

25 July 2019

Subject: How dementia friendly is Wiltshire?

Executive Summary

- I. Over the last four years dementia has been a priority area for Healthwatch Wiltshire. We wanted to get an overall picture of how dementia friendly initiatives are now working across Wiltshire and what people living with dementia and their carers value most about dementia friendly initiatives.
- II. We carried out two surveys, one for dementia friendly initiatives to gather information from them, and the second for people living with dementia and their carers.
- III. There were 24 responses from dementia friendly initiatives and 109 responses from people living with dementia and their carers.

IV. What were the key findings?

- Most people living with dementia and their carers feel that their local community is dementia friendly and feel part of it.
- People told us they most valued greater dementia awareness, understanding and assistance from individuals, and community groups.
- The effects of dementia friendly initiatives for people living with dementia and their carers are positive and wide-ranging including improved physical and mental health, well-being, independence, activity and community involvement.
- The successes of dementia friendly initiatives closely aligned with what people living with dementia and their carers said they found most useful.
- Dementia friendly initiatives would value support with promotional materials and publicity.
- Volunteers play a key and valuable role in dementia friendly initiatives

V. Next steps and recommendations

There are seven recommendations which will involve key organisations working together. They aim ensure that dementia friendly initiatives can be sustained and further developed to deliver the positive benefits that people living with dementia and their carers have told us about.

Proposal(s)

It is recommended that the Board:
i. Notes the key messages from the report.

- iii. Confirms its commitment to listening to the voice of local people to influence commissioning and service provision.

Reason for Proposal

Healthwatch Wiltshire has a statutory duty to listen to the voice of local people with regard to health and social care services and then feed this back to commissioners and providers to influence change. Healthwatch Wiltshire therefore ask the board to receive our latest report, make comment and reaffirm its commitment to listening to the voice of local people.

Presenter name: Stacey Plumb

Title: Manager

Organisation: Healthwatch Wiltshire

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Purpose of Report

1. The aim of this project was to get an overall picture of how dementia friendly initiatives are now working across Wiltshire, their effect on people living with dementia and their carers, and what people living with dementia and their carers value most about dementia friendly initiatives.

Background

2. Over the last four years dementia has been a priority area for Healthwatch Wiltshire, and we have gathered over 1600 views and experiences from people affected by dementia. One of the key things that we have been told is that dementia awareness is improving and that this is important. People living with dementia have told us that they want to be active and involved in their local communities.
3. Between 2015 and 2017 Wiltshire Council funded a Dementia Aware Project which involved them working in partnership with Alzheimer's Society and Alzheimer's Support. This involved a project worker delivering Dementia Friends sessions and supporting Area Boards to make their communities dementia friendly. By 2017, as a result of this project over 5,600 dementia friends were created and 17 of the 18 Area Boards in Wiltshire had been supported to set up Dementia Action Alliances. (Ref: Alzheimer's Support Dementia Awareness Project Final report)
4. Healthwatch Wiltshire hosts a dementia engagement steering group where we work in partnership with voluntary organisations to ensure that people living with dementia are heard. This includes Alzheimer's Support, Alzheimer's Society, Rethink, Carers Support and Age UK. Our partners supported us with this work by sharing our surveys and welcoming us to their groups to talk to people there.
5. This project had two elements, the first aimed to gather information from dementia friendly initiatives and the second was to talk to people living with dementia and their carers:
 - Information from Dementia Friendly Initiatives

We designed a survey for people involved in dementia friendly initiatives. We asked questions about how well they thought their initiative was working overall, what they have achieved, what they would like to develop further and if there were areas that may need further support. It aimed to assess how

'linked in' dementia action alliances are with other dementia initiatives and identify any areas where improved communication would be beneficial.

- Views of people living with dementia and their carers

We wanted to find out from people living with dementia and their carers about their experiences and views of living in their local communities. The aim was to find out how 'dementia friendly' people thought their local communities were, to identify what aspects were most valued and the impact of these, and to see what they would like to see prioritised in the future.

7. To assist us to design a survey that would do this, we involved the Laverstock Memory Support Group for people living with dementia. We held a group discussion and they shared some initial views with us about what they regarded as being dementia friendly in their local communities. We asked for this group's views on some proposed questions to find out whether they made sense, how they were interpreted, and whether there was anything that was missing. We used these responses to inform what we asked and how our survey questions were phrased. We would like to acknowledge and thank the Laverstock Memory Support Group for working with us to design this survey. The survey was designed so that it could be completed by people either on line, on paper, or through a 1-1 interview.
8. Between January and March 2019, both our surveys were widely shared throughout our dementia engagement steering group partners, other voluntary organisations, the Dementia Action Alliances, Wiltshire Council Community Engagement Managers and through social media. We also visited a number of dementia groups and day clubs to talk to people there.
9. There were 23 responses to our survey about dementia friendly initiatives and one person had an informal interview.
10. We spoke to 109 people living with dementia and their carers in total. 89 of these completed our survey and 20 people took part in a group discussion. Of these 109 people, 61 (56%) were people living with dementia and 48 (44%) were unpaid carers.
11. Of those people who shared information about their demographics:
53 were female and 34 were male
84 identified themselves as White British, and 5 as from an ethnic minority group.
The age range of those we spoke to was:

45 -54	7%	(6)
55 -64	9%	(8)
65 – 74	23%	(20)
75 – 84	50%	(43)
85 +	10%	(9)

(Some of those in the younger age ranges were carers who were children of people living with dementia)

Main Considerations

Information from Dementia Friendly Initiatives

12. We had a total of 24 responses; 23 to the survey, and one informal interview.
Most dementia friendly initiatives thought that they were working well overall. 17 of the 23 survey responses indicated this compared to 2 who thought they weren't working well.

13. **What were the successes of dementia friendly initiatives?**
We were given a range of examples of what dementia friendly initiatives thought that their main successes had been. Many of these responses covered several different things that had been successful.

14. One of the most frequently mentioned concerned increasing dementia awareness. Many initiatives mentioned that they had either organised dementia friends' sessions or given people information about them. Other ways of increasing dementia awareness included involving people living with dementia in local initiatives and bringing them together with other members of the local community.

“Holding a session for children which included rock painting (the current craze) around the dementia theme.”

15. Initiatives talked about their successes providing information about dementia and dementia services. These included providing information guides and holding dementia information stands and a dementia roadshow.
16. Establishing community groups and arranging social activities were also highlighted as a success of several dementia friendly initiatives. This included both groups that meet regularly such as memory cafes' and activity groups and one-off social events for example day trips out, plays and film showings.

“By opening it to the public as well as to people with dementia we have brought the community together and given people a better understanding of what it is like for the person living with dementia and their carers.”

17. **What difficulties or barriers have they faced?**
Dementia friendly initiatives mentioned a variety of different difficulties or barriers they faced. There was no one aspect that stood out as being common across the initiatives. However, the following things were mentioned:
- Need for someone to lead the initiative
 - Recruiting enough volunteers, volunteer availability and getting new people involved
 - Publicity for events, poor attendance at some events

- Lack of understanding and reluctance to talk about dementia
- Getting local businesses, GP surgeries and schools involved
- Transport

18. **Information about Dementia services**

We asked whether dementia friendly initiatives could access the information they needed about dementia services in their area:

- 10 responses said that they could access all the information they needed,
- 9 said that they could access some information but that there were some things they would like more information about,
- 3 said they were not able to access the information they needed about services
- 2 didn't answer this question

19. **Volunteer Involvement**

Volunteers were involved in all except one of the dementia friendly initiatives who completed our survey and we were given many examples of the role of volunteers in dementia friendly initiatives. It was clear from the responses that they make a very significant contribution to the initiatives in Wiltshire.

20. We were told that volunteers organised and ran community events and dementia friends' sessions that increase dementia awareness. It was also mentioned that they contribute to dementia awareness by informally talking to people in their local communities. Providing emotional support and understanding was also highlighted as an important role of volunteers, including welcoming people, befriending, and including people who may be isolated. We were told that people living with dementia and their carers volunteer by meeting with others and sharing their experiences and that this is greatly valued.

“Our volunteers who are living with dementia giving us their experiences and offering to meet with others”

21. A huge range of practical ways that volunteers support dementia friendly communities was mentioned. This including giving talks, providing activities, collating information, making teas and coffees, leading walks, knitting 'tweedle muffs', and providing transport.

22. **What would further support Dementia Friendly Initiatives**

We asked dementia friendly initiatives if there was anything that they would like more support with. The most commonly mentioned issue was support with communications and publicity. This was mentioned by 5 of the initiatives and we were told that support with both publicity materials, and publicising events would be appreciated, as well as support to ensure that information reached those whom it would be of benefit to.

23. More information about dementia services and information sharing about the work of dementia friendly initiatives was mentioned twice. One dementia action alliance said that they thought they needed a paid person to lead their initiative and one said that they thought a paid dementia awareness worker across Wiltshire would be beneficial.
24. Other things that were mentioned included more volunteers, finances, more referrals, greater involvement of people affected by dementia, advice about running a memory café, advice about engaging businesses and the local community and assistance with registering as a charity.

Views from people living with dementia and their carers about dementia friendly initiatives

25. We asked people overall how dementia friendly they felt their local community was. Most people we spoke to thought that their local community was dementia friendly with 66% saying they thought their community was either dementia friendly or very dementia friendly, compared with 9% who thought that their community was either not that or not at all dementia friendly. The majority of those we spoke to during our focus groups discussions also told us that they thought their communities were dementia friendly.
26. We compared the responses of people living with dementia and carers of people living with dementia. We found that more people living with dementia (69% of those who answered the question) thought that their local community was dementia friendly compared with 60% of carers.
27. We asked whether people felt part of their local communities. Of those who answered this question 79% (61) said that they did, 18% (14) said they didn't and 3% (2) responses were neutral.
28. Of those who said they didn't feel part of their local community, two people said that was down to personal choice. The others said that they felt isolated, lonely and could not find much to do in their local communities. Some carers also mentioned that the demand of caring meant that they were restricted in terms of getting out.
29. Those who said that they did feel part of their local communities gave us lots of examples of how people were involved. The majority of these included being involved in things that were going on in the local area including church and local clubs. Many responses also mentioned having good social relationships with neighbours as the reason why people felt part of their community.

"I've got good neighbours. They know me in my local supermarket and I go there for fish and chip lunch on a Saturday"
30. Also frequently mentioned by people living with dementia was the attitude of others in their local community. People gave examples of how they were included, felt understood and offered help when they needed it.

These comments related to both the general public and to people working in businesses and services. We were told about a wide range of people in Wiltshire who demonstrated an understanding of dementia and how to offer support to people. People living with dementia told us how this approach had a positive impact on their lives and supported them to remain independent. Carers who felt that their community was 'dementia friendly' told us that this helped to reassure them and could enhance their day to day experience as a carer.

"People don't think I'm barmy, they help me find places. I take people's deliveries in return."

31. Another thing that was mentioned as having been helpful was local organisations and services. The most common ones mentioned were Alzheimer's Support, Alzheimer's Society, Carers Support and GP surgeries.

"The Alzheimer's Group in Trowbridge (Mill Street) has made a big difference. it helps me discuss issues and enjoy singing. I have noticed my epilepsy fits have not been more frequent, and I feel more confident."

32. Relatively few people mentioned 'dementia friendly' changes to physical environments, compared to those who talked about the 'dementia friendly' approach of people which was seen as much more important. However clear signage was mentioned, and people with dementia told us that it was important that signage in buildings also included directions for the way back to communal areas.

Next Steps

33. The information that people have shared with us would seem to indicate that Wiltshire has made significant progress towards being 'dementia friendly'. People with dementia and their carers have clearly described the benefits that this can bring to them. It is important that this work is sustained and built upon in the future.
34. With this in mind, we recommend that key organisations work together towards the following recommendations:
 - The findings of this report to be shared with dementia friendly initiatives, providing them with opportunities to share successes and to hear what people with dementia and their carers told us.
 - Information about the dementia delivery board to be periodically shared with key people involved in dementia friendly initiatives.

- Follow up with dementia friendly initiatives who said they weren't working well and dementia action alliances who didn't respond to see how they can be supported.
- Sources of information about dementia services to be shared with dementia friendly initiatives.
- Community groups for people living with dementia and their carers to continue to be supported and developed.
- The contribution of volunteers should be encouraged and supported.
- Consideration of how dementia friendly initiatives can be supported with communications and publicity.

The Full report can be found on our website.

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