



# Dementia Engagement Report

An  
independent voice  
for the  
people of Wiltshire

# Contents

<b>Overview of Dementia Engagement</b>	<b>Page 3</b>
<b>What we did</b>	<b>Page 4</b>
<b>Who we talked to</b>	<b>Page 6</b>
<b>Key Messages</b>	<b>Page 7</b>
<b>Next steps</b>	<b>Page 12</b>

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# Overview of dementia engagement


Healthwatch Wiltshire (HWW), along with voluntary sector partners, has been talking to local people about their experiences and views of dementia services in Wiltshire. This report provides information about the outcomes of engagement which has been carried out since November 2014.

HWW has designed an approach so that it can gather information about people's experiences and views of dementia services. The aim is to analyse this information and reflect it back to commissioners and providers of services. HWW will highlight good practice and areas where people have poor experiences so that these can be addressed. We intend to continue to talk to people throughout 2015 and 2016. This is our first report based on our wider engagement on dementia.


Wiltshire's Dementia Strategy was approved by the Health and Wellbeing Board in July 2014 with its purpose to provide the strategic direction for commissioning bodies to support people with dementia and their unpaid carers.

You can read the strategy on the HWW website here

- <http://www.healthwatchwiltshire.co.uk/wiltshire-dementia-strategy>



Healthwatch Wiltshire is an independent organisation which has an important role in assessing the quality of health and social care services today and influencing the design of services for tomorrow.



“More information is needed about support services - what's available, what's coming up, facilities”  
Devizes Workshop

# What we did

## 1. Dementia Monitoring Workshops

Our aim was to involve at least 100 people in monitoring the strategy over its life through workshops held around the county (12 per year). The first workshops were held in February. We held workshops in Malmesbury, Devizes, Salisbury and Westbury. We also visited a memory group in Tisbury who would have found travel to Salisbury difficult. The sessions began with a short introduction to HWW and explained that we have brought together voluntary and community sector groups in Wiltshire to form a partnership that will make sure that the new Wiltshire dementia strategy is delivering in practice what it promises on paper. We explained that the partnership includes representatives from Alzheimer's Support, Alzheimer's Society, Age UK Wiltshire, Age UK Salisbury District, Carer Support Wiltshire and Swan Advocacy and that these organisations are promising to work together to share knowledge about local services.

For the first workshop we focussed on 5 of the outcomes from the Wiltshire Dementia Strategy.

- I am encouraged and given the opportunity to have a healthy, active lifestyle.
- I was diagnosed early and with the correct medication and treatment package.
- I understand the implications of my diagnosis in order for me to make good decisions and provide for future decision making.
- I get the treatment and support which are best for my dementia and my life.
- Those around me and looking after me are well supported

We developed these outcomes into discussion questions in order to gather information about people's views and experiences:

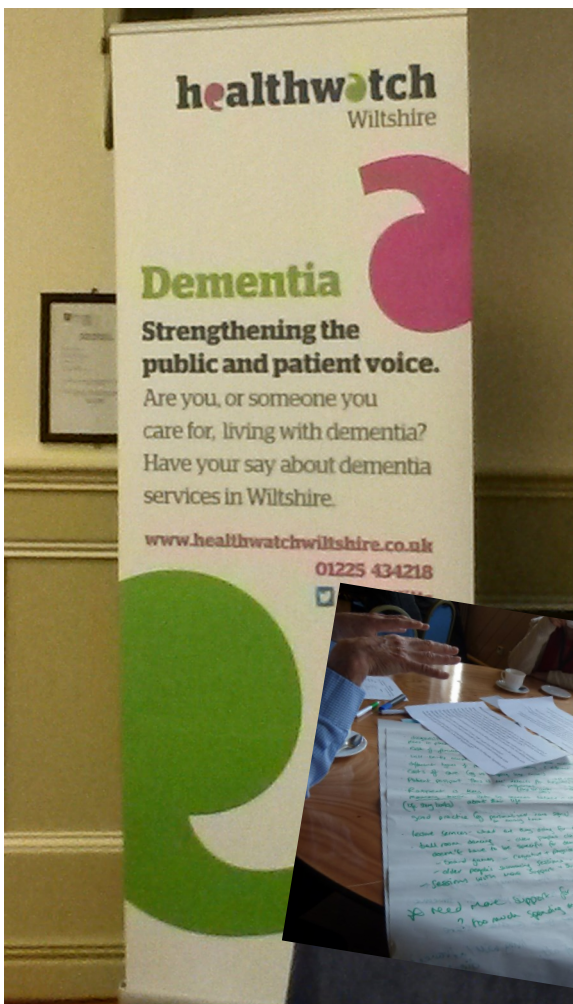
1. What sort of things can people with dementia do to keep active and healthy?
2. Who, if anyone, has encouraged and supports people with dementia with this?
3. In your experience are people with dementia diagnosed early?
4. How have people with dementia been diagnosed?
5. In your view are people with dementia given appropriate medication or treatment?
6. What sort of decisions do you think are important to people with dementia now and in the future?
7. What support and treatment do you know about that is available for people with dementia?
8. Do you feel that this is adequate? If not, how could this improved?
9. What do you know of now that is available to support carers of people with dementia?
10. Is there anything else that you think should be available for friends, families and carers of people with dementia to be well supported?

We also said to people that we were interested in anything else that they wanted to say about dementia and that there was no need to stick to the discussion questions. The workshops split into groups of 6 -10 people for table discussions which were facilitated and recorded by HWW.

## 2. Dementia Consultation

From 1<sup>st</sup> December - 10<sup>th</sup> March HWW independently facilitated a public consultation on behalf of NHS Wiltshire CCG about where to permanently locate specialist dementia hospital care in Wiltshire. We held 3 public meetings in Trowbridge, Salisbury, and Devizes. We also presented at the Trowbridge Area Board meeting in January on the proposals and received feedback. We also provided plenty of other opportunities for people to contribute to the consultation if they were unable to attend, or chose not to attend, a public meeting. We attended 22 other meetings and events in local communities including memory cafés, day centres, and older people's forums. A couple of community based groups and a local charity discussed the consultation and sent their feedback direct to HWW. At all of the meetings and events we arranged or attended we invited discussion and recorded what people told us. We also invited people to complete the survey.

During this consultation, as well as asking people about the location of specialist hospital care, we asked people what they thought about the care that is needed to support people with dementia to live at home or closer to home. We also collected any other information that people told us about their experience of services for people living with dementia. This feedback has also been included in this report although there is a separate report about the public consultation. If you would like a copy of this report then please contact HWW.



## 3. Other Engagement

HWW has noted any views about dementia that have come up during its engagement work about Better Care. We have noted views of people who have called us for advice or to give their views about dementia. We also noted what people told us about their experiences of dementia at other events, for example, attending hospitals and community events.

HWW has also reached people through its engagement at Acute Hospital Trusts and through Community First's Community Organisers (who carry out 'listening's' with isolated elderly people in rural areas).

# Who we talked to

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

## At our dementia monitoring workshops we spoke to 129 people:

- 22 people living with dementia
- 58 carers
- 49 professionals or others

We also spoke to 6 people who were interested in the workshops but unable to attend.

## During the public consultation about specialist dementia hospital care beds we engaged with:

- 82 people living with dementia
- 124 carers
- 110 professionals and volunteers
- 215 members of the public
- 26 people in 1 -1 interviews
- 20 people with learning disabilities
- 209 people completed questionnaires
- 10 completed easy read questionnaire

## Community Organisers carried out 'listening's':

- 53 semi-structured interviews in peoples own homes or community settings, 14 of these were with people living with dementia or their carer
- Covering Calne, Devizes, Melksham and Trowbridge Community Areas



# Key Messages

There were many interesting and wide ranging discussions in all of the workshops and we also gathered information from our engagement events as described above.

Some key themes emerged from the people we spoke to:

1. Information provision is a big issue for people
2. Inconsistent quality of services
3. Specialist services for people with dementia good but not always accessible
4. Dementia awareness and education is improving and really important

## 1. Information provision is a big issue for people

Many people talked about difficulties in getting the information they needed and at the right time. This included information about dementia, dementia services, health and social care services, benefits and community services. Some people said that after receiving their diagnosis they felt they were on their own and had to do their own research to get information.

People said that they needed to contact many different agencies to get the information they needed and that they didn't always know who they should be contacting. This meant that sometimes people didn't find out information about services that would have been useful to them at the time when they would have been most beneficial.

A number of people commented that signposting could be like 'going round in circles', and some people said that they felt information would be better given face to face in some instances. Many people at our workshops used the opportunity to share information about the services they used, from this, it was very apparent that it was difficult for many people to obtain 'the full picture' of services that were available.

The main recommendation that came from the people we spoke to was that there should be better good quality consistent information available for the person living with dementia and their carer in one well-advertised place so that people know where to go when they need advice or support.

"I want ALL services, advocacy and support, to be advertised more widely"

Salisbury Workshop

## 2. Inconsistency of quality of services

There was a lot of discussion about people's experiences of health and social care services. From what people reported there seems to be a wide variation in the quality of services with some people having excellent experiences and some having very poor experiences of the same service.

Many people talked about their experiences of using their GP surgeries, and people reported recent experiences of GP's and surgeries showing a lack of awareness of the importance of giving and explaining diagnosis, explaining about medication and signposting to other services, for example the dementia adviser services. Some people said that the GP diagnosis had speeded things up and that their GP had been very supportive.

People talked about their experience of care in general hospital for people with dementia. The majority of people told us that, at present, hospitals were not able to tailor their care to meet the needs of people with dementia. Some people told us that they were told that a person living with dementia would be treated 'exactly the same as anyone else' and they didn't feel that this was helpful. A person living with dementia told us that fixed visiting hours meant that they could not have visitors during lunchtimes which was something they would have liked and would have been helpful to them.

Care at home was a topic that many people wanted to talk about both during the consultation and at the dementia monitoring workshops. The majority of people we spoke to during the consultation did not think that there was good care available to support people with dementia to stay at home. Many people were very concerned about the quality of domiciliary care that is available for people with dementia. Concerns were raised about missed visits, lack of continuity of visit times and carers, and agreed tasks not being carried out. Many people felt that domiciliary care staff needed more dementia training. Some people reported that they had received good quality care at home. They felt that this was due to the particular carers or agency they used.

People discussed their experiences of care homes. Overall the feedback was that the quality was varied and that some were very good and some very bad. People thought that management and organisation, and staff training contributed a lot to poor quality care homes for people with dementia. Several people reported that their concerns and complaints about care homes had not been addressed by the home and they had been forced to move the person with dementia to a different home. All these people said that they were much happier with the home that the person moved to and felt it offered better quality care.

Self-funders and their carers reported many concerns about the expectations that were placed upon them to organise and co-ordinate care and many didn't feel that they had either the expertise and/or the time to do this.

The main recommendations that came from the people we spoke to was that there should be more robust monitoring of services to ensure that people in Wiltshire receive a consistently good standard, and care workers should have better training. People should expect to receive a good quality service, and have access to the same services, wherever they live in Wiltshire.

"The GP diagnosis has speeded up which is positive"

Malmesbury Workshop





### **3. Services designed specifically for people with dementia are good but not always easily accessible.**

Many people talked about their experiences of using services that were specifically for people with dementia. Almost everyone we spoke to who had used these services said that they found these services to be very valuable and felt that they were high quality. However people told us that they were not always able to access them for a variety of reasons.

Lots of people said that they had not been made aware of the Alzheimer's charities and other specialist support services after receiving their diagnosis, and had only found out about either through their own research or by chance. Sadly, some people only found out about the support on offer when it was no longer needed.

People told us that specialist day centres with activities focussed towards people with dementia had many benefits for people living with dementia and their carers. However people told us that they are oversubscribed and that they either had to wait for a place to become available or could only have one day when they would prefer several. Some people said that the cost of these was an issue for them.

Many people living with dementia said that they would like to be more socially active. Groups such as Singing for the Brain and Memory Cafes were felt to be particularly good opportunities for this. Some people with dementia said that they felt more relaxed and understood in such groups. The groups mentioned included those run by Alzheimer's charities and those run by other community organisations. People who used these services said that they provided positive and empowering experiences for people living with dementia.

People spoke about their experiences of using support or ‘sitting service’ with a regular weekly visit. Many people said that their experience of this service was positive and provided good quality, well trained staff. Many carers said that the 2 hours a week provided wasn’t long enough for them to be able to do the things they needed to. Some carers also said that the assessment process to access funding for this had been very long, in at least one case, taking six months.

People said that domiciliary care that specialised in caring for people with dementia provided a much better quality of service. Some people had identified smaller agencies that provided better continuity with the same carers coming to provide the service. Somerset Care’s ‘Petals’ service was praised for its specialist dementia domiciliary care.

A few people talked about having a Dementia Adviser and said that they had been helpful to them in both giving advice and support about dementia and accessing services. However it became evident in the workshops that not many people know about this service. Many people said that they thought such a service would be useful to them.

The main recommendation that came from the people we spoke to was that more needs to be done to ensure that people are aware of services designed specifically for people with dementia, and that there needs to be more investment in such services, particularly day support and groups that are targeted towards people with dementia and their carers.

“Although the sitting service is welcomed and well thought of, 2 hours isn’t enough time for the carer to go off and do something meaningful. You couldn’t go to a support group or meet a friend for coffee in 2 hours, especially with the poor public transport”  
Westbury workshop



## 4. Dementia Education and Awareness is improving and is really important - People living with dementia want to be involved in making decisions

Many people talked about the importance of dementia awareness, in terms of both health and social care agencies and in society in general. People living with dementia and their carers said that, in their experience, some small changes could make a big difference to their quality of lives.

People felt that promoting greater knowledge and understanding about dementia in society can make many aspects of people living with dementia's day to day lives more positive. The Alzheimer's Society 'Dementia Friends' initiative and the development of Wiltshire's 'Dementia Friendly Communities' were thought to be good initiatives for promoting awareness and understanding.

People living with dementia said it was really for important to them to be involved in making decisions. Some people talked about experiences when they had been excluded from discussions or things hadn't been well explained to them and they weren't happy about this. Some people with dementia talked about their experiences of using memory groups and advocates for support and said they found this helpful.

During its engagement work HWW found that some professionals doubted that people living with dementia would be interested and/or able to be involved. However our experience of consulting and engaging with people living with dementia has shown that people living with dementia are interested in being involved and can provide unique insights into their experiences, as well as making suggestions about how services could work better for them.

The main recommendations that came from the people we spoke to was the work around dementia education and awareness needs to continue and be built on and that people living with dementia must be involved in their care and in decision making as much as is possible.



It is important that a person with dementia feels in control”

Salisbury Workshop

## Next Steps

1. This report will be presented to Wiltshire's Health and Wellbeing Board. The members of the Board are responsible for commissioning and providing services in Wiltshire. The Board is also ultimately responsible for the Wiltshire Dementia Strategy. We will also take the report the Wiltshire Dementia Delivery Board which is responsible for the action plan for the Wiltshire Dementia Strategy. We are asking that the action plan is reviewed to take account of all the things which people told us.
2. We will continue to engage with people living dementia and their carers to ensure services meet people's needs and provide the right outcomes through:
  - a) Monitoring Workshops. At the next sessions we will focus on information provision and look for ways that this might be improved.
  - b) Targeted engagement with people living with dementia who have moderate or severe dementia in small groups or on a 1:1 basis to ensure their experiences are captured.
  - c) Carrying out visits to premises where services are being delivered directly to people with dementia to check the quality of these services directly with the people accessing them.
3. We will work with Wiltshire People First to deliver a pilot project which will see people with learning difficulties (LD) trained to check the quality of dementia services.
4. We will continue to report what people tell us about their experiences and views of dementia services in Wiltshire and share this with the organisations which commission and provide them. We promise to let local people what difference it has made.




## Finally, thank you!

HWW would like to thank everyone who took the time to contribute their views and experience through the many engagement activities as described, including the dementia monitoring workshops, public consultation events or through one of the many community engagement group sessions.

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

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



**“Your Voice  
is our  
Voice”**

## Engagement Approach

Public consultation on the permanent location of specialist dementia hospital care beds

The '100' dementia monitoring workshops

Community Organisers Listening's in rural areas focused on isolated older adults

Information from local specialist charities on service user experience

HWV engagement at acute hospital trusts and community settings

## Engagement Reach

82 People living with dementia  
 124 Carers  
 110 Professionals and volunteers  
 215 Members of the Public  
 129 Interested individuals at HWV workshops  
 26 1:1 interviews  
 20 People with a learning disabilities  
 209 Completed questionnaires  
 10 Completed easy read questionnaires

129 individuals through 4 workshops throughout Wiltshire

Community First's Community Organiser team, commissioned by HWV, undertook 53 semi-structured interviews with older people in rural more isolated locations, over three months between December 2014 - March 2015

Through our VCS partners organisations:

- Alzheimers Support
- Alzheimers Society
- Age UK Wiltshire and Salisbury District
- Carer Support Wiltshire
- SWAN Advocacy

Through planned visits using HWV Enter and View trained and DBS checked volunteers to:

- Salisbury District Hospital
- Camelot Care Home
- Warminster
- Community Hospital
- Royal United Hospital
- Great Western Hospital

## Outcomes

### 1st Report Key Messages

1. Information provision
2. Inconsistency in the quality of services
3. Accessible services
4. Training and awareness

## Why not get involved?

**Visit our website:** [www.healthwatchwiltshire.co.uk](http://www.healthwatchwiltshire.co.uk)

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**Phone us:** 01225 434218

**Write to us:** 20 Hampton Park West, Melksham,  
SN12 6LH

March 2015

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