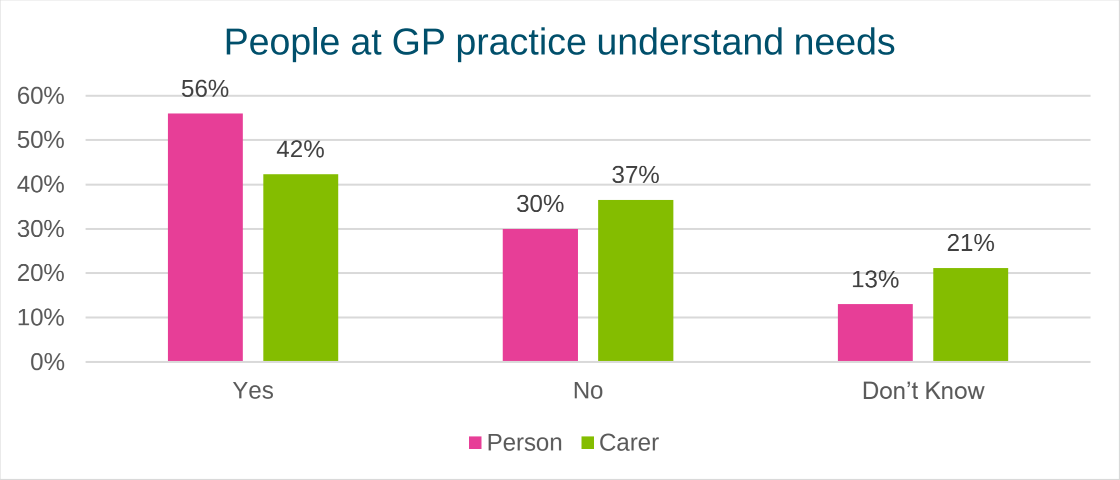
reasonable adjustments to be made and other services notified of the dementia diagnosis as appropriate.

Understanding of dementia

Dementia can often make everyday tasks like booking and attending GP appointments, as well as monitoring and managing other health conditions, more difficult.

People wanted GPs (practice staff and other health professionals) to show understanding, empathy and a willingness to make reasonable adjustments to accommodate their needs as a carer, as well as the needs of the person with dementia.

We asked carers and people living with dementia if they felt that the people they saw at their GP practice understood the needs of people living with dementia.



The chart shows that people living with dementia were more confident about this than their carers, with 56% feeling they were understood by health professionals at the practice. Over half of carers (58%) felt unsure, or that staff at GP practices did not understand the person they cared for.

'On our latest visit, staff leant over Mum in her wheelchair which appears to frighten and intimidate her. Staff talk loudly to her and ask too many questions'
Carer, Survey respondent

Support for people with dementia and for carers

Through our Focus Groups and Interviews we heard about varying levels of support provided by GP surgeries to people living with dementia and their carers.

Good Practice

We heard of some good practice. For example, where the practice had a **specialist dementia nurse or a dementia champion**, these roles were particularly valued.

One Carer described the support they received from the **Social Prescriber** at their Surgery, which they found very helpful. However, social prescribers were rarely mentioned by the carers we spoke with despite being a potential valuable source of information and support.

We heard from carers who had been **assisted through their GP practice** with applying for benefits, given information about and encouraged to engage with local support groups, and helped to organise care at home.

We were told of one practice where the person living with dementia was **booked a GP appointment in advance at 6 month intervals**, in addition to the Annual Health Check (see below)

Carers really valued **consistency of care**. We were told of a carer being told by their GP they could ring at any time should they need to. The carer described the sense of reassurance this had provided, and was really positive about their experience of their GP surgery, which was in marked contrast to others at the Group.

We heard of the kindness of NHS staff, and how greatly appreciated this is by carers and patients.

'I've just struck it lucky, it's like a raffle and I've had the golden ticket' Carer, Focus Group participant

Issues experienced by people living with dementia and their carers accessing GP services

A person living with dementia described the **inconsistency of care** at their GP practice, they rarely saw the same GP and felt their needs were not understood.

'GP doesn't know I exist. GPs are like clouds, allocated as I make an appointment. I will see a GP once then never see them again' Person with dementia, Interview

This person illustrates how important it for people living alone in the community with dementia, to have access to the same GP on a consistent basis. The health and care system aims to support people to live independently for longer, this highlights a need for GP services to make reasonable adjustments to ensure accessibility for vulnerable patients.

Carers described the difficulties they experienced **booking appointments** at their GP practice, this included both same day appointments and home visits. Some carers had struggled to convince their Surgery that home visits were required as the person could no longer cope with attending the Surgery.

'GP surgery don't give support I would expect. Took 5 months to get a home visit for person cared for as they are unable to cope with visiting the surgery.' Carer, Survey respondent

We also heard from a number of people about **issues with medication**. Carers reported feeling unsupported in trying to find out information about their loved one's medication including dosage, side effects, whether changes were needed and whether new medications that had become available may be suitable for their loved one.

'More support regarding medication and any side effects that it causes. You're left to be their doctor and nurse as well as a carer' Carer, Survey respondent

However, there was a feeling from many carers that we spoke with that unless carers said they could not cope, and reached out for support, this was not forthcoming in a proactive way.

'If you're not proactive, if you're not prepared to say you're not coping, which many people wouldn't be, you don't get anything', Carer, Focus Group participant

Our observation, from both the quantitative and qualitative work that we have undertaken, is that the understanding and support provided by GP practices is inconsistent and varies by practice, creating a 'postcode lottery' for carers and their loved ones.

Annual Reviews

The Alzheimer's Society website states that:
'Annual reviews are a key part of a person with dementia's care. In an annual review the GP will ask questions, do a medication review, check for new symptoms or changes in behaviour, and discuss planning ahead and support for carers.'

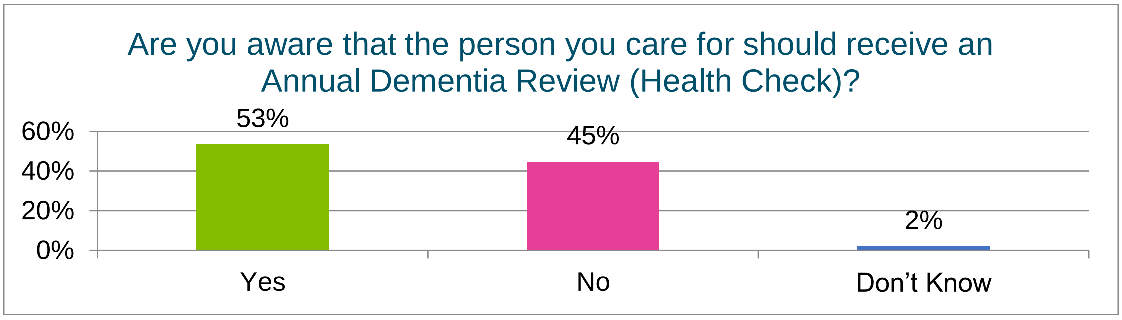
Furthermore, the NHS Quality and Outcome Framework (QoF) 2023/24 requires GPs to report on[15]:

'The percentage of patients diagnosed with dementia whose care plan has been reviewed in the preceding 12 months'

The QOF recommends that the Review should follow the D.E.M.E.N.T.I.A. framework[16] set out in NHS England Dementia: Good personalised care and support planning guide, 2020

The 2023/24 QOF document also states:
'The practice will agree with the patient and their carer, what is to be covered in the review and the duration of the consultation – where appropriate, extended consultations may take up to 30 minutes …. Ideally the first such appointment would be within six months of diagnosis.'

Not all carers were aware of the Annual Dementia Review (Health Check). The chart shows that just under half (45%) of carers were not aware of the Annual Dementia Review.



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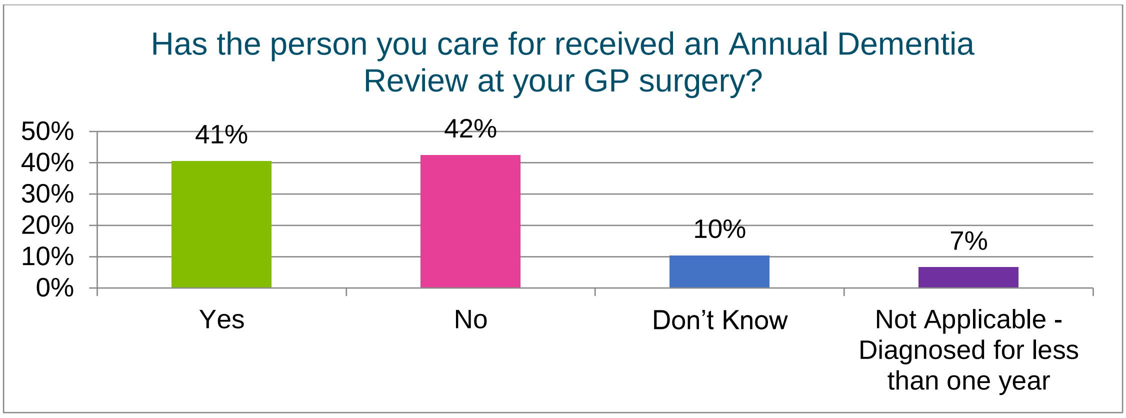
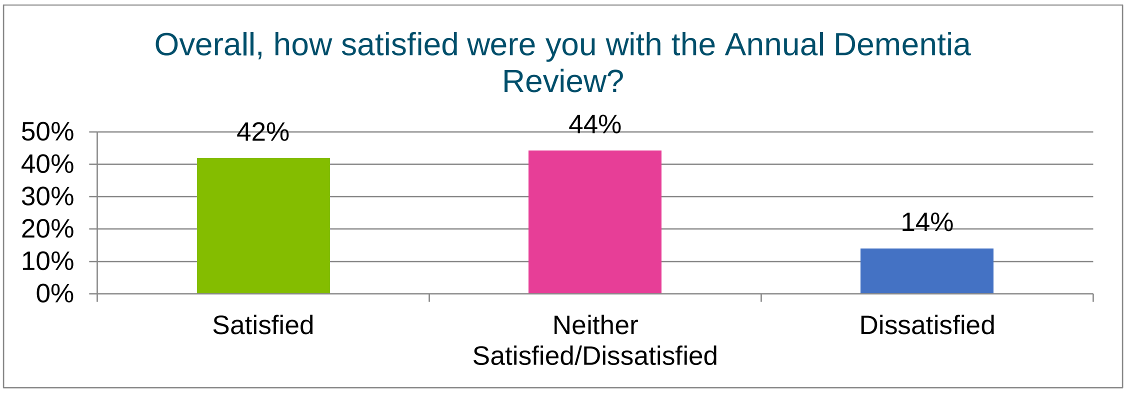
[15] NHS QOF 2023/24: **Ongoing management** DEM004. The percentage of patients diagnosed with dementia whose care plan has been reviewed in the preceding 12 months
[16] D.E.M.E.N.T.I.A. framework set out in NHS England Dementia: Good personalised care and support planning guide, 2020

We asked if people had received a Review, and if so how satisfied they were with this .



Responses varied, 41% said they had received a check, whilst 42% had not. 10% did not know and the question did not apply to 7% of respondents as their loved one had been diagnosed for less than a year.

We asked those who had received a Review how satisfied they were with this.



Whilst 42% were satisfied with the Review, 14% were dissatisfied and 44% were neither satisfied or dissatisfied.

This finding reflects discussion in our Focus Groups and Interviews. Many carers were not aware of the Annual Review, and their loved one had not had a Review despite being diagnosed for a number of years.

Whilst some participants had experienced the Annual Health Review and were happy with this, others had not found it a useful experience.

'My wife receives 6 monthly appointments plus the annual health check and those appointments are made by the GP in advance' Carer, Survey respondent

We were told that the Review was sometimes included in an appointment about another health issue, and neither the person or the carer knew that it was going to be conducted. The Review was sometimes described as a 'tick box' exercise, or with the focus on medical issues such as blood pressure rather on the persons dementia or changes in their behaviour. A number of participants described the Review being undertaken by a nurse practitioner, rather than by a GP.

'We were not told it was a dementia review, we went about a different health issue. It felt like a tick box exercise' Carer, Survey respondent

There was a feeling from some carers that the Reviews were a missed opportunity, in that they did not get the chance to talk about issues that were important to them in respect of their loved one, or about themselves as carers. This was particularly the case for people who had been living with a dementia diagnosis for a number of years and behaviour changes were occurring which were unfamiliar to the carer.

'It should be more meaningful and if dementia is progressing there should be a reassessment so you can be advised what to do' Carer, Focus Group participant

One person described how they had not discovered until four years after their partners diagnosis with a rare form of dementia that they were entitled to an annual Review.

'I told the GP of the diagnosis in advance and said you will need to read up on this. What we got was a 7 minute appointment. The GP went through a checklist and that was it. We were in and out. I left feeling really disgruntled' Carer, Interview

A few carers mentioned that they had used the Review meetings to ask for referrals to a psychologist, or for some specialist input about the potential for accessing or changing medication, or for more help with coping strategies. They did not always feel heard, or that they got an empathetic response.

'The GP said, 'well he will get worse' and refused to make the referral as he said there was nothing could be done. As X is changing, which is quite rapidly at the moment, I don't know what to do. X spent all yesterday morning crying, just sobbing. I don't know what to do' Carer, Focus Group participant

For some the Annual Reviews were simply not enough.

'Once a year to check is not enough…..my husband's Alzheimer's is changeable on a daily basis so seeing a doctor once when he might be having a 'good day' is not enough' Carer, Survey respondent

Understanding individuals' needs and preferences and providing person-centred care through regular review should be a key priority.

It would seem from our work that there is significant variation in the awareness of Annual Reviews, and the way in which these are carried out by GP practices. Reviews which follow the D.E.M.E.N.T.I.A. framework set out in the 2023/24 QOF document have the potential to offer significant benefits to people living with dementia and their carers, and could address some of the issues about lack of care planning, support and co-ordination of services raised by carers through this work. At present however we cannot be confident that this is the case.

SUPPORT FROM OTHER HEALTH SERVICES

People living with dementia and their carers need the same access to health care as any citizen, but delivered with a recognition of the additional challenges which dementia can bring. People require personalised care, which wraps around the person and their loved ones, and recognises the specifics of their circumstances.

Admiral Nurses

The Admiral Nurse service is described as follows by the Herefordshire & Worcestershire Health and Care Trust:

'Admiral Nurses are registered nurses who specialise in dementia. Admiral Nurses offer support to families throughout their experience of dementia using interventions tailored to each family's individual needs. Admiral Nurses provide carers with the knowledge to understand the condition and its effects, the skills and tools to improve communication, and offer emotional and psychological support to help family carers sustain their caring role.'

Through our Focus Groups and Interviews carers told us of their experience of the Service.

Some people described the excellent support that they had received, using phrases such as *'brilliant', 'a lifeline'* or *'the most support I have had from anyone'.*

Descriptions of the support received included home visits, help arranging respite care, securing medication reviews, dealing with financial problems, and assistance with claiming benefits.

We also heard about regular telephone support calls being provided to carers, which addressed difficult subjects such as domestic abuse, mental health and depression and which really sought to understand the carers needs.

For some carers the Admiral Nurse is the first point of call when help or support is required.

Conversely we heard from Carers who had contacted the service but had not received the support they hoped for.

We heard some carers describe the person they spoke with as 'not very helpful'; they had not been offered any support other than being sent some leaflets and information about the service. Another described receiving lots of links to information from a 'lovely lady' but

'Links is not what I needed' Carer, Interview

We were told by a carer that they believed that Admiral Nurses were phone contact only now, that they no longer did home visits. If a face to face appointment was needed this is via an outpatient's appointment at Evesham Hospital.

We appreciate that response from services are likely to be based on an assessment of individual circumstances, nevertheless from a carers perspective a clear description of the assessment process and the service offer would be beneficial.

Hospital

Hospitals are a difficult environment for people with dementia to be in. Whilst we did not specifically focus on inpatient care we received the following feedback about hospital services.

Some people had received excellent care:

‘When Mum returned to hospital (Worcester Royal) the care she received .. was the best you could ever wish for. Mum hated hospitals (like a lot of the older generation) but they were great’ Carer, Written Submission

However, carers told us that staff do not always have the time, skills or knowledge to deal with the specific issues of patients with dementia.

‘Periods of time father was in hospital was horrendous – staff lack basic training in how to manage people with dementia’ Carer, Survey respondent

‘We need staff trained specifically in dealing with dementia patients - not just online learning - but actual in person learning’ Carer, Survey respondent

Accessing health services at home

As people progress in their dementia journey they may need to access more health services in their home setting. Services may need to come to them if hospital admissions are to be avoided and carers supported in their caring role.

Carers told us of the difficulties that they had experienced accessing the following services.

- Home hearing visits and sight tests
- Dental care at home
- A dosette box from the chemist … tablets are proving a big problem, taking too many or none at all
- Chiropody at home
- Incontinence Services
- Occupational Therapy services - long waiting lists for assessments and home adaptations
- Falls - better response times for falls – carers can’t always move their loved one or don’t know what to do

Medical Trials

Some carers we spoke with would have welcomed more information about medical trials and how they could access these.

Spotlight - Learning Disability and Dementia

There is a recognised link between Learning Disability and Dementia.

The Alzheimer’s Society website says:

‘People with a learning disability are more likely to get dementia at a younger age. About 1 in 5 people with learning disabilities who are over the age of 65 will develop dementia. People with Down’s syndrome have an even higher risk,

with about 2 in 3 people over the age of 60 developing dementia, usually Alzheimer's disease.

People with learning disabilities may find that their dementia gets worse more quickly than someone without a learning disability….This makes it even more important to get the right care and support.'

Furthermore the website states:

'It is recommended that every adult with Down's syndrome is assessed by the time they are 30 to provide a record or 'baseline' with which future assessments can be compared.'

Down's Syndrome and Dementia - Tracey's Story

Tracey is the parent of Sue, an adult with Down's Syndrome. Sue has been living independently in the community for over 20 years. At the age of 46 Sue was diagnosed with Dementia.

Tracey said:

'We thought we were pretty well informed about Downs Syndrome, but we were shocked, because we were not aware of the link between Downs Syndrome and Dementia.

Anybody going into the care sector looking after people should we say above 50, particularly with Downs Syndrome, dementia, and the early diagnosis of that …looking out for the signs, being aware of what might signify that somebody might be beginning to experience the early symptoms of dementia … must be something that is very important.

We'd like to see that a dementia check is an automatic part of the [Learning Disability] Annual Health Check as they get older. We don't know if it is or not, but it should be.

When we found out that Sue had dementia it was all a bit of a whirlwind, because the place she was living said they couldn't cope with her any longer and she would have to move, that was a big worry to us.

I think a fact sheet of advice for carers, that might be useful. It could be fairly simple, with pictures as well, everything in the simplest terms. I don't think anyone would be offended if it was very simplistic.

Sue moved house quickly, but we didn't feel that staff in her new place had enough knowledge or understanding of dementia, and particularly dementia in people with Downs Syndrome.

Staff who are working in care settings need more knowledge about what Dementia looks like and how you can support and care for somebody who is living with dementia in that setting.

It's things like design too, plain rather than pattern on the carpets, things that can act as a barrier to movement, things like that.

We are not sure that where Sue lives now will be able to meet her end of life needs, we are not willing to start thinking about hospice care yet, but that may come.

We'd like to think that Sue should be able to get the same help and support as anyone else with dementia.

We are in our mid 70's. Our biggest worry is that Sue has the proper care should anything happen to us, we would like to feel 100% confident about that.'

Although the Case Study is based on one person it highlights some of the issues experienced by people with a learning disability who may be requiring / have a diagnosis of dementia.

There are potential lessons for the System in respect of:

- **Raising awareness of the link between Learning Disability and dementia**
- **Ensuring that a baseline is established against which future assessments can be measured**
- **Using the Learning Disability Annual review as an opportunity to look for and discuss signs and symptoms of dementia**
- **Ensuring that there is an appropriate pathway for people with a learning disabilities requiring a dementia diagnosis and ongoing support and review through their dementia journey.**

What would help improve people's experience of GP and other Health Services

Carers told us how even small adjustments could make a big difference to their own and their loved one's experience.

We asked carers what would help improve health services. They told us the following:

- *A clear flag on patients notes so any GP practice staff know immediately that the patient has dementia*
- *To be flagged on GP system as a carer and for which patient*
- *GP practices could be funded to have a dementia specialist e.g. Nurse/Paramedic*
- *It would be helpful if you saw the same doctor throughout for consistency*
- *To be given a time for nurses to visit so I don't have to take a day off work to wait for them to come*
- *Priority using GP surgery services*
- *Ease to make appointments at quieter times to avoid upset and enable longer appointments.*
- *Ease of physical accessibility*
- *Appropriate support when required, regular reviews*
- *Meaningful annual health checks*
- *Awareness raising for health service staff of rare dementias*

- *Clear indication of patients' dementia diagnosis when looking at other appointments e.g. eye screening, hearing tests, diabetic clinic*
- *Improved information, signposting and referral to other support services that are available*
- *Greater understanding that dementia is individual to the person with the diagnosis and that the diagnosed and the carers needs change over time*

9. SUPPORT FROM SOCIAL CARE SERVICES

Dementia is a progressive disease and over time people living with dementia and their carers may need support to maintain their independence at home or assistance to plan for the future.

64 people shared their experiences of contacting Worcestershire County Council Adult Social Care services with us.

The Care Act 2014

The Care Act 2014 is the legislation which provides the framework for the provision of social care services. A key underpinning principle of the Act is the responsibility on local authorities to promote the well-being of adults[17] (aged 18+) with care and support needs and their carers. Local Authorities have a duty to provide information and advice about care and support services and a range of services which the local authority believes prevents or delays the development of need for care and support for the adult or their carers.

Local Authorities also have a duty under the Act to assess where it appears to a local authority that an adult may have needs for care and support, the authority must assess—
(a)whether the adult does have needs for care and support, and
(b)if the adult does, what those needs are.

Care and Support Statutory Guidance[18] says:

Needs assessment

Local authorities must undertake an assessment for any adult with an appearance of need for care and support, regardless of whether or not the local authority thinks the individual has eligible needs or of their financial situation. (6.13)

The purpose of an assessment

The purpose of an assessment is to identify the person's needs and how these impact on their wellbeing, and the outcomes that the person wishes to achieve in their day-to-day life. The assessment will support the determination of whether needs are eligible for care and support from the local authority, and understanding

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[17] Well-being includes personal dignity, physical and mental health and emotional well-being, protection from abuse and neglect; control over day to day life; participation in work; education, training or recreation; social and economic well-being; domestic, family and personal relationships; suitability of living accommodation and the "individuals contribution to society".

[18] https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

how the provision of care and support may assist the adult in achieving their desired outcomes. An assessment must be person-centred, involving the individual and any carer that the adult has, or any other person they might want involved. (6.9)

Eligibility determinations must be made on the basis of an assessment and cannot be made without having first carried out an assessment. Once an eligibility determination has been made, and the local authority has determined whether it will meet the person's needs (whether eligible or not). (6.12)

Appropriate and proportionate assessments

The assessment must be person-centred throughout. Local authorities must find out the extent to which the person being assessed wishes to be involved in the assessment and should meet those wishes as far as is practicable do so, as the person is best placed to understand the impact of their condition(s) on their outcomes and wellbeing. (6.35)

Where it has been evidenced that the person is eligible for support from Adult Social Care. The outcome of the assessment is the development of a Care and Support Plan. A financial assessment is undertaken to see whether people need to contribute to the cost of their care. This will depend on the level of people's income and savings. People who have savings over the upper capital[19] limit of £23,250 are often described as self-funders, as they will be expected to meet the cost of care themselves.

Where the authority determines that the person has needs that are not eligible it must provide advice and information on what services are available in the community that can support the person in meeting those needs.

At 08/11/2023 **704 people** who were listed as having a health condition of dementia were receiving a service from WCC Adult Social Care. Of these 15 were aged Under 65 and 689 were aged 65+.

480 are female and 221 are male

Main reason for contacting WCC Adult Social Care

We asked Carers responding to our Survey their main reason for contacting ASC, either for the person they care for or for themselves.

Reasons were ranked as follows, with the most frequent reason listed first

- Support at home (e.g. help with personal care)
- Advice & Information about social support or activities in the community
- Advice & Information about living with dementia
- Crisis situation
- Planning for the future
- A break from caring – respite or replacement care
- Support for self as a carer

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[19] For further information see Covering the cost of your care (Financial Assessment) | Worcestershire County Council

Discussion at our Focus Groups and with interviewees revealed that not everyone was aware of Adult Social Care, or the service which they could provide. There was some concern that Adult Social Care workers were ‘checking’ on carers, and that the involvement of a social worker could somehow lead to their loved one being taken away from them, or the situation escalating beyond the carers control. This fear had prevented some carers for reaching out for support.

‘If I start asking the wrong questions will it be taken the wrong way?’ Carer, Focus group participant

A clear description of the role of Adult Social Care, and the assessment process may help to alleviate this concern.

Assessment - Understanding of dementia

We heard praise for both Adult Front Door staff and social workers for their role in working alongside people to understand their situation and provide support. Carers described how domiciliary care had been put in place for their loved one or respite care or residential care organised.

‘Social Services have been excellent providing us with home care and respite for me’ Carer, Survey respondent

‘Mum had support from two fantastic social care workers at various stages of her condition’ Carer, Survey respondent

A consistent, allocated social worker was particularly valued, as people recognised the importance of building a relationship with a social worker over time.

‘The relationship needs to be built to understand the individual and how their needs change over a period of time.’ Carer, Survey respondent

However, some Carers described frequent changes of social worker. We also heard of difficulties navigating the Duty system, including long waits for calls to be answered or returned and for agreed decisions to be recorded and actioned.

Some carers reported that the social worker seemed to lack an understanding of dementia, and its impact on the individual and on the carer. Examples given included asking closed questions, speaking only with the person living with dementia and undervaluing the carers experience of the person.

‘They asked X lots of closed questions. To which X said yes, and no and everything is fine. I said ‘ask X to explain how they do things’, which they couldn’t. There was no conversation. I felt like she [the social worker] had a better understanding of our actual situation after that’ Carer, Interview

‘The social worker, like so many others, clearly thought of dementia as memory problems. She’s been quite surprised at some of the things I’ve told her. It’s not her fault. Social Workers aren’t trained in rarer dementias’ Carer, Survey Respondent

Constraints on the system

There was an awareness from the people we spoke with of the constraints on the social care system, both on social workers themselves and of the financial situation of the local authority.

This awareness impacted on people's experience of the service.

'I know they are overstretched. If you book an appointment to see somebody the chance of them turning up on time is remote. It's not because they don't care it's because they will tell you what they thought would be a one hour session at the previous one took two, so it's very difficult for them. I have a lot of sympathy' Carer, Interview

Some carers said that the emphasis from the social worker had been on financial issues

'It was all about the money, the money, I said 'I don't want to hear this, what can you help me with, I'm at my wits end', they said 'well let's get the finances sorted out first' Carer, Focus Group participant

'The social worker said three times that the County Council was £10 million in the red. I don't want to know that, I've been a taxpayer all my working life. I want to know what you can do for me, not what you can't' Carer, Interview

The concern is that this awareness will lead to people not seeking the support they need in a timely way, which could lead to increased needs and increased costs in the future.

Support received from Adult Social Care

We asked people who had contacted ASC what the outcome of their contact had been.

48% of respondents contact with ASC resulted in them being provided with a service where WCC paid for or contributed to the cost of the care.

Of these 37% have a personal budget, 16% do not and 42% did not know.

Looking only at those who receive a funded service we asked how far people agreed or disagreed with statements about the quality of care services.

The statements most frequently agreed with by respondents are:

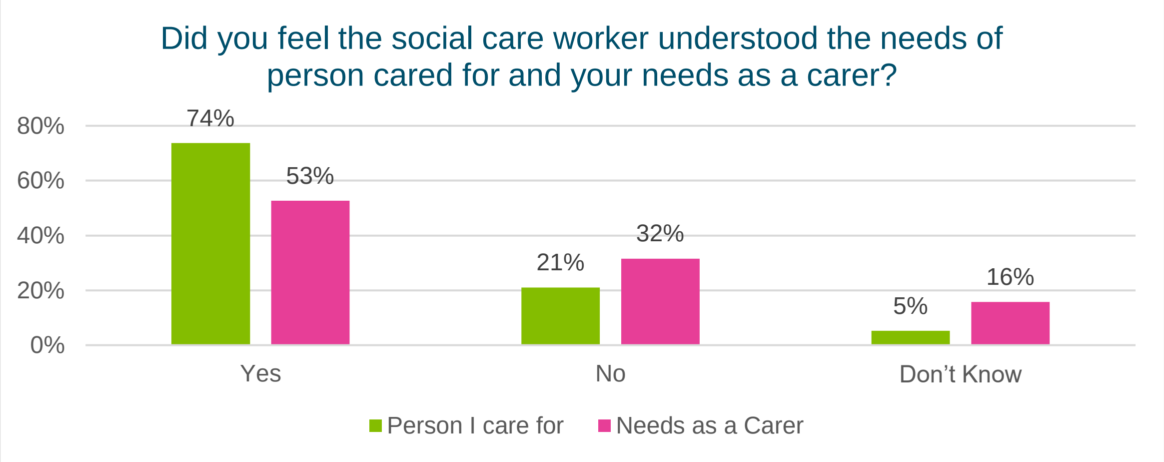
- I am satisfied with the quality of the care provided
- I can rely on the support received from care services
- I would be listened to if I had any concerns over the quality of care
- The support I receive from care services meets the needs of the person I care for

The statements with which respondents most frequently disagreed are:

- I can contact care services in a crisis and feel confident that I will get the support I need
- The support provided is consistent
- I can rely on the support received from care services
- The support I receive enables me to take a break from caring

Some of these themes are reflected in the comments that we heard about the types of services used by carers, and their experiences of them reported below.

Carers who responded to our Survey who were receiving a funded service from WCC felt that social care workers more frequently understood the needs of the person that they cared for than their needs as a carer



About 1 in 3 Carers who receive service funded by WCC felt that their needs as a carer were not understood by social care workers.

Some described their experience in terms of a battle.

'You have to fight so hard for everything' Carer, Interview

'You have to take social services to the brink before you can get what you need' Carer, Focus Group participant

The quote below illustrates how some of the challenges that we have outlined in this Report are likely to be exacerbated for people whose first language is not English.

'First carer was paid by government but she resigned and then social worker could not find Polish speaker carer, so the case was closed. I even agreed [for the case] *to be closed because it was too difficult for me to ask again for somebody who could deliver care for my mum.'* Carer, Survey respondent

Self-funders

Carers who were self-funding felt particularly unsupported.

They reported that once it had been established, they had savings over the threshold they received no further help or support from Adult Social Care with finding care.

'Once Social Services were aware Mum was self-funding I was just given a list of phone numbers and told to get on with it. Completely in the dark, no help or advice given.' Carer, Survey Respondent

'No help or guidance…. just a list of phone numbers. Makes you feel helpless and bogged down. If Mum couldn't afford care she would get a lot more help and support' Carer, Survey respondent

‘I would have welcomed some continued support even if the person is self-funding. Self-funding feels like a barrier to services.’ Carer, Survey respondent

75% of self-funding Carers reported they would have liked more support from Adult Social Care to organise care.

Social Care – ALL respondents

We asked all Carer survey respondents, whether or not they had contacted WCC Adult Social Care Service, about what care services, if any, they used for themselves and the person they care for.

Most respondents did not use any care services.

Of those that did use a service the most frequently used were:

Service	Frequency (Number)
Home Care or Domiciliary Care	36
Support, social activity or training provided for the person you care for in the community	26
Someone to sit with the person you care for or take them out during the day while you do other things	26
A short break/respite when the person you care for is looked after away from home	23
Day Care service where you can leave the person you care for	19
Support, training or an activity organised to support you in your caring role	14
Extra care or support provided through a housing provider	10
A nighttime sitting service at home to help you get a full night's sleep	5

Note: respondents could select all services that applied

Domiciliary Care

We heard mixed feedback about domiciliary care. For some this was working well and providing much needed consistent and high quality support within the home.

Others told us of unreliable care when at times paid carers did not attend when expected, there was a lack of continuity of care staff, which made it difficult for ongoing relationships to be established and paid carers who did not seem to be well trained in respect of people living with dementia.

‘Finding the right carers was hard, it’s very expensive to find good care but worth it’ Carer, Survey respondent

Comments from our Interviews, Focus Groups and Survey indicate that the aspects of home care that are valued by carers are:

- Consistency of carers
- Reliability
- Being on time for appointments
- Staff trained in dementia awareness
- Treating people with dignity and respect

Respite or Replacement Care

Carers indicated that they wanted / needed a break from caring, but had not always been able to find respite or replacement care.

'Some respite, if only for a few hours. My husband and I are both 85 and he doesn't like me being away from him which is very wearing' Carer, Survey respondent

'I would like a break but can't find a suitable place for respite' Carer, Survey respondent

Carers described different types of respite they felt could help them, from being able to leave the house for short periods of time; accessing day care; to longer periods of respite both in the home and outside of it and respite in an emergency.

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

In all circumstances carers wanted respite that was:

- Available
- Affordable
- Appropriate for the needs of the person they care for
- Able to be booked far enough in advance for the carer to make arrangements to organise their own break
- Flexible

Day Care Services

Whilst day care services were greatly appreciated we also received some comments about barriers to access to these services. These included:

- Cost
- Transport
- A programme/activities that are appropriate for the needs of the person living with dementia

'More funding for day centres, which are fully staffed with well-trained people who can cater to the interests and needs of dementia sufferers' Carer, Survey respondent

Residential care settings

The loved one's of a few people we spoke with were now living in residential care settings. Their carers described the conflicted feelings they had about this:

'At the time you are so frazzled, you can't cope, but afterwards you feel so guilty' Carer, Focus group participant

'You feel it [guilt] *every time you go into the nursing home'* Carer, Focus group participant

Carers we spoke with were satisfied with the care provided, and felt able to raise any issues they may have with the home.

One carer said:

'When we go in we see it through our eyes, oh there's a bit of dust over there, look how they're dressed, but to them that doesn't matter, it's the kindness that matters, that's what they remember' Carer, Focus group participant

What carers told us would improve social care services

- Better information on how to get help all in one place
- More linked up, easily accessible services. More transparency about care services available
- Allocated social worker
- More training and understanding from professionals about the problems dementia's create
- More care at home
- Closer monitoring of care companies
- More respite services
- Support for self-funders
- More funding and support for care services in general, raising the profile of these roles in society so they are paid better.

10. SUPPORT IN THE COMMUNITY FOR PEOPLE LIVING WITH DEMENTIA

Support from the Voluntary and Community Sector and that provided in the community is highly valued. Some, but not all, of these services are commissioned locally by the public sector.

We heard praise for local (District based) Age UK groups and activities and for other local organisations and faith based groups who are supporting carers and people living with dementia. Carers also praised the volunteers who ran or supported these activities.

These groups and organisations provided valuable opportunities for carers to find vital peer support. We repeatedly heard from carers how they gained more from this peer support and learnt more from each other than from other more formalised forms of support.

'It saved my life, I thought I was going insane' Carer, Focus Group participant

'The support from [name of organisation] is invaluable. All volunteers are dementia aware and brilliant!' Carer, Focus group participant

'I get a lot of information through other carers, you know like places to go and what benefits you can get, I get a lot of information and support from them' Carer, Focus group participant

We also heard that carers often found about these groups and activities through word of mouth.

One faith based group told us that in 10 years they had never received a single referral from their local GP practice, they had learnt recently that there are 60 people at the practice with a diagnosis of dementia.

People living with dementia also told us that they valued the support they got from each other through attending Groups and activities with other people.

'We're here to support each other!' People Living with Dementia, Age UK H&W Group session

86% of people living with dementia who responded to our Survey said that they felt they had the support they needed to do the things that were important to them.

However carers reported that they experienced barriers trying to access community support.

Barriers to community based support

We asked Carers in our Survey what, if anything, prevents them for getting the support they need for the person that they care for and for themselves.

The main barrier identified by carers was difficulty finding information about services or activities that are available.

Carers think that following this the top four **barriers** to support for **People Living with Dementia** are:

- Services / activities are not suitable
- Lack of transport to attend services / activities
- Timing of services / activities
- Do not have the support needed attend services / activities

Carers think that the top four **barriers** to **support for themselves** are:

- Lack of information about benefits
- Timing of services / activities
- Services / activities are not suitable
- Lack of transport to attend services / activities

These themes were reflected in our Focus Group and interview discussion where transport, the timing of activities, the appropriateness of what was available for their loved one and the cost of services were all issues raised by carers.

Transport

The availability and affordability of transport so that carers and people living with dementia could attend activities was an issue that was raised frequently.

‘Transport is the main issue for us. I don’t drive and X is now not able to. I wish there were more opportunities to go out for the day with X to meet other people to chat with.’ Carer, Survey respondent

‘Transport is a problem …. even if I was able to book transport to take her somewhere she is familiar with .. she may not be able to get herself ready on time, so I would need someone who could help her to get ready for when the transport arrives.’ Carer, Interview

‘I don’t drive. It is £30 return to X Meeting Centre and back’ Carer, Focus group participant

Timing of activities

Some carers would like activities to be available in the evenings and at weekends so that they can do things together with their loved one, perhaps after work.

They would also like sitting services to be available in the evening to give them the opportunity to go out and do things for themselves.

‘[A] good carer to sit in with my wife whilst I do other things, especially in the evening 19.00 – 21.30’ Carer, Survey respondent

Suitability of activities

We heard that attending a group is not right, or possible, for everyone. **One to one support** was felt to be very important for people unable to leave their home to provide stimulation, company and a short break for carers.

Befriending services were seen as having a role for both home and community based care.

‘If my husband had someone who took him out and about other than me. Befriended him if you like so he had someone else to engage with’ Carer, Survey respondent

Some carers would like more information about the content of the Maintenance Cognitive Stimulation Therapy courses (MSCT) so that they could reinforce this or use this knowledge at home with their loved one.

Carers also wanted more community facilities where they could safely leave their loved ones and take a short break. Some described how places such as Care Farms or Men in Sheds groups, whilst not necessarily dementia specialist, provided an opportunity for their loved one to be themselves, focus on the activity and enjoy the company of others.

A gap in service reported to us through both the Survey responses and our qualitative work was **community support services, particularly dementia specialist services, which are able to deal with some more challenging behaviours** or changes in personal care needs that are symptomatic of dementia.

Carers told us this could leave them struggling to find support at a time when their loved one’s needs were increasing and the responsibilities and dependency on them as carers were increasing.

Cost

We heard from Carers how they sometimes struggled to meet the costs of attending Day Care, Groups and Activities.

‘There is precious little out there that is reasonably priced’ Carer, Survey respondent

‘Some support that isn’t expensive’ Carer, Survey respondent

Awareness in the community of dementia

Carers shared anecdotes, both positive and negative about awareness of the public and local community about dementia and its impacts.

We heard of how their loved ones were able to continue long standing interests/hobbies, or to attend church or existing social groups which were not dementia specialist, and how this was facilitated by other attendees, who had known their loved one for a long time.

We also heard of examples where the wider community perhaps lacked dementia awareness. For example we were told by one carer that their loved one had managed to take a long bus journey, which necessitated the police becoming involved. The carer wondered if the bus driver or other passengers may have been able to offer support had they been more aware about signs and symptoms of dementia.

We know of the good work going on in places in Worcestershire to make them Dementia Friendly communities and of the Dementia Champions programme.

These findings suggest that there is scope to further educate the public about dementia and its affects.

11. YOUNG ONSET DEMENTIA

Dementia is often described as ‘young onset’ when it is diagnosed before the age of 65, typically between the ages of 30 – 64 years old. In Worcestershire there are 122 people who have received a diagnosis of young onset dementia.

We heard from 25 people who are caring for someone with young onset dementia and 2 people living with the diagnosis.

People engaged with us via:

- Our surveys - 14 carer respondents and 1 person living with a diagnosis
- Young Onset Focus group – 7 carers
- Interviews – 4 carers and 1 person living with a diagnosis

Dementia UK report that when compared to older people, younger people affected by dementia are more likely to: experience different symptoms to older people and the impact on their lives is likely to be greater, for example:

- Younger people are more likely to still be working when they are diagnosed
- Many will have significant financial commitments such as a mortgage

- They often have children to care for and dependent parents too

This can make accessing information and support more challenging and is evidenced by what people told us.

Many issues raised by people with young onset dementia are mirrored by people with a diagnosis after the age of 65. In this section we are highlighting issues that are specific to those with a diagnosis at a younger age.

Information at diagnosis

Most people we heard from had received their diagnosis from either EIDS or their GP. However, some received their diagnosis via other pathway, including the private sector. The diagnostic process for most had been lengthy and involved a range of assessments due to the additional complexity of making a diagnosis of dementia at a young age.

The majority of respondents caring for someone with young onset dementia report that the information they received was too little. However, via our interviews, three people reported receiving a lot of information and leaflets often provided in a folder by EIDS. For them the information was a mixed blessing as on the one hand it held potentially useful information but at a time when they were unable to engage with it as they were struggling to come to terms with the diagnosis.

……'we were overwhelmed with booklets, which, you know, X is not going to read. So, it was just me…… we have booklets here and booklets there. And this is the early intervention, absolutely. loads of information, which sometimes you just didn't want to read' Carer, Interview

Another carer said:

'At the time this was too much information to take in when we were trying to absorb the reality of the diagnosis' Carer, Interview

One carer said the information and timing was right for them:

….'found the information provided at diagnosis via EIDS was about right. Two weeks later were contacted again and received more information'. Carer, Focus Group

Carers of this age group particularly needed accurate information and support about working age benefits and Personal Independence Payments (PIP) from agencies who are knowledgeable and able to provide accurate information. We heard from one carer who shared:

'…..we were told everyone is eligible for a reduction in Council Tax, everyone is eligible for Attendance Allowance, however, when we enquired we found we were not eligible for all of these things'. Carer, Interview

We heard about the challenges some had faced trying to navigate the financial aspects of a diagnosis. These related to navigating and understanding benefits they were eligible for such as Incapacity benefit and PIP to longer term planning for the potential cost of care home provision at a young age.

One carer had contacted Citizen’s Advice for information about benefit’s and echoed what many carers had shared with us:

‘…..we were struggling to get incapacity benefits. So, then it was about, you know, trying to do the PIP and stuff like that. Luckily, I'm computer literate and have quite a senior job so I was able to put something together and word things…… but yeah, it's a lot to have to take on board…’ Carer, Interview

It was clear that financial concerns were pronounced in this age group and the need for someone to expertly guide them through this was needed.

Age UK H&W Dementia Wellbeing Service

Only 7 carers in this age group responded to our questions about this service. 4 carers said they had heard of the service and only 2 had been referred to it. In our interviews 4 carers had heard of it but none had been referred to it.

Age specific support for this group of people is very limited in Worcestershire. Whilst we were undertaking this project there was only one dementia café for people with a young onset diagnosis. For a number of years, it had been held at a venue in Kidderminster and in December 2023 it moved to the Hive in Worcester for a more central location in the county.

Attendees of this group spoke well of the support they received. Carers were grateful for the opportunity it had provided to gain valuable peer support.

We heard from some about the difficulties they experienced trying to access other support opportunities that predominantly cater for people aged 65+. This was particularly referred to in the early stages of the diagnosis when carers explained how the person they cared for felt uncomfortable in a group of older people who they couldn’t relate to. **The younger age group wanted to mix with people who were more their own age. Carers also expressed a desire to benefit from the peer support of sharing knowledge and experiences affecting people of a working age.**

We are aware of some dementia café’s/activity groups who successfully engage people of a working age with those 65+ by diversifying the nature of activities that has resulted in a more inclusive provision for all ages.

An example of this was found at the group in Inkberrow where it is open to anyone of any age in the local community who would just like to meet others and have a cup of coffee. This has enabled a wider group of people to engage and people spoke positively about the wider connections they now have in the community.

We also heard from some about the additional challenge of carers being able to support their loved one to attend any of the groups on offer (the wider range of dementia cafés and meeting centres).

This particularly related to working carers who struggled to take time off work to accompany their partners. For some it wasn’t appropriate to utilise schemes such as community transport as their partners would have difficulty either remembering someone was coming to collect them or, be troubled by going somewhere with a stranger.

Some carers expressed a need for more provision to be available during the evenings and weekends to enable them to take their partners along.

However, the challenge of providing this age specific support is recognised due to the very low numbers of people living with a diagnosis of young onset dementia in the county.

12. SUPPORT FOR CARERS

Identification as an unpaid carer is a complex and often sensitive issue, as carers do not always see themselves as such, with many feeling caring for their spouse/partner or relative as their duty, which is often willingly undertaken. It often takes around two years before a carer acknowledges themselves as such[20].

Carers may experience poor physical and mental health and also may have unmet care needs themselves. There is mounting evidence that unpaid care should be considered a social determinant of health.[21]

One of the overriding messages from this project is that unpaid carers feel they need more support. This was a theme that emerged from all of our Focus Groups, across our interviewees and is reflected in Carer Survey findings and comments.

The impact of caring for someone living with dementia

63% of respondents to our Carers Survey told us they spent over 50 hours a week caring for their loved one.

Carers we spoke with described the **full time** nature of the role.

'Being a carer is 31/7 not 24/7. If you think of all the things that you have to do for yourself in a day, administratively and personally. Then think about doing all of that again for another person. You become responsible for everything' Carer, Interview

'My ability to have a life has just been parked, because I have to be there 24/7' Carer, Focus group participant

'When you've got somebody with dementia, then everything is on your shoulders.' Carer, Interview

As well as the difficulties that caring could bring we heard of many **long and happy relationships**, and moments of lightness in what could be a difficult and challenging situation. Many carers we spoke with felt that their needs were less important than the person they cared for.

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

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

'I'm not worried about me, but I am concerned that it frightens her. That she's not quite sure where she is or where should she be, and where's home? and where's my house? … We've been married for nearly 50 years … I'm learning whether I like it or not, that my wife repeats things and and she needs to know what time it is sort of, you know, continuously and these sorts of things… I'm very patient with her because I've learned that's the only way to be, and I will, I always answer her questions… She's happy if she knows I'm around, that's the thing for her' Carer, Interview

We heard through our Focus Groups and interviews of **the impact of caring on carers own physical and mental health**. Some carers described feeling guilty when they felt overwhelmed by the situation they found themselves in or if they acknowledged that their own needs were not being met or that they were having to make adjustments to their lifestyle which they may prefer not to do.

'Managing the care and needs of an elderly (91 year old) parent with dementia, mobility difficulties, a heart condition and frailty takes mental and emotional energy that means I have less capacity for other things in my life.' Carer, Survey respondent

'Changed completely, I can't go cycling or fishing anymore, my lifestyle and attitude to life have changed' Carer, Interview

'At the age of 75 I have had to start driving again. I gave up driving when I was 35 because I absolutely hate it. X used to do all the driving, but now it's down to me. I do it, but I still hate it' Carer, Focus Group participant

Carers highlighted the challenges they face trying to **balance caring and a working life.**

'Being able to work! I have to go each day to cook, clean, shop, care, wash' Carer, Survey respondent

'I basically organise my working life around taking Mum out to Groups and activities. .. I am lucky that I can organise myself so that Mum gets out and can do things, while she is able to, I don't want her to miss out' Carer, Survey respondent

'I think probably financially, if I could give up work and be with, you know, spend more time with X, because … we could go out more and X could do more. But you know the problem is I'm at work and, you know, X hasn't got that.' Carer, Interview

We heard how some carers felt that for some professionals the needs of the person living with dementia were the priority, and they **felt unheard and unacknowledged**.

'The message is you're the carer, you don't matter' Carer, Focus Group participant

'No one talks and listens to you, they don't understand what we need. They don't have a clue what we go through' Carer, Focus Group participant

'An understanding from all departments that caring can be extremely stressful, frustrating and exhausting and it's not a 9 - 5 role!' Carer, Survey respondent

Not everyone acknowledged or accepted the description of themselves as a Carer. Some felt that **professionals and services made this assumption**, sometimes to the detriment of the Carer.

'Hang on a bit, I'm his wife!, I'm not 'the carer' … it's a label that got stuck on me.. it felt like I don't have a right to a life. I have to be available 24 hours a day. I hate it, the term'. Carer, Focus Group participant

The role of being an unpaid carer of someone living with dementia is a complex and demanding one, and carers feel they need support along the way. Many carers emphasised that the **situation they were in was unknown and new** to them, and they needed information, training, support, reassurance and sometimes, a break from it all.

'We have never done this before and don't always know if what we are doing is the best for the person we care for' Carer, Survey respondent

'I worry for people who are struggling and not coping, but are not able to pick up the phone and ask for help' Carer, Focus Group participant

Through our focus groups we heard powerfully about the importance of **peer support**, some carers said they had learnt more from each other than from organisations or health professionals. It was apparent that access to peer support was challenging for some due to the lack of provision in the evenings and weekends.

An additional barrier for some was the **lack of respite** support to enable them as carers to engage in carer support activities.

Only 10% of Carer Survey respondents told us that they felt supported in their caring role.

Young Carers

A young carer is someone aged 25 and under who cares for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support.

in January 2023 young carers were added to the Spring school census for schools in England for the first time. The data showed that there was significant under-reporting of the number of young carers in schools (both when compared to the estimated number of young carers in schools, and the numbers known to local young carer services)[22].

In Worcestershire, schools have 77 young carers recorded, however, Youth Support Services (YSS) have supported more than 500 young carers in the last year.

We heard from one young carer who received regular text messages from a young carers support group. However, when they asked to bring a friend with them to an event they were told they couldn't due to insurance cover. This resulted in the young carer having no further contact with the group.

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[22] Carers Trust – Young Carers and the School Census 2023

We are aware of excellent support for young carers in Worcestershire, however, this highlights the importance of accessibility and inclusion to enable young carers to engage with support where required.

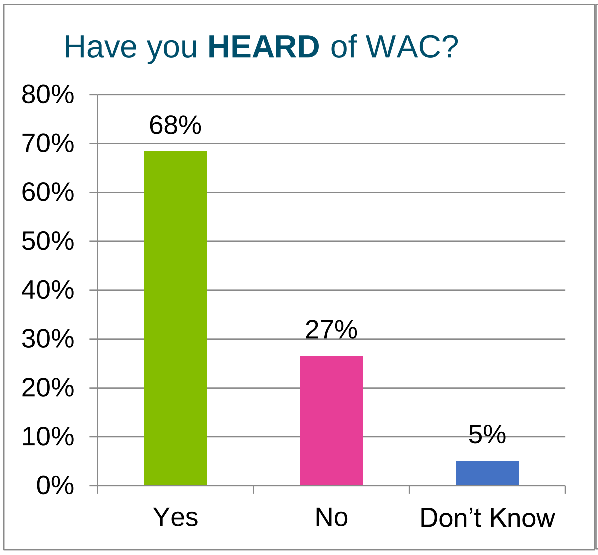
Worcestershire Association of Carers

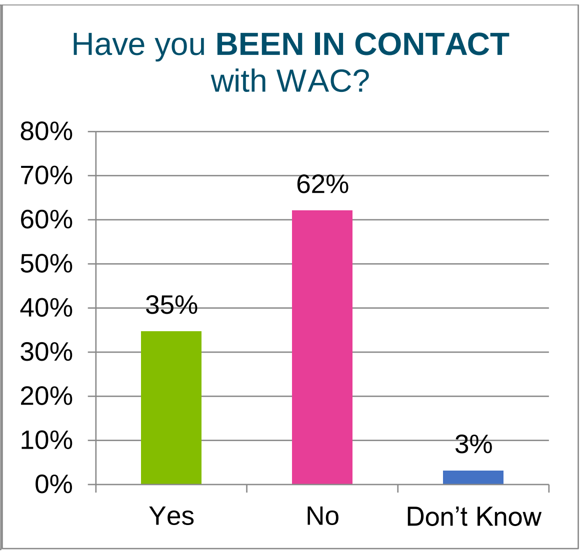
The Worcestershire Association of Carers provides a range of services for unpaid carers across Worcestershire. These include the Worcestershire Carers Hub. The Hub is funded by Worcestershire County Council. WAC website says:

'The Hub supports unpaid adult carers across the County and builds on Worcestershire Association of Carers current provision, by providing a one stop shop for carers.'

The services provided include: Information, advice and support; Carer training; Carer Talktime (regular telephone contact with a trained volunteer); Carer Wellbeing sessions and Carer Support Groups.

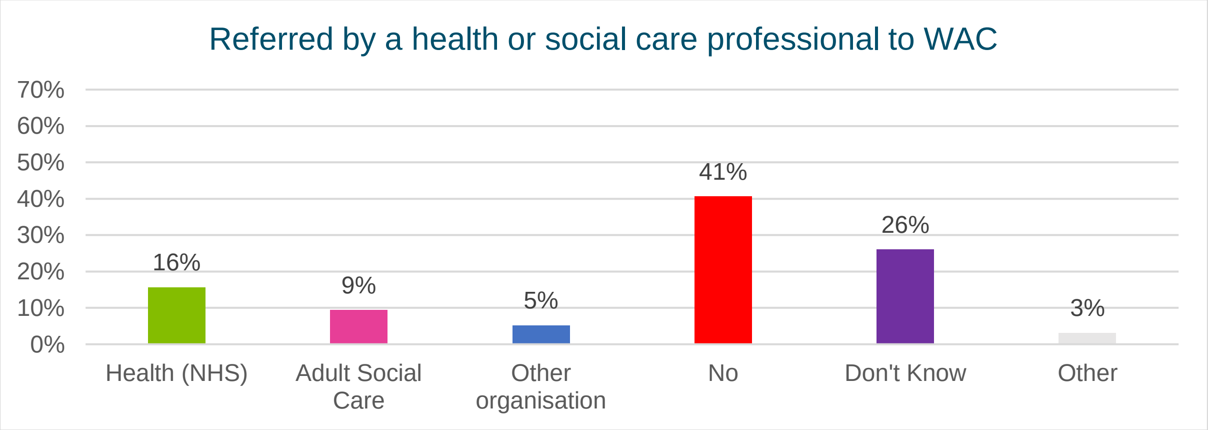
We asked respondents to our Carers Survey if they had heard of or been in contact with Worcestershire Association of Carers.





65% of respondents had heard of WAC and 35% had been in contact with the organisation.

We asked Carers if they had been referred to WAC by a health or care professional.

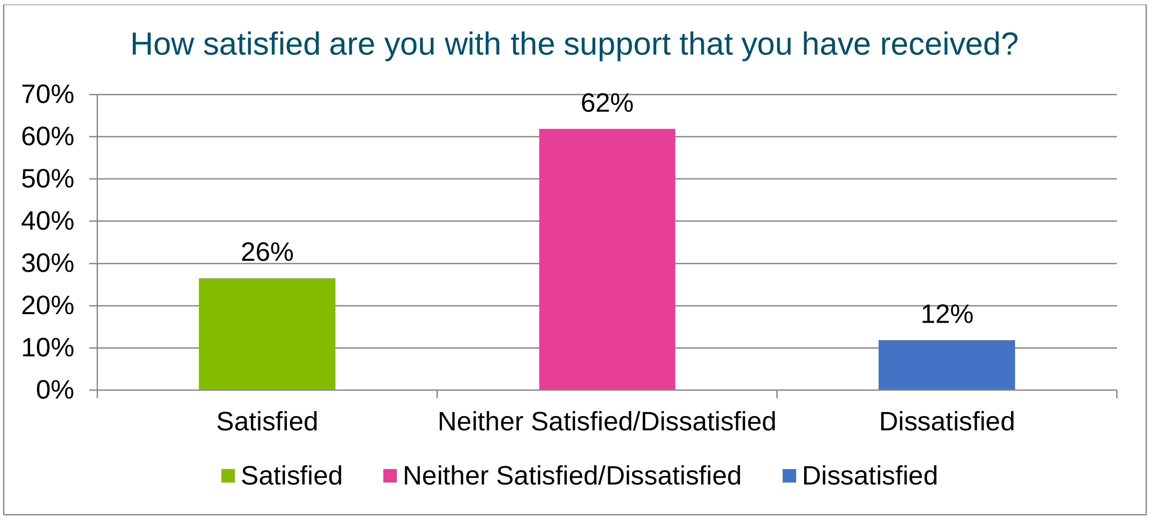


Most (67%) had not been referred to WAC, or did not know if they had been referred or not . Most referrals to WAC came from the NHS (16%), followed by Adult Social Care (9%).

It would appear that there is scope for NHS, ASC and other organisations to play a more proactive role in referring Carers to WAC.

There is a gap between those who have heard of the service and those who had contacted it.

We asked only people who had contacted WAC (n34) how satisfied they were with the support received.



62% reported that they were neither satisfied or dissatisfied with the support received, 26% were satisfied and 12% were dissatisfied.

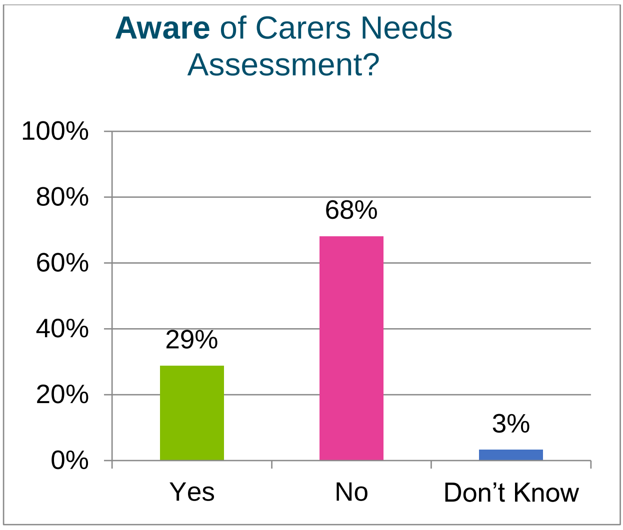
Through our conversations in focus groups and interviews, carers indicated a need for more proactive contact from support staff at WAC. Some carers spoke about times when they had built a relationship via regular phone calls with a support worker. They had valued the calls and were disappointed when they stopped due to redundancies.

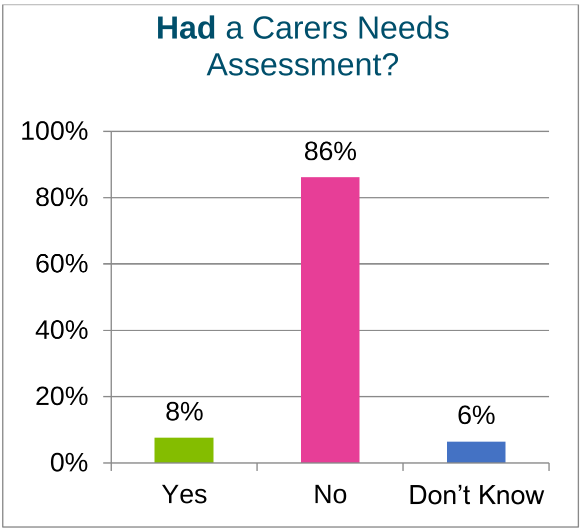
Carers described receiving the WAC bulletin, which some found helpful. Not all the Carers we spoke with were aware of the range of training and activities that WAC provide. Some carers reported that they were unable to take up some of these due to difficulties in finding replacement care.

Carers Needs Assessments

Under the Care Act 2014 adults who provide regular unpaid care are entitled to an assessment of their needs. A Carer's Assessment is an opportunity for carers to focus on how caring affects them, and any help they may need to support them in their caring role and protect their health and wellbeing.

Worcestershire Association of Carers is the delegated authority for carrying out Carers Assessments across Worcestershire and completes Carers Assessments on behalf of Worcestershire County Council.





The charts illustrate that most respondents (68%) are not aware of their entitlement to a Carers Needs Assessment, and only 8% have had a Needs Assessment.

This suggests that there is a need to promote Carers entitlement to a Needs Assessment and highlight to them the potential benefits that this could bring.

Where do carers get support?

We heard of the important role provided by friends and family in offering support and respite to carers.

We also heard of the benefits provided by carers support groups, particularly those which ran alongside activities for the person that they care for, so carers could get a break and be with people who understood their situation.

What support did carers tell us would help them?

- Time to themselves / a break from caring (Respite)
- Improved access to services / activities for their loved one
- Support – at home and in general
- Someone to talk to
- Improved information
- More affordable / less expensive services
- Changes to loved one’s condition/behaviours

13. CONCLUSIONS

A diagnosis of dementia is life changing for the person living with the condition and their family and friends.

As a County with a higher than average older population the challenge which dementia presents for the individual, their carers, our communities and for the health and care system locally is set to increase.

Through this work we have heard of both the positive aspects of care and support provided to people living with dementia and their loved one's and also some of the struggles and issues encountered.

There is a lack of consistency in the information and support that people living with dementia and their carers receive and this is influenced by the pathway through which they are diagnosed. They are not routinely offered referral to key services such as the Dementia Wellbeing Service and Worcestershire Association of Carers.

There is a lack of awareness of Care Plans and Annual Reviews. Implementation of these is patchy, yet they offer the potential to address some of the needs so clearly expressed by the voices that we have heard through our work.

There is some lack of understanding of the role of Adult Social Care, and how it can be of benefit in understanding and meeting people's existing needs and planning for the future. Carers require support in navigating an unfamiliar care system regardless of their financial circumstances.

People need health and care services where staff understand the challenges that dementia presents, and services will make reasonable adjustments to accommodate them.

Activities and support in the community is highly valued, yet barriers to access exist which need to be addressed.

For many caring is a 24/7 role, which can significantly impact on carers own quality of life. Carers should not have to fight, chase or push to uncover care and support that should be available to them. Nor should they be further burdened by the difficulties people have reported navigating the system of health and care.

It is clear that while each person and their carer's needs, experiences, and preferences are unique, they need to know that our Integrated Care System is there for them, providing regular, proactive advice and support when needed, throughout this unpredictable journey.

As such it is critical that within the Integrated Care System, the issues that we have identified in this Report are addressed.

14. RECOMMENDATIONS

Diagnosis - information and support

1. Ensure that diagnosis is the key to accessing a clear pathway of consistent support for people living with dementia and their carers
2. Ensure those who choose not to access a diagnosis are not denied information, advice and access to services.
3. Introduce an 'opt out' approach for referrals to the Dementia Wellbeing Service and Worcestershire Association of Carers
4. Consider how the EIDS service manages discharge, and whether there is potential for people to move into and out of the service over time as needs change, to prevent feelings of invisibility and abandonment.

5. Ensure that people have access to a named individual contact who is knowledgeable about dementia and can provide proactive and ongoing information, advice, signposting and emotional support.
6. Develop a clear and consistent information and support offer at diagnosis, which provides people living with dementia and their carers with access to the same level of training, information and support, regardless of which pathway they are diagnosed through.
7. Consider how diagnosis, reviews, local community spaces and activities, health, care and voluntary sector settings, and online opportunities can be maximised to better promote the wide range of resources (particularly local resources) which are available to inform & support people living with dementia.
8. Ensure that information is accessible, and available in a range of formats to meet individual need including for people with additional communication needs or whose first language is not English
9. Develop a pictorial representation of what might happen at each stage of the dementia journey and identifies the main sources of information and support, including practical and financial information and advice

Age UK Herefordshire & Worcestershire (Age UK H&W) Dementia Wellbeing Service

10. Ensure that all diagnostic pathways are aware of the Dementia Wellbeing Service, and introduce an ‘opt out’ approach to referrals to the service.
11. Ensure that the Service is sufficiently resourced to deal with demand.
12. Ensure that the Service is able to offer a timely response and consistent offer to the people who contact it.
13. Develop a plan to increase the visibility of the service across relevant parts of the NHS, Adult Social Care (Front Door & ASC Teams) as well as Voluntary, Community and Social Enterprise organisations including dementia groups.

Care Planning

14. Provide all people living with dementia with a key worker or meaningful contact for support, recognising continuity is important to people, over the long term (see Recommendation 5)
15. Ensure that every person who is diagnosed with dementia has a personalised Care Plan, which is developed alongside an appropriately qualified practitioner.
16. Ensure the Plan identifies what matters most to the person living with dementia, considers the wider family in care planning, pays attention to their own and their carers’ needs, including their wider health and wellbeing.
17. Give families a copy of the Care Plan so they can refer back to it and share plans with other health and care services.
18. Monitor how this is being implemented.
19. Consider how connectivity between services to ensure continuity of care, information, and care plans can be facilitated and developed, including through the use of the Shared Care Record.

Support from GP's and Other Health Services

GPs

20. Ensure that the diagnosis of dementia is added to the person's medical record and GP dementia register, and that service users and carers where possible, are made aware of this addition to a medical record
21. As a minimum, ensure carers are identified and recorded on a GP practice carer register, along with a contingency plan - should they be unable to provide care
22. Consider how to build on people's positive experience of dementia-specific roles in primary care, and ensure equity in access across the County. This could include consideration of how social prescribers could support people living with dementia and their carers.
23. Ask GP Surgeries to identify how they will make reasonable adjustments to ensure easy and consistent access to care and services within the practice for people living with dementia and their carers
24. Provide all people living with dementia with an annual review by an appropriately qualified practitioner, ensuring more frequent reviews for those with greater need – as identified through effective care planning.
25. Reviews should follow the D.E.M.E.N.T.I.A. framework set out in the QOF; addressing the needs of carers as well as those living with dementia and signposting to other services and support, as appropriate.

Other Health Services

26. Raise awareness, and provide education and training, among health and care staff to ensure they can recognise the symptoms of dementia and know who is at risk.
27. Ensure health and care staff know how to recognise and identify carers and can help carers to recognise their caring role.
28. Consider what information, education, training and skills health and care staff may need to ensure that they can appropriately meet the needs of people living with dementia and their carers across a wide range of health and care settings.
29. Ensure that all health and care services make reasonable adjustments to meet the needs of people living with dementia and their carers so that services are accessible to them, including in the home setting where appropriate.
30. Ensure people are aware of the Admiral Nurse service offer and are clear about how to access this.
31. Ensure that health and care staff working with people with a learning disability are aware of the link between learning disability and dementia
32. Ensure that signs and symptoms of dementia are considered as part of the Annual Learning Disability Review
33. Set an age at which a baseline assessment is established, with which future assessments can be compared
34. Ensure there is a clear pathway for diagnosis, support and review of people with a Learning Disability who are diagnosed with dementia.

Support From Adult Social Care Services

35. Promote awareness of Adult Social Care and people’s entitlements under the Care Act 2014 using a range of formats and channels (see Recommendations 7 & 8)
36. Explain the role of Adult Social Care and how the journey through Adult Social Care works using a range of formats and channels.
37. Ensure people who are self-funding feel supported, recognising that finding and organising high quality care will be unfamiliar to many people who contact the service.
38. Ensure that people in receipt of Adult Social Care services have access to an allocated social worker.
39. Ensure that Adult Front Door and Social Care staff have the necessary information, skills and training to engage effectively with people living with dementia and with their carers.
40. The Integrated Care System (ICS) should ensure that there are a range of opportunities for respite which includes helping carers to take a break for a few hours in the day or to sleep at night, as well as residential respite care for longer periods of time, and ensure that carers are aware of these opportunities.
41. The ICS to consider how the feedback we received about care services can be utilised effectively within the system.

Support In the Community for People Living with Dementia

The Integrated Care System should:

42. Continue and expand support groups and activities through non-statutory services in areas where provision is limited, including in the evenings and at weekends.
43. Increase opportunities for people living with advanced-stage dementia, who may also have physical health needs, to engage in meaningful activities.
44. Ensure that one to one and befriending support is available to those who need it
45. Consider how barriers to access such as transport to activities, the appropriateness of the activity for the individual, timing (particularly a lack of activities in the evenings and weekends) and cost can be addressed.
46. Support the development of more dementia-friendly or dementia inclusive activities and communities and consider what resources, information and advice may be required to do this

Young Onset Dementia

47. Ensure that consistent and accurate information and advice is provided, to people with young onset dementia and their carers, including financial advice and practical support where required (e.g. to complete benefit applications)
48. Introduce an ‘opt out approach for referrals to the Dementia Wellbeing Service and Worcestershire Association of Carers.
49. Consider how existing support groups might develop a more inclusive approach to accommodate all ages.

Support for Carers

50. On diagnosis make Carers aware of Worcestershire Association of Carers and introduce an ‘opt out’ approach to referrals to the service.
51. Ensure that the Service is sufficiently resourced to deal with demand.
52. Carers should be informed about the Carer’s Needs Assessment, and how this might be of benefit to them.
53. Develop opportunities for peer support, particularly for younger, working carers.