

## West Midlands Dementia Support Survey - People Living With Dementia

This survey is for people living with dementia. We are asking people from across the West Midlands to take part. Thank you for your interest. The survey should take a maximum of 20-30 mins to complete.

We want to find out about any services that you find helpful and any that you think are missing. We also want to know if you have had any problems finding out about or getting the support you feel you need.

Three other surveys are taking place. These are to find out the views of family and carers for people with dementia, people who commission (design and pay for) services and organisations who provide services to support people living with dementia and/or their family and carers. We will combine the results of all three surveys to highlight good services in the West Midlands that help people living with dementia and their carers. We will also identify any common problems and any gaps that may exist. We will share the results of the surveys to help improve support for people with dementia and their family and/or carers in the future.

The survey is designed to capture individual experiences, opinions and perspectives. Please answer from your own point of view, rather than on behalf of another individual or a group. Please feel free to share this survey with anyone else you feel might be interested. You can send them this link:

<https://www.surveymonkey.com/r/VTT65NY>

Thank you for your time and for completing the survey.

West Midlands map



West Midlands  
Strategic Clinical Networks



Directors of  
**adass**  
adult social services



## West Midlands Dementia Support Survey - People Living With Dementia

If you would like any further information or you have any questions, please contact Sharon Adams:  
sharon.adams1@nhs.net

If you are completing this survey as a paper copy, please return the completed survey to:

**FAO: Sharon Adams**

**West Midlands Strategic Clinical Network and Senate**

St Chad's Court  
213 Hagley Road  
Edgbaston  
Birmingham  
B16 9RG

**Thank you for your time and for completing the survey.**

## West Midlands Dementia Support Survey - People Living With Dementia

If you are completing this survey on behalf of or alongside someone with dementia, please remember to complete all answers from their point of view.

Firstly, we would also like to understand a little more about you and your living situation.

\* What is your living situation?

- I live alone
- I live with my spouse or a family member
- I live in residential/nursing care
- Other (please specify)

\* What is your post code? (This information will not be used to identify you. It will simply be used to ensure we are covering all geographical areas.)

## West Midlands Dementia Support Survey - People Living With Dementia

Throughout this survey, we have included some statements (devised by patients and family carers as part of the national Dementia Action Alliance) that describe what they would like to be able to say about their lives. We would like to find out what the reality is for people living with dementia.

For each of the following statements, please think about your own life and indicate to what extent you agree or disagree.

\* I feel safe and supported to live in my home

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I feel safe and supported in my local community (shops, pubs etc)

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* People with whom I come into contact in my local community are helpful and supportive

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I continue to have the opportunity to develop new interests and new social networks

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I have personal choice and control or influence about the decisions that affect me

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I can make decisions now about the care I want in my later life

Strongly agree

Somewhat agree

Neither agree nor  
disagree

Somewhat disagree

Completely disagree



## West Midlands Dementia Support Survey - People Living With Dementia

We are committed to promoting equality and eliminating unlawful discrimination, and we are seeking to find out whether current dementia services meet the needs of the population in the West Midlands. You do not have to answer the following three questions, and we understand that some of this information is personal and sensitive in nature. However, gathering this data helps us to understand whether services are meeting the needs of people from a diverse range of backgrounds.

Are your day to day activities limited because of a health problem or disability (in addition to dementia) that is expected to last at least 12 months?

	No	Limited a little	Limited a lot
Vision (eg due to blindness or partial sight)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hearing (eg due to deafness or partial hearing)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Mobility (such as difficulty walking short distances, climbing stairs, lifting and carrying objects)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learning disabilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Stamina or breathing difficulty	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other impairment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please expand on any answers above with as much information as you feel is relevant.

## West Midlands Dementia Support Survey - People Living With Dementia

What is your ethnic group?

- White British
- White Irish
- Any other white background
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background
- African
- Caribbean
- Any other black background
- White and black Caribbean
- White and black African
- White and Asian
- Any other mixed background
- Any other background
- Prefer not to say

## West Midlands Dementia Support Survey - People Living With Dementia

What is your religion?

- No religion
- Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- Buddhist
- Hindhu
- Jewish
- Muslim
- Sikh
- Any other religion
- Prefer not to say



## West Midlands Dementia Support Survey - People Living With Dementia

Now, we would like to understand a little about how you received your diagnosis of dementia. Please indicate the extent to which you agree with the following statements:

\* I received an early diagnosis

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* When I received an early diagnosis it was sensitively communicated to me

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* Approximately how many years ago did you receive your diagnosis of dementia?

\* Who made the diagnosis of dementia?

- GP
- Memory Assessment Service
- Other (please detail below)

Please use this space to tell us anything about your experiences of your diagnosis that you feel is relevant, including your type of dementia and anything else you would like us to know:

\* Were you aged 64 or younger at the time of diagnosis

- Yes
- No

## West Midlands Dementia Support Survey - People Living With Dementia

Please consider the following statements and indicate to what extent you agree with them:

\* I know that services are designed around me and my needs

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I know how and where to get information and advice about the range of benefits I can access

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I know how to get support and I am confident it will help me

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## West Midlands Dementia Support Survey - People Living With Dementia

\* Who told you where/how to find information and ongoing support?

- GP
- Memory Assessment Services
- Someone from a third sector organisation (such as the Alzheimer's Society)
- Someone working for the council or local authority (such as a social worker)
- Other (please detail below)
- Don't Know
- I have not been offered any information or ongoing support

Please use this space to tell us anything about your experiences that you feel is relevant and that you would like us to know, including any problems you may have encountered when trying to find the information, advice and support you want or need.

\* I can easily access any information or support I need to help me live my life

Strongly agree

Somewhat agree

Neither agree nor  
disagree

Somewhat disagree

Completely disagree



## West Midlands Dementia Support Survey - People Living With Dementia

\* Please tell us about any services that you are using or have experience of:

	Currently using	Previously used	Aware of this service but do not wish to use	Not appropriate	Not aware of this service locally
Information and guidance about dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Local information pack or information prescription	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist named dementia nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist named dementia adviser (not a nurse or doctor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Memory support services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information and guidance about young onset dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other services specific to younger people living with dementia (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Singing for the brain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Peer support/Dementia cafes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Opportunity to get involved in dementia research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Currently using	Previously used	Aware of this service but do not wish to use	Not appropriate	Not aware of this service locally
Assistive technology (any device or system that makes day to day tasks easier and possible)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Medication support (for example Telecare)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Training in managing your own dementia (self care)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fall prevention services (advice, education, exercises etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Counselling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal care (such as help with washing, dressing etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Independent Advocacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite/replacement care services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify below)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please expand upon your answers above and also tell us about any support you feel would make a real difference to you that is currently not available or accessible. It would be useful to know at what point during your journey so far that you would have needed this support.

## West Midlands Dementia Support Survey - People Living With Dementia

\* I am aware that there is research going on that will lead to a better life for people with dementia now and hope for the future

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* I know how I can contribute to dementia research

Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Completely disagree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

\* Are you or have you been involved in dementia research?

- Currently
- Previously
- No

Please tell us anything you wish about your views on research into dementia

## West Midlands Dementia Support Survey - People Living With Dementia

Thank you for completing our survey. The results will be compiled once the survey closes on 31st May 2015. If you would like to receive updates on the progress of this project, including the results of the survey and invitations to upcoming events, please enter your details below:

Name

Email Address

Telephone Number

Address

Please indicate whether you would like to be kept informed of the work of the West Midlands Strategic Clinical Networks and Senate, ADASS and IEWM around dementia and other health and social care topics. This may include opportunities to become involved in further projects

Yes

No

If you would like to find out further information about the project, please visit our website:

[www.wmscnsenate.nhs.uk/strategic-clinical-networks/our-network/mental-health-dementia-and-neurological-conditions/current-projects/post-diagnostic-support](http://www.wmscnsenate.nhs.uk/strategic-clinical-networks/our-network/mental-health-dementia-and-neurological-conditions/current-projects/post-diagnostic-support)

If you have any queries or need any assistance, please contact Sharon Adams: [sharon.adams1@nhs.net](mailto:sharon.adams1@nhs.net)