



Analysis of Dementia Community Support Services in Wiltshire

**An
independent
voice for the
people of
Wiltshire**



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Background

Healthwatch Wiltshire has an important role in assessing the quality of local health and social care services and influencing the design of future services, so we were pleased when Alzheimer's Support approached us to assist them to evaluate the provision and quality of dementia community support services across Wiltshire.

Alzheimer's Support is an independent charity which currently offers a range of services to people living with all types of dementia and their carers in east and west Wiltshire. They have recently been awarded the contract to provide dementia specific services across the whole of Wiltshire. This means that from April this year they will be responsible for providing community services across the entire county. Alzheimer's Support is committed to using service user experience to inform how their services are planned and managed. As an independent body, Healthwatch Wiltshire can impartially evaluate services and service users can be open and honest. Alzheimer's Support welcomes this and have signed up to Healthwatch Wiltshire's Collaboration Agreement which is designed to safeguard our independence.



Overall aim and structure of the project

The aim of this project is to map and evaluate dementia community support services across Wiltshire, considering both equity and quality of provision.

In order to do this the project includes:

Analysis of current dementia community support services across Wiltshire:

- Researching provision of current services to get an up to date picture.
- Reviewing previous dementia engagement data and collating people's views and experiences.

Developing a quality framework

- Specific new engagement about what people think is important in dementia community services.
- Evaluating some existing frameworks and guidance.
- Proposing a quality checklist which incorporates service user views about what is important to them.

Findings:

Analysis of current dementia community support services across Wiltshire

Researching provision of current services to get an up to date picture

This part of the project looked at the spread of dementia community services across Wiltshire. In order to do this, we undertook some research to find out about what dementia community services were available to people.

This consisted of:

- Liaison with two organisations who currently provide the majority of dementia services across Wiltshire; this included telephone interviews with Activity Organisers and Dementia Advisers to find out about their own services as well as other services that they are aware of.
- We contacted all the Community Engagement Managers and asked them to tell us what dementia community services they knew about in their area.
- We completed some desk top research. We looked at information about services websites such as *Your Care Your Support Wiltshire* and *Dementia Connect*.
- We reviewed data from previous dementia engagement and noted any services mentioned there.
- We visited six groups as part of this project and asked people there about all the services they attended.
- We emailed and phoned a number of services and providers to update information and get more details.



Gathering up to date information presented a considerable challenge for a number of reasons. This was partially due to organisational sensitivities about sharing information. In addition to this, it was often necessary to email and phone many organisations a number of times in order to make contact and many of the smaller groups are run by staff and volunteers, who work part time and were frequently not available. Also, when we did make contact some of the information requested wasn't known or gathered by organisations. Our experience reflects what local people have told us about their difficulties in finding out about services.

We collated all the information showing the spread of services across Wiltshire listed by Community Area. The spreadsheet detailing this has been shared with Alzheimer's Support to inform their future planning.

Reviewing previous dementia engagement data and collating people's views and experiences

Healthwatch Wiltshire wanted to ensure that the key messages from local people about community dementia support services, are taken into account in forward planning. Over the last two years Healthwatch Wiltshire have been involved in a programme of dementia engagement. We have reviewed all our engagement data and analysed everything that people have told us about community groups for people living with dementia and their carers.

The dementia engagement that we have carried out includes:

- Over 1200 conversations about dementia
- 39 visits to community groups
- 10 visit to services for people living with dementia
- 6 dementia workshops or events
- 250 conversations with people living with dementia
- 310 conversations with carers of people living with dementia
- 11 one-to-one detailed interviews



The key messages as identified from this engagement are:

Community groups and community involvement are valued

Across all of Wiltshire most people living with dementia and their carers told us that they wanted to play an active part in their local community and that they valued the community based groups that took place. The groups that were mentioned most frequently were dementia specific community services such as Singing for the Brain groups and Dementia Cafes. However, some people also mentioned library groups and groups at their community centre or church as being good opportunities to join in things. Some people living with dementia carried out voluntary work and said they valued this.

For both dementia specific and more informal groups, people reported increased well-being as a result of being involved in their local communities, and felt that these groups could have a preventative function in supporting people to access other services when they need them to avoid crisis situations, particularly in light of pressures on health and care services.

“Getting yourself through the door can be the hardest thing but the day I walked in people were so kind..”
Carer

“Support that is available can be inconsistent and heavily reliant on volunteers, little pockets of groups set up quite randomly but then no one know about them.”
Carer of person living with dementia

We have spoken to some people in the past who had stopped using community groups. They mentioned a variety of reasons. These included difficulties getting to the group, not enjoying the particular activity on offer and feeling that the group wasn't suitable for someone at their 'stage' of dementia. Although this was a relatively small number of people it would be good to look at how these issues can be addressed in the future.

What people want to do

The people we spoke to were keen to emphasise that everyone is unique and that different groups would suit different people. People mentioned a wide variety of things that they would like to do at groups. The majority of these were based on activities or social events. Singing and music groups were particularly popular. Art, exercise, games and visiting animals were also mentioned as being enjoyable. People said that the social aspect of groups such as having time for a chat and coffee was very important. Some people said that they liked listening to speakers, but the feedback about this was more mixed.

The value of dementia specific community groups

The people we spoke to across all of Wiltshire felt that groups that are specifically for people living with dementia were high quality but not always accessible. Some people told us it had been hard to find out about these groups, some said they didn't feel their area had enough of these groups. People commented that emotionally they found it hard to 'get through the door' but when they did, they got a great welcome and often wished they had started going sooner.

People said that they particularly valued the supportive environment in these groups and that they felt relaxed and understood. People told us they liked to have fun at these groups. People also talked about receiving practical and emotional support at these groups. This support seemed to be most useful to people when it was given informally by staff at the groups as and when people has questions or concerns. An added value of these groups was that participants often met informally when the group wasn't running and people said they enjoyed these occasions.

Healthwatch Wiltshire visited some groups that were just for people with dementia. People living with dementia told us that they appreciated the friendship, humour and time to talk and share experiences that these groups offered. We observed that people living with dementia spoke more at these groups than at other groups we visited. Some of these groups, also had a separate session for carers running at the same time, which was also valued.





People with specific needs

People told us they thought that there was a lack of community services that were suitable for particular groups of people with dementia. This particularly related to people in the later stages of dementia who may have specific needs, and we were told that this is becoming more of a concern as people living with dementia are now remaining at home for longer. Some people said that they found Singing for the Brain groups accessible for these people but this was mixed.

People also highlighted the need for groups for people with early onset dementia who may want to be involved in more physical activities. There was also concern for people living with dementia who lived alone and it was questioned whether they were able to find out about access and use the groups without support from a carer.

Geographical issues

Generally, people said that they didn't feel that community services were integrated or planned across Wiltshire and that there was a need for a positive action plan to address this. From talking to people Healthwatch Wiltshire noted that there didn't seem to be equality of access to dementia community services across Wiltshire. Further to this, a number of people told us they weren't aware of services that were outside their town or village, but still near to them. People from Malmesbury and areas north of Chippenham felt that they were generally not well served in terms of dementia community support services, although people said that they valued the Singing for the Brain group in Malmesbury. A lack of dementia community services was identified in Mere and people told us that they felt isolated there. Some people from Trowbridge said that they felt that there was a lack of services available there considering it is the county town. People from Marlborough also said there wasn't much going on there but recognised that there were a number of popular dementia groups in nearby Pewsey.

Carers

Carers told us that they value dementia community groups and the support they offer. Carers also said that they value courses and training about different aspects of dementia and pointed out that many people would need replacement care in order to attend these. Carers said that they would value groups and/or training that helped them with tasks that they may have had to take over, for example finances, driving, cookery, using computers and home maintenance. Some carers said that they would like there to be some groups at evenings and weekends as they were unable to access weekday services and that the timing of groups should be not too close to meal times.

“Singing makes you feel good - the songs come back when the music starts.”

Person living with dementia

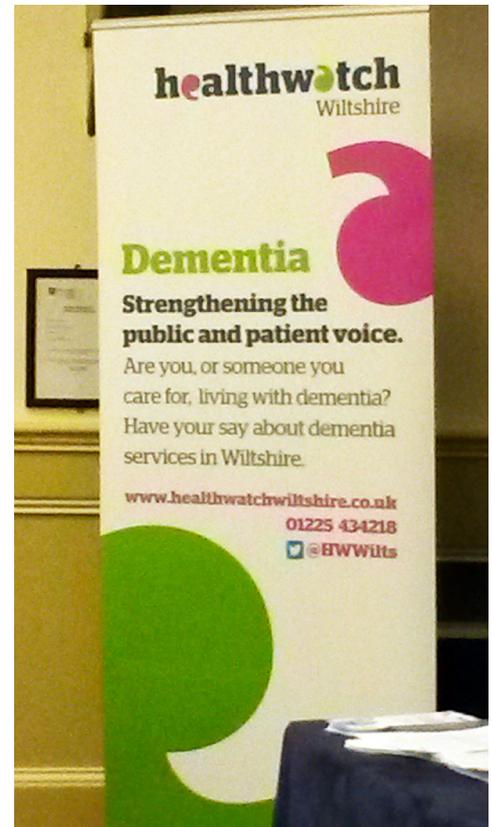
Other feedback

People living with dementia and their carers told us that they want to be involved in decisions about their own support but also dementia services more widely.

People stressed the importance of being able to find out about groups. It is important that accurate information is available on the internet and through a range of professionals. DVD's/films can be a useful way of 'explaining' services to people living with dementia.

Problems with transport to groups was something that was widely raised, and people felt that there was a lack of easily accessible public transport, particularly for people living in rural areas. A dementia friendly transport service was suggested.

Many people living with dementia and their carers talked about using day centres. People have told us they particularly value specialist day centres for people living with dementia and think they are good quality. People have expressed concern that there is a lack of such specialist provision in North Wiltshire.



Developing a quality framework

In order to develop a quality framework, we carried out a new piece of engagement which focused specifically on what people thought made good quality dementia community support services and we looked at some existing service specifications and guidelines.

Specific new engagement about what people think is important in dementia community services

We wanted to ensure that service user views were a central part of our proposed quality framework. So as part of this project we carried out some new engagement that specifically aimed to find out what was important to people in terms of dementia community groups. We visited a variety of community groups including Singing for the Brain groups and dementia cafes. 6 groups were involved and 73 people gave their views.

Two organisations also shared their own evaluations of dementia community groups with us and these have been incorporated into the responses. We also spoke to a number of dementia advisers, group organisers and volunteers about what their service users had told them about community groups for people living with dementia.

We had informal conversations based on the following discussion questions:

a) What groups do you go to at the moment? What do you think of these?

Most people we spoke to attended more than one community group or service. People talked about Dementia Café's, Singing for the Brain Groups, Movement for the Mind, Wildlife groups and Day Centres. The majority of the groups that were mentioned were dementia specific and mostly run by organisations which are principally focussed on dementia. Only a few people mentioned local community groups they attended that were not dementia specific.

The feedback people gave us about what they thought of the groups they attended was extremely positive. For example, people said "All good - good variety", "Great", "I think the people who go enjoy it" and "very good, well run".

b) What do you think makes a good group for people living with dementia?

People said that getting out and seeing other people was very important to them. The social aspect was important and being with other people with dementia who may be in similar situations. People enjoyed the opportunity to have a cup of tea and chat together informally. Many people talked about the importance of the groups having the right atmosphere. People used words such as warm, friendly, understanding, laughter and kindness to describe what they valued about the groups and thought were important. People said that any activity at the groups should be appropriate so that people living with dementia could participate with support from carers and volunteers as needed.

People with dementia who attended a group that was just for people living with dementia said that they enjoyed the camaraderie and “laughter and banter” of the group and valued being able to share problems and help each other to find solutions.

c) What do you think makes a good group for carers of people living with dementia?

The comments about what makes a good group for carers were generally very similar to those above relating to what makes a good group for people living with dementia. Again, the importance of the right atmosphere and a social aspect was emphasised.

Carers also said that groups offered them the chance to share experiences and ‘off load’. Carers talked about getting support, understanding and picking up useful tips from each other and staff attending the group. Carers also said that they valued being able to relax and let someone else “take charge” for a short time.

d) What sort of things would you most like to do at a dementia group?

In general, people said that the social aspect and ‘feel’ of the group was the most important thing. However, people did identify some things that they thought worked well as activities. Many people named singing and music, other popular activities mentioned were exercise, art and craft, games, activities involving animals, and outings. Most people said that they wanted to have fun at groups rather than a focus on more serious topics. Most people said that they prefer activities that they could participate in as opposed to talks or information sessions. People did value groups to get information and/or advice but felt this was best given informally as and when they need it.

e) Is there anything else you would like to say about community based groups for people living with dementia?

People also talked about stability and regularity as being important. A number of people talked about how groups gave structure to their week. The consistency of having groups in the same place, same day and same time was valued. At several groups, people have told that when the group isn’t on, some group members and volunteers meet up informally at the same time at a local café. These people told us that they value these occasions. Some people said that they didn’t like long gaps when groups weren’t running, for example if they didn’t run over the summer.

Some people said that they would like more groups nearer to them and some people told us that they would have liked to have started coming to groups earlier but didn’t find out about them initially.

People talked about the benefits of groups for general wellbeing. These included looking forward to going to the groups, improved mood, increased confidence and support to make new friends. Whilst visiting a number of groups Healthwatch Wiltshire observed that many people with dementia became more animated as the group went on and people remained more alert at the end of the group. It was also mentioned that attending the groups can be a ‘bridge’ to support people to accept other services, preventing crisis situations.

“We are glad you have been asked to ask us these questions, as how can you run services without talking to the people who use them.”

People living with dementia from a support group in south Wiltshire

Some people said that they felt groups worked better once there was a certain number of people attending, this was particularly the case with singing groups, which it was felt could work well with quite large numbers. Other services, such as discussion groups just for people with dementia, people felt worked better in smaller groups.

People told us that they were pleased to have been asked what they thought of these groups. People living with dementia and their carers have consistently told Healthwatch Wiltshire that they want to be involved how dementia services are planned and run in Wiltshire.

Evaluating some existing service specifications and guidelines

We looked at some existing guidelines and service specifications for dementia community groups. These have included *Alzheimer’s Society Singing for the Brain*[®] specification⁽¹⁾, the *Alzheimer Café UK model*⁽²⁾, and *Alzheimer’s Support Tips and Guidelines for Café Speakers*⁽³⁾. We considered whether these were consistent with how community groups operate in Wiltshire and what service users have told us about what they think is important about community groups.

The *Alzheimer’s Society Singing for the Brain*[®] service specification is a detailed document setting out how the groups should be run. It sets out the aims of the service:

“Principle service aims:

The provision of a facilitated structured group session for people with dementia and their carers designed around the principles of music therapy and singing. The Singing for the Brain[®] sessions are planned to incorporate social interaction, peer support, engagement and active participation. Specifically, the service is designed to help families with dementia to feel part of society where they have a right to artistic and social stimulation. To encourage carers and people with dementia to play an active part in networking with others in the same position as themselves.”

The aims and detail in this specification appears to be consistent with how these groups are currently operating in practice in Wiltshire and is also consistent with what people living with dementia and their carers have said is important to them about these groups.

References:

⁽¹⁾ Alzheimer’s Society Singing for the Brain[®] specification - December 2009

⁽²⁾ <http://www.alzheimercafe.co.uk/default.htm>

⁽³⁾ *Alzheimer’s Support - Tips and Guidelines for Café Speakers*

The Alzheimer Café UK give a description of their model of an *Alzheimer Café*:

“An Alzheimer Café (AC) is a gathering of people affected by and/or interested in dementia. Monthly gatherings are for the purpose of education, discussions, exchanging information about dementia, and for opportunities to socialize and meet others. Attending an AC is free of charge. People and come and go as they please, just like at a café.”



Comparing this description to how dementia cafés are operating in Wiltshire, some cafés run like this or have sessions that are run like this but by no means all. Healthwatch Wiltshire’s experience of attending groups and listening to people’s descriptions of the groups indicate that many of them involve a greater emphasis on participating in an activity rather than listening to a speaker, education or discussion. This aspect of The Alzheimer Café description also doesn’t seem consistent with what most people have told us they would like to do at community groups, which again is more focused around participation in an activity

with an emphasis on fun rather than education. However, in terms of the groups offering opportunities to meet others and socialize, this seems to be consistent across groups in Wiltshire and very much in line with what people say is important to them. People also have told us that they want to be able to talk openly about dementia at these groups.

The *Alzheimer’s Support Tips and Guidelines for Café Speakers* are in line with what people have told us about the way they would like to be spoken to, but perhaps, don’t reflect the shift towards more participatory based ‘fun’ activities that people say they enjoy most.

Proposing a quality checklist which incorporates service user views about what is important to them

In order to develop a quality framework for dementia community support groups in Wiltshire we analysed the key messages people told us through our engagement, and looked at relevant service specifications and guidelines. As a result of this analysis we have developed a framework based around six themes that people felt were most important to them in terms of what makes a good quality dementia community support group:

- Clear information about groups
- Structure and regularity
- Warm atmosphere
- Opportunities to socialize
- Fun activities
- Service user involvement



Using these themes, we have developed a checklist which can form a basis of measuring the quality of dementia community support services and incorporates the views of local people. The checklist is a guide to what might be seen as an ‘ideal’ group. It is not expected that groups would meet every point on the list, more that the checklist would give an overall impression of the quality of the groups and would identify areas for improvement.

This checklist is detailed at the end of this report as **Appendix 1**.

Recommendations for dementia community services in Wiltshire

People feel that specialist dementia community services are good quality and value them. These groups are the most popular and well attended by people living with dementia and their carers. People have told us that they feel these groups have lasting positive effects to their well-being and day to day lives. The provision and variety of such groups is not evenly spread across Wiltshire.

1. Prioritise areas where there appears to be under provision for establishing new groups, most particularly in North Wiltshire area (Malmesbury, Royal Wootton Bassett area). Also, consider how access to groups may be improved for people from Warminster, Mere and Marlborough.
2. Consider the variety of different groups on offer in different areas of Wiltshire and try to address any imbalances identified. For example, the lack of an exercise or dance group in North Wiltshire.
3. Continue promoting informal social opportunities amongst people with dementia and their carers, for example when groups aren't meeting. Look at whether this can be promoted across other groups and taken into consideration when planning new dementia community services.
4. Continue to look at ways in which information provision about dementia community services can be improved, including involvement with GP surgeries. For example, by identifying opportunities for more contact between GP surgeries and Dementia Advisers.
5. Ensure that people are aware of groups that may be outside their immediate town but still close to them, particularly where these may be across 'traditional boundaries', i.e. from North to West Wiltshire. For example, people in Calne and surrounding villages may be able to access nearby services in Devizes and Melksham.
6. Consider ways that people in rural areas can be supported to have better access to community services through establishing and supporting locally run dementia groups in villages and/or improving access to transport to enable people to travel to nearby towns.
7. Adopt a quality framework along the lines of the one suggested to measure the quality of groups and identify areas for improvement.
8. Review some of the information and guidelines about dementia cafés so that it reflects the shift towards more activities that people can join in, that have taken place and people say that they enjoy.
9. Work with other organisations and informal groups that provide dementia community services. In particular, to support them to ensure their services are promoted and specialist support and information provision is available at regular intervals. For example, by attendance from dementia advisers to groups from time to time.



10. Work with other organisations that provide general community services to support them to be 'dementia friendly'. Examples could include holding monthly sessions at cinemas and swimming pools for people living with dementia and their carers and/or providing Dementia Friends sessions.
11. Investigate opportunities for further partnership working and/or local funding with area boards and other community groups in order to establish some smaller groups in rural areas.
12. Liaise with other organisations to see if any clash in service times can be avoided. One current example is Salisbury Library Memory Group runs at the same time as a popular Singing for the Brain session in Salisbury, meaning that people have to choose to attend one or the other.
13. Consider ways in which transport to groups can be addressed. Provide information about public transport, and dementia friendly taxi or transport services, promote lift sharing, consider whether transport can be provided to some groups.
14. Consider how more people living with dementia across Wiltshire can have access to groups that are just for people living with dementia.
15. Look at provision of groups for people in the early and late stages of dementia.



Acknowledgements

We are grateful for the following organisations for supporting this work:

- ★ **Alzheimer's Support** supported discussions with their Dementia Advisers, Activity Organisers and engagement with Service Users through our engagement at their groups.
- ★ **Ludgershall Memory Café** supported discussions with their service users through our engagement at their group.
- ★ **Laverstock Experiential Memory Support Group and Peer Support Group** considered our discussion questions at their groups and shared their views about these with us.
- ★ **Alzheimer's Society** supported discussions with some of their Dementia advisers and shared some of their evaluations of their groups.
- ★ **Wiltshire and Swindon User Network** shared the evaluation report of their memory cafes with us.

And finally, huge thanks to the individuals we spoke to and our dedicated volunteers who carried out the visits and spent time with people living with dementia and their carers to ensure what is important to them was reflected within this piece of work.

Appendix 1

Checklist for evaluating dementia community groups:

Group:

Date of evaluation:

People involved in evaluation:

Clear information available about groups

- Is group publicised locally?
- Are there up to date details about the group on Your Care, Your Support Wiltshire, organisation's website and dementia road map?
- Clear readily available leaflet about the group including information about any costs?
- Is there a DVD/film available to show people how such groups are run?
- Is there evidence that people are signposted to group by others e.g. Dementia Advisers, Care Coordinators, Older people's Champions?
- Does the organisation running the group readily share information with other organisations?
- Is it clear what people need to do if they want to attend?

Atmosphere of the group

- Is the group welcoming?
- Are the staff and/or volunteers friendly?
- Do the staff/volunteers have an understanding of dementia?
- Is dementia openly discussed at the group?
- Are there opportunities for people to share experiences?
- Are people able to get advice and information at the groups if they need it?
- Are people referred to other agencies for advice and information if they need it?

Structure and regularity

- Is the group regular? (Same day, same time, same place)
- If there are gaps, are there opportunities for people to meet up informally during these?
- Do the groups follow a clear structure?

Opportunities for socialising

- Is there time set aside for people to chat informally to each other?
- Can people move around and talk to others if they wish to?
- Do staff/volunteers introduce people to each other?
- Are there refreshments available that promote a social environment?
- Is there evidence that people develop friendships at these groups?

Fun activities

- Does the group involve an activity that people can join in with?
- Are people told in advance what the activity will be?
- Is the activity appropriate for people living with dementia?
- Do people enjoy the activities that take place?

Service User views

- Are service users involved in evaluating the group?
- If so, what happens as a result of these evaluations?
- Are the people attending the group involved in planning and selection of activities?
- Is there any independent evaluation of the group?

Why not get involved?

Visit our website: www.healthwatchwiltshire.co.uk

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Phone us: 01225 434218

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SN12 6LH

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April 2017

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