



Talking to people about dementia: a focus on primary care

An
independent
voice for the
people of
Wiltshire

Notes:

Primary Health Care

The term primary health care refers to health care provided in the community for people making an initial approach to a medical practitioner or clinic for advice or treatment. It covers GP practices, dental practices, community pharmacies and high street optometrists.

General Practitioner and Health Care Centres

GPs usually work in practices as part of a team, which includes nurses, healthcare assistants, practice managers, receptionists and other staff. The people we spoke to use a variety of terms to refer to their GP and GP practice.

For consistency throughout the report we are using 'health care centre' when people talked about their health centre, GP practice or surgery and we are using 'GP' when people talked about their General Practitioner or doctor.

Carers

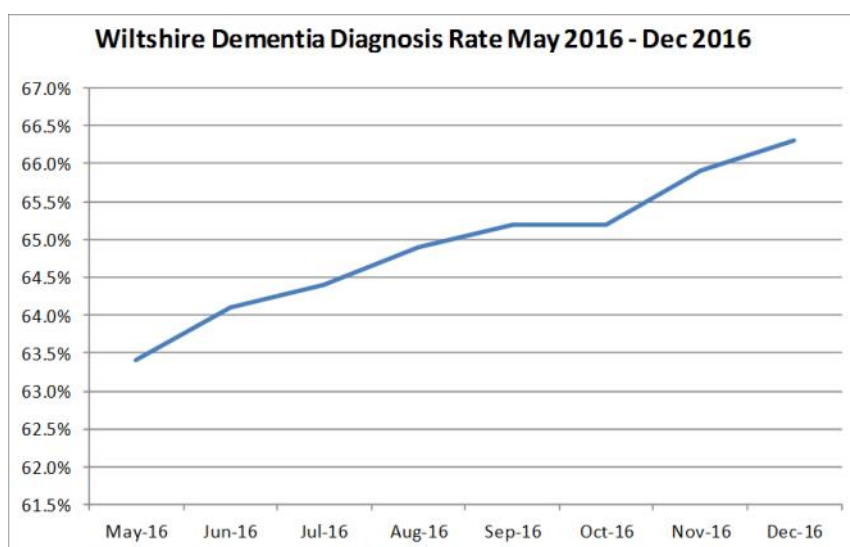
Where we talk about carers in this report we are referring to unpaid carers:

“A carer is anyone who cares unpaid for a family member or friend who cannot manage without their support. They might look after someone with a physical disability, long term health condition, mental health issue or a problem with substance misuse.” (Source: Carers Support Wiltshire⁽¹⁾)

Where the report refers to paid care workers, we will make this clear, for example by stating “agency care worker”.

Dementia Diagnosis in Wiltshire

In recent years dementia diagnosis rates in Wiltshire have been gradually increasing. Figures from NHS England⁽²⁾ indicate that in August 2015 64.5% of people aged over 65 who were living with dementia had received a formal diagnosis. In January 2017 this figure had increased to 66.3%, just below the national average of 67.8%. The table below shows a steady increase in the dementia diagnosis rate from 63.4% in May up to 66.3% in December.



Numerical Data

Figures used in this report refer to January 2017 dementia diagnosis rates from NHS England.

⁽¹⁾ <http://carersinwiltshire.co.uk/are-you-a-carer/>

⁽²⁾ <https://www.england.nhs.uk/mentalhealth/dementia/monthly-workbook/>

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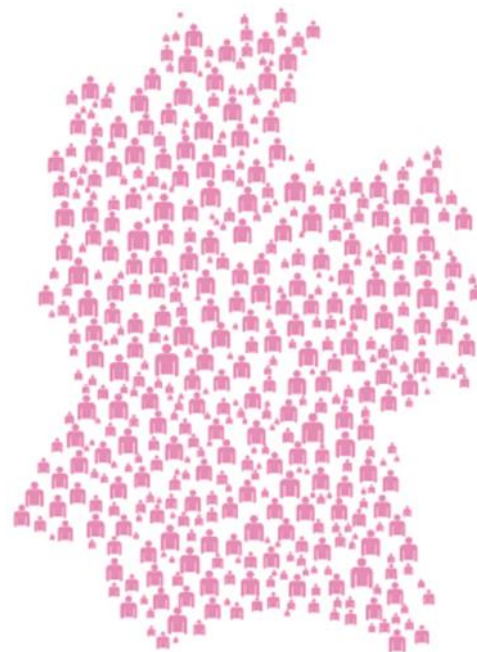
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Overview

Healthwatch Wiltshire, along with voluntary sector organisations, has been talking to local people about their experiences and views of dementia and services in Wiltshire. This report tells you what people said when we spoke to them about primary health care. Primary health care is provided in the community for people making an initial approach to a medical professional or clinic. This covers health care centres, dental practices, community pharmacies and high street optometrists.

We designed our approach to gather people's experiences and views of the dementia services they use. Our aim is to analyse this information and reflect it back to the people who plan and provide health and care services. We will highlight good practice and areas where people have poor experiences so that these can be addressed. This is our third report based on our engagement on dementia.

Wiltshire's Dementia Strategy ⁽³⁾ was approved by Wiltshire Health and Wellbeing Board in July 2014 with its purpose to provide the direction for commissioning bodies to support people with dementia and their unpaid carers. You can read the strategy on the Healthwatch Wiltshire website here – <https://www.healthwatchwiltshire.co.uk/project/dementia-engagement/>.



6,624 estimated number of people in Wiltshire living with dementia

What we did

In our earlier engagement people living with dementia and their carers said that if they were worried about their memory they would firstly talk to their GP and people reported varied experiences of this. We wanted to find out more about people's experiences of using primary health care services, what they had found useful and what they felt could be improved.

We talked to people living with dementia, unpaid carers, older people, the general public, volunteers and professionals.



195 people spoken to during this engagement

We spoke to 195 people in total:

- 61 people living with dementia (31%)
- 64 carers (33%)
- 62 professionals or others (32%)
- 8 members of the public (4%)

We held one workshop in Devizes, and carried out more targeted engagement with people living with dementia and their carers. Our outreach included visiting local groups around Wiltshire including memory cafés, Singing for the Brain groups, groups for people living with dementia and a Leg club. We also attended two of the Dementia Champions Forums of Community Health services and facilitated carers involvement in these. We engaged with some people individually either by face to face meetings, phone or email.

⁽³⁾ <https://www.wiltshire.gov.uk/wiltshire-dementia-strategy.pdf>

The style of our engagement varied according to the group; some were focus groups and some were more informal group or individual discussions. However we engaged, we talked to people about these questions:



1. What is your experience of accessing primary health care services in Wiltshire?
2. How easy did you find it to access these services?
3. How do you think primary health care services could be improved for people living with dementia?
4. What do you think people living with dementia should expect from their GP practice?
5. What do you think would make quality, timely assessments, diagnosis and reviews by GPs for people living with dementia?
6. Do you think that other primary care services are dementia friendly?

We also said to people that we were interested in anything else that they wanted to say about dementia.



Key messages

Some key themes about primary health care emerged from our engagement:

1. There is a lack of clarity and consistency in the dementia care people can expect and experience from their health care centre
2. People said that they valued a clear, direct dementia diagnosis and onward referral - not everyone had this experience
3. People appreciated proactive dementia reviews where offered. However many people were concerned about the lack of ongoing support from their health care centre for people living with dementia
4. Unpaid carers said that the approach of their health care centre had an impact on their quality of life
5. Most people said that they could access opticians and dentists fairly easily
6. People found local pharmacists useful and felt more people may benefit from their services

1. There is a lack of clarity and consistency in the dementia care people can expect and experience from their health care centre

The people we spoke to reported very different experiences of the care they received from their health care centre. Variations were identified in what service people might receive both between different health care centres and between different GPs within the same health care centre.

People's experiences were wide ranging. Some people talked about GPs who were dismissive of their concerns about their memory, did not give clear diagnosis, and did not refer on to other services or offers reviews. Others reported GPs who listened to people's concerns and carried out memory tests, gave a clear diagnosis, prescribed medication, referred to other support services and reviewed regularly.

There were some indications that people's recent experiences were better than those some time ago. Most of those people who were given a diagnosis by their GP felt that this happened

as promptly as could be expected. More people felt that their GPs took their concerns about their memory seriously, however there were still some incidences of GPs dismissing such concerns reported to us.



55 GP Practices in Wiltshire

"I'm with x surgery. It is good, they seem efficient and know what they are doing. I see the same doctor each time which is good. My doctor has made referrals to specialists when needed. I get an appointment when I want one."

Person living with dementia

"The quality of dementia care can depend on your surgery - there are some positive experiences." *Unpaid carer of someone living with dementia*

2. People said that they valued a clear, direct dementia diagnosis and onward referral - not everyone had this experience

Some people living with dementia and their carers reported that their GP had given them a clear diagnosis of dementia. People said that they valued an honest direct approach. Several people living with dementia told us that although it was initially a shock to get their diagnosis they thought it was the best way to be told directly that they had dementia. They said that they felt that this enabled them to come to terms with this more quickly and to look forward, making plans for the future.

People also said that they found it very helpful to be referred on to other support services. A number of people told us that they had been referred to the Dementia Adviser Service by their GP or health care centre. Everyone who had been referred to this service said that they found it useful. People talked about Dementia Advisers both helping them access services directly, for example Singing for the Brain Groups, and onward referral to other organisations such as Carer Support Wiltshire.

"Getting the GP diagnosis was a difficult experience. The GP gave it straight out but I think that was the best thing. He gave me a number to ring and someone came to see me (a Dementia Adviser). They gave me lots of information including leaflets about special clocks." *Person living with dementia*



9 Dementia Advisers in Wiltshire

“GPs are frightened of the dementia problem and find it difficult to talk about.”

Person living with dementia

Some people said that they were given a diagnosis that was clear but were then ‘left hanging’ and were not told about organisations who may be able to support them. Some of these people had later found out about Dementia Advisers and said that they wished they had heard about them earlier.

A number of people said that they had not had a clear diagnosis from their GP. Some people living with dementia told us that they thought their GP was scared to talk about dementia. Some carers told us that the GP had told them the diagnosis but did not talk about it to the person living with dementia, they said that this left them unsure how to approach this with the person they cared for. Some people said that their GP had ‘hinted’ but was not direct and found that this was not helpful.

“My father was diagnosed last July by his GP and was given tablets to slow the progress of dementia. I found it very isolating. The GP didn’t inform us about what we could do and didn’t explain to me that they were starting on a low dose of tablets that would then be upped. Later on the GP casually mentioned the Dementia Advisers and said they would refer us. No one got in touch so I phoned the surgery and then rang Alzheimer’s Support direct. I think the services offered by the two Alzheimer’s charities are great.” *Unpaid carer of someone living with dementia*



3. People appreciated proactive dementia reviews where offered. However many people were concerned about the lack of ongoing support from their health care centre for people living with dementia

One of the outcomes of the Wiltshire Dementia Strategy 2014 -2021 is: “I get the treatment and support which are best for my dementia and my life”. NHS Choices Dementia Guide talks about ongoing dementia assessment and states: “Once you have been given a diagnosis, your GP should arrange to see you from time to time to see how you’re getting on”⁽⁴⁾. Many of the people we spoke to talked about the issue of ongoing dementia support from their health care centre.

A number of people told us they did not feel that they received regular ongoing support with their dementia from their health care centre. Some people reported that they had not talked to their health care centre about their dementia for a number of years. Some people said that they thought some GPs didn’t offer reviews because they thought “what can I do?” However most people we spoke to thought that a six monthly or annual appointment to talk things through would be helpful.



4,391 people 65+ with a diagnosis of dementia in Wiltshire

⁽⁴⁾ <http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-diagnosis.aspx>

“My GP never asks me how I am getting on with my dementia medication, for example, whether I am having any side effects.”

Person living with dementia

People reported different experiences of the ongoing support that they received from their GP and during discussions it became evident that it was not clear to people what support their GPs should be offering them. For example, one person told us that they had written to their GP requesting six monthly reviews as they felt they had been led to believe they were entitled to this by NHS Wiltshire. This had been refused by the GP who had said they would see them annually. As they were still unhappy with this they wrote to the CCG again and were then told that there is no local protocol that required six monthly GP follow up. Following this they had learnt that people living with dementia in a nearby health care centre were having six monthly reviews. This was taken up with their health care centre and they are now being offered six monthly reviews. They said that they are pleased that they are now getting what they wanted but that this process had taken nearly a year.

Some people told us that they were receiving regular support from their health care centre from either the GP or a specialist nurse. Everyone we spoke to who had this said that they found it useful to talk things over. People said that these reviews had sometimes led to medication changes or onward referral or signposting to other services that had been beneficial to them. Carers said that they appreciated being asked how things were going for them during these reviews. Some people said that they had been offered a review but had not accepted it if nothing had changed but that they were glad that they were given the opportunity.

“My GP calls me to see how I am getting on - this is good support.” *Person living with dementia*

“In my support group for carers of people living with dementia 11 of the 12 people there said that the person living with dementia had not seen their GP about dementia in the last 12 months.”

Unpaid carer of person living with dementia



“The doctors are not particularly helpful around dementia. We saw a consultant but then seemed to fall through the net - there was no follow up from the GP. Every time I spoke to my GP about it they said ‘Well, it’s going to get worse’.”

Unpaid carer of person living with dementia

4. Carers said that the approach of their health care centre had an impact on their quality of life

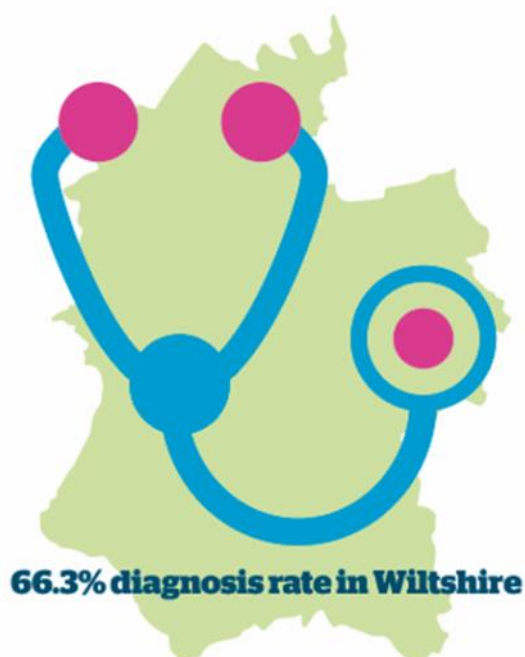
Unpaid carers of people living with dementia talked about their experience of health care centres and the impact that this could have on them and the person they cared for. Carers reported different experiences of the support they received from their health care centres.

Carers who felt that the support offered by their health care centres had a positive impact on their quality of life mentioned a number of things that contributed to this. Some examples of these were: Being recognised as a carer and given priority for GP appointments, flexibility to talk to the GP on the phone if this was easier for them, the GP asking how things were for them, health care centre staff explaining particular aspects of dementia to them, carer health checks and reviews at health care centres, being informed of other support services available, health care centres organising carer events and informing carers of these by email and text.

A number of carers we spoke to felt that they received good quality support from their health care centre and that this supported them to care for someone living with dementia. However it was evident that this support was not consistent across all health care centres in Wiltshire. Some carers said that they weren't aware that they were registered as carers with their GP and some that they were, but this made little difference to the service they received. These carers said they thought it would be beneficial to them to have support from their health care centre around their caring role.

"When I was in Devon - I had a check-up from my GP surgery for carers. This was good - it has not happened at my surgery in Wiltshire" *Carer of Person living with dementia*

"We see the same Dr every time and this is really helpful. If I have worries they can arrange for the Dr to phone me - I appreciate this as we can discuss whether we need to visit. The last time I took my husband in for an appointment to see the nurse. The nurse wanted the doctor to see him. The doctor came down to see us in the nursing room. I thought this was really thoughtful - it made a difference as my husband is in a wheelchair and it can take time to move him around. Another good thing is that our Dr has also asked me if I was alright as a Carer. Our GP is really good." *Carer of Person living with dementia*





5. Most people said that they could access opticians and dentists fairly easily

We spoke to people about whether they found it easy to access other primary health services. Most people said that they had found it relatively easy to access dentists and opticians. Some people talked about the need to go on a waiting list to get an NHS dentist but said that this had not been a particular problem to them. People said that they felt their dentists understood as much as they needed to when treating people living with dementia. Similarly people said that they had not experienced any difficulties accessing optician's services. Some people talked about being able to arrange home visits which they found helpful. Some people said there were now specific 'dementia friendly' eye tests and that this was a good thing.

6. People found local pharmacists useful and felt more people may benefit from their services

A number of people talked about the services that they received from their local pharmacy. People living with dementia and their carers said that they found the 'dosette boxes' that pharmacists made up very helpful, enabling them to take their medications correctly. People also told us that they had been able to get advice about minor health issues from pharmacists. They said they found this useful and felt that pharmacists were easily accessible, knowledgeable and helpful. Some people felt that not everyone may be aware of what local pharmacies could offer and that more people could potentially benefit from all of their services.

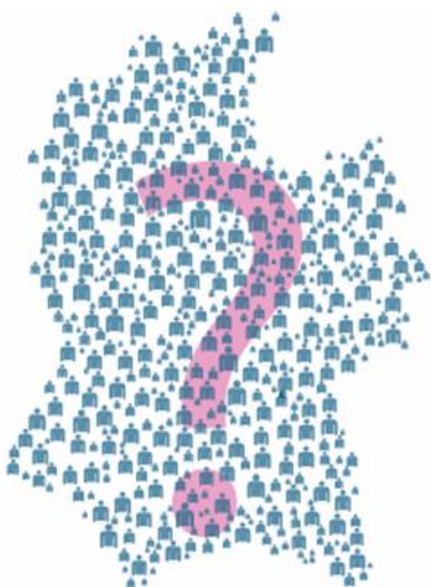
Other things people told us

"I like my doctor and they always explain everything to me. I think my doctor knows me well ." *Person living with dementia*

"They are very dementia minded at the surgery. The doctors are trained in dementia and are wonderful." *Unpaid carer of someone living with dementia*

People living with dementia told us that they valued seeing the same GP and having longer appointments. Some people told us that their health care centre was aware they had dementia and ensured they saw the same person, but not everyone had this experience. People reported different experiences of how much GPs know about dementia. Some people said that their GP was very knowledgeable about dementia and that this was helpful, other people felt that their GP was uninterested in dementia. Some people also talked about other health care centre staff who were helpful for example nurses and care coordinators. There was mixed feedback about the approach of reception staff towards people living with dementia and their carers. Carers and people living with dementia who used Leg Clubs said they enjoyed going to them and felt they helped motivate them to keep active. People reported different experiences of how well integrated GPs are with other services such as dementia advisers, and social care staff.

Although it is not a primary care service, several people told us that they had experienced difficulties accessing podiatry services. This seemed to be problematic for people with dementia living in both the community and residential homes. People talked about stringent criteria and long waiting lists for NHS podiatry services. Many people told us that the only way that they could access podiatry was to pay for it privately. A few people also said that hearing assessments and aids could be problematic.



Estimated 2,491 people in Wiltshire living with dementia who don't have a diagnosis



National estimated diagnosis rate of 67.4%

Dementia diagnosis: case studies

During our dementia engagement we have carried out a number of one to one interviews with people living with dementia and their carers. These two Case Studies show two differing experiences of dementia diagnosis and highlight what people have told us about what they think is important about this process.

Case Study One – Unclear diagnosis from GP (names have been changed)

Maggie is a carer for her husband Jack who has dementia. She explained that things started a couple of years ago. Jack started to put things in the wrong place and forget things that she had told him.

They first went to the GP in May last year. The GP gave Jack a memory test and he scored 4 out of 10 - this really brought things home. During all of this the word dementia was never mentioned by the GP or anyone else involved.

Jack is alright with their group of close knit friends but is now much more reluctant to go to larger social events where he may not know people well. Jack doesn't want to visit family members - Maggie feels that this is because he would find it difficult finding his way around their homes.

Jack doesn't accept he has dementia, he puts his memory loss down to a fall he had earlier in his life when he banged his head. Maggie said that it has been difficult to move forward without being given a diagnosis. She has been with Jack to GPs appointments and the GP has said "You do know this is more than just a poor memory don't you" - but the word dementia has never been mentioned.

Maggie said that Jack is totally dependent on her. He makes no decisions himself - he wouldn't eat if she didn't prepare his meals. Maggie finds it difficult to have to make every decision. Maggie has grandchildren and it is very important to her that she keeps in touch with them. It is a concern to her that this might become more difficult in the future if Jack's dementia gets worse.

Maggie is aware of some of the support agencies, for example, Alzheimer's Support. However she said that it's hard to start going to things without a clear diagnosis.

Maggie says that she does get stressed and feels isolated. She would like some more support from her husband's family and assurance for the future.

People have told Healthwatch Wiltshire of the drawbacks of not being given a clear dementia diagnosis:

- It is hard for the person and their families to come to terms with the fact that they have dementia
- They may not be able to access support services that would benefit them
- Carers may become stressed and not be supported
- The person may become socially isolated

Case Study Two – Clear diagnosis (names have been changed)

Robert first thought that he might have problems with his memory when his family started to say “Dad your memory is not so good”. He went to his GP and found them very supportive. He was told that he had dementia - this came as a shock to him. Robert was put in touch with the Alzheimer’s Society. A Dementia Adviser came to see him. Robert said “I’ve got their number I know I can chat to them if I need to.”

Every Monday morning Robert goes to Sainsbury’s pharmacy to collect his dosette box. He says: “The dosette box is marvellous, it controls me taking my medication when I need to.” Robert says: “I have a regular GP - touch wood I don’t need to go very often, I only go as and when I need to. My surgery are very nice, very supportive. I go if I need a repeat prescription. I have all my contact numbers in a list in my diary.”

Robert described how he received a letter from DVLA and had to go for a driving assessment. He went and he failed - he was devastated by it at the time, but he has accepted it. He now uses his bus service to get into town and also uses the local Link service to take him to appointments.

Robert uses his diary to help him decide what to do on a daily basis - all his appointments are in there. He keeps active and walks most days. He also sings in a local choir and is picked up and dropped off by other choir members: Robert says: “Going to the choir is a great joy, they are a lovely group of people.” Robert also goes to a meeting for people living with dementia which he thinks is good. Robert said “Every so often someone from the Alzheimer’s Society comes to see me to make sure I’m alright - that’s good. I also have a gardener.”

Roberts’s son oversees his money. He runs a spreadsheet and goes through it with him from time to time. Robert also tries to keep up a cashbook and “the cashpoint tells me my account balance.”

“I realise I’m fortunate to be able to be still living at home and have a normal life. I don’t usually think about myself as having dementia, I tend to forget about it and just get on with living my life.”

People with dementia and their carers have told us that they value early dementia diagnosis. This is what people who have clear, early dementia diagnosis from their GP have told us:

- They value honest, direct conversations about their dementia from their GP surgeries
- People can understand, and come to terms with, why they are having difficulties with their memory and/or day to day living
- They are put in touch with agencies that can support them and their carers
- People can be supported to manage risks
- People can make decisions about their future
- People’s families and the local community can support people living with dementia to remain active and participate in social activities



Next steps

Engaging with people about dementia services has always been a priority for Healthwatch Wiltshire. Since November 2015 Healthwatch Wiltshire has spoken to over 500 people gathering their experiences and views about support for people living with dementia in Wiltshire. We have produced a number of reports which cover key topics that people have told us are important. We have shared what people told us with the people who plan, pay for and run these services as well as Wiltshire's Health and Wellbeing board and Dementia Delivery board.

We know that it is important to people to know what has happened as a result of them sharing their experiences with us. We are already working with voluntary sector organisations and commissioners to respond to the issues raised during this, and our earlier, engagement. Our "Dementia - You said, we did" report will bring together the key messages that people have told us and the action that is underway to address these.

Acknowledgements

Finally, thank you! Healthwatch Wiltshire would like to thank everyone who took the time to contribute their views and experience through the many engagement activities as described.

Thanks also to our voluntary and community sector partners. Without their help to recruit people with dementia and their unpaid carers we would not have been able to reach the numbers of people that we did.

One in fourteen people over 65 have dementia at any one time and that's why 'dementia is everyone's business'. Healthwatch Wiltshire is always interested in finding out about your experiences and views on health and social care services. Please get in touch with us

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