

Everyday Heroes

Unpaid carers for someone living with
Dementia /Alzheimer's/Memory Loss



Contents

| | |
|---|----|
| Contents | 0 |
| Subtext | 1 |
| Project theory of change..... | 2 |
| Survey Introduction & Case Studies..... | 3 |
| Findings | 8 |
| Summary..... | 9 |
| Recommendations..... | 10 |
| Acknowledgements..... | 11 |
| Responses..... | 12 |
| Questions..... | 13 |
| Results..... | 16 |

Why Dementia?

Everyday Heroes Project

At Healthwatch West Berkshire, part of our 2024/2025 workplan focused on supporting unpaid carers.

However, we wanted to approach this in a way that would yield meaningful results and make a real difference in their lives.

Given the large number of unpaid carers in West Berkshire, we decided to concentrate on a specific group to ensure the greatest impact. Currently, in West Berkshire:

In **West Berkshire**, there are approximately **15,000 unpaid carers (9.3% of the population)**.

A significant portion of unpaid dementia carers take on the bulk of care responsibilities. For example, the [Alzheimer's Society](#) reports that **80% of unpaid dementia carers are primary carers**. (Alzheimers Society, 2023)

1,900 people have been diagnosed with dementia.

Less than half of people living with **dementia in the UK have a formal diagnosis**, according to [West Berkshire Council](#). (West Berks Council, 2024)

With this in mind, we chose to focus on unpaid carers who support individuals living with memory loss.

Unpaid carers dedicate their time to looking after loved ones, often becoming their sole source of support. This role often develops gradually, without formal recognition, and many carers don't even identify themselves as such—it's simply part of caring for someone they love.

Our goal is to ensure that these carers have a voice, that their experiences are acknowledged, and that they receive the support they need.

To gather this information, we conducted **6 case studies, 8 interviews and 2 focus groups** to understand the everyday experience of unpaid carers.

We attended Dementia Friendly West Berks Meetings, 'Dementia Café's' and we spoke with the memory clinic.

People told us they often feel guilty, isolated and powerless in their caring role. Carers tend to prioritise the needs of those they care for over their own health and care needs.

Project Theory of Change



Survey Introduction

Everyday Heroes!

Welcome to our Unpaid Carers Project.

This year we wanted to focus specifically on Unpaid Carers for someone living with Dementia.

Unpaid carers face many challenges and there should be support available for them throughout the Living with Dementia process!
We want to know the wider issues that you face, when it comes to accessing support services for you.

At Healthwatch West Berkshire we want to hear your experiences as unpaid carers for someone living with Dementia.
We use feedback from the public to identify themes and trends within local health and social services and then make decision makers aware of them. This will then in turn help to improve local services where necessary.

Please help us by sharing your views and experiences.

(Please see full question set attached at the end of this report.)

Case Studies

We spoke to 16 unpaid carers living in West Berkshire and below are just a few of their recorded experiences.

Some of these carers look after spouses, while others care for parents—many as sole carers with no additional support. Among our participants, 50% identified caregiving as their full-time role, while the other half balanced it alongside paid employment.

The number of carers we were able to engage with reflects the challenges they face in finding time away from their responsibilities. Many expressed a willingness to speak with us but found it difficult to step away or were uncomfortable discussing their loved ones in their presence.

These case studies highlight just how all-consuming the role of an unpaid carer can be. For those caring for someone with Alzheimer's or memory loss, caregiving often becomes their entire life, leaving little to no opportunity for respite.

Healthwatch West Berkshire Unpaid Carers project (for someone living with memory loss) unveils the reality of their lived experiences and daily struggles.

* **Paul's Ordeal:**

"Before Dementia daily life was simple, now it's a bog of chaos!"

Quote from Paul – June 2024



When Paul's wife was diagnosed with Dementia, after a simple cognitive test with the GP (who turned out to be Thatcham's memory specialist), Paul asked a lot of 'obvious questions' and none of the answers received were good listening. His wife was then referred to The Memory Clinic for official diagnosis. It was a Traumatic time for Paul!

After initial diagnosis:



'Once the penny drops you can do a lot of kicking yourself, why didn't I work this out for myself? It just wasn't something that entered my mind at all!'

Paul. June 24



Unfortunately, three years after the diagnosis, Paul is still overwhelmed by an avalanche of information while navigating the steep learning curve of managing incontinence.

Nothing is simple for him anymore, and every decision feels difficult.

Sadly, Paul's experience is not unique. If these carers had not spoken out, many of these challenges would have remained unnoticed.

* The Hidden Fight for Proper Wound Care

Sal's Pressures:

Sal has cared for her husband since he was diagnosed with dementia in his late 50s. The couple initially received help from the British Legion, but that help sadly ended two years ago, leaving Sal to manage her husband's worsening pressure sores alone.

Regulations currently prohibit paid carers from dressing open sores. This regulation, while intended to protect individuals, appears to create a significant gap in care provision. When individuals like Sal require wound care for their loved one, the current triage process with district nurses involves a phone call or email, followed by the submission of photographs.

This process, while seemingly efficient, can lead to delays in care, particularly when urgent attention is required. This also means that Sal is providing the wound care herself without proper medical training.



'I felt my only choice was to buy Medihoney (Medical grade honey) for my husband's pressure sores and I felt very uncomfortable doing that. I did not like that paid carers refused to help (because of regulations), but also because I was not medically trained and not sure if I was helping my husband or actually making his condition worse.'



Sal – June '24

The anxiety and stress of trying to provide proper care weighs heavily on Sal, combined by her "previous experience of GP's arriving without necessary dressings for home visits" and the lack of communication among hospitals, making it difficult to co-ordinate her husband's care.

* Navigating Inconsistent Medical Care

Jay Struggles

Jay lost access to vital support networks when the COVID-19 pandemic caused local groups to shut down, leaving her to manage alone while caring for her husband. She endeavours to deal with his pressure sores, without the help of district nurses who are struggling to make regular visits. Jay feels they are unhelpful to her when asking for help and advice, as they have large caseloads and time constraints, and are unable to provide relevant guidance.

She would like support workers to visit her place of residence to provide much-needed respite:



'It would be better if the support groups' workers come to our residential home.

Me and many others, who are looking after their loved ones who suffer from dementia can't leave their spouses alone without care.' Jay – June '24



Like Sal, Jay experiences frustration when GPs arrive for home visits without the right equipment, often resulting in postponed appointments. She echoes the concerns about poor coordination between hospitals, further complicating access to necessary medical care.

* Plight for the silent

True Gentleman Ted

Ted, who also cares for his wife, finds that there is insufficient information to help distinguish between normal forgetfulness and early signs of dementia, which could help with timely intervention:



'I did not find or receive any information about the difference for when somebody is just forgetful because of old age, and when there are actually first 'red flags' which are in fact beginning of Dementia/Alzheimer's.'

Ted – June'24



Ted's real sufferance is that he carries the burden alone, not wanting to be a 'bad husband' in sharing any experiences he had at home with his wife or how he feels in certain circumstances.

He admitted to removing himself from any 'outside of the home' social interactions, as this tends to upset his wife in her worsening mental state.

His other experiences mirror those of Sal and Jay; struggles with pressure sores, unprepared GPs, and the process for triage with district nurses must be done via phone or email. The disjointed communication between local hospitals adds another layer of complexity.

* **Gaps in training, medical support and communication.**

Hope's difficulties

Hope cares for her husband who along with his memory loss is also a stroke survivor and is frustrated by the lack of continuity in GP care. She would rather see the same doctor who knows the medical history:



'I do not like the changes with the GP, every visit I book is with different doctor.

I would prefer it, if me and my husband could be under the care of one doctor who knows our medical history and who we are.' Hope – June'24



Although she appreciates the Royal Berkshire Hospital stroke department's daily follow-ups, she faces challenges with securing timely home visits and coordinating care across hospitals.

* **Communication is key.**

Ray's Stresses

Ray found there is no free training available for unpaid carers specifically on how to use catheters safely. As a result, he made mistakes that caused them both significant stress and anxiety.

His bedbound wife hasn't received any physiotherapy visits, despite his repeated concerns to GPs about her physical deterioration.

Ray also frequently faces issues with hospital communications, often receiving letters after appointment dates.



'We often receive appointment notices too late to arrange transport or sometimes they arrive after the appointment date itself.' Ray – June'24



Findings

Themes Throughout Research

Confusion surrounds West Berks Council's invoices for 'Carers in your Home' -

- Invoices contain incorrect and unclear pricing information, making them difficult for carers to understand.
- Outdated WBC (West Berks Council) contact information on the invoices.

Lack of Early Recognition of Dementia Symptoms -

- Families struggle to distinguish between normal ageing and dementia symptoms. There is little accessible information on early warning signs.
- No simple, accessible resources are available to guide families.

Information Overload at Diagnosis -

- Carers receive a flood of information upfront, much of which is not immediately relevant.
- There is no clear roadmap outlining what to expect at different stages of Dementia /Alzheimer's.

Poor Coordination between Healthcare Services -

- Carers struggle with fragmented communication between hospitals, GPs, and district nurses, making it difficult to navigate care options.

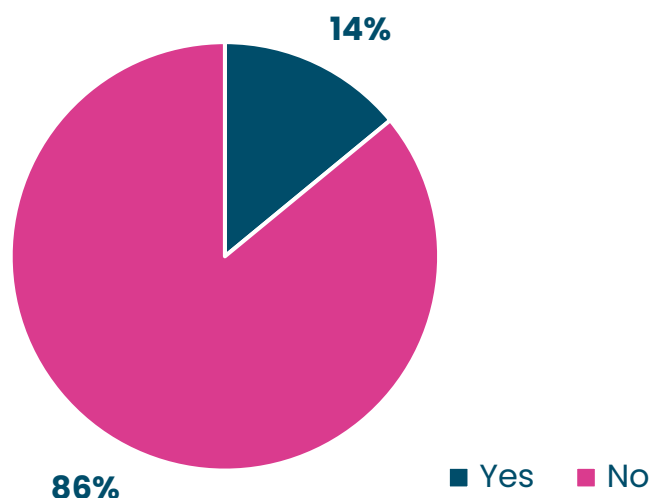
Gaps in Training and Medical Support -

- Unpaid carers are left to manage complex medical needs without adequate training
- District nurses sometimes refuse visits, and paid carers are restricted by regulations.

Health Checks for Unpaid Carers -

- Not being utilised, as most unpaid carers are not aware that this is a service available to them.

Do you have your Yearly Carers Health Check?



Summary

Urgent support for unpaid carers.

These stories collectively reveal systemic gaps in support for unpaid carers in West Berkshire. The barriers they face range from inadequate training to disjointed healthcare service communication – these underscore the need for reform.

By addressing these issues, the aim is that healthcare providers can better support the **"Everyday Heroes"** who care for their loved ones (young and old), ensuring that carers are not left to navigate these challenges alone.

It is plausible that many of the estimated 14,000 unpaid carers in West Berkshire encounter comparable challenges regarding unclear social care invoicing, dementia support (including early identification, information overload, and inconsistent coordination), gaps in training provision, and underutilisation of available health checks – issues often reflecting wider systemic problems.

However, it's important to acknowledge the specific scope of this research. This report reflects the experiences of a limited group of unpaid carers. Consequently, the findings presented may not be fully representative of the diverse experiences of all unpaid carers across West Berkshire, and further exploration is needed to understand the full range of their needs and experiences.

The feedback and insights shared by these carers have informed the development of the following recommendations.



Recommendations

1. Simplify and Clarify Adult Social Care 'Care at Home' Invoicing –
West Berkshire Council should redesign invoices to ensure clarity, accuracy and user-friendliness.

2. Development of an Information Binder or Booklet –

This resource could be designed both online and in hard copies to support unpaid carers by providing essential guidance in a structured and accessible format.

It could include the following: Comprehensive Service Directory, Dementia Stages Timeline, Service Access Guide, Practical Daily Care Guidance, along with visual aids such as infographics.

3. Improving Training Gaps for Carers –

Develop free training on management of pressure sores, catheter use and wound care.

4. Improving Communication and Hospital Co-ordination –

- Establish a centralised digital system for across hospitals, GP's and district nurses.
- Ensure appointment letters are sent well in advance to allow for transport arrangements.

5. Yearly Health Checks –

Awareness of these annual checks need to be better publicised and performed as close to yearly as possible.

6. Provision of a Carers Co-ordinator –

This position would provide a singular vital link between unpaid carers and the services they rely on.

Acknowledgments

The **Everyday Heroes Project** would not have been possible without the dedication, time and support of so many individuals and organisations. We are deeply grateful to everyone who contributed to this initiative, helping to amplify the voices of unpaid carers and ensure they receive the recognition and support they deserve.

To all Unpaid Carers

A heartfelt thank you to the unpaid carers who selflessly gave their extremely limited and precious time to participate in this project. Your insights, experiences and resilience have been invaluable. This report would not have been possible without you.

For access, support and guidance in this project.

- Sarah Swift – Alzheimer’s Society
- Stephen Hammond – Age UK Berkshire
- Sue Young – Dementia Friendly West Berks
- Hannah Cole – West Berks Council Adult Social Care

For helping us understand the workings of Memory Clinics

- Emily Chandler – Berkshire NHS, Memory Clinic Newbury

For hosting an engagement event with residents.

- Hayley Telford – Turners Place Thatcham.

For sharing and promoting our live project

- Connecting Communities in Berkshire,
- West Berks GP Surgeries,
- Fair Close Centre Newbury

For additional project support

- Fatima Ali – Primary Care Support Manager, Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board. (BOB ICB).

For providing space and opportunities to engage with family carers

- Winchcombe Place Care Home – For welcoming us to their cafes to connect with family carers and for hosting Dementia Friendly West Berkshire (DFWB) meetings.

Responses

Question set and results

Q1

Are you a full time or part time unpaid carer? *

Full Time

Part Time

Comment:

Q2

Are you caring for your family member at home or are they in a residential facility? *

Home

Residential facility

If applicable: Which Residential home and Comment:

Q3

Do you feel supported by local services, as an unpaid carer (excluding family, loved ones and friends)? *

Yes

No

Comment:

Q4

Were you offered support or guidance as an unpaid carer, at the time of diagnosis? *

Yes

No

Q5

If Yes: Who were you offered support/ guidance by?

Adult Social Services

Age UK

Corn Exchange

Carers UK

Carers Trust

Crossroads

Family/Friends

Fairclose

Dementia Friendly West Berks

Reading and West Berkshire Carers Partnership

Phoenix Centre

West Berks Council

Other (please specify):

Q6

Did you take the support offered to you, as a carer at the time of diagnosis? *

Yes

No

Q7

What type of help was offered? *

Advice

Carer Cafe's/Memory Cafe

Emotional

Financial

Training Courses

Support groups

Respite

Online

Information Leaflets

Equipment/Technology - Hoists/Chairs/Alarms/Safety button

Other (please specify):

Q8

Is this support for you as an unpaid carer ongoing? *

Yes

No

If Yes: From whom? If No: When and Why did it stop?

Q9

If you needed more support, where would you access it? *

Carers/Dementia Cafes

Family/ Friends

Fairclose Centre

GP/Hospital

Groups

Leaflets

Online

PIP – Patient Information Point

Phoenix centre

Support Worker

Social Worker

Other (please specify):

Q10

If you currently receive support, Who is the support from?

Adult Social Services

Age UK

Carers UK

Carers Trust

Corn Exchange

Crossroads

Dementia Friendly West Berks

Fairclose Centre

NHS

Reading and West Berkshire Carers Partnership

Phoenix Centre

West Berks Council

West Berks Directory

Other (please specify):

Q11

What type of support do you currently receive? *

Advice and Information

Counselling

Emotional

Financial

Leaflets/Booklets/Pamphlets/etc

Online Support

Respite services

Support Groups

Training Courses

Other (please specify):

Q12

Is the support that you are currently receiving enough? *

Support is Good

Support is Sufficient

Need more Support*

N/A

2.

Q13

Have you heard of any of these local services? *

Yes/No

Adult Social Services

Age UK

Yes/No

Carers UK
Carers Trust
Crossroads
Corn Exchange
Dementia Friendly West Berks
Fairclose Centre
NHS
Reading and West Berkshire Carers
Partnership
Phoenix Centre
West Berks Council
West Berks Directory
Other (please Specify)

Other (please specify) and Comments:

Q14

How did you hear about them? *

Cafes
Forums
Friends/Family
GP/Primary Care
Groups
Leaflets
Online
Other (please specify):

Q15

Did you know there is a Patient Information Point (PIP) at West Berks Community Hospital? *

Yes

No

Comment:

Q16

Have you heard of West Berks Directory (local authority website)?

This is the directory of all Health and Social Care Services in West Berkshire. *

Yes

No

West Berkshire Directory Link: <https://www.westberks.gov.uk/carers support>

Q17

Have you accessed any of the following local Primary Care Services in the last year? *

Yes/No

Adult Social Care
Dentist
GP
Optometry
Pharmacy

Q18

What have your experiences been with these local Primary Care Services? *

Excellent/Positive

Good

Fair/Indifferent

Poor/Negative

Adult Social Services

Adult Social Services

Adult Social Services

Adult Social Services

Adult Social Ser

Dentist

Dentist

Dentist

Dentist

Dentist

GP

GP

GP

GP

GP

Optometry

Optometry

Optometry

Optometry

Optometry

Pharmacy

Pharmacy

Pharmacy

Pharmacy

Pharmacy

Q19

Which West Berks GP Surgery do you attend/registered with? *

ID: 22364082

Q20

Do you know that you are entitled to, a yearly Carers Health Assessment with your GP Surgery? *

Yes

No

Q21

If Yes: Do you have your yearly Carers Health Assessment?

Yes

No

Comments:

Q22

Has being a carer affected you in any of the following ways? *

Yes/No

Your Physical wellbeing?

Your Mental wellbeing?

Do or have you experience any financial difficulties as a result of being a carer?

Do you feel like you've reached crisis point in the last year or so?

Have you reached out for help with any of the above?

Comments:

Q23

Do you know there is manual handling training available? (For resources use Patient Information Point at WBCH) *

Yes

No

Q24

Are you still in paid employment? *

Yes

No

If No: Was this by choice?

Q25

Do you think more should be done to raise awareness of dementia in West Berkshire? *



Yes



No


How do you think this could be done?










Results

| 1. Are you a full time or part time unpaid carer? | | | | |
|---|-----------|-------------|------------------|----------------|
| Answer Choices | | | Response Percent | Response Total |
| 1 | Full Time | <div></div> | 50.00% | 4 |
| 2 | Part Time | <div></div> | 50.00% | 4 |
| | | | answered | 8 |
| Comment: (8) | | | | |





| 2. Are you caring for your family member at home or are they in a residential facility? | | | | |
|---|----------------------|---|------------------|----------------|
| Answer Choices | | | Response Percent | Response Total |
| 1 | Home |  | 75.00% | 6 |
| 2 | Residential facility |  | 25.00% | 2 |
| | | | answered | 8 |
| If applicable: Which Residential home and Comment: (1) | | | | |

| 3. Do you feel supported by local services, as an unpaid carer (excluding family, loved ones and friends)? | | | | |
|--|-----|---|------------------|----------------|
| Answer Choices | | | Response Percent | Response Total |
| 1 | Yes |  | 37.50% | 3 |
| 2 | No |  | 62.50% | 5 |
| | | | answered | 8 |
| Comment: (4) | | | | |

| 4. Were you offered support or guidance as an unpaid carer, at the time of diagnosis? | | | | |
|---|-----|---|------------------|----------------|
| Answer Choices | | | Response Percent | Response Total |
| 1 | Yes |  | 100.00% | 8 |
| 2 | No | | 0.00% | 0 |
| | | | answered | 8 |

| 5. If Yes: Who were you offered support/ guidance by? | | | | |
|---|------------------------------|---|------------------|----------------|
| Answer Choices | | | Response Percent | Response Total |
| 1 | Adult Social Services |  | 50.00% | 4 |
| 2 | Age UK |  | 37.50% | 3 |
| 3 | Corn Exchange |  | 37.50% | 3 |
| 4 | Carers UK |  | 12.50% | 1 |
| 5 | Carers Trust |  | 12.50% | 1 |
| 6 | Crossroads |  | 25.00% | 2 |
| 7 | Family/Friends |  | 25.00% | 2 |
| 8 | Fairclose |  | 25.00% | 2 |
| 9 | Dementia Friendly West Berks |  | 37.50% | 3 |



5. If Yes: Who were you offered support/ guidance by?

| | | | | |
|----|---|---|----------|---|
| 10 | Reading and West Berkshire Carers Partnership |  | 12.50% | 1 |
| 11 | Phoenix Centre |  | 12.50% | 1 |
| 12 | West Berks Council |  | 37.50% | 3 |
| 13 | Other (please specify): |  | 50.00% | 4 |
| | | | answered | 8 |










Other (please specify): (4)

| | | |
|---|---|--|
| 1 | 08/05/2024 12:06 PM ID: 244041724 | Found these myself |
| 2 | 17/05/2024 12:55 PM ID: 244809239 | Don't remember |
| 3 | 24/06/2024 12:34 PM ID: 247229016 | GP gave me lots of other organisation's leaflets |
| 4 | 24/06/2024 2:55 PM ID: 247245572 | GP |



6. Did you take the support offered to you, as a carer at the time of diagnosis?

| Answer Choices | | | Response Percent | Response Total |
|----------------|-----|---|------------------|----------------|
| 1 | Yes |  | 50.00% | 4 |
| 2 | No |  | 50.00% | 4 |
| | | | answered | 8 |



7. What type of help was offered?

| Answer Choices | | | Response Percent | Response Total |
|----------------|--------------------------|---|------------------|----------------|
| 1 | Advice |  | 50.00% | 4 |
| 2 | Carer Cafe's/Memory Cafe |  | 25.00% | 2 |
| 3 | Emotional |  | 25.00% | 2 |
| 4 | Financial |  | 25.00% | 2 |
| 5 | Training Courses |  | 12.50% | 1 |
| 6 | Support groups |  | 62.50% | 5 |
| 7 | Respite |  | 25.00% | 2 |
| 8 | Online |  | 37.50% | 3 |
| 9 | Information Leaflets |  | 37.50% | 3 |

7. What type of help was offered?

| | | | | |
|-----------------------------|---|---|----------|---|
| 10 | Equipment/Technology - Hoists/Chairs/Alarms/Safety button |  | 37.50% | 3 |
| 11 | Other (please specify): |  | 50.00% | 4 |
| | | | answered | 8 |
| Other (please specify): (4) | | | | |











8. Is this support for you as an unpaid carer ongoing?

| Answer Choices | | | Response Percent | Response Total |
|----------------|-----|---|------------------|----------------|
| 1 | Yes |  | 37.50% | 3 |
| 2 | No |  | 62.50% | 5 |
| | | | answered | 8 |


If Yes: From whom? If No: When and Why did it stop? (8)

| | | |
|---|---|---|
| 1 | 08/05/2024 12:06 PM ID: 244041724 | Because you think you can do it on your own at the beginning, so you don't take the support. Then after 2 months I stopped coping because he never slept and would go walking around in the middle of the night. That's when I started to use temporary respite at Winchcombe Place care home. |
| 2 | 08/05/2024 12:30 PM | No longer required as mum now in well supported care facility and staff support us as a family as well. |
| 3 | 13/05/2024 2:20 PM | GP |
| 4 | 17/05/2024 12:55 PM ID: 244809239 | It was offered but I didn't take it as like I said I don't think of myself as a carer. |
| 5 | 24/06/2024 11:46 AM ID: 247225345 | Too much information is given at time of diagnosis, unless relevant then you don't read it or take information in. Signposting needs to be more structured with each stage of the disease not in one lot, bam. No where to go for ongoing support, lots of organisations but you forget about half of them. |
| 6 | 24/06/2024 12:34 PM ID: 247229016 | There is a lot of information at the beginning but then no more for us as carers someone needs to be checking in on us or available for us to call with silly question, like what clothes should I dress my wife in now that she is incontinent and incontinence clinic is a joke. Long wait and then the knickers they give them to wear is completely unsuitable for someone that cannot place the pad in the right place. Really, she needs some kind of pants that are all absorbent but there is no one around for me to ask and it seems like a service that is sorely needed!!!! |
| 7 | 24/06/2024 2:55 PM ID: 247245572 | Don't need it as we share as a family and have carers coming in twice a day currently whilst we work |
| 8 | 24/06/2024 3:04 PM | WBC very limited and invoices are averaged, not person-centred care as it should be. |

9. If you needed more support, where would you access it?

| Answer Choices | | | Response Percent | Response Total |
|-----------------------------|---|--|------------------|----------------|
| 1 | Carers/Dementia Cafes |  | 62.50% | 5 |
| 2 | Family/ Friends |  | 75.00% | 6 |
| 3 | Fairclose Centre |  | 25.00% | 2 |
| 4 | GP/Hospital |  | 75.00% | 6 |
| 5 | Groups | | 0.00% | 0 |
| 6 | Leaflets |  | 25.00% | 2 |
| 7 | Online |  | 50.00% | 4 |
| 8 | PIP – Patient Information Point |  | 37.50% | 3 |
| 9 | Phoenix centre |  | 12.50% | 1 |
| 10 | Support Worker | | 0.00% | 0 |
| 11 | Social Worker |  | 25.00% | 2 |
| 12 | Other (please specify): |  | 25.00% | 2 |
| | | | answered | 8 |
| Other (please specify): (2) | | | | |
| 1 | 13/05/2024 2:20 PM ID: 244401730 | Physio. open invitations | | |
| 2 | 24/06/2024 12:34 PM ID: 247229016 | Go to GP who refers you to memory clinic and after initial diagnosis they refer you back to the GP, you go round and round in circles. WB Adult Social services in general feels like it's made to deter people from using them | | |

10. If you currently receive support, who is the support from?

| Answer Choices | | | Response Percent | Response Total |
|----------------|---|---|------------------|----------------|
| 1 | Adult Social Services | | 0.00% | 0 |
| 2 | Age UK |  | 25.00% | 2 |
| 3 | Carers UK | | 0.00% | 0 |
| 4 | Carers Trust | | 0.00% | 0 |
| 5 | Corn Exchange | | 0.00% | 0 |
| 6 | Crossroads | | 0.00% | 0 |
| 7 | Dementia Friendly West Berks | | 0.00% | 0 |
| 8 | Fairclose Centre | | 0.00% | 0 |
| 9 | NHS | | 0.00% | 0 |
| 10 | Reading and West Berkshire Carers Partnership | | 0.00% | 0 |

10. If you currently receive support, who is the support from?

| | | | | |
|-----------------------------|---|------------------|----------|---|
| 11 | Phoenix Centre | | 0.00% | 0 |
| 12 | West Berks Council | | 37.50% | 3 |
| 13 | West Berks Directory | | 0.00% | 0 |
| 14 | Other (please specify): | | 62.50% | 5 |
| | | | answered | 8 |
| Other (please specify): (5) | | | | |
| 1 | 08/05/2024 12:06 PM ID: 244041724 | Winchcombe Place | | |
| 5 | 24/06/2024 2:55 PM ID: 247245572 | Family | | |

11. What type of support do you currently receive?

| Answer Choices | | | Response Percent | Response Total |
|-----------------------------|---|---|------------------|----------------|
| 1 | Advice and Information | | 25.00% | 2 |
| 2 | Counselling | | 0.00% | 0 |
| 3 | Emotional | | 50.00% | 4 |
| 4 | Financial | | 12.50% | 1 |
| 5 | Leaflets/Booklets/Pamphlets/etc | | 0.00% | 0 |
| 6 | Online Support | | 0.00% | 0 |
| 7 | Respite services | | 25.00% | 2 |
| 8 | Support Groups | | 25.00% | 2 |
| 9 | Training Courses | | 0.00% | 0 |
| 10 | Other (please specify): | | 37.50% | 3 |
| | | | answered | 8 |
| Other (please specify): (3) | | | | |
| 1 | 08/05/2024 12:30 PM ID: 244044326 | N/A | | |
| 2 | 13/05/2024 2:20 PM ID: 244401730 | Can apply for attendance allowance but doesn't need to | | |
| 3 | 24/06/2024 12:34 PM ID: 247229016 | AGEUK Carer support groups are my lifeline and only place I have to ask questions but they don't have enough capacity really. Funding seems to be the real crux of it. There needs to be some kind of Alzheimer's co-ordinator that can help in each step of the disease progression. | | |

| 12. Is the support that you are currently receiving enough? | | | | |
|---|---|--|------------------|----------------|
| Answer Choices | | | Response Percent | Response Total |
| 1 | Support is Good | <div></div> | 37.50% | 3 |
| 2 | Support is Sufficient | <div></div> | 12.50% | 1 |
| 3 | Need more Support* | <div></div> | 37.50% | 3 |
| 4 | N/A | <div></div> | 12.50% | 1 |
| | | | answered | 8 |
| *Please give more details: (4) | | | | |
| 1 | 17/05/2024 12:55 PM ID: 244809239 | Family and friends. | | |
| 2 | 24/06/2024 11:46 AM ID: 247225345 | Need a local dementia specialist whom you can call at any time in the dementia process to get help and advice for each stage. | | |
| 3 | 24/06/2024 12:34 PM ID: 247229016 | the more publications you read the more you realise that these things aren't necessarily relevant now and need to be updated. There are also lots of cliches like not everyone with Alzheimer's or dementia is the same which of course is true but characteristics of the illness are the same and that's what I need to know about. Information given is way too much, you are over loaded! The memory clinic has an inordinate wait time too. Information given need to be written in a friendly way or more easily readable, as right now it is not user friendly. | | |
| 4 | 24/06/2024 3:04 PM ID: 247246290 | Never given enough information, I had to find out myself online all the assessments that could be carried out because at the start they gave me too many leaflets to read so I binned them all. | | |

2. Page 2

| 13. Have you heard of any of these local services? | | | |
|--|--------------|-------------|----------------|
| Answer Choices | Yes | No | Response Total |
| Adult Social Services | 100.00% 8 | 0.00% 0 | 8 |
| Age UK | 87.50% 7 | 12.50% 1 | 8 |
| Carers UK | 37.50% 3 | 62.50% 5 | 8 |
| Carers Trust | 25.00% 2 | 75.00% 6 | 8 |
| Crossroads | 62.50% 5 | 37.50% 3 | 8 |
| Corn Exchange | 75.00% 6 | 25.00% 2 | 8 |
| Dementia Friendly West Berks | 62.50% 5 | 37.50% 3 | 8 |
| Fairclose Centre | 75.00% 6 | 25.00% 2 | 8 |







13. Have you heard of any of these local services?

| | | | |
|---|--------------|-------------|---|
| NHS | 100.00% 8 | 0.00% 0 | 8 |
| Reading and West Berkshire Carers Partnership | 25.00% 2 | 75.00% 6 | 8 |
| Phoenix Centre | 37.50% 3 | 62.50% 5 | 8 |
| West Berks Council | 87.50% 7 | 12.50% 1 | 8 |
| West Berks Directory | 37.50% 3 | 62.50% 5 | 8 |
| Other (please Specify) | 20.00% 1 | 80.00% 4 | 5 |
| | | answered | 8 |

Other (please specify) and Comments: (3)

| | | |
|---|---|--|
| 1 | 08/05/2024 12:30 PM ID: 244044326 | I work in local family services. |
| 2 | 13/05/2024 2:20 PM ID: 244401730 | Alzheimer's Society |
| 3 | 24/06/2024 12:34 PM ID: 247229016 | We need a dementia specialist within west berks, really at each surgery. |



14. How did you hear about them?

| Answer Choices | | | Response Percent | Response Total |
|----------------|-------------------------|---|------------------|----------------|
| 1 | Cafes |  | 12.50% | 1 |
| 2 | Forums | | 0.00% | 0 |
| 3 | Friends/Family |  | 25.00% | 2 |
| 4 | GP/Primary Care |  | 75.00% | 6 |
| 5 | Groups | | 0.00% | 0 |
| 6 | Leaflets |  | 62.50% | 5 |
| 7 | Online |  | 37.50% | 3 |
| 8 | Other (please specify): |  | 25.00% | 2 |
| | | | answered | 8 |



Other (please specify): (2)

| | | |
|---|---|------|
| 1 | 08/05/2024 12:30 PM ID: 244044326 | Work |
| 2 | 17/05/2024 12:55 PM ID: 244809239 | Work |

15. Did you know there is a Patient Information Point (PIP) at West Berks Community Hospital?

| Answer Choices | | | Response Percent | Response Total |
|----------------|---|---|------------------|----------------|
| 1 | Yes |  | 75.00% | 6 |
| 2 | No |  | 25.00% | 2 |
| | | | answered | 8 |
| Comment: (2) | | | | |
| 1 | 24/06/2024 11:46 AM ID: 247225345 | Very useful and nice women | | |
| 2 | 24/06/2024 12:34 PM ID: 247229016 | Great resource and I can ask them questions when needed | | |

16. Have you heard of West Berks Directory (local authority website)? This is the directory of all Health and Social Care Services in West Berkshire.

| Answer Choices | | | Response Percent | Response Total |
|----------------|-----|--|------------------|----------------|
| 1 | Yes |  | 37.50% | 3 |
| 2 | No |  | 62.50% | 5 |
| | | | answered | 8 |

17. Have you accessed any of the following local Primary Care Services in the last year?

| Answer Choices | Yes | No | Response Total |
|-------------------|--------------|-------------|----------------|
| Adult Social Care | 50.00% 4 | 50.00% 4 | 8 |
| Dentist | 87.50% 7 | 12.50% 1 | 8 |
| GP | 100.00% 8 | 0.00% 0 | 8 |
| Optometry | 75.00% 6 | 25.00% 2 | 8 |
| Pharmacy | 87.50% 7 | 12.50% 1 | 8 |
| | | answered | 8 |



18. What have your experiences been with these local Primary Care Services?

| Answer Choices | Excellent/Positive | Good | Fair/Indifferent | Poor/Negative | N/A Not Applicable | Response Total |
|-----------------------|--------------------|-------------|------------------|---------------|--------------------|----------------|
| Adult Social Services | 0.00% 0 | 25.00% 2 | 0.00% 0 | 37.50% 3 | 37.50% 3 | 8 |
| Dentist | 0.00% 0 | 37.50% 3 | 50.00% 4 | 0.00% 0 | 12.50% 1 | 8 |
| GP | 0.00% 0 | 37.50% 3 | 50.00% 4 | 12.50% 1 | 0.00% 0 | 8 |
| Optometry | 12.50% 1 | 50.00% 4 | 12.50% 1 | 0.00% 0 | 25.00% 2 | 8 |
| Pharmacy | 0.00% 0 | 25.00% 2 | 0.00% 0 | 62.50% 5 | 12.50% 1 | 8 |
| | | | | | answered | 8 |



19. Which West Berks GP Surgery do you attend/registered with?

| Answer Choices | | | Response Percent | Response Total |
|----------------|---|---|------------------|----------------|
| 1 | Open-Ended Question | | 100.00% | 8 |
| 1 | 08/05/2024 12:06 PM ID: 244041724 | Strawberry Hill now and not keen on the idea of being with them. I used to be with Downland Practice - they were great. | | |
| 2 | 08/05/2024 12:30 PM ID: 244044326 | Strawberry Hill: So far so good. | | |
| 3 | 13/05/2024 2:20 PM ID: 244401730 | Kingsclere | | |
| 4 | 17/05/2024 12:55 PM ID: 244809239 | Eastfield House | | |
| 5 | 24/06/2024 11:46 AM ID: 247225345 | Thatcham Medical Practice | | |
| 6 | 24/06/2024 12:34 PM ID: 247229016 | Burdwood Surgery | | |
| 7 | 24/06/2024 2:55 PM ID: 247245572 | Wooton Hill | | |
| 8 | 24/06/2024 3:04 PM ID: 247246290 | Falkland Surgery | | |
| | | | answered | 8 |

20. Do you know that you are entitled to, a yearly Carers Health Assessment with your GP Surgery?

| Answer Choices | | | Response Percent | Response Total |
|----------------|-----|---|------------------|----------------|
| 1 | Yes |  | 62.50% | 5 |
| 2 | No |  | 37.50% | 3 |
| | | | answered | 8 |

21. If Yes: Do you have your yearly Carers Health Assessment?

| Answer Choices | | | Response Percent | Response Total |
|----------------|-----|---|------------------|----------------|
| 1 | Yes |  | 14.29% | 1 |
| 2 | No |  | 85.71% | 6 |
| | | | answered | 7 |


Comments: (4)

22. Has being a carer affected you in any of the following ways?

| Answer Choices | Yes | No | Response Total |
|--|-------------|-------------|----------------|
| Your Physical wellbeing? | 50.00% 3 | 50.00% 3 | 6 |
| Your Mental wellbeing? | 83.33% 5 | 16.67% 1 | 6 |
| Do or have you experience any financial difficulties as a result of being a carer? | 66.67% 4 | 33.33% 2 | 6 |
| Do you feel like you've reached crisis point in the last year or so? | 33.33% 2 | 66.67% 4 | 6 |
| Have you reached out for help with any of the above? | 66.67% 4 | 33.33% 2 | 6 |
| | | answered | 6 |

Comments: (3)



23. Do you know there is manual handling training available? (For resources use Patient Information Point at WBCH)

| Answer Choices | | | Response Percent | Response Total |
|----------------|-----|---|------------------|----------------|
| 1 | Yes |  | 66.67% | 4 |

23. Do you know there is manual handling training available? (For resources use Patient Information Point at WBCH)



| | | | | |
|---|----|---|----------|---|
| 2 | No |  | 33.33% | 2 |
| | | | answered | 6 |

24. Are you still in paid employment?

| Answer Choices | | | Response Percent | Response Total |
|----------------|-----|---|------------------|----------------|
| 1 | Yes |  | 50.00% | 4 |
| 2 | No |  | 50.00% | 4 |
| | | | answered | 8 |

If No: Was this by choice? (4)

25. Do you think more should be done to raise awareness of dementia in West Berkshire?

| Answer Choices | | | Response Percent | Response Total |
|----------------|-----|---|------------------|----------------|
| 1 | Yes |  | 75.00% | 6 |
| 2 | No |  | 25.00% | 2 |
| | | | answered | 8 |

How do you think this could be done? (7)

| | | |
|---|---|---|
| 1 | 08/05/2024 12:06 PM ID: 244041724 | People don't talk about it that much. Now my husband is in permanent care, I will be joining the WI. There needs to be more money put into services. It's too stressful to take the person you are caring for out as it is too difficult to try and manage them out and about. |
| 2 | 08/05/2024 12:30 PM ID: 244044326 | I think things have improved dramatically in recent yrs but there is always room for more. Social worker consistency needs improvement. better support with respite care without having to escalate the situation. At home caring companies - Staff need better training, consistency across their staff and better overall monitoring by WBC. More care homes to take dementia patients with incontinence. |
| 3 | 13/05/2024 2:20 PM ID: 244401730 | In the last decade or so awareness has increased remarkably, through media and organisations. Basingstoke memory clinic. Blue badge got very bureaucratic response as she hadn't been diagnosed yet, now sent GP letter along with it. |
| 4 | 17/05/2024 12:55 PM ID: 244809239 | It's hard to talk about in some societies, as it's just part of growing old, isn't it? |
| 5 | 24/06/2024 11:46 AM ID: 247225345 | not awareness but to co-ordinate better nationally yes |
| 6 | 24/06/2024 12:34 PM ID: 247229016 | Not to raise awareness but some kind of dementia specialist is needed in West Berks. |

25. Do you think more should be done to raise awareness of dementia in West Berkshire?

| | | |
|---|--|---|
| 7 | 24/06/2024 3:04 PM ID: 247246290 | Needs to be better structure to services for memory and memory clinic is horrific waiting times and help minimal. |
|---|--|---|

Thank you for your time.



Healthwatch West Berks
Broadway House,
4-8 The Broadway,
Newbury,
RG14 1BA

www.healthwatchwestberks.org.uk

T: 01635 886210

E: contact@healthwatchwestberks.org.uk

🐦 @Healthwatchwestberks

📘 [Facebook.com/Healthwatchwestberks](https://www.facebook.com/Healthwatchwestberks)