

People with dementia who live alone in Wiltshire

What is this report about?

Healthwatch Wiltshire has made dementia one of its priority areas. This report focusses specifically on what people said about people with dementia who live alone in Wiltshire. It aims to inform Wiltshire's Dementia Commissioners and providers of services so that they can incorporate the voice of local people into future plans.

What did we do?

Healthwatch Wiltshire along with voluntary sector partners has been gathering 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, highlighting good practice, and areas where people have poor experiences so that these can be addressed. Since November 2014 we have held workshops across Wiltshire and attended a number of local groups for people living with dementia. Overall we have spoken to over 500 people. We don't have details of the exact numbers of people living with dementia who live alone that we have spoken to, but we estimate it to be at least 30. In addition we have also spoken to families and friends, and volunteers and professionals who are involved with people with dementia who lived alone.

The Key Messages - What people told us about the issues for people with dementia who live alone

Information, advice and support

- People with dementia who lived alone said that it was very important to them that they were involved in decisions about their care and support. This included making arrangements and plans for the future. Several people with dementia said they would have liked more opportunities and support to do this, for example, one person said they would have liked a discussion of what might happen if they were no longer able to manage living at home as they were not aware of the options that were available.
- People living with dementia told us that advice and support was most useful when given in small chunks as and when they needed it. It was also important that this was written down for future reference. People also told us that they thought a short video was a good way of getting information across about dementia.
- Several people with dementia who lived alone said that they appreciated visits from dementia advisers and having their contact details to get in touch with them as and when they needed.
- People with dementia who lived alone also said they appreciated visits from home support workers and befrienders. Family members who were distant also said they felt reassured that someone was popping in and would be able to support with any concern.
- People with dementia living alone, and their families, highlighted dealing with paperwork (with forms, benefits, bills etc.) and organising house maintenance as being problematic, particularly where there was a lack of other family support or family were distant.
- People with dementia living alone told us about the things they used to help them with daily living. These included specialised clocks, calendars, diaries, and dosset boxes for medication. These were all thought to be useful to support them to be independent.

Potential risks

- Many people who took part in our engagement expressed concern for people with dementia who live alone.
- People talked about people with dementia living alone who were socially isolated and not accessing the support that was available. It was felt that this was worse for those who did not have family who lived close by. These people were felt to be particularly vulnerable.
- People with dementia living alone, family members and professionals all shared concerns about the risks of financial abuse. Scam mail, charity 'begging' letters, phone scams, cold callers and salesman and 'rouge builders' were all mentioned as potential risks.
- It was felt that reducing social isolation and improving access to services and community support could identify and reduce some of these potential risks.

Health and social care

- Variations in the quality of home care was felt to particularly affect people with dementia who lived alone. Particular issues that were mentioned were lack of continuity; poor coordination of visit times; communication issues and lack of dementia awareness and training of staff. Examples were given where care workers weren't aware of the need to use a key safe to gain entry and/or notify relatives if they were unable to gain access.
- People with dementia living alone and their families said that it was important that they were given written details about medical appointments, as it was often difficult to remember the detail of what they had been told. Particularly people said that they wanted written confirmation of their dementia diagnosis.

Community and social activities

- People with dementia who lived alone told us that it was very important that they were involved in their local communities and social activities. They talked about a wide variety of activities that they were involved with. These included library groups, singing groups, exercise groups, memory clubs, lunch clubs, volunteering, gardening groups, and day centres/clubs. Many people with dementia who lived alone had needed some support to initiate contact with new groups, but once they had started attending, did not need further support.
- People living with dementia alone said that they thought transport was a particular issue for them, particularly if they had to stop driving. Some people living alone said that they used the LINK service for medical appointments and found it useful. Some people told us that they had to discontinue attending social activities as they could no longer get to them. Family members of people with dementia who lived alone said that they thought some specialist transport/taxi's with drivers who were dementia aware and could, for example, make sure the person got in safely, would be useful and enable people to get out more in their local community.

Conclusions

People with dementia who live at home, their families and people who work with them identified a number of issues that affected them as have been detailed above. Some of these are different to those of someone who lives with their family or partner, some are the same but may be more severe or difficult to resolve. However people identified many ways by which people with dementia who live alone can be supported to be independent and to remain active and involved in their local community. From the people we spoke it was appeared that not everyone living alone with dementia was accessing all the support they may benefit from to maximise their wellbeing.