

**Data included: Turning Up the Volume: unheard voices of dementia**

**1. Topline results: Survey of the General Public**

- This document details results from an Ipsos MORI i-omnibus survey conducted with 2356 adults aged 16-75 in the United Kingdom between 13 – 17 January 2017.
- All participants were interviewed online.
- The data is weighted to the known population profile for the United Kingdom.
- Booster interviews were carried out to ensure at least 100 interviews each in the North East and Northern Ireland.
- Where results do not sum to 100, this may be due to multiple responses, computer rounding or the exclusion of don't knows/not stated.

Q	To what extent do you agree or disagree with the following statements?	
Q	<b>I worry that any savings I have will be spent on future care and support and leave nothing to pass on to my children or other loved ones</b> Base: All respondents (2356)	%
	Strongly agree	16
	Tend to agree	24
	Neither agree nor disagree	25
	Tend to disagree	11
	Strongly Disagree	9
	Don't Know	4
	Not Applicable	10
	<b>Agree</b>	41
	<b>Disagree</b>	20
Q	<b>I have started saving for the care and support I may need in the future</b> Base: All respondents (2356)	
	Strongly agree	7
	Tend to agree	19
	Neither agree nor disagree	23
	Tend to disagree	21
	Strongly Disagree	26
	Don't Know	3
	<b>Agree</b>	26
	<b>Disagree</b>	47
Q	<b>Do you know any of the following people who have or have had dementia? Please select all that apply</b>	

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Base: All respondents (2,356)		
		%
	A neighbour or someone in my community has or had dementia	13
	One or both of my parents/ step parents have or had dementia	10
	A personal friend has or had dementia	9
	One or both of my grandparents or spouse`s grandparents have or had dementia	8
	I have a cousin, aunt or uncle who has or had dementia	7
	One or both of my partner or spouse`s parents have or had dementia	6
	Somebody else I know	4
	I know a work colleague or former colleague who has or had dementia	4
	Other family member(s)	1
	I have a brother or sister who has or had dementia	1
	My partner or spouse has or had a brother or sister with dementia	1
	My partner or spouse has or had dementia	1
	I have dementia	*
	I have a child/ step child who has or had dementia	*
	I don't know anyone who has dementia	48
	I do not know what dementia is	1
	Prefer not to say	3
	<b>Personally has dementia or knows someone with dementia</b>	<b>49</b>
	<b>Personally has dementia or knows family member(s) (includes spouses family) who has or had dementia</b>	<b>31</b>
	<b>Knows someone outside of family who has or had dementia</b>	<b>24</b>

Q	To what extent do you agree or disagree with the following statements?	
Q		%
	<b>Dementia is a health condition that should be dealt with by society and communities, not just by the friends and family of those with this condition</b>	
	Base: All respondents (2356)	
	Strongly agree	37
	Tend to agree	41
	Neither agree nor disagree	14
	Tend to disagree	2
	Strongly Disagree	1
	Don't Know	6

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		<b>Agree</b>	78
		<b>Disagree</b>	3
<b>Q</b>	<b>It's just as easy for people with dementia to play an equal part in society as anyone else</b>		
	Base: All respondents (2356)		
		Strongly agree	5
		Tend to agree	18
		Neither agree nor disagree	27
		Tend to disagree	28
		Strongly Disagree	13
		Don't Know	9
		<b>Agree</b>	23
		<b>Disagree</b>	41
<b>Q</b>	<b>People with dementia inevitably experience worse care and support than people with other long term conditions (such as cancer or heart disease)</b>		
	Base: All respondents (2356)		
		Strongly agree	15
		Tend to agree	35
		Neither agree nor disagree	28
		Tend to disagree	8
		Strongly Disagree	1
		Don't Know	13
		<b>Agree</b>	49
		<b>Disagree</b>	9

<b>Q</b>	<b>Which of the following statements, if any, reflect your understanding of dementia?</b>	
	<b>Please select all that apply.</b>	
	Base: All respondents (2356)	
		<b>%</b>
	Dementia cannot currently be cured	72
	Dementia is a condition that results in death	22
	Dementia usually runs in the family	17
	Dementia only affects a person's memory	12
	It's usually easy to tell if someone has dementia	8

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	Dementia is an inevitable part of ageing	8
	None of these reflect my understanding of dementia	10
	Don't know	9

Q	To what extent do you agree or disagree with the following statements?	
	<b>Dementia is the health condition I most fear developing</b> Base: All who do not have dementia (2350)	%
	Strongly agree	16
	Tend to agree	28
	Neither agree nor disagree	32
	Tend to disagree	13
	Strongly Disagree	5
	Don't Know	5
	<b>Agree</b>	44
	<b>Disagree</b>	18
<b>Q</b>	<b>If I had dementia, I would feel that my life is over</b> Base: All who do not have dementia (2350)	
	Strongly agree	21
	Tend to agree	35
	Neither agree nor disagree	25
	Tend to disagree	8
	Strongly Disagree	3
	Don't Know	8
	<b>Agree</b>	56
	<b>Disagree</b>	10

Q	To what extent do you agree or disagree with the following statements?	
	<b>Before this interview I hadn't considered the cost of dementia care and support (for example, help with things like washing, dressing, eating, getting out and about and keeping in touch with friends or family)</b> Base: All respondents (2356)	%
	Strongly agree	12
	Tend to agree	26
	Neither agree nor disagree	23

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	Tend to disagree	20
	Strongly Disagree	13
	Don't Know	6
	<b>Agree</b>	37
	<b>Disagree</b>	34
<b>Q</b>	<b>The UK Government should pay for my care and support if I developed dementia</b>	%
	Base: All respondents (2356)	
	Strongly agree	20
	Tend to agree	34
	Neither agree nor disagree	32
	Tend to disagree	4
	Strongly Disagree	1
	Don't Know	9
	<b>Agree</b>	54
	<b>Disagree</b>	5
<b>Q</b>	<b>If I had dementia I would know where to find the care and support I needed</b>	%
	Base: All respondents (2356)	
	Strongly agree	5
	Tend to agree	17
	Neither agree nor disagree	23
	Tend to disagree	30
	Strongly Disagree	17
	Don't Know	7
	<b>Agree</b>	22
	<b>Disagree</b>	47

<b>Q</b>	<b>How comfortable, if at all, would you feel in the following situations?</b>	
	<b>If someone I knew told me they have dementia</b>	%
	Base: All respondents (2356)	
	Very comfortable	26
	Fairly comfortable	44
	Fairly uncomfortable	14

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	Very uncomfortable	2
	Don't know	14
	<b>Comfortable</b>	70
	<b>Uncomfortable</b>	17

**Profile Information**

<b>Q</b>	<b>Gender</b> Base: All respondents (2356)	%
	Male	50
	Female	50

<b>Q</b>	<b>Age</b> Base: All respondents (2356)	%
	16-24	16
	25-34	18
	35-44	18
	45-54	19
	55-75	29

<b>Q</b>	<b>Working status</b> Base: All respondents (2356)	%
	Working	59
	Not working	41

<b>Q</b>	<b>Social grade</b> Base: All respondents (2356)	%
	AB	26
	C1	28
	C2	22
	DE	23

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Q	Government Office Region Base: All respondents (2356)	%
	North East	4
	North West	11
	Yorkshire and the Humber	9
	West Midlands	9
	East Midlands	7
	East of England	9
	South West	9
	South East	13
	Greater London	13
	Wales	5
	Scotland	8
	Northern Ireland	3

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**2. Topline results: Survey of unpaid carers of people with dementia**

- Ipsos MORI interviewed a nationally representative quota sample of 3,462 adults aged 40 years and over across the UK. Of those who chose to complete this survey 500 interviews were achieved with people who claim to look after, or give any unpaid help or support to a family member, neighbour or someone else who has been diagnosed with dementia.
- All participants were interviewed online.
- Fieldwork took place between 7 - 8 November 2016.
- The data was not weighted as the profile of unpaid carer's of people living with dementia is unknown.
- Where results do not sum to 100%, this may be due to multiple responses, computer rounding or the exclusion of don't knows/not stated.
- An asterisk (\*) represents a value of less than one half or one percent, but not zero.

Q	<b>Do you live in the same household as the person you look after or provide help and support for?</b>	
	Base: All respondents (500)	
		%
	Yes – same household	15
	No – not the same household	85
	Don't know	0

Q	<b>Roughly how long have you been looking after or providing help and support for the person living with dementia?</b>	
	Base: All respondents (500)	
		%
	Less than 6 months	10
	6 months to less than 1 year	20
	1 year to less than 3 years	38
	3 years to less than 5 years	17
	5 years to less than 10 years	11
	More than 10 years	2
	Don't know	1



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<b>Q</b>	<b>Thinking about all the things you do for this person, about how many hours during a typical a week do you spend looking after or helping them? Please include any time you spend travelling so that you can do these activities.</b>	
	Base: All respondents (500)	
		<b>%</b>
	1-4 hours a week	31
	5-9 hours a week	23
	10 – 19 hours a week	17
	20 – 34 hours a week	7
	35 – 49 hours a week	4
	50 – 59 hours a week	3
	60 – 69 hours a week	1
	70 – 79 hours a week	*
	80 – 89 hours a week	1
	90 – 99 hours a week	*
	100 or more hours a week	4
	Varies – under 20 hours a week	4
	Varies – 20 or more hours a week	1
	Don't know	4

<b>Q</b>	<b>How has looking after or providing care and support affected your personal relationships and social life? Has it made it...</b>	
	Base: All respondents (500)	
		<b>%</b>
	A lot better	6
	A little better	13
	Not made a difference	43
	A little worse	26
	A lot worse	11
	Don't know	1
	<b>Better</b>	<b>18</b>
	<b>Worse</b>	<b>37</b>

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Q	In which, of any, of the following ways has looking after or providing help and support for someone with dementia impacted upon your personal relationships and social life? Base: All respondents (500)	%
	I have less time for myself	35
	It worries me to leave them	33
	I have learnt to be more caring and empathetic	33
	I am being a more useful person	32
	It has strengthened my relationship with the person I care for	29
	Spend less time with friends	24
	I often feel too tired to go out	19
	Spend less time with family members	17
	Unable to go on holiday	16
	Not able to go out for long	14
	It is difficult balancing work and caring	14
	Have no time to myself	12
	Spend more time with family members	11
	I have made new relationships	8
	Feel that I have lost who I am	7
	Spend more time with friends	1
	Other	3
	None of the above	13
	Don't know	1

Q	Have you felt lonely recently? Base: All respondents (500)	%
	Yes - very lonely	8
	Yes - fairly lonely	20
	No - not very lonely	33
	No - not at all lonely	37
	Don't know	2
	<b>Lonely</b>	<b>28</b>
	<b>Not lonely</b>	<b>70</b>

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Q	To what extent do you agree or disagree with the following statements: Base: All respondents (500)	
	<b>As a carer of someone living with dementia I feel cut off from society</b>	<b>%</b>
	Strongly agree	7
	Tend to agree	20
	Neither agree nor disagree	26
	Tend to disagree	22
	Strongly disagree	22
	Don't know	3
	<b>Agree</b>	<b>27</b>
	<b>Disagree</b>	<b>44</b>
	<b>There is enough support available for those who care for people with dementia</b>	<b>%</b>
	Strongly agree	5
	Tend to agree	12
	Neither agree nor disagree	17
	Tend to disagree	34
	Strongly disagree	31
	Don't know	2
	<b>Agree</b>	<b>17</b>
	<b>Disagree</b>	<b>65</b>

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Q	Which of the following services, if any, have provided you with support or advice about caring for the person with dementia? Base: All respondents (500)	
		%
	Your NHS GP	37
	Alzheimer's Society	23
	Your Local Authority	20
	An NHS nurse	17
	Memory clinic	14
	Other charities	8
	Church or other faith group	7
	A private nurse	5
	A private GP	5
	Friends	1
	Care home staff/nursing home (Sunrise Homes, Hospice)	1
	Private carer/carers	1
	Dementia/memory nurse	*
	Neurologist	*
	Social services / worker	*
	Other	6
	No one has provided advice or support about caring for someone with dementia	27
	Don't know	3
	<b>Medical (NET) (includes: Your NHS GP/a private GP/an NHS nurse/a private nurse)</b>	<b>47</b>
	<b>Charity (NET) (includes: Alzheimer's Society/other charities)</b>	<b>29</b>

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Q	To what extent are you aware of any of the following types of support? Base: All respondents (500)	
	<b>Carer's Assessment</b>	<b>%</b>
	Yes – fully aware of	20
	Yes – aware of but not in detail	37
	No – not aware of	27
	Heard nothing about	12
	Don't know	4
	<b>Carer Personal Budgets</b>	<b>%</b>
	Yes – fully aware of	12
	Yes – aware of but not in detail	30
	No – not aware of	36
	Heard nothing about	18
	Don't know	5
	<b>NHS continuing health care</b>	<b>%</b>
	Yes – fully aware of	15
	Yes – aware of but not in detail	42
	No – not aware of	27
	Heard nothing about	13
	Don't know	3

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Q	<b>Have you been assessed for or been offered any of the following support?</b> Base: all aware of support type	
	<b>Carer's Assessment (285)</b>	<b>%</b>
	Yes	29
	No	65
	Don't know	6
	<b>Carer Personal Budgets (206)</b>	<b>%</b>
	Yes	20
	No	69
	Don't know	10
	<b>NHS continuing health care (282)</b>	<b>%</b>
	Yes	25
	No	62
	Don't know	13

Q	<b>Has your financial situation, got better, stayed the same or got worse, as a result of you caring for this person with dementia?</b> Base: All respondents (500)	
		<b>%</b>
	Got better	2
	Got worse	26
	Stayed the same	70
	Don't know	3

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Q	In which, if any, of the following ways has caring for this person with dementia affected your finances for the worse?	
	Base: All whose financial situation has got worse (130)	
		<b>%</b>
	Spent money on items for the person I care for	57
	Dipped into my/our savings	38
	Spent money on paid care	26
	Reduced my hours at work	25
	Used my annual leave to care	21
	Given up work	17
	Changed the type of work I do	15
	Retired early	15
	Become overdrawn	11
	Had to borrow money	10
	Other	8
	Don't know	2

Q	In which, if any, of the following ways has <u>your health</u> been affected as a result of caring for a person with dementia?	
	Base: All respondents (500)	
		<b>%</b>
	Feeling tired	38
	General feeling of stress	35
	Feeling frustrated	28
	Disturbed sleep	27
	Short tempered/irritable	21
	Feeling depressed	18
	Physical strain (e.g. back)	12
	Stronger sense of purpose	9
	Developed my own new health condition(s)	6
	Made an existing condition worse	6
	Loss of appetite	4
	I am more active / it has made me fitter	4
	Other	1
	My health has <b>not</b> been affected by caring for someone with dementia	32
	Don't know	2

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Q	What advice would you give to someone who has recently taken on caring responsibilities for someone living with dementia? Base: All respondents (500)	
	<b>Help (NET)</b>	<b>42</b>
	<b>Help in general (SUB-NET)</b>	<b>38</b>
	Ask/get as much help/support as possible (from family, neighbours, friends, etc.)	26
	Don't try to do everything yourself/share responsibility (with other family members/professional carers)	8
	Seek professional help/apply for carers/get help from agencies	3
	Talk about it with friends/people relieve pressure and emotions	3
	Find out what help is available	3
	Speak to others in similar situation	2
	Find support groups	1
	Others on help in general	1
	<b>Service interaction (SUB-NET)</b>	<b>8</b>
	Contact Alzheimer's Society/Alzheimer organizations	2
	Be prepared to get no support from official agencies/to perceive unfairness in the system/push for support	2
	Ask help from NHS	1
	Consult GP	1
	Find out (from the local council) all your entitlements	1
	Ask help from charities	1
	Keep a record of all communication with social services	*
	Others on service interaction	2
	<b>Behaviour towards patients (NET)</b>	<b>25</b>
	Be patient/keep calm	10
	Be kind/compassionate caring/understanding/tolerant/love	4
	Do your best for the patient/look after the patient/do what you can	3
	Be supportive	2
	Be strong/firm	2
	Don't get upset to the patient/don't stress them/don't argue/shout	2
	Be a good listener	2
	Have sense of humour/keep smiling/laugh together/make them happy	1
	Don't keep correcting person/agree with everything they say	1
	Be available/make time for them	1
	Deal with them as you always have/treat them as equal	1

Continued.



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	Keep their mind active/keep repeating things/write stuff down/involve the person in decisions	1
	Talk to them	*
	Be open/honest	*
	Ask only one question at a time/give only one instruction at a time	*
	To get out and about with the person/keep in contact with community	*
	Value your time with the person living with dementia	*
	Talk about the old times past/dig out old photos/memories	*
	Others on behaviour towards patients	2
	<b>Taking time for yourself (NET)</b>	<b>21</b>
	Make time for yourself/have a break/don't feel guilty for claiming time for yourself	9
	Look after yourself/take care of yourself/think of your own health (eat well/exercise/get enough sleep)	8
	Relax/take it easy/pace yourself/don't become stressed	3
	Make time for your family/make sure you keep relationships with friends/family going	1
	Be positive/don't get despondent	1
	Live a normal life	1
	Others on taking time for yourself	1
	<b>Advice in general (NET)</b>	<b>19</b>
	Get advice/get as much advice (from all sources)	5
	Get as much information as possible (related to the disease)/research	3
	Think well before you agree to take all the responsibility	2
	Keep going/carry on	1
	Be prepared for bad times/don't expect everything to go right	1
	Be organised/make plans/a routine/be prepared	1
	Take each day as it comes	1
	Don't take things personally	1
	Learn about acceptance	*
	Pray	*
	If you cannot cope you might have to put them in a nursing home	*
	It will fully take over your life and take a tremendous toll	*
	Taking notes	*
	Do not feel guilty	*
	You have to do it on your own/expect no help	*

Continued.

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	Others on advice in general	2
	<b>Miscellaneous (NET)</b>	<b>7</b>
	Run away/don't do it	2
	It is hard work	1
	Good luck!	1
	It is fulfilling/you will feel rewarded	1
	You need savings/apply for financial help	*
	Others on miscellaneous	1
	Nothing	3
	No answer	3
	Don't know	4

**Profile Information**

<b>Q</b>	<b>Gender</b> Base: All respondents (500)	%
	Male	48
	Female	52

<b>Q</b>	<b>Age</b> Base: All respondents (500)	%
	40-54	44
	55-64	28
	65-74	19
	75+	9

<b>Q</b>	<b>Ethnicity</b> Base: All respondents (500)
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		%
	White	95
	Black Caribbean	*
	Black African	0
	Black Other	*
	Indian	1
	Pakistani	*
	Bangladeshi	*
	Chinese	0
	Other Asian	0
	Mixed or multiple ethnic group	2
	Other	*
	Prefer not to say	1

Q	<b>Working status</b> Base: All respondents (500)	
		%
	Full time (30 hrs/wk)	30
	Part time (8-29 hrs/wk)	23
	Retired	33
	Looking after home or family	12
	Refused/ not stated	2

Q	<b>Social grade</b> Base: All respondents (2356)		%
		AB	36
		C1	31
		C2	13
		DE	19

Q	<b>Region</b> Base: All respondents (500)

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		%
	North East	6
	North West	15
	Yorkshire and The Humber	10
	East Midlands	5
	West Midlands	6
	East of England	8
	London	9
	South East	16
	South West	10
	Wales	3
	Scotland	9
	Northern Ireland	3

Q	Is the person you are looking after or providing help and support to in the early, middle or late stage of dementia? Base: All respondents (500)	
		%
	Early	33
	Middle	40
	Late	20
	Don't know	7

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**3. Topline results: Survey of 966 people with dementia**

- A survey of 966 people living with dementia who access Alzheimer’s Society services was carried out between February – April 2017
- Due to the ambitious nature of this research, an initial pilot survey of 148 was conducted between November – December 2016. Key learnings from the pilot survey were built into the main stage survey.
- Fieldwork was led by and carried out by Alzheimer’s Society employees and volunteers across England, Wales and Northern Ireland.
- All participants provided consent to take part and 18% completed the questionnaire themselves and 82% were assisted by an Alzheimer’s Society team member at various Alzheimer’s Society services.
- Ipsos MORI assisted with the design of the questionnaire and advised on the methodological approach. All completed questionnaires were sealed in an envelope and sent back to Ipsos MORI for data capture and analysis.
- An asterisk (\*) represents a value of less than half of one percent, but higher than zero.
- Where results do not sum to 100%, this may be due to multiple responses, computer rounding or the exclusion of don’t knows/not stated.

Q	Who have you told that you have dementia? Base: All respondents who provided a response (961)	%
	Family	91
	Friends	70
	Neighbours	48
	Other people I know	44
	Nobody at all	5
	Don’t know	2
	<b>Told others have dementia</b>	<b>93</b>

Q	Generally, since you have had dementia, do people treat you...? Base: All respondents who provided a response (946)	%
	Better	19
	Worse	8
	No difference	65
	Don’t know	8

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Q	Have you felt lonely recently? Base: All respondents who provided a response (957)	%
	Yes – I have felt lonely recently	35
	No – I have not felt lonely recently	62
	Don't know	4

Q	How often do you get out of your home and go out? Base: All respondents who provided a response (958)	%
	Nearly every day or every day	68
	A couple of times a week	25
	Once a week	4
	Every 2 weeks	1
	Once a month or less often	1
	Don't know	1

Q	Which of the following do you worry about? Base: All respondents who provided a response (946)	%
	Becoming a burden	48
	Not being able to do things I used to enjoy	47
	Losing precious memories	37
	Going into a care home	37
	Getting lost outside of my home	25
	People not seeing me for who I am	20
	Not seeing my friends	20
	Relationships breaking down	14
	Not having enough money to live on	13
	I do not worry about any of these things	20
	Don't know	1

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Q	Which of the following help you in your day-to-day life? Base: All respondents who provided a response (953)	%
	Family members	87
	Alzheimer's Society	71
	Friend(s) who do not have dementia	47
	Doctor (your GP)	34
	Memory clinic	29
	Friend(s) who do have dementia	25
	Local faith group (Church, Temple, Mosque or other faith group)	20
	Paid carer	14
	Other charities or voluntary groups	20
	I do not get help from any of these in my day-to-day life	2
	Don't know	*
	<b>Total Charity</b>	74
	<b>Total friends</b>	55
	<b>Doesn't receive help from any</b>	2
	<b>Receives help from one or more</b>	98

Q	I feel I have/do not have a say in the decisions about my care Base: All respondents who provided a response (946)	%
	I feel I have a say in the decisions about my care	81
	I feel I do not have a say in the decisions about my care	9
	Don't know	10

**Profile Information**

Q	Gender Base: All respondents who provided a response (961)	%
	Male	57
	Female	43
	Transgender	-
	Prefer not to answer	2

**Data included: Turning Up the Volume: unheard voices of dementia**

Q	Age	%
	Base: All respondents who provided a response (959)	
	Under 55	1
	55 - 64	11
	65 - 74	27
	75 - 84	43
	85 - 99	16
	100+	-
	Don't know	2
	Prefer not to answer	*

Q	Housing	%
	Base: All respondents who provided a response (958)	
	Live alone	24
	Live with other people	76
	Don't know	*

Q	Ethnicity	%
	Base: All respondents who provided a response (948)	
	White	96
	Black Caribbean	2
	Black African	*
	Black Other	*
	Indian	1
	Pakistani	*
	Bangladeshi	-
	Chinese	*
	Other Asian	*
	Mixed or multiple ethnic group	1
	Other	*
	Prefer not to say	-
	Don't know	-

Q	Survey completion	%
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***Data included: Turning Up the Volume: unheard voices of dementia***

	Base: All respondents who provided a response (952)	
	I filled in this survey alone	18
	I had help from the Alzheimer's Society volunteer	82