



# Talking to people about dementia: a focus on information provision

An  
independent voice  
for the  
people of Wiltshire

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## Notes:

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

“A Carer is someone who provides unpaid support to a family member, partner, friend or neighbour. This could be because they are ill, frail, disabled or have mental health or substance misuse problems.”

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

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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 during 2015.

We have 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 commissioners and providers of services. We will highlight good practice and areas where people have poor experiences so that these can be addressed. We will continue to talk to people throughout 2016. This is our second 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 our 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.

## What we did

Information about dementia and services was identified by people at our first workshops as an important issue of concern. We wanted to find out more about what information people felt they needed and in what form.

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

### We spoke to 145 people in total:

- 41 people living with dementia (28%)
- 71 carers (49%)
- 33 professionals or others (23%)



We held four workshops around the county. At the beginning of the workshop a presentation was given about the 'Your Care, Your Support Wiltshire' website.

We asked these questions:

1. What information have you been able to find out about dementia, services for people with dementia and their carers, and community services?
2. Where did you get this information from?
3. How easy was it to access this information, was it in the right format?
4. Is there any information you would like that you don't have at the moment?
5. Are there any support services that we might not know about?
6. Is there anything else you would like to tell us? (Including "Wish list" - What would you like to support people to live well with dementia?)

We 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 throughout the workshops.

We also felt that it was important to carry out more targeted engagement with people living with dementia and their carers. Our outreach visits to groups and services were more informal. We let people know that we were interested in their views about information, but we also listened and recorded any other things that people wanted to tell us about health and social care. We visited a memory group and a peer support group in Laverstock, a dementia carers group in Chippenham, a Singing for the Brain group in Malmesbury and a Memory club in Tisbury. We have also reached people through our engagement at Acute Hospital Trusts and through Community First's Community Organisers who carry out 'listening's' with isolated elderly people in rural areas. We carried out a small number of case studies where we spoke to people on a 1-1 basis in order to illustrate personal stories.

## Key Messages

Some key themes about information provision emerged from the people we spoke to:

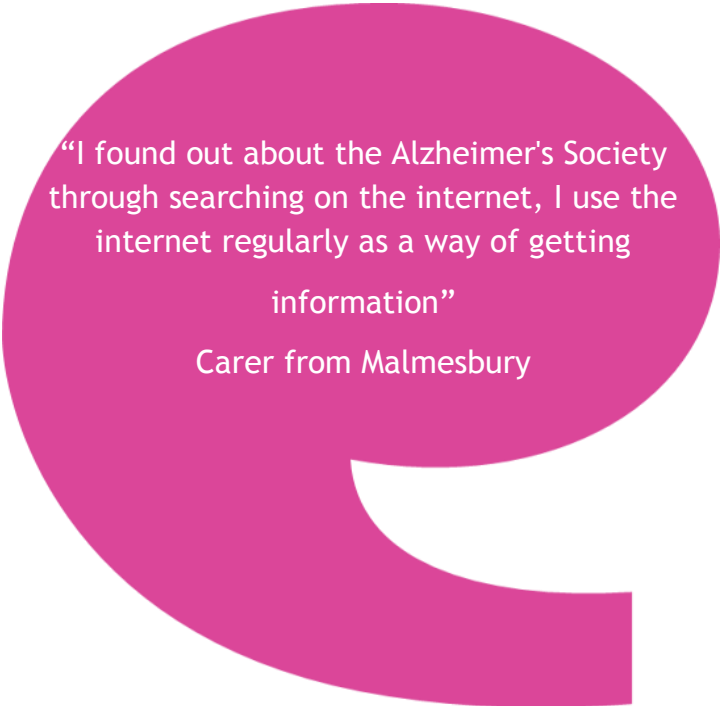
1. Many people use the internet as a way of getting information. The 'Your Care, Your Support Wiltshire' online directory will be useful.
2. Concern that people who don't have internet access will still be able to get the information they need.
3. People want more clear and easily accessible information about available services.
4. People thought a short film was a good way of providing information.
5. Information provision needs to be timely: right information—right time.
6. Information and training would be welcomed by unpaid carers.

**1) Many people use the internet as a way of getting information. The ‘Your Care, Your Support Wiltshire’ online directory will be useful.**

Many people said that they already use the internet as a way of getting information and keeping in touch with people. People felt that, even though initially this might have been more prevalent amongst younger people, older people were now using technology more readily. Many people gave examples of using searches to find out more information about services and support organisations. This was often described as the starting point for people living with dementia and their families when they first become concerned.

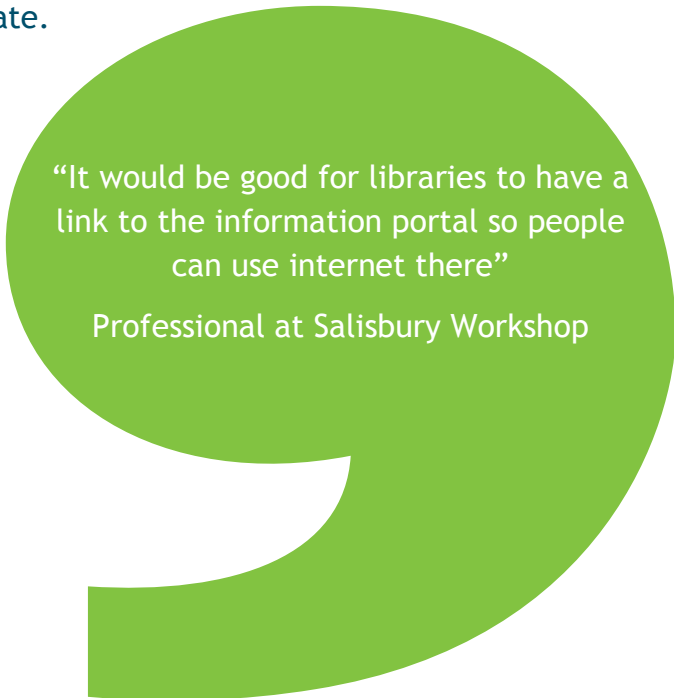
People talked about the growing use of the internet to keep in touch with family members. An example was given of a 92 year old who regularly uses the internet to keep in touch with family who were not nearby.

We gave a presentation of the ‘Your Care, Your Support Wiltshire’ website. People thought this would be a useful website and they would use it. People liked the design of the website, particularly the tiles. Some people said that they would need support and/or training to use the website but would still like to do so. People said that they thought it was important that any information on the internet was kept up to date.



“I found out about the Alzheimer’s Society through searching on the internet, I use the internet regularly as a way of getting information”

Carer from Malmesbury



“It would be good for libraries to have a link to the information portal so people can use internet there”

Professional at Salisbury Workshop

**2) Concern that people who don’t have access will still be able to get the information they need.**

People were concerned that there would be a significant number of people who didn’t have access to the internet or either didn’t want to or weren’t able to use it. It was thought to be very important that they were still able to access information about services.

Many people said that they thought that professionals would have a key role in searching the website for people. This included Customer Coordinators, Care Coordinators, Dementia Advisors, and other voluntary organisation staff members and volunteers. People felt that it was important that information about the website could be printed out in a clear user friendly style.

“People who don’t have internet access—how do they find out what is out there?”

Carer at Westbury Workshop

“I can’t use the internet, I wouldn’t know how but I am very interested in community services”

Person living with dementia at Westbury Workshop

### 3) People want more clear and easily accessible information about available services

We asked people to tell us about the information they had been able to access and where they thought the gaps were. Most people said that they had been able to access good quality clear information about the symptoms and types of dementia itself. People said dementia sections in libraries and Alzheimer’s Society fact sheets were particularly useful.

People told us that they had more difficulty finding clear, easily accessible, information about local services. They said that they found information about services to be overwhelming and confusing. Many people said that they thought the GP Surgery would be the first port of call if they were concerned about their memory. People reported very mixed experiences about the information they received from their GP Surgeries. People said that it was very important that people were given information about the support available when they received their diagnosis. Several people said that they thought they should have been referred to a Dementia Adviser at this point but that this had not happened.

People who had seen a Dementia Adviser said they found the service useful, and it had increased their awareness of what support was available, even if they didn’t need it at that stage. People said that it had encouraged them to use, at least some services, straight away. It also helped people to know that they could go back and ask for more information as and when they needed it.

People gave examples of services that they would like to have known about sooner, these included Dementia Advisers, dementia cafes, support groups for carers, and a variety of other community groups that were taking place. Many people said that they were confused about what benefits and services that they were entitled to.

“I would like to say that I was surprised that there wasn’t, and that there should be information provided at the point of diagnosis. Obviously about the various support agencies, but also about dementia advisors. I met ours some months after diagnosis. She visited me at home and had a wealth of information. Had I known about her I would have sought her advice straight away. It still seems incredible to me that I was not informed of the support network that exists.”

Email response from Carer

#### 4) People thought a short film was a good way of providing information

Many people thought that a short film would be a good way of providing information. They said that a film that featured people living with dementia, their carers and dementia services would be an accessible way of giving information. People said that they thought that seeing people using services ‘demystified’ them and may mean that more people would give them a try. People told us that seeing and hearing the experiences of real people had greater impact than information on paper.



“A video would be good, visual impact is good, short and succinct, the Dementia Advisers’ could do a video”

Member of the public at Westbury Workshop

“Produce a DVD please”

Carer at Westbury Workshop



### 5) Information provision needs to be timely: right information—right time

People said that the most useful way to be given information was gradually, as and when they need it. People talked about being given information verbally and in booklets from a variety of agencies. This was usually done during a first visit or assessment. Some people talked about these visits being overwhelming, in terms of the amount of information that was given. They said often they were unable to take it all in. Some people talked about being given lots of information when they were given their diagnosis and said that they felt too shocked to take it in at this time. Some people said that they didn't want to plan things too far into the future, as there were many uncertainties about what support they would need and when.

People said that the most useful information was that which they could use at that particular time. Some people said that they knew that they could go back to their Dementia Adviser and ask for more information when they needed it. These people said that they found this reassuring and useful.

“I felt as though I was drowning, I just got a pack of information. I never saw a Social Worker”

Carer at Westbury Workshop

“We got the diagnosis from our GP, they told me that I must get in touch with a Dementia Adviser, who came and visited and gave me information”

Carer from Salisbury Area



“The CRISP carer course is really useful”

Devizes workshop

“Support groups help carers to handle difficult situations in the best way for the person with dementia—sharing experiences is really useful”

Carer at Salisbury group

#### 6) Information and training would be welcomed by carers

Some carers talked about attending groups and training sessions that were designed to support them to care for people living with dementia. These included carers groups, and carer’s information and support programmes. All the carers who had attended dementia courses said that they found these very useful, both in terms of providing information and about the different ways of supporting someone living with dementia. Carers talked about changing their approach to some situations following these courses and said this had led to increased well-being for the person living with dementia and themselves. A few carers had also attended courses about aspects of personal care (for example Moving and Handling) and found this useful.

Some carers said that a “sitter” had been arranged, so that they could attend training and that this was essential to them being able to attend. Other people weren’t aware that this was available and felt they couldn’t attend courses because of this.



## Other issues which people talked about:

As well as talking about information provision, many people also wanted to tell us their views and experiences about other aspects of dementia services. These included:

### Social activities are very important for people living with dementia and their carers

People living with dementia said that it was important to them to get out and about. They said they enjoyed attending groups, for example Singing for the Brain, Library Groups and Memory Cafes.

At a support group that was just for people living with dementia the group members talked about how much they valued and benefitted from the support that they give to each other, in sharing experiences and information. They said that there are few such groups in Wiltshire and thought that more people living with dementia could potentially benefit from this support.

“I like coming to this group, it is very important I get out and about. It makes me feel better”

Person living with dementia at Singing for the Brain in Malmesbury

### Transport in Wiltshire is an issue for people living with dementia and their carers

Transport was an issue for people living with dementia. More people living with dementia may be able to attend groups alone if they had a transport service with a clear understanding of people with dementia. Carers and people living with dementia have difficulties attending hospital appointments at Bath RUH and Swindon GWH that are early in the morning.

### Regret about the closure of Westbury Hospital and the use of the site

People at the Westbury workshop expressed regret around the closure of Westbury hospital. They felt that the building should be used for health and/or community services.

### Domiciliary Care Agencies

There was concern about the quality of domiciliary care for people living with dementia particularly around lack of continuity of support workers and visit times, and poor communication. Issues were highlighted of agency care workers not alerting relatives when they couldn't get a reply at the door and not using key safes that the agency had previously been made aware of. Several people whose care was funded privately said that they had changed care agency due to poor quality care. The majority of these said that this had resulted in dramatic improvement in the quality of care.

“we changed to another agency, they are keeping to the same group of about 5 staff, great for continuity, really important for people with dementia. The comparison is poles apart. It is more expensive but worth it... We self-fund - other people don't have a choice.”

Carer from Chippenham

## GP Surgeries

People reported very different experiences of dementia care from their GP surgeries. People who felt they had a good service from their GP surgery said that their GP had referred them to a dementia adviser and/or made them aware of other support services. They also said that they had regular reviews. People who thought that the service from their GP surgery wasn't good said that this was because of a lack of dementia awareness at the practice and a feeling that nothing can be done to support people living with dementia.

“My experience of my GP is not altogether good, there is a lack of interest, I feel I have been written off”

Person living with dementia from Salisbury area

“ My GP calls me to see how I am getting on—this is good support”

Person living with dementia from Salisbury area

## Hospital Care

People reported very different experiences of hospital care for people living with dementia. Some people gave examples of poor quality care for people living with dementia in hospitals. This included issues about pressure care, support with eating, lack of understanding of dementia by hospital staff, frequent ward moves and lack of communication with unpaid carers and relatives about treatment and discharge. People also talked about difficulties making complaints about hospital care. However some people did mention positive experiences of hospital stays. These people said that clear communication about treatment and staff who listened to them and demonstrated an awareness of dementia in their approach contributed greatly to making their hospital stay positive. This indicates that the quality of care in hospitals is inconsistent, not just across the different acute hospitals but also within the same hospital setting.

“Dementia care in hospitals is patchy. Some wards are excellent but some are really bad. Staff training makes a big difference”

Carer event in Salisbury



## Concern about accessing NHS Continuing Healthcare funding

Several people highlighted long delays and difficulty in accessing NHS Continuing Healthcare Funding.

## Case Studies

We wanted to talk to some people living with dementia and/or their carers on a one to one basis. The aim of this is to build up some personal stories of people's experiences of using dementia services. We wanted to find out what things had worked well for people and what people thought could be improved for people living with dementia in Wiltshire. We are reporting these anonymously and people's names have been changed. Here are summaries of two of our case studies:

### Case study one—an elderly carer of someone with early onset dementia



Alison is an 89 year old lady who cares for her son John who is 54 and has early onset Alzheimer's disease. Alison now has to do more or less everything for John. This includes looking after his clothes, prompting him to wash and shave, helping him in the shower, and all cooking and household tasks. John is now afraid of losing contact with Alison. He doesn't go out on his own and likes to keep Alison in sight. He will no longer go into the gents alone, Alison takes him into the disabled toilet.

They first noticed problems with John's memory about 5 years ago when John was 49. He was working as a mechanic, and started to forget what he had to do. Eventually he had to leave. At this stage they didn't know he had dementia. John was referred to the memory clinic - it took a year to get a diagnosis of Alzheimer's disease. They couldn't believe it was Alzheimer's at such a young age. They were told about the diagnosis together at Green Lane Hospital. Alison was shocked at the time. John didn't show much reaction at the time, but afterwards he started to spend a lot of time in this room - Alison thinks he was trying to take it in.

Alison was looking for a club for John to go to. She got in contact with Alzheimer's Support. Alison said: "they've been very good, supported us all along." John has a home support worker who visits him and takes him out - they have made an album of all the things they have done together. John has taken to the Mill Street club (Alzheimer's Support) "amazingly". Alison is also visited by a befriender from Age UK every week. They visit whilst John is at the day club. The befriender takes Alison out. They often go out for a coffee and shopping. John also has an Age UK befriender who goes for a walk with him.

Alison said that she had a difficult phone call with social services in 2011 when she seemed to have offended someone and couldn't understand why. This meant that she didn't feel comfortable going to them for help. John has quite a lot of savings and they are self-funding their support. Alison said that it is getting to the stage when she will have to start calling on other people to do a bit more; they are planning to have respite care together in a residential home. Alison has talked to John about this, he is happy about this as they are both going. Alison sees this as a way of gradually introducing John to a residential home. Alison has arranged that a solicitor will take care of John's money if anything happens to her. She is going to write directions about what they would like to be arranged for his support.

“Coming up to 90 I don't know from day to day what will happen. I want to get everything in place - it's a bit of a worry what will happen to him if I'm not around. I'd like to get it all settled so I know he will be well looked after.”

### Case study two—a person living with dementia and their carer

Frank was diagnosed with Alzheimer's disease in 2009. He lives with his wife, Patricia and they spoke to Healthwatch Wiltshire together about their experiences of dementia services.



In 2009, they realised that Frank was having memory problems and went to Frank's GP. He was given a memory test and referred to RICE (The Research Institute for Care of the Elderly) in Bath. They found RICE to be excellent - one particularly valuable thing was that staff spoke to Patricia and Frank separately. They were then referred on to Green Lane, Devizes and Frank was initially prescribed

medication. They didn't feel as comfortable at appointments as they were all in the same room together. Frank was then discharged to his GP and they felt quite cut off. Patricia thinks the GP's sometimes feel “What can I do?” However Frank and Patricia think a six monthly or annual appointment to talk things through would help.


They applied for Frank to be part of a research project in Swindon and were part of this for 2 years. This was good - it meant there were regular check-ups and someone was keeping an eye on things. Recently Frank saw his GP and they suggested they see a Dementia Adviser. They visited and told Patricia that they would be able to access the 'sitting service'. Patricia said she didn't feel they needed this at the moment but it was useful to see the Dementia Adviser and to know that if they wanted any advice they could contact them in the future.

Frank says he likes going out, and to participate and get involved. He enjoys going to the Mill Street club in Trowbridge. Frank and Patricia have been going to Singing for the Brain group at Fullingbridge for well over a year now and have met so many lovely people. When it is not on they meet the other group members for a coffee - about 20 people do this. Patricia and Frank also persuaded some other friends to give this a try and it has made a big difference to them. Patricia says she feels often people think they won't like things, the hardest thing can be "getting yourself through the door". Patricia and Frank want to urge other people just to try it. They say that by being together as a group, they can all help each other, especially during difficult times.


Twice a week Patricia plays golf and Frank goes with her. They both used to play regularly. Frank is no longer able to play - however he goes along with Patricia and her friends. Frank drives the buggy and provides the coaching and tips! Patricia says her friends and the golf club are great with Frank. She is not sure that this would have been the same if it was her who had dementia. Patricia feels that men find it more difficult to talk to people. Patricia and Frank have a good set of friends and supportive family. They go out for lunch with friends almost every Friday. This means that they are doing something most week days. Patricia and Frank both feel that they have all the opportunities they need at the moment for them to have an active and social life. Patricia and Frank both feel that it is not good just to sit at home.

Patricia and Frank say that they don't want to plan too far ahead about what might happen in the future - they would rather tackle things as they come. However they have got a Power of Attorney sorted out for both of them and feel this is an important thing that everyone should do. This means that they know that in an emergency things can be dealt with quickly.

Frank and Patricia said that they have not experienced any issues regarding people's attitudes towards people living with dementia whilst out in the community. Patricia thinks people are more understanding than they used to be. They feel that the fact that there has been a lot in the press about dementia may have helped this. Patricia feels that Wiltshire has good services for people living with dementia compared to other parts of the country. She said that people she knows who live in other parts of the country haven't had nearly as good experience of support.



"Singing makes you feel good – the songs come back when the music starts"



"Getting yourself through the door can be the hardest thing but the day I walked in people were so kind"

# What we learnt and what we will improve at future engagement

People said they enjoyed the presentation - we plan to have speakers at future workshops.

Our workshops were not as well attended as previously. However we spoke to many people living with dementia and their carers by attending existing groups and talking to them there. Therefore, we decided we will do more outreach at existing groups and services for future engagement.

## Next steps

Our next dementia engagement will focus on people's views and experiences of primary health care. We want to find out how 'dementia friendly' primary care services are in Wiltshire.

We are already working with voluntary sector organisations and commissioners to respond to the issues raised during this engagement.

In 2016 we plan to update local people on what is different because of what they told us and we reflected in our 1st and 2nd reports.

## Finally, thank you!

We 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 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'. 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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