

Dementia 2020 Citizens' Engagement Programme

Survey on Dementia Care, Support and Awareness

Introduction

Over recent years great progress has been made to improve dementia care and support. More people than ever before are receiving a diagnosis of dementia. Improvements have also been made in raising awareness in local communities with over 1 million people becoming Dementia Friends¹ The health and care workforce are also receiving dementia training to better support you.

But there is still more to do. The Government's aim is for England to be the best place in the world for people with dementia, their families and carers to live and the best place to undertake research into dementia.

This is your opportunity to tell us how we are doing. We want to hear first-hand from people with dementia, their families and carers if we are making a difference to your day to day lives.

Your views will be used by the Department of Health and the partner organisations we work with to check our progress. We want to continue to work harder than ever to improve dementia care, support and awareness.

Who should complete the survey?

The survey is for:

- any person in England who has received a diagnosis of dementia in the last two years (between November 2014 and November 2016) and;
- any person in England who currently provides unpaid care or support to a family member, friend or neighbour who has been diagnosed with dementia in the last two years (between November 2014 and November 2016)

¹ A Dementia Friend learns a little bit more about what it's like to live with dementia and then turns that understanding into action.

When is the closing date?

The survey will close on **31st January 2017**. After this we will be looking at what you have told us.

Confidentiality

Any information you provide will be confidential and is anonymous .The results will be used by the Department of Health:

- to help us to see if policies on improving dementia care and support are making a positive difference;
- to see where further improvements may be needed and;
- to influence and improve the delivery of services and support at a local level.

Your information will be used for this purpose and no other.

Accessibility

We have made the survey as accessible as possible . The questions have been informed by work we did over the summer of 2016 with groups of people with dementia and carers. We do appreciate that some people may need help to complete the survey and suggest that you ask someone in a support role such as – a carer, friend, family member, or personal assistant.

About you

It is helpful for us to know a bit about you.

You do not have to answer any of these questions, but if you do it will help us understand more about the results.

Anything you tell us will be in confidence.

Question 1 What is your email address?

This is optional, but if you enter your email address then you will be able to return to edit your consultation any time until you submit it. You will also receive an acknowledgement email when you complete the consultation.

Email

Question 2 Have you received a diagnosis of dementia in the last two years (between November 2014 and November 2016)?

- Yes
- No
- Don't know

Question 3 Do you currently provide unpaid care or support to a family member, friend or neighbour who has been diagnosed with dementia in the last two years (between November 2014 and November 2016)?

- Yes
- No
- Don't know

If you have answered 'No' to questions 2 and 3, this survey is not intended for you. But there will be other opportunities in the future to tell us about your experience of dementia.

Question 4 **Please give the first half of your postcode. This is to help us see how services can be improved locally.**

Question 5 **How old are you?**

- Under 18 years old
- 18 to 35 years old
- 36 to 50 years old
- 51 to 65 years old
- 66 to 75 years old
- 76 to 85 years old
- 86 to 95 years old
- Over 95 years old.

Question 6 **What is your gender?**

- Male
- Female
- Other
- Prefer not to say

Question 7 What is your ethnic origin?

White

- English / Welsh / Scottish . Northern Irish / British
- Irish
- Gypsy or Irish traveller
- Any other white background, please describe:

Mixed/multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian

Asian/Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, please describe:

Black/African/Caribbean/Black British

- African
- Caribbean
- Any other Black / African / Caribbean background, please describe:

Other ethnic group

- Arab
- Any other ethnic group, please describe:

Other ethnic group

- Prefer not to say

Question 8 Do you have a learning disability?

- Yes
- No
- Don't know

In the rest of this survey we will be asking you some questions about your experiences and views.

Some of them might be relevant to you, some might not. You can choose which questions you answer.

The survey has been designed in such a way that the questions can be answered by either **people with dementia** based on their personal experience or by **unpaid carers of people with dementia** giving their own perspective as carers. We are interested in hearing the views of both.

About getting a diagnosis of dementia

Question 9 **How long ago were you or the person you provide care for diagnosed?**

- In the past 3 months
- Between 3 and 6 months ago
- Between 6 and 12 months ago
- Between 1 year and 18 months ago
- More than 18 months ago

Question 10 **Following the diagnosis of dementia, were you, or if you are a carer, the person you care for, given a more specific diagnosis?**

- Yes
- No
- Don't know

If yes, was the diagnosis of:

- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy bodies
- Frontotemporal dementia
- Mixed dementia
- Other – please describe below:

Question 11 **Where was the diagnosis given?**

- At the GP surgery
- At hospital
- At a memory clinic/service
- At a neurological clinic
- At home
- I'm not sure
- Somewhere else. Please say where:

Question 12 **If your GP referred you or if you are a carer, the person you care for, to a memory service how long did you have to wait to attend the first appointment?**

- Less than 2 weeks
- Between 2 and 4 weeks
- Between 4 and 8 weeks
- Between 8 and 12 weeks
- Between 12 and 16 weeks
- Between 16 and 20 weeks
- More than 20 weeks
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 13 **How well was the diagnosis communicated to you as a person with dementia or as a carer?**

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure

Please provide any additional information here. For example did you understand what was said and did you feel well supported?

Question 14 **Were you happy with the amount and quality of the information given?**

- Yes
- No
- I'm not sure

- I didn't receive any information

If you want to give us more information about this, please tell us here.

Question 15 **Following the diagnosis, were you told about what would happen next?**

- Yes
- No
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 16 **Could anything be improved about the way the diagnosis was made? For example what you were told or the process you had to go through.**

About the help you had after the diagnosis

Question 17 **What kind of support did you get as a person with dementia or as a carer in the 12 months after the diagnosis? Please select all that apply.**

- Support to help you manage the symptoms of dementia.
- Review of your medication
- Support for stress, anxiety or depression
- Help for your family or carer
- Support to help improve and maintain your memory (e.g. cognitive stimulation therapy)
- Support to improve and/ or maintain your quality of life (e.g. information and advice, art, music or reminiscence activities, living well with dementia groups)
- Support for your physical health (e.g. occupational therapy, falls prevention support or physiotherapy)
- Support to remain at home i.e Home Care, meals on wheels etc
- Peer support such as Dementia Café's
- Support for you to maintain your relationships
- Support with communication
- Support with your finances
- I did not feel I needed any support at this stage.
- No support was given
- Other – please say what this was

Question 18 **If you, as a person with dementia or as a carer, have received support, how easy or difficult was it to get the support?**

- Very easy
- Quite easy
- Quite difficult
- Very difficult
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 19 **Who provided this support ? Please tick all that apply.**

- My GP practice
- My Local Authority
- Charities
- Healthcare professionals such as District Nurses or therapists
- Church or faith group
- Someone else. Please say who this was.

Question 20 **How involved were you in decisions about the support you were given?**

- I was very involved
- I was quite involved
- I was involved a little
- I was not involved at all
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 21 **Overall, how would you rate the support you received?**

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 22 **Could the support you received have been improved?**

- Yes
- No

Please provide more information below

About how well people understand dementia

Raising awareness of dementia and supporting local communities to be more understanding of dementia is important.

We know that when people understand about dementia, it helps to dispel misunderstandings and makes it easier for people to live better and to get any help they might need.

In this section we would like to find out about your experience of how other people understand dementia, and respond to you.

Question 23 **Have you told people you have dementia or that you are caring for someone with dementia?**

- Yes
- No

If you want to give us more information about this, please tell us here.

Question 24 If you have told people you have dementia or that you are a carer caring for someone with dementia, how have people responded?

- Positively
- Negatively
- A mixed response
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 25 In your experience, what is your overall impression of how well people understand dementia?

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 26 **If you have told people you have dementia or are a carer caring for someone with dementia, have you seen a change in the attitudes and behaviour of people towards you?**

- Yes
- No
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 27 **Has this been a positive or negative change?**

- Positive
- Negative
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 28 **Do you as a person with dementia or a carer feel you can still take part in the things that are important to you?**

- Yes

- No
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 29 **As we go about our daily lives we come into contact with all sorts of people, and some of these are listed below. In your experience as a person with dementia or as a carer how well do you think these people understand dementia?**

Your own family

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Your friends

- Very well
- Well
- Not very well
- Not very well at all

- I'm not sure
- Doesn't apply to me

Clinical staff in hospitals (e.g doctors, nurses etc)

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Non-clinical staff in hospitals (e.g porters, receptionists etc)

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff at your GP surgery

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure

- Doesn't apply to me

Staff from social services

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Housing staff

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff and volunteers from charities

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff in shops

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff in transport – buses, trains, taxis

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff in banks

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff in restaurants and cafes

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff at leisure centres and sporting events

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff in libraries, museums and parks

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Staff at theatres and cinemas

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Travel Insurers

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

The general public

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

Employers

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure
- Doesn't apply to me

If you want to give us more information about this, please tell us here.

Question 30 **How well do you, as a person with dementia or as a carer, think you understand dementia?**

- Very well
- Well
- Not very well
- Not very well at all
- I'm not sure

If you want to give us more information about this, please tell us here.

Question 31 **What do you think, as a person with dementia or as a carer, people need to know about dementia?**

Question 32 **What are the three most effective ways of helping people to understand more about dementia? Please choose three options.**

- Dementia Friends
- Education in schools
- Training for all staff groups
- Promoting research findings
- Online information (e.g on the website)
- Information on the TV and Radio
- Information in newspapers and magazines
- Information and advice available in the community (e.g leaflets etc)
- Community events
- I'm not sure
- Other - please provide details below.

Thank you for taking the time to complete this survey. All of your answers will remain anonymous. We will be telling people what we found out in Spring 2016.

If you would like us to email you about the results of this survey, or other work we are doing on dementia, don't forget to tick 'yes' next to the relevant question below and enter your email address on the next page, if you haven't already entered it.

To help us improve any future surveys please can you feedback how easy or difficult you found it completing this survey?

Question 33 How easy or difficult was it to complete this survey?

- Very easy
- Quite easy
- Quite difficult
- Very difficult
- I'm not sure

Question 34 Are there any ways we could improve future surveys?

Question 35 Would you like us to email you about the results of this survey?

- Yes
- No

Question 36 Would you like to hear more about the work we are doing on dementia?

- Yes

- No

If you provide an email address you will be sent a receipt and a link to a PDF copy of your response.

Email address