

Alzheimer's Support

Barriers to Dementia Diagnosis in Wiltshire Survey Report

October 2012



alzheimers
support

Funded by

COMIC
RELIEF

Improving the lives of people with dementia in Wiltshire

Contents

Summary	page 3
Background and scope of research	page 4
Survey of Service Users - summary of findings	page 5
Survey of Well Older People - summary of findings	page 14
Focus Groups - summary of findings	page 17
Survey of GPs - summary of findings	page 20
Other health and social care staff – summary	page 29
Conclusions	page 32
Recommendations	page 34

About Alzheimer's Support

Alzheimer's Support is a voluntary sector organisation providing practical services to people with dementia and their family carers in East and West Wiltshire.

We have been operating since 1990 and around 450 people use our services in any one month.

Our services include day clubs, support at home, training for carers, carers' groups, Alzheimer cafes, Singing for the Brain, Movement for the Mind, counselling and Life Story groups.

This research was conducted by Development Manager Stephany Bardzil.



www.alzheimerswiltshire.org.uk

Summary

This report provides insight into why rates of dementia diagnosis in Wiltshire are so low. (Wiltshire was ranked 161st out of 169 PCT areas with 33% diagnosis rate in 2010/11.)

The report collates information from three surveys carried out by Alzheimer's Support between April and August 2012. They gathered information from people with dementia and their family carers, older people without a cognitive impairment, and health and social care staff including GPs.

The survey revealed delays in patients coming forward to seek help, with people waiting an average of 16 months before taking concerns to their GP. The biggest single cause of delay was the belief that "getting forgetful is a normal part of ageing".

It also revealed shockingly long waiting times for memory services in the county. People in Wiltshire are currently waiting around 9 months for an initial assessment at a memory clinic with a further 4 – 5 month wait to see a consultant for diagnosis. Current waiting times are significantly longer than in previous years and have led to some new patients paying to be diagnosed at private clinics.

Some respondents reported that GPs had not taken their symptoms seriously. GPs said that, while they would welcome more training and better diagnostic tools, they were reluctant to make referrals when waiting times for memory services were so long. "Disgraceful," "woeful," "unacceptable" and "dreadful" were among the words used by GPs to describe the current service.

When asked how matters could improve, GPs who took part in the survey were split between those who called for more funding of the existing service, and those who wanted to explore new ways to diagnose and prescribe in primary care.

Older people without a cognitive impairment were also surveyed and took part in focus groups. This part of the research demonstrated a need for greater understanding of the differences between early stage dementia and normal ageing. It also showed that those taking part were more aware of dementia than in the past and were keen to find out more about the condition.

Background and scope of the research

This research into barriers to diagnosis in Wiltshire was a response to published low rates of diagnosis in the county.

Wiltshire Primary Care Trust was ranked 161st out of 169 PCTs with a diagnosis rate of 31 per cent in 2009/10. This rose to 33 per cent in 2010/11.

As an organisation we were aware of long waiting times at Wiltshire memory clinics and receive frequent anecdotal information from carers and people with dementia about the delays and difficulties in obtaining a diagnosis.

The purpose of the research was to find out reasons for the low rates of diagnosis and to plan a project to help identify and support people in the early stages of diagnosis. The research and project are being funded by Comic Relief.

The research is based on three surveys:

Survey One (April and May 2012) asked Alzheimer's Support service users (people with dementia and family carers) in East and West Wiltshire to give information about their experience of diagnosis. It asked where they were diagnosed, how long the process took and whether they had delayed seeking help. It also asked how they felt about the diagnosis and about the kinds of information they were given during the process.

Survey Two (May and June) asked healthy older people for their views and perceptions of dementia, whether they felt people with a diagnosis of dementia could lead a good quality of life and how they might respond to concerns about memory in themselves or a family member.

Survey Three (July and August) asked professionals working in health and social care, including GPs, for their views about the barriers to diagnosis and how services could be reorganised to improve diagnosis rates.

In addition, three groups of well older people took part in **focus groups** dealing with questions similar to those asked in Survey 2.

Survey One – People with dementia or family carers

1.1 This survey was completed by 146 respondents. Most supplied their names and contact details.

Responses included:

110 from service users/carers, representing a 52% response rate from our service users or family carers (210 forms sent out via invoices, mailing list, or distributed at community services)

14 from care homes

16 from memory clinics

7 from website/requested from offices

1.2 Of these, 117 (or 83.5%) have, or care for someone with, a diagnosis of dementia. The others are awaiting diagnosis.

This diagnosis rate is well above the Wiltshire average of 33%. This was expected as those targeted were either known to us or to memory services, or self-selecting, and therefore more likely to have a diagnosis or experience of dementia services in Wiltshire.

Findings

1.3

Summary: This survey confirmed our suspicions that two key barriers to diagnosis are

- people not coming forward to report symptoms for many months, then
- facing long delays and waits when they did seek medical help.

The picture was not uniform with some people reporting a good or reasonable experience and others an unsatisfactory experience.

One disturbing pattern to emerge is that those most recently diagnosed, or still awaiting diagnosis at the time of the survey, had faced the longest waits.

1.4 **Delays in seeking help**

- People who now have a diagnosis waited an average 16.3 months before seeking medical help.
- 24 % waited more than two years to seek help
- 8.5% waited more than four years to seek help

- Conversely 14.5% sought help within two months of first noticing symptoms.
- People who were not yet diagnosed at the time of the survey reported a delay of 18.7 months before seeking medical help.

The most common reason for delaying, cited by 50 per cent of respondents in the diagnosed group, was “Getting forgetful is normal as you get older so I/the person I care for did not think it was a serious problem”

The second most common reason was “I/the person I care for did not acknowledge memory problems”

<i>Reasons for delaying:</i>	Total numbers	%
Getting forgetful is normal as you get older so I/ the person I care for did not think it was a serious problem	59	50.40%
I/the person I care for did not think anything could be done	11	9.40%
I/the person I care for was worried about the potential diagnosis and did not want to know	17	14.50%
I/the person I care for was worried about losing their home and independence	15	12.80%
I/the person I care for did not acknowledge memory problems	47	40.20%
I the person I care for did not want other people to know	18	15.40%
Other reasons for not seeking help	25	21.40%

1.4.1 Comments of people with memory problems who have not sought medical help:

“I have not spoken to my doctor about this as it is only names and faces (names of people, things, places) and I presume it is ‘my age’ (69).”

“I have never been diagnosed. I forget things but I have never asked for a diagnosis because I am too embarrassed.”

“I have a good memory of facts and experiences but a poor recall at the time I want them. The same applies to words and this can make it difficult in discussions to join in. Names and words often come back to me when I don’t need them later on.”

“I didn’t think my memory was bad enough to warrant a diagnosis. I lose things a lot but always find them and I forget people’s names. My memory is definitely worse than it used to be. I think I might mention it to my GP when I next visit her – if I remember!”

1.4.2 Carers too commented on the difficulties in getting people to talk to their GPs about memory problems:

“On visiting the GP I had to use subterfuge. On a visit for blood pressure tests I told the doctor what I was putting up with. He said bring your husband in on your next visit and I will talk to him without him being aware of anything. Result – referred to RICE at Bath (on the NHS contract that then existed.) Diagnosis should take place as soon as possible but in my experience it is not easy to get the patient to a doctor.”

“Because my wife was unwilling to admit to a memory problem it was not possible to persuade her to attend the GP’s surgery. After two appointments which I had to cancel because she refused to go, I finally attended on my own. GP was very helpful on this occasion and on the next when my wife did attend and was initially diagnosed with having a problem.”

1.5 **Long delays for memory services**

Delays were reported for both first appointments for an assessment with a memory nurse and for subsequent appointments for diagnosis by a consultant. Others reported delays, in some cases of several years, in getting their GP to refer them to memory services.

- On average, people waited 13.5 months for diagnosis after reporting concerns to their GP
- 14.5% reported waits of more than 2 years
- 5% reported waits of more than 3 years
- Once referred to memory services in Wiltshire, on average people waited 3.66 months for their first memory clinic appointment. NB This figure includes those who opted to pay for a private diagnosis rather than wait for a memory clinic appointment.
- Those diagnosed pre-2007 waited on average 4.8 months from first appointment to formal diagnosis
- Those diagnosed post 2009 waited on average 7 months from first appointment to formal diagnosis.

- 100% of those diagnosed in 2005 were diagnosed within 3 months
- Those still seeking a diagnosis [as of May 2012] were expecting to wait 8.75 months for their first memory clinic appointment. Those who had had a first appointment were expecting to wait 5.2 months for the formal diagnosis.

1.5.1 Respondents report appointments cancelled at very short notice, and instances where they are told to expect an appointment within a time frame of about seven months, only to find that the actual wait was much longer.

“We had a letter from the North Wilts Memory Service in July 2011 saying we were likely to wait 6-7 months so we decided to wait for this appointment. We are still waiting. [May 2012] I wish we had now gone for a private assessment.”

“It took 8 to 9 months to get the initial assessment with a memory nurse. Since then we have been referred on to an occupational therapist and have seen a nurse at Charterhouse. But now we have to wait around 4 months to see a doctor.”

“The GP was very quick to recognise we needed an appointment at the memory clinic. We have been waiting since October 2011. Two appointments were cancelled the day before.” [as of May 2012]

“My aunt’s GP referred her at the beginning of August 2011. I was told there was a 6 – 7 month waiting list. I waited until the 7 months had expired and got in touch again, only to be told the service had only just got to the beginning of June 2011. I complained by my MP and by a miracle an appointment was arranged for May 2012.”

1.5.2 A significant number of recently diagnosed respondents paid privately to be diagnosed at RICE (Research Institute for Older People) in Bath, rather than face long waits at Wiltshire memory clinics.

“We never wanted to go private but we felt we had no choice and I am so glad now that we did. Getting the diagnosis was a devastating blow, but at least we knew what was wrong at last.”

“We went to the GP in August 2011 and my father was put on the waiting list for the memory clinic. In January this year I phoned to see what was happening but they couldn’t say when he would get an appointment. I took Dad privately that same week and he was prescribed Aricept.”

“I paid for the diagnosis as the waiting list for the NHS was so long. It was worth every penny for the diagnosis is best done asap.”

1.5.3 Others self-referred to private clinics because their GP did not take their concerns seriously.

“The doctor said there was nothing wrong with mum, so I went to RICE.”

“My husband scored well on the mini mental test and the doctor said there was nothing wrong. Eventually we decided the only thing to do was to go private. We asked to go to the Bath Clinic and six days later we had a consultation and diagnosis of Lewy Body Disease.”

“My mum had Alzheimer’s and passed away two years ago. It took years and lots of pushing to get help and diagnosis through our surgery. When my dad showed signs of dementia we paid privately for a diagnosis to speed things up.”

“My mum was not diagnosed by her GP. He didn’t seem to understand it. I pushed very hard for her to go to RICE which eventually happened. I recognised signs which mother-in-law had had so I was a step ahead.”

1.5.4 A great variation was reported in the response of GPs to concerns about memory problems. Some were found to be supportive and helpful, others unresponsive.

“To say we had inept and apathetic support is an understatement. I had to chase and make numerous phone calls to secure some degree of acknowledgment from the GP who in my opinion was patronising and had no empathy skills. My husband was left in the surgery for five hours when attending for a blood test. No-one had the sense to ask my husband why he was there. We are now with another surgery who are totally supportive.”

“I wrote to mum’s doctor – information ignored. I took mum to her doctor’s and was told all the tests had been done and there was nothing wrong.”

“My GP was not to be bothered. So six months went by and my wife, when visiting the GP for something else brought up the subject again and once again not bothered. However two years on we made an appointment and asked specifically to have a referral done which he then accepted. But two years had already gone by so we felt that early treatment could have helped sooner.”

“The GP told me there was nothing the matter with mum, she had done all the tests and Mum was fine. The doctor was quite definite and dismissive of my concerns.”

“We had to swap GPs to get anything done. I asked to be referred straightaway. I think you should be diagnosed as soon as possible, and early diagnosis is essential to get drugs and help.”

1.5.5 More positive experiences were also reported:

“My father does not feel that he has serious memory problems and refuses appointments. The memory clinic team are visiting him at home to get a better picture and do blood tests. Dr Hamid has agreed to a visit at home in the next few weeks to form a diagnosis.”

“I can only sing the praises of those people we have dealt with from Dr Rowlands at the surgery to Prof Jones at RICE. I am in regular contact with Trowbridge mental health team and social worker. I have no complaints.”

“The GP was very helpful. I saw a notice up in the doctor’s surgery and I was a bit concerned about my husband so I rang the RICE Clinic and they made us an appointment. This was about four years ago. It is best to be diagnosed in the early stages. It has helped being on Aricept. -

“Dr Meaden was helpful from the start and arranged an appointment to see Mr Kipps. He made arrangements to go to Southampton for brain scan, had quick return trip for more scan then went to see Mr Kipps who

explained the Lewy Body Disease. At all times everything was explained to me."

- 1.5.6 Some respondents made other comments about how the diagnosis process could be improved. The most common complaint was that letters were sent to the person with the memory problem despite a family member or carer requesting correspondence was sent to them.

"I am still astounded at the poor connectivity/sharing of information between various institutions eg appointments missed because letters were sent to the patient not to me, despite having Power of Attorney."

"The memory test involved complicated instructions and did not ensure that instructions had been understood, this was difficult for a 90 year old. Assessors did not check hearing aids were both working and made little adjustment for a very hard of hearing patient. I could have got better score for my mother simply by talking clearly and looking directly at her face."

"I was disappointed the radiographer took the word of a confused old man not to continue with the investigation. I was upset I wasn't included so I could have explained this confusion and there seen the investigation followed through to its proper conclusion."

"An appointment was received for a consultation at Charterhouse. Mum, who is frequently unwell, could not attend and has very poor mobility. A home visit was requested but refused. When people have poor physical health as well as dementia the services need to be more flexible."

- 1.5.7 When asked about support and treatment following diagnosis, the picture again was mixed.

- 59.8% are receiving medical treatment as a result of diagnosis.
- 64% of people are receiving regular dementia reviews.
- 66% of people were told about services and support at diagnosis.

"Diagnosis greatly helped in securing suitable accommodation via local authority and made management of patient/carer roles a lot easier."

“The barrier between medical health and mental health need to be removed, it’s too easy to be passed from one to the other. Mental health issues make medical health problems worse and vice versa. We need a team who can cope with both!”

1.5.8 When asked about their reaction/feelings about diagnosis (from a list of options of which they could select more than one):

- 60% said they had expected the diagnosis.
- 42% said it was a relief to know
- 47% said it the diagnosis came as a shock
- 39% said it was a devastating blow
- 40% said it made it easier to plan for the future
- 56% said it made it easier to explain to family and friends
- 81% said they had told other people about the diagnosis

1.5.9 When asked for ‘other feelings’ at diagnosis, comments included:

“Relief that I could stop fighting”

“Frustration about lack of consultation or access to experienced medical advice”

“Sadness”

“Sadness of loss of person as she was”

“Helpless and frustrated”

“Completely lost”

“Some anger at what seemed to be limited resources to seek cures”

“Feelings of bereavement without the closure”

“Pathways for help not adequately explained to established and everything appears very fragmented”

“It was not part of the retirement plan to become a 24/7 carer”

“Helplessness for my own life from time to time”

“Frustrated at poor services”

“Anger at extended family who refused to help or acknowledge the problem”

“Anger at family and friends of patient who turned away/didn’t face up to difficulty and didn’t share concerns with next of kin”

“I will never forget Mum’s phone call. My whole world stood still as she spelled out the word Alzheimer’s Disease. I was frozen when she told me the diagnosis.”

“Definitely worth being diagnosed, much better knowing how to deal with it.”

Survey Two - 'Well' older people

2.1 Survey Two had 84 respondents, all individuals over the age of 65 without any cognitive impairment. The average age of respondent was 74.5 years old.

These were from University of the Third Age (33), Probus Club (7), church groups (4) AgeUK (11), our website (9), day centres not run by Alzheimer's Support (4), focus groups (14)

2.2 When asked: How do you think you might react if you started to experience memory problems in the future?

Try to ignore it - it is a normal part of growing older	27.90%
Try to ignore it - there is no treatment that can help	2.90%
Keep my fears to myself	14.70%
Discuss with family and/or trusted friends	60.20%
Take my concerns to my GP and take his/her advice	70.60%
Take my concerns to my GP and insist on a referral to specialist memory services	20.50%
Seek information online and from books	36.70%
Talk to specialist agency e.g. Alzheimer's Support	35.30%
Don't Know	5.90%
Other	4.40%

2.3 When asked: How would you respond if a close friend or family member started to show signs of memory loss?

Do nothing - it's none of my business	2.90%
Talk to them about concerns	48.50%
Talk to their family or close friends about concerns	64.70%
Seek information online or from books on how to support them	25%
Talk to a specialist agency e.g. Alzheimer's Support	41.20%
Don't know - it would depend on circumstances	27.90%

2.4 When asked: Is it possible to live well with dementia?

- 33.3% said YES
- 13.2% said NO
- 48.5% said DON'T KNOW

2.5 When asked: Do you think there are any ways which we as a society can improve the quality of life for someone with a diagnosis of dementia

- 55.9% said YES
- 1.5% said NO
- 39.7% said DON'T KNOW

2.6 When asked for ways to improve quality of life the following suggestions were made:

“Surround with family and friends. Keep normal, everyday conversations.”

“Support for the carer is vital. Early intervention is essential to establish relationships and routines that might help when things get really tough.”

“A person with dementia can attend a club to give the carer some respite”

“Support groups for the dementia sufferer and carers. GP awareness, approachable professionals. Practical advice”

“Provide professional carers who understand dementia and can also support the family. Use male carers when this is the better option. I asked for two years for this for my father and only in the last 6 weeks did it happen – he would not do anything for a female carer or me. Doctors need to be proactive if the person goes for help not remove them from their list once dementia is confirmed – this was also my experience.”

“Keep the person within the family as long as possible.”

“More information for family and person themselves”

“Provide electronic aids”

“Treat them with respect and kindness. Talk to them about their memories of the past”

“Talk to others. Join a group. Support carers”

“Understanding”

“Don’t fuss and hurry them”

“I’m sure early diagnosis will help”

“An early diagnosis will be beneficial to plan the way ahead for all concerned”

“Not to shun the situation”

“By interacting with groups, eg hobbies”

“Early diagnosis is essential. Talking about the condition openly, encouraging interaction with groups and friends”

“Kind and sympathetic carers”

“Specialised services”

“Major funding for support groups. Provide a wide range of activities which may revitalise memory so that there is some sort of anchor. Music is essential.”

“Day care centres to stimulate interest. Upkeep of independence. GPs to be upgraded in knowledge and special training for carers in dementia care. Open awareness of dementia in society to take away the stigma and fear of dementia in all its forms.”

“More people should be trained in how to deal with dementia, nurses, carers, parents, children can all benefit from learning how to handle the situation , as so many people are unaware of the signs.”

“There should be much faster diagnosis and referral to specialists. Early medication, no postcode lottery. Many more specialist care homes.”

- 2.7 It should be noted that although a high percentage in Survey 2 said they would take their concerns to their GP (70 per cent), this does not match the actual behaviour of those diagnosed in Survey 1, who waited on average at least a year before going to their GP.

Focus groups findings

- 3.1 We conducted three focus groups of well older people, each with around 12 participants. Two were in sheltered housing settings and a third was at a regular village social group. The people attending the focus groups were all over 65 and felt comfortable in each others' company. The conversations were recorded.

Summary of findings

- 3.2 People were typically unclear about the difference between normal ageing and dementia. Many reported instances of forgetting things, or walking into rooms forgetting why they were there, and were unsure of whether that could be the start of a more serious condition. Many expressed a fear of dementia, especially if it had been present in their own families.

"Sometimes I stand there and I just can't think where I put that thing. People don't realise that it creeps up on you as you get older and perhaps that's another reason why they don't go to the doctor."

"You lose the thread of what you are talking about. I suppose it's knowing where you need to go and ask somebody what's going on. I think a lot of people don't want to think that's what their problem is. They don't want to face it."

People were typically unaware of the different types of dementia, or that there were different types.

Some were surprised to learn there were drug treatments available.

People mostly know of examples of people who had had the illness and expressed great sympathy for their plight, which was described as unremittingly awful. Most had a poor view of residential care.

Virtually everyone who took part felt the illness was worse for the family carer than for the person with dementia.

"I think it's sad for the families" "Much worse for the families"

- 3.3

However, there was agreement that awareness of dementia had increased dramatically in recent years and people felt pleased to be part of a generation which would deal with dementia better than in the past.

“I do remember a family a long time ago when I was young and the lady used to put the wrong clothes on and used to wander around. It was very sad and you did see people taking the mickey. You felt sorry for the family but you had no understanding that this was a condition that you could treat.”

“I think people are frightened as well. They don’t want to face it so they put off as long as they can. It is frightening and when you go back years they were called ‘mental’ weren’t they, and that’s another stigma.”

One group had watched a storyline in Coronation Street which they felt dealt with a case of early-onset dementia sensitively and which had raised their awareness of the issue.

- 3.4 When asked how life could be better for people with dementia, suggestions included spending time with people and their carers to come up with a list of the person’s interests and photographs to aid conversation – life story work suggested by someone who had never heard of a ‘life story.’

Slightly in contradiction to the feeling that society was making progress in terms of understanding, there was a feeling that in the past we had better support structures in place.

“We’ve slipped back a long way in our community centres. We should be building more of these places where people would go to and get all those services and where people could support each other. It would solve a lot of things instead of having all these pockets of things all over the place and everything spread out but people not feeling they can go there.”

“I remember my uncle. He would go to the paper shop and luckily there was this young lad who really knew him and he would bring him home. That wouldn’t happen now.”

Participants felt strongly that social stimulation was very important. Some cited examples from their own experiences where people had ‘deteriorated’

because of a lack of company and stimulation that perhaps would have been available in the past.

“What you need are people that go round and hold quizzes and that sort of thing to try to stimulate people in the earlier stages, to keep the brain active.”

“They should be kept, for the want of a better word, in ‘normality’ for as long as they possibly can.”

“That’s why I don’t think it’s good sticking people in homes where everyone is like it as then they are all going to slide down.”

In the sheltered settings the group bonds and looking out for each other in older age came across strongly.

“It’s important that if someone in one of these sheltered situations is going down that way, we all include them and bring them out as much as possible. I think it’s important that they stay where they are for as long as possible.”

“We have a dear friend here whose memory is not very good and it would be good to be well informed so we can to support him and understand what’s happening.”

3.5 On the benefits of diagnosis there was no clear response

“I honestly don’t know”

“I think sometimes it’s not good to tell the person.”

“For the relatives it’s a good thing because they understand what is going on.”

“If it were me I would want to know. I would want to be told so I could deal with it.”

3.6 Participants were mostly very open and appeared to welcome the chance to discuss dementia.

“We’ve been here seven years and this is the first time we’ve every talked about dementia.”

“It’s best to get it out in the open isn’t it?”

Survey Three - GPs responses

- 4.1 This survey was circulated to health and social care staff in Wiltshire. They were not asked for the names, but for job areas.
There were 102 responses in all, including 33 from GPs.

The GPs' responses are given in the tables below.

4.2

Please rate your knowledge of dementia	Numbers	%
Very good	1	3%
Good	13	39%
Adequate	16	48%
Poor	3	9%

4.3

How important is it for people with dementia to receive an early diagnosis?		
Very important	23	70%
Moderately important	10	30%
Not important	0	

- 4.3.1 When asked for reasons for their answers, those who said early diagnosis was 'very important' added the following comments:

"Uncertainty is worse than not knowing"

"So that the patient can consider care options, drug treatment and family support"

"To enable future care to be planned appropriately"

"Access appropriate health care and support"

"Best practice, use of medication earlier, support services"

"Help them and families plan for future, getting necessary help early on"

"To access medication"

"To organise their lives"

"Early recognition so that support, planning and treatment can be put in place"

"Early diagnosis = early access to Aricept and better response to treatment."

*“Reassuring for family and patient to have an explanation for behaviour.
 “Early intervention with medication if appropriate.”
 “I think it’s important to equip patients and their families with information to make good decisions about their future. My GP colleagues disagree with this view.*

4.3.2 Those who answered ‘moderately important’ made the following comments:

*“Not necessarily helpful in very early stages as no treatment or social support generally necessary, worry and live with diagnosis for longer”
 “Limited evidence for benefit from early diagnosis”
 “Can cause more anxiety, especially if support is not present and no treatment is offered.”
 “Diagnosing dementia in the very elderly who are in care already might not be beneficial for the patient re funding issues.”*

4.4

When should a person get a diagnosis of dementia? (NB some respondents ticked more than one box)		
When they or their family are first worried about their memory	13	39%
When symptoms start to interfere with daily life	18	55%
When there is an appropriate drug treatment	5	16%
When there is local support in place	2	6%
Other “when diagnosis is firm”	2	6%

4.4.1 When asked for reasons for their answers, those who said diagnosis should happen ‘when symptoms interfere with daily life’ added the following comments:

*“Minor memory worries are very common”
 “One of the difficulties we have is making an accurate diagnosis. We will see many older people worried about their memory and only a few will actually have dementia.”
 “It is hard to define if a person is getting dementia in the early stages. A wait and watch approach is often adopted.”
 “We are all forgetful. Many people present with memory problems and it’s not logistically possible to assess fully at first presentation. A short*

period of watchful waiting is appropriate. Once symptoms start to interfere with daily activity we need to investigate them.”

“More people are worried about their memory than have dementia. I would use a similar framework to that for defining alcoholism ie when it starts to impact on someone’s life.”

4.5

Do you think waiting times for memory clinics are:		
About right	1	3%
Too long	32	97%

4.6

Do you think health staff have sufficient training in dementia awareness to be able to support people effectively at all stages of the diagnosis process?		
Not enough training	20	61%
About right	11	33%
Don't know	2	6%

4.7

Do you think people should pay to be diagnosed at private clinics?		
Yes	0	
No	28	85%
Maybe	4	13%

When asked to give their views about barriers to diagnosis in Wiltshire, the majority of GPs cited long waits for memory services.

“Very, very long waiting times for patients to be seen by old age psychiatrist/memory clinic for an assessment (minimum waiting time 8 months!)”

“Poor access to assessment services”

“Memory clinic waiting lists”

“Access to secondary care”

“Access to the service !!!!!!!!!!!!! Referral time wait can exceed 6 months.”

“Memory clinic wait times”

“Six months to get a consultant assessment”

“There is a year wait to see the memory clinic. It is a disgrace and I dread having to refer patients because of this.”

“Delay in appointments for memory clinics”

“Excessive waits”

“The wait is very long. I think some GPs put off referral”

“Lack of timely access to a memory clinic for diagnosis”

“Long waiting times to see specialists. Lack of follow up for mild cognitive impairment leads to patients with early dementia not being followed up”

“Long waits of approximately 6 months for memory clinic appointments which patient can then forget to attend”

“Long waits for memory clinics. Dementia drugs have been consultant only drugs because of their cost”

“Woeful mental health provision from AWP. System should revert to primary community care with joint working from social services. Money should be vired from AWP”

“Access to specialist care”

“Memory service is dreadful. I referred someone with a full set of screening investigations including CT. It took so long for an appointment that the memory service said that the tests were out of date and needed repeating!!”

“Fear of diagnosis by professional due to difficulty accessing support, meds etc for patient and family”

“No treatments available in early cognitive decline”

“Lack of secondary care facilities”

“Inadequacy of local mental health services. Too long to wait”

“Poor access to memory clinics. Complex referral process.”

“Waiting times for investigations and clinic appointments”

4.8 Some GPs pointed to difficulties in knowing which diagnostic tools to use and to general difficulties in identifying early stage dementia

“Unclear which memory assessment/cognitive test to do”

“Fluctuations in memory ability are common in the early stages, so they may be ‘good’ when you assess them. A GP cannot easily rule out co-

existing anxiety/depression which if tested may improve concentration/memory."

"No universal accurate screening test, both GPCOG and MMTS have their limitations"

"Patients presenting with other conditions"

"Primary care screening tools often patients score 'normal' when they are not. Difficult to distinguish early dementia from normal ageing effects on memory and also co-existing depression and worry about memory loss."

"QoF requirements might lead to other diagnostic codes being used in early diagnosis to avoid having to jump through excessive tick box exercises when initially we want to monitor the situation."

"[Lack of]Enthusiasm of clinicians"

"Lack of time and resources"

- 4.8.1 A much smaller number (9%) highlighted the reluctance of patients to seek help for memory problems.

"Stigma although this is not specific to Wiltshire. Reluctance from patients to see specialists, social isolation makes access to care difficult."

"Patients unwilling to address"

"Fear of diagnosis by the patient"

- 4.9 **When asked 'How services could be reorganised' to improve diagnosis rates GPs were divided as to the best course of action.**

- 4.9.1 Some called for shorter waiting times and more funding of the existing service.

"Fund more time at appropriate clinics"

"Memory clinic more available and much shorter wait times. Also more active follow up when diagnosed."

"Seen earlier in clinics. 12month wait is unacceptable."

"Fund the service !!!!!!!!!!"

"Shorter waiting lists for assessment. No point in the GP making relevant diagnosis and waiting >6 months for memory clinic appointment."

“More clinic, more doctors, more money”

“Quicker access to memory clinics”

“Employ extra staff at the memory clinics to get rid of the backlog”

“Better funding for secondary care”

“Shorter wait times especially as we have done all the work beforehand with blood tests and scans and dementia screening tool to assess severity. Government push public for earlier diagnosis but then no resource to get that done”

“I would prefer investigations to be organised by the memory/dementia clinic to prevent inappropriate tests”

“More memory clinics for assessment”

“More memory clinic appointments.”

- 4.9.2 Others called for a re balancing of responsibilities between primary and secondary care with a greater role for GPs in the diagnostic process.

“Relocate whole process to primary care. Attached social worker to liaise/co-ordinate with local voluntary services. GPs should prescribe dementia medication.”

“Once the dementia drugs are off patent, I think GPs will be encouraged to prescribe them and patients will be given the diagnosis and treatment much sooner.”

“Trained nurse specialist attached to each GP practice”

“Assessment by specialist nurses, backed by a doctor”

“An agreed local pathway between primary and secondary care for diagnosis and treatment”

“Develop a local enhanced service so work can be done at practice level. I feel secondary care resource should be used for severe disease. In particular we need shared care guidelines for prescribing (with funding to follow)”

“A clear local diagnostic pathway would be useful with a telephone advice line for consultant advice, maybe on a dedicated day for the consultant.”

“Diagnosis and prescribing should be done by GP. Services for patients and family should be more plentiful, more varied and more located in communities. “

“Outreach. Members of memory clinic should come to the GP surgery to review any patients GPs are concerned about, without needing to refer each one. Also to talk about early management strategies for dementia.”

“I think there need to be more local dementia service available - with a shorter waiting time - maybe a GPSi Dementia could run a clinic - with support from a local specialist consultant.”

“Improve GPs’ knowledge, implement referral pathways and resource timely specialist reviews”

“An alternative could be to improve primary care training with proper resources so primary care can be better at making a reasonable diagnosis of early diagnosis and know what services are available for patients at an early stage. No GP wants to make a diagnosis of a life threatening illness when the patient doesn't have it.”

4.9.3 Other suggestions included:

“Annual screening if services set up to cope, educating health professionals”

“Regular health checks”

“Proper exact diagnosis, not just memory impairment”

“55 years onwards review screening. National strategy.”

“Use of the best screening tools (and appropriate training in their use)”

“More community services and support. More psychiatric services.”

4.10 When asked to suggest ‘Ways to encourage more people to be diagnosed’, the following responses were received:

“A national advertising campaign may help to reduce fear and stigma”

“General media and recently public figures are providing cues for this which previously did not exist.”

“TV ads seem to have increased/quicken presentation with possible early signs of bowel and lung cancer. Similar adverts for dementia?”

“TV media campaign. If memory failing seek early appointment with GP. Aricept very early on seems to be more effective”

“Awareness campaign of symptoms and of available support, to show that independence and enjoyment of life can be maintained for longer than people think.”

“Educate people about normal memory changes and signs of possible abnormal changes.”

“Demystify the condition. Focus on ways to improve cognitive function rather than concentrating on the disability. Have roadshows. Self assessment. Post out MMSE or equivalent to all patients over 75.”

“Public awareness”

“More publicity”

“Encouraging earlier presentation. Destigmatising”

“Posters in doctors’ waiting rooms, and leaflets for patients to read while waiting for appointments.”

“Promote dementia as an illness rather than a shortcoming”

- 4.10.1 A significant minority of GPs (19%) felt it was not a good idea to encourage people to seek a diagnosis until the service was in place to deal with additional numbers.

“Public awareness campaign along the lines of the recent cancer ones but only once the suggestions above in Q9 have been implemented”

“Only ok if there is a service to back this up.”

“I wouldn't do anything more at present until the memory services can cope - why just add to frustration and worry?”

“Until there are more services there is no point.”

“Public health promotion, though as services are so scanty in south Wiltshire this would swamp the referrals and consultation process. So at present we GPs feel quite demoralised by making early diagnoses and then not being able to offer anything to the patient.”

Other comments in this section:

“Very early diagnosis not helpful in my opinion. Huge level of anxiety currently in older worried well, currently clogging pathway seeking unnecessary cognitive testing”

“People do seek diagnosis when they are ready for it - the delay is in waiting to see a specialist.”

“I think if people thought their GPs were more responsive to their concerns - they would come earlier. But at the moment - word of mouth probably communicates that there is about a years wait for review.”

Survey Three – other responses

5.1 In addition to the GPs, Survey 3 was circulated to other health and social care staff in Wiltshire.

73 non-GP responses were received, from:

- 4 Memory nurses
- 28 Other nurses
- 13 Social workers
- 5 Occupational therapists
- 4 Old Age Psychiatrists/Memory specialists
- 4 Care workers
- 3 GP receptionists/practice managers
- 7 Dementia support workers
- 6 Others, including an A&E doctor, a consultant in palliative care, a bereavement support co-ordinator, a psychotherapist, a Singing for the Brain co-ordinator and a hospital support worker.

A breakdown of responses is given in the table overleaf.

5.2 Of the total

- 96% agree that the dementia awareness training is ‘insufficient’
- 96% agree that it is ‘very important’ to get a diagnosis
- 65% say waiting times are ‘too long’
- 37% say they ‘do not know’ what waiting times are like

5.3 Of nurses not working in memory clinics

- 86% say their knowledge of dementia is ‘adequate’
- 18% say their knowledge is ‘poor’

*“I have never received any training with regards to dementia. I would anticipate an early diagnosis would be good for the patient and family”
- nurse*

5.4 This survey produced some insightful comments from staff involved in memory services:

“Memory clinics fall into the mental health services and therefore the paperwork and assessments are the same as for an acute mental health patient...this is a time consuming system.”

“It takes twice as long to record the assessment as to do it.”

5.5 It is also interesting to note comments of staff who are not experts in this field, who but bring a different perspective to the subject.

“Maybe now is the right time for the development of a palliative care approach to dementia as happened in cancer care 30 to 40 years ago.”

- psychotherapist

“Perhaps some development of psychological/supportive therapy services for anyone affected by a diagnosis of Alzheimer’s.”

– psychotherapist

“I never thought about a cervical test until I get a letter inviting me for a test. I think it would be a great idea to send similar invitations to people to come to a session to inform them about dementia.” – social worker

“Ensuring health and social care professionals encourage people to talk about their concerns over deteriorating, significant memory problems.”

– social worker

“Place memory health specialists within primary care for the initial screening, say GP surgeries.” – social worker

“Drop in sessions with the emphasis on fun – come and have your memory check/tea and cake/dancing.” - nurse

*“Clinics at GP surgeries especially for worried patients and families”
- nurse*

	Rate your knowledge of dementia				How important is it to be diagnosed ?			Do staff have enough dementia training?			Are waiting times... ?			Should people pay for private diagnosis?		
	Very good	Good	Adequate	Poor	Very important	Moderately	Not important	Not enough	About right	Don't know	Too long	About right	Don't know	Yes	No	Maybe
Memory nurse	4	2	2		4			3			4			4		
Other nurse	28		6	24	5	3		28			12		12		16	9
Social worker	13	3	3	6	1			10		3	10		3		9	4
Occupational therapist	5	1	1	3				4	1		2		3		3	2
Old age psychiatrist	4	3	1		4			4		4					3	1
Support worker	7	3	4		7			7		4		3	1	5	1	
Care worker	4		3	1	4			4		2		2		3	1	
Practice manager	3	1			3			2	1	2		1		2	1	
Other	6		2	3	6			6		4		2		5	1	
Percentage or total		17%	30%	53%	8%			96%			61%		37%		69%	28%

Conclusions

1. A significant factor in delaying diagnosis is people not coming forward to seek help, with respondents waiting on average more than 16 months before seeking medical help. The most common reason, given by just over half of all respondents, is thinking the symptoms are normal signs of ageing. Others do not want to acknowledge the problems because they are fearful of the future.

Focus groups too, reveal a level of confusion between normal ageing and the more serious symptoms of early dementia. Most people who took part agreed they would be unlikely to seek help for memory loss because they would assume forgetfulness to be usual in older age, and because they did not feel anything could be done to prevent cognitive decline in older age. Well older people completing Survey 2, however, reported they would seek medical help and would talk to friends and family.

2. People with suspected dementia are currently waiting unacceptably long periods for memory clinic appointments in many parts of Wiltshire. The average time from reporting problems to a GP and getting a diagnosis is 13 months. (This includes people who gave up waiting and paid for a private consultation.) Around 14.5 per cent of people waited two years or longer for a diagnosis.

This situation has become significantly worse over time, with respondents diagnosed prior to 2007 reporting shorter waiting times. The most recently diagnosed and those still awaiting a diagnosis, are experiencing the longest delays. Several people who completed the survey form in May 2012 had been waiting since July 2011 for an initial appointment at the memory clinic and still had no date.

Looking back, of those diagnosed in 2005, 100% reported receiving a diagnosis within three months of being referred by their GP. This was a small sample but suggests that the system, which at that time allowed

NHS referrals from Wiltshire to the Research Institute for the Care of Older People (RICE) clinic in Bath, was meeting the levels of demand then experienced.

3. GPs report high levels of frustration at the waiting times for memory clinic appointments. Ninety-seven per cent said waiting times were too long. Adjectives used by GPs to describe the current situation include “woeful”, “inadequate”, “disgraceful”, “dreadful” and “unacceptable”. Some report a reluctance to make referrals because of the long waits.

GPs offer two broad suggestions when asked how the service can be improved. Most call for more investment in existing services in secondary care (memory clinics). Others advocate a rebalancing between primary and secondary care so that more diagnosis and prescribing can be carried out in GP surgeries. Those suggesting the second route also call for more training and better diagnostic tools: *“No GP wants to make a diagnosis of a life threatening illness when the patient doesn't have it”*

A note of caution is sounded by a significant minority of GPs who say there is ‘no point’ encouraging people to seek help for memory problems until the service is able to cope with them.

4. Too many people are paying for consultations at private clinics or research centres as the only way of getting a timely diagnosis.
5. Some GPs have difficulty identifying some forms of dementia or distinguishing it from the normal ageing process. This is implied in a number of the diagnosis stories from patients who were told by their GP there was ‘nothing wrong’, often before a rare form of dementia was diagnosed in a specialist clinic. Of GPs taking part in the survey, only one claimed to have ‘very good’ knowledge of dementia. 42% said their knowledge was ‘good’, 45% said it was ‘adequate’ and 9% that it was ‘poor’.

The Next Steps

1. Increase public awareness of dementia through a media campaign focusing on case studies. The campaign should highlight:
 - the differences between normal ageing and dementia
 - the benefits of an early and accurate diagnosis
 - the possibility of living well with dementia.
2. Target awareness-raising among older people in projects centred in GP surgeries and sheltered housing schemes.

Alzheimer's Support will take a lead in the above recommendations steps through our Comic Relief funded project.

Other recommendations:

3. Set an ambitious but achievable target for dementia diagnosis in Wiltshire, and make achieving this a priority for the new Clinical Commissioning Group.
4. Invest in appropriate memory service resources to improve the experience of people presenting with symptoms, in particular to speed up the process and end the long waiting times before assessment and diagnosis. When a referral is made to a specialist memory service, appointments should take place within four weeks. Consider re-commissioning a service from RICE in Bath or extending Choose and Book so that patients can exercise choice.
5. Seek out and listen to the views of carers and people with dementia as part of the commissioning process.
6. Reconsider where dementia is treated within the health service, with a view to redefining it as a long term condition rather than as a part of mental health.
7. Ensure support is available for the newly-diagnosed and their family carers by investing in dementia advisors and community services

including memory cafes, peer support groups, day care and support at home.

8. Encourage dementia awareness training for all health and social workers who come into contact with people with dementia.

9. Improve training for GPs who need to have the confidence to diagnose where appropriate and refer to secondary care where appropriate. GPs need to be seen as gatekeepers not barriers to diagnosis.

10. Convey GPs' concerns about diagnostic assessment tools to national bodies.

11. Review outcomes annually.