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Instructions for completing this survey

This survey contains questions about how the coronavirus outbreak has affected both you and your relative/friend with dementia (referred to as "your relative/friend" for the remainder of the survey) as well as questions about how you are both doing at the moment. Most of the questions have fixed responses, please say which of the options you think best applies to you.

There are also some open-ended questions which ask about how the coronavirus outbreak has affected both you and your relative/friend and any additional or missing support that you would have found useful. These will appear as an empty box for you to type in and there will be some prompts to indicate the kind of things we would like you to touch on. These questions in particular are really important for the purpose of this study so if you can touch on as many of the prompts as possible in your answer that would be really helpful for us.

Please be as honest and as accurate as you can throughout. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

If you don't want to complete the questionnaire all in one go, close the window at the point you want to stop. When you decide to resume the questionnaire, simply click on the link sent to you via email which will allow you to carry on from the point you left off.

If you need to go back to an earlier question, please use the "Click here to get to the previous page" button at the bottom of each page, you can go back to as many questions as you need. Responses to questions you have already answered will not change if you go back to an earlier question so you will not need to answer these questions again.

Later on there will be a question about the medication that your relative/friend has been prescribed. If you have a prescription handy it would be useful to get this before you start the survey.

A researcher may contact you in a few days to ask about any missing questions or ask for clarification, if needed, with some of your responses.

The survey will start with some questions about you and your own experiences, and then it will ask more about your experiences of supporting your relative/friend and how you think s/he is doing.

First of all there are a few questions about how the coronavirus outbreak has affected you.

C_Q1_1_inc. Have you had the coronavirus?

- ☐ Yes
- ☐ No

C_Q1_2_inc. Were you tested for coronavirus?

- ☐ Yes
- ☐ No

C_Q1_3_inc. Were you treated in hospital for coronavirus?

- ☐ Yes
- ☐ No

C_Q2_inc. Has anyone close to you had the virus?

- ☐ Yes
- ☐ No

C_Q3_inc. Overall how do you feel the coronavirus outbreak has affected you?

Could also say if you have received the coronavirus vaccine?

Your response could include things like life during lockdown, keeping occupied at home, activities undertaken, impact on confidence, restrictions since lockdown.

C_Q4_inc. What have been the most difficult aspects of the coronavirus outbreak for you?

Your response could include things like life during lockdown, keeping occupied at home, activities undertaken, impact on confidence, restrictions since lockdown.

C_Q5_inc. Have there been any positive aspects or benefits of the coronavirus outbreak?

☐ Yes

☐ No

C_Q6_inc. What were/have been the positive aspects or benefits of the coronavirus outbreak?

C_Q7_inc. How do you feel your financial situation now compares to before the coronavirus outbreak?

☐ Much worse off

☐ A little worse off

☐ About the same

☐ A little better off

☐ Much better off

C_Q8_inc. How easy or difficult was it to keep yourself occupied at home during the coronavirus lockdown?

- ☐ Very easy
- ☐ Fairly easy
- ☐ Not very easy

C_Q9_1_inc. Have your healthcare needs been affected by the coronavirus outbreak – for example, appointments postponed or planned operations delayed?

- ☐ Yes
- ☐ No

C_Q9_2_inc. In what ways have your healthcare needs been affected by the coronavirus outbreak?

C_Q10_1_inc. Did any healthcare services you were already receiving stop due to coronavirus?

- ☐ Yes
- ☐ No

C_Q10_2_inc. What healthcare services stopped due to coronavirus?
Please provide details (e.g. what services, when, were they replaced by phone calls).

C_Q10_3_inc. What impact did these healthcare services stopping have on you?

C_Q11_1_inc. Have you avoided seeking help for any health issues because of the coronavirus?

☐ Yes

☐ No

C_Q11_2_inc. Why did you avoid seeking help for any health issues because of the coronavirus?

C_Q12_inc. Overall how well do you feel you have coped since the coronavirus outbreak?

☐ Very well

☐ Fairly well

☐ Not very well

C_Q13_inc. Can you think of anything that would have made the situation more manageable and/or help you cope better?

Now we're going to ask a few questions about how you feel generally about your life at the moment.

C_Q14_inc. Overall, how would you rate your health in the **past 4 weeks**?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very poor

C_Q15_inc. How would you rate your quality of life in the **last two weeks**?

- ☐ Very good
- ☐ Good
- ☐ Neither poor nor good
- ☐ Poor
- ☐ Very poor

C_Q16_inc. On a scale of zero to 10, where zero is “not at all” and 10 is “very”, how satisfied are you with your life **nowadays**?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10

C_Q17_inc. On a scale of zero to 10, where zero is “not at all” and 10 is “very”, to what extent do you feel the things you do in your life are worthwhile?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10

Next are some questions about your mood.

C_Q18_inc. On a scale of zero to 10, where zero is “not at all” and 10 is “very”, how happy overall did you feel **yesterday**?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10

C_Q19_inc. On a scale of zero to 10, where zero is “not at all” and 10 is “very”, how anxious overall did you feel yesterday?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10

C_Q20_inc. In the last two weeks, how much of the time have you felt cheerful and in good spirits?

- ☐ All of the time
- ☐ Most of the time
- ☐ More than half of the time
- ☐ Less than half of the time
- ☐ Some of the time
- ☐ At no time

C_Q21_inc. Do you feel lonely?

- ☐ Never
- ☐ Hardly ever
- ☐ Occasionally
- ☐ Some of the time
- ☐ Often or always

C_Q22_inc. Now we're going to ask you to indicate the extent to which you agree or disagree with the following statement: Overall, would you say you expect more good things to happen to you than bad?

- ☐ Strongly agree
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Strongly disagree

C_Q23_inc. These next questions are more about the contact you have with other people. Considering the people to whom you are **related either by birth, marriage or adoption**, how many relatives do you see or hear from at least **once a month**?

- ☐ 0 (none)
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 11 or more (write number in space provided)

C_Q24_inc. Has this changed since the coronavirus outbreak?

- ☐ Yes
- ☐ No

C_Q25_inc. What is different about it now?

C_Q26_inc. How satisfied are you with the support you receive from **family**?

This question is **only** about family, we will ask about friends in the next few question.

- ☐ Very satisfied
- ☐ Slightly satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Slightly dissatisfied
- ☐ Very dissatisfied

C_Q27_inc. Considering all of your **friends** including those who live in your neighbourhood, how many friends do you see or hear from at least **once a month**?

- ☐ 0 (None)
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 11 or more (write number in space provided)

C_Q28_inc. Has this changed since the coronavirus outbreak?

- ☐ Yes
- ☐ No

C_Q29_inc. What is different about it now?

C_Q30_inc. How satisfied are you with the support you receive from **friends**?

- ☐ Very satisfied
- ☐ Slightly satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Slightly dissatisfied
- ☐ Very dissatisfied

C_Q31_inc. How satisfied are you with your neighbourhood, by which we mean your street or surrounding area, as a place to live?

- ☐ Very satisfied
- ☐ Slightly satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Slightly dissatisfied
- ☐ Very dissatisfied

C_Q32_inc. Do you have access to the internet at home?

- ☐ Yes
- ☐ No

C_Q33_inc. Do you use the internet?

- ☐ Yes
- ☐ No

How do you use the internet? Do you...

(Please click all that apply)

- ☐ C_Q34_1_inc. Sending and/or receiving emails
- ☐ C_Q34_2_inc. Telephoning over the internet (e.g. Skype, Facetime, Whatsapp)
- ☐ C_Q34_3_inc. Social networking (e.g. using Facebook, Twitter, Instagram)
- ☐ C_Q34_4_inc. Reading online news
- ☐ C_Q34_5_inc. Playing or downloading entertainment (e.g. games, films, music, TV)
- ☐ C_Q34_6_inc. Buying groceries
- ☐ C_Q34_7_inc. Buying household or electronic items (e.g. books, toys, games, tablets, mobile phones, cameras)
- ☐ C_Q34_8_inc. Organising home repair and maintenance services (e.g. plumbers, electricians, gardeners)
- ☐ C_Q34_9_inc. Booking and organising travel services (e.g. holidays and flights)
- ☐ C_Q34_10_inc. Making an appointment with a doctor or other health practitioners
- ☐ C_Q34_11_inc. Selling goods or services (e.g. via websites such as eBay)
- ☐ C_Q34_12_inc. Internet banking
- ☐ C_Q34_13_inc. Visiting websites or online forums that offer practical advice for carers of people with dementia
- ☐ C_Q34_14_inc. Visiting non-profit organisations' websites (e.g. Alzheimer's Society, Age UK, Carers UK)
- ☐ C_Q34_15_inc. Visiting health-related websites (e.g. NHS Choices, local NHS services)
- ☐ C_Q34_16_inc. Visiting websites or online forums that offer peer support for carers of people with dementia
- ☐ C_Q34_17_inc. Other (please specify)

C_Q34_17_oth_inc

C_Q35_inc. Has your internet use changed since the coronavirus outbreak started?

- ☐ Yes
- ☐ No

C_Q36_inc. How has your use of the internet changed since the coronavirus outbreak?
Do you use it more or less now? Any different sites, if so what sites? etc.

C_Q37_inc. Now we'd like to ask about your experiences of supporting your relative/friend. Do you live with your relative/friend?

- ☐ Yes
- ☐ No

This question is about the **current** relationship between you and your relative/friend.
C_Q38_inc. Generally how well do you and your relative/friend get along together?

- ☐ Extremely well
- ☐ Very well
- ☐ Well
- ☐ Quite well
- ☐ Not too well
- ☐ Not well at all

The next set of questions contain some thoughts and feelings that people sometimes have about themselves as carers. You may not see yourself as a carer, but this is a term that is often used, and we have used it here for convenience. Please answer the questions in relation to your relationship with your relative/friend. How much does each statement describe your thoughts about your role as a carer?

C_Q39_inc. How often do you feel confident that you are meeting the needs of your relative/friend?

- ☐ Never
- ☐ Some of the time
- ☐ Most of the time
- ☐ All of the time

C_Q40_inc. How often do you feel that you are doing a good job as a carer?

- ☐ Never
- ☐ Some of the time
- ☐ Most of the time
- ☐ All of the time

C_Q41_inc. How often do you feel competent in your ability to care for your relative/friend?

- ☐ Never
- ☐ Some of the time
- ☐ Most of the time
- ☐ All of the time

C_Q42_inc. Do you feel you cope well as a carer?

- ☐ Never
- ☐ Sometimes
- ☐ Often
- ☐ Always

C_Q43_inc. If you were ill, is there anybody who would step in to help your relative/friend?

- ☐ Yes, I could find someone quite easily
- ☐ Yes, I could find someone but with some difficulty
- ☐ No, there is no-one

C_Q44_inc. If you needed a break from your caring role, is there someone who would look after your relative/friend for you?

- ☐ Yes, I could find someone quite easily
- ☐ Yes, I could find someone but with some difficulty
- ☐ No, there is no-one

C_Q45_inc. How much do you wish you were free to lead a life of your own?

- ☐ Not at all
- ☐ Just a little
- ☐ Somewhat
- ☐ Very much

C_Q46_inc. How much do you feel trapped by your relative/friend's dementia?

- ☐ Not at all
- ☐ Just a little
- ☐ Somewhat
- ☐ Very much

C_Q47_inc. How much do you wish you could just run away?

- ☐ Not at all
- ☐ Just a little
- ☐ Somewhat
- ☐ Very much

These next few questions are about the support you receive as a carer.

C_Q48_1_inc. Have you had a carer's assessment?

A carer's assessment is where someone from the council visits you (though sometimes it can be a phone call) and asks how you're coping with caring for your relative/friend. They typically ask how caring for your relative/friend is affecting your physical and mental health, your work, your free time and your relationships with others. It normally takes at least an hour. More information can be found on the Dementia UK webpage which is on the last page of this survey.

- ☐ Yes
- ☐ No

C_Q48_2_inc. When did your carer's assessment take place?

C_Q49_inc. On a typical day, how many hours do you spend looking after or providing help for your relative/friend?

- ☐ Provide no help in a typical day
- ☐ less than 1 hour
- ☐ More than 1 hour and up to 2 hours
- ☐ More than 2 hours and up to 3 hours
- ☐ More than 3 hours and up to 5 hours
- ☐ More than 5 hours and up to 10 hours
- ☐ More than 10 hours, but not overnight
- ☐ More than 10 hours and/including overnight
- ☐ Other

C_Q50_1_inc. Are you a registered carer?

A registered carer is someone providing informal unpaid care can register with his/her GP as a carer. This enables the registered carer to receive access to additional support from his/her GP, such as providing more convenient appointment times, information packs about being a carer and a free annual flu vaccination, as well as registering for any benefits s/he may be eligible for such as carer's allowance. Contact your local GP and see what services they have if you are not already a registered carer.

- ☐ Yes
- ☐ No

C_Q50_2_inc. What support do you receive as a carer?

Do you attend a support group, do you get respite services, etc.? If yes please say which groups, though please **do not include** people's names or names of towns instead write "local group" etc.

C_Q51_1_inc. Is there a named health professional whom you or your relative/ friend can contact at any time, for example a care coordinator, key worker, specialist nurse, dementia navigator, GP, Admiral nurse etc.?

☐ Yes

☐ No

C_Q51_2_inc. Please describe his/her job and professional role in relation to you (e.g. dementia navigator, GP, Admiral nurse etc.; please **do not** record names of Drs or names of hospitals.

If there is more than one please say, if applicable, which is/are in place to help with your relative/friend's dementia.

C_Q51_3_inc. Is the health professional in place to help with your relative/friend's dementia?

☐ Yes

☐ No

C_Q52_inc. What, if anything, would help you feel more supported?

This could include things like someone to talk to, support group, new carer's assessment etc. Please do not include specific people's name or places such as name of hospital.

Now we'd like to get your views on how well your relative/friend is doing at the moment.

From this list we'd like you to indicate which of the following events your relative/friend has experienced in his/her life in the **last 12 months**?

(Please click all that apply)

- ☐ C_Q53_1_inc. Death of spouse or child
- ☐ C_Q53_2_inc. Death of a close family member (e.g. parent or sibling)
- ☐ C_Q53_3_inc. Death of a close friend
- ☐ C_Q53_4_inc. Divorce
- ☐ C_Q53_5_inc. Marital separation
- ☐ C_Q53_6_inc. Retirement
- ☐ C_Q53_7_inc. Moved home
- ☐ C_Q53_8_inc. Major change in financial state (e.g. a lot worse off or a lot better off)
- ☐ C_Q53_9_inc. Major change in health or behaviour of family member
- ☐ C_Q53_10_inc. Major personal injury or illness
- ☐ C_Q53_11_inc. Other

C_Q53_oth_inc

- ☐ None of the above

Now we're going to ask about how you feel the coronavirus has affected your relative/friend.

C_Q54_1_inc. Has your relative/friend had the coronavirus?

☐ Yes

☐ No

C_Q54_2_inc. Was your relative/friend tested for for coronavirus?

☐ Yes

☐ No

C_Q54_3_inc. Was your relative/friend treated in hospital for coronavirus?

☐ Yes

☐ No

C_Q55_inc. Overall how do you feel the coronavirus outbreak has affected your relative/friend? Could also say if your relative/friend has received the coronavirus vaccine? Your response could include things like confidence, day-to-day skills and/or abilities, activities, mood.

C_Q56_inc. How easy was it for your relative/friend to keep occupied at home during the coronavirus lockdown?

☐ Very easy

☐ Fairly easy

☐ Not very easy

C_Q57_1_inc. Did your relative/friend try any new activities during the coronavirus lockdown?

- ☐ Yes
- ☐ No

C_Q57_2_inc. What were they?

C_Q58_1_inc. Have there been any positive aspects or benefits of the coronavirus outbreak for your relative/friend?

- ☐ Yes
- ☐ No

C_Q58_2_inc. What were/have been the positive aspects or benefits of the coronavirus outbreak?

C_Q59_inc. How worried, if at all, have you been about your relative/friend having enough food during the coronavirus outbreak?

- ☐ Not at all worried
- ☐ Not very worried
- ☐ Somewhat worried
- ☐ Very worried
- ☐ Extremely worried

C_Q60_inc. Overall how well do you feel your relative/friend has coped since the coronavirus outbreak?

- ☐ Very well
- ☐ Fairly well
- ☐ Not very well

C_Q61_inc. Is there anything you can think of that would have made the situation more manageable for your relative/friend or enabled him/her to cope better?

Next are a few questions about your relative/friend's mood.

C_Q62_inc. In the **last two weeks**, how much of the time has your relative/friend felt cheerful and in good spirits?

- ☐ All of the time
- ☐ Most of the time
- ☐ More than half of the time
- ☐ Less than half of the time
- ☐ Some of the time
- ☐ At no time

EQ-5D questions removed in line with user agreement

C_Q64_inc. How is your relative/friend's life as a whole? When you think about your relative/friend's life as a whole, everything together, how do you feel about his/her life? Would you say it is poor, fair, good or excellent?

- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Excellent

C_Q65_inc. How would you rate your relative/friend quality of life in the **last two weeks**?

- ☐ Very good
- ☐ Good
- ☐ Neither poor nor good
- ☐ Poor
- ☐ Very poor

These next questions are about your relative/friend's social contacts and getting out and about.

C_Q66_inc. Considering the people to whom your relative/friend is **related either by birth, marriage or adoption**, how many relatives does your relative/friend see or hear from at least **once a month**?

Please include yourself in this number if you live with your relative/friend, or include the person they with live if they live with someone currently.

- ☐ 0 (none)
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 11 or more (write number in space provided)

C_Q67_inc. Has this changed since the coronavirus outbreak?

- ☐ Yes
- ☐ No

C_Q68_inc. What is different about it now?

C_Q69_inc. Considering all of your relative/friend's **friends** including those who live in the neighbourhood, how many friends does s/he see or hear from at least **once a month**?

- ☐ 0 (none)
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10
- ☐ 11 or more (write number in space provided)

C_Q70_inc. Has this changed since the coronavirus outbreak?

- ☐ Yes
- ☐ No

C_Q71_inc. What is different about it now?

Now we're going to ask you some questions about social groups or organisations your relative/friend may belong to.

Which of these activities does your relative/friend attend? Does s/he attend...

(Please click all that apply)

- ☐ C_Q72_1_inc. Political parties
- ☐ C_Q72_2_inc. Trade unions (including student unions)
- ☐ C_Q72_3_inc. Environmental groups
- ☐ C_Q72_4_inc. Tenants, residents' groups or neighbourhood watch
- ☐ C_Q72_5_inc. Evening classes
- ☐ C_Q72_6_inc. University of the Third Age (U3A)
- ☐ C_Q72_7_inc. Other adult learning
- ☐ C_Q72_8_inc. Arts, music or singing group
- ☐ C_Q72_9_inc. Memory cafe or group
- ☐ C_Q72_10_inc. Charity, voluntary or community group
- ☐ C_Q72_11_inc. Group for older people (e.g. lunch club)
- ☐ C_Q72_12_inc. Youth group (e.g. scouts/guides/youth club)
- ☐ C_Q72_13_inc. Women's Institute, Townswomen's Guild
- ☐ C_Q72_14_inc. Social club (Rotary, working men's club)
- ☐ C_Q72_15_inc. Sports club, gym, exercise/dance group
- ☐ C_Q72_16_inc. Religious group
- ☐ C_Q72_17_inc. Other group or organisation (please specify):

C_Q72_17_oth_inc

- ☐ C_Q72_18_inc. None

C_Q73_1_inc. When these stopped face-to-face due to coronavirus, did anyone from these groups keep in contact with your relative/friend during that time?

- ☐ Yes
- ☐ No

C_Q73_2_inc. How did they keep in contact with you and/or your relative/friend?
How frequently did they contact you?
Did they keep you updated with changes?

C_Q74_inc. Have any of these started up again now?

- ☐ Yes
- ☐ No

Which activities have started up again?

- ☐ C_Q75_1_inc. Political parties
- ☐ C_Q75_2_inc. Trade unions (including student unions)
- ☐ C_Q75_3_inc. Environmental groups
- ☐ C_Q75_4_inc. Tenants, residents' groups or neighbourhood watch
- ☐ C_Q75_5_inc. Evening classes
- ☐ C_Q75_6_inc. University of the Third Age (U3A)
- ☐ C_Q75_7_inc. Other adult learning
- ☐ C_Q75_8_inc. Arts, music or singing group
- ☐ C_Q75_9_inc. Memory cafe or group
- ☐ C_Q75_10_inc. Charity, voluntary or community group
- ☐ C_Q75_11_inc. Group for older people (e.g. lunch club)
- ☐ C_Q75_12_inc. Youth group (e.g. scouts/guides/youth club)
- ☐ C_Q75_13_inc. Women's Institute, Townswomen's Guild
- ☐ C_Q75_14_inc. Social club, (Rotary, working men's club)
- ☐ C_Q75_15_inc. Sports club, gym, exercise/dance group
- ☐ C_Q75_16_inc. Religious group

C_Q75_17_inc. Which of these "other" group or organisations have started up again? Please write only those that have started up again

C_Q75_17_oth_inc

C_Q76_1_inc. Before the coronavirus outbreak, did your relative/friend normally go to a day centre?

- ☐ Yes
- ☐ No

C_Q76_2_inc. When this closed due to coronavirus, did anyone keep in touch with your relative/friend?

- ☐ Yes
- ☐ No

C_Q76_3_inc. Has it restarted now?

- ☐ Yes
- ☐ No

Now we're going to ask you about how much your relative/friend gets out and about.
C_Q77_inc. During the **past 3 days** has your relative/friend been to places outside his/her immediate town or community?

- ☐ Yes
- ☐ No

C_Q78_inc. During the **past 3 days** has your relative/friend been to places outside his/her immediate area, but within his/her town or community?

- ☐ Yes
- ☐ No

C_Q79_inc. During the **past 3 days** has your relative/friend been to places in his/her immediate area, beyond his/her own home or place of residence?

- ☐ Yes
- ☐ No

C_Q80_inc. During the **past 3 days** has your relative/friend been to an area outside his/her home or place of residence, such as a garden, yard, driveway or parking space?

- ☐ Yes
- ☐ No

C_Q81_inc. During the **past 3 days** has your relative/friend been to an area immediately outside his/her home or place of residence, such as his/her porch, patio, hallway of an apartment building, or garage?

☐ Yes

☐ No

C_Q82_inc. During the **past 3 days** has your relative/friend been to other rooms of his/her home or place of residence besides the room where s/he sleeps?

☐ Yes

☐ No

C_Q83_inc. Does your relative/friend have a garden or outside area that s/he can spend time in?

☐ Yes

☐ No

C_Q84_1_inc. Does your relative/friend use public transport, such as buses, trams or trains?

☐ Yes

☐ No

C_Q84_2_inc. Has your relative/friend's use of public transport changed since the coronavirus outbreak?

☐ Yes

☐ No

C_Q84_3_inc. How safe does s/he feel using public transport?

☐ Very safe

☐ Safe

☐ Unsafe

C_Q84_4_inc. Why doesn't your relative/friend use public transport?

C_Q85_inc. Does your relative/friend have access to the internet at home?

- ☐ Yes
- ☐ No

C_Q86_inc. Does your relative/friend use the internet?

- ☐ Yes
- ☐ No

C_Q87_inc. Do you help your relative/friend to use the internet, or does s/he use the internet independently?

- ☐ Help
- ☐ Use independently

In what ways does your relative/friend use the internet?

(Please click all that apply)

- ☐ C_Q88_1_inc. Sending and/or receiving emails
- ☐ C_Q88_2_inc. Telephoning over the internet (e.g. Skype, Facetime, Whatsapp)
- ☐ C_Q88_3_inc. Social networking (e.g. using Facebook, Twitter, Instagram)
- ☐ C_Q88_4_inc. Reading online news
- ☐ C_Q88_5_inc. Playing or downloading entertainment (e.g. games, films, music, TV)
- ☐ C_Q88_6_inc. Buying groceries
- ☐ C_Q88_7_inc. Buying household or electronic items (e.g. books, toys, games, tablets, mobile phones, cameras)
- ☐ C_Q88_8_inc. Organising home repair and maintenance services (e.g. plumbers, electricians, gardeners)
- ☐ C_Q88_9_inc. Booking and organising travel services (e.g. holidays and flights)
- ☐ C_Q88_10_inc. Making an appointment with a doctor or other health practitioners
- ☐ C_Q88_11_inc. Selling goods or services (e.g. via websites such as eBay)
- ☐ C_Q88_12_inc. Internet banking
- ☐ C_Q88_13_inc. Visiting websites or online forums that offer practical advice for people with memory problems or similar difficulties
- ☐ C_Q88_14_inc. Visiting non-profit organisations' websites (e.g. Alzheimer's Society, Age UK)
- ☐ C_Q88_15_inc. Visiting health-related websites (e.g. NHS Choices, local NHS services)
- ☐ C_Q88_16_inc. Visiting websites or online forums that offer peer support
- ☐ C_Q88_17_inc. Other (please specify)

C_Q88_17_oth_inc

These next couple of questions are about whether you have noticed changes in your relative/friend's memory and thinking skills.

C_Q89_1_inc. Since the coronavirus outbreak, have you noticed any changes in your relative/friend's ability to remember everyday things?

- ☐ Yes
- ☐ No

C_Q89_2_inc. Is this better or worse than before the coronavirus outbreak?

- ☐ Better than before
- ☐ Worse than before

C_Q90_1_inc. Since the coronavirus outbreak, have you noticed any changes in your relative/friend's ability to remember recent events?

- ☐ Yes
- ☐ No

C_Q90_2_inc. Is this better or worse than before the coronavirus outbreak?

- ☐ Better than before
- ☐ Worse than before

C_Q91_1_inc. Since the coronavirus outbreak, have you noticed any changes in your relative/friend's ability to concentrate?

- ☐ Yes
- ☐ No

C_Q91_2_inc. Is this better or worse than before the coronavirus outbreak?

- ☐ Better than before
- ☐ Worse than before

C_Q92_1_inc. Since the coronavirus outbreak, have you noticed any changes in your relative/friend's ability to say what s/he wants to say?

- ☐ Yes
- ☐ No

C_Q92_2_inc. Is this better or worse than before the coronavirus outbreak?

- ☐ Better than before
- ☐ Worse than before

C_Q93_1_inc. Since the coronavirus outbreak, have you noticed any changes in your relative/friend's ability to plan ahead?

- ☐ Yes
- ☐ No

C_Q93_2_inc. Is this better or worse than before the coronavirus outbreak?

- ☐ Better than before
- ☐ Worse than before

C_Q94_1_inc. Since the coronavirus outbreak, have you noticed any changes in your relative/friend's ability to make decisions?

- ☐ Yes
- ☐ No

C_Q94_2_inc. Is this better or worse than before the coronavirus outbreak?

- ☐ Better than before
- ☐ Worse than before

C_Q95_inc. Since the coronavirus outbreak, do you feel your relative/friend gets confused more often?

- ☐ Yes
- ☐ No

Next are a few questions about your relative/friend's health. If your relative/friend is in care or if you have not seen them within the specified timeframe please answer the questions with how you thought they were when you last saw them.

C_Q96_inc. Overall, how would you rate your relative/friend's health in the **past 4 weeks**?

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Very poor

EQ-5D questions removed in line with user agreement

The next few questions are about the help and support that people provide to your relative/friend in his/her home.

Thinking about the **last 3 months**, in an average week, what tasks do you usually help your relative/friend with?

(Please click all that apply)

- ☐ C_Q101_1_inc. Personal care
- ☐ C_Q101_2_inc. Helping with finances
- ☐ C_Q101_3_inc. Practical help (housework, laundry)
- ☐ C_Q101_4_inc. Taking your relative/friend out to appointments (e.g. medical appointments)
- ☐ C_Q101_5_inc. Medications
- ☐ C_Q101_6_inc. Making sure your relative/friend is safe (e.g. supervision)
- ☐ C_Q101_7_inc. Other

C_Q101_7_oth_inc

☐ None

C_Q102_1_inc. In an average **week** how many hours do you spend helping your relative/friend with these kinds of tasks?

- ☐ None
- ☐ Less than one hour
- ☐ 1-4 hours
- ☐ 5-8 hours
- ☐ 9-14 hours
- ☐ 15-22 hours
- ☐ 23-30 hours
- ☐ 31-49 hours
- ☐ 50-99 hours
- ☐ 100 hours or more
- ☐ C_Q102_2_inc. Other (write exact number of hours in space provided)

C_Q103_1_inc. In the **last 3 months** have relatives or friends, **apart from you**, regularly helped your relative/friend with tasks that s/he had difficulty with or could not do?

- ☐ Yes
- ☐ No

C_Q103_2_inc. Thinking about an **average week**, and about all such friends or relatives, for how many **hours** do they usually help your relative/friend with these tasks? This doesn't include any help that you give him/her.

- ☐ Less than one hour
- ☐ 1-4 hours
- ☐ 5-8 hours
- ☐ 9-14 hours
- ☐ 15-22 hours
- ☐ 23-30 hours
- ☐ 31-49 hours
- ☐ 50-99 hours
- ☐ 100 hours or more
- ☐ C_Q103_3_inc. Other (write exact number of hours in space provided)

In the **last 3 months**, has your relative/friend used any of these services?

(Please click all that apply)

These include professional/paid for services only

- ☐ C_Q104_1_inc. Home care/home help/a support worker
- ☐ C_Q104_2_inc. Meals on wheels (including Wiltshire Farm Foods etc.)
- ☐ C_Q104_3_inc. An incontinence laundry service
- ☐ C_Q104_4_inc. A cleaner/cleaning service
- ☐ C_Q104_5_inc. Has there been someone to stay with your relative/friend so you can have a break/respite
- ☐ C_Q104_6_inc. Has there been someone to support you, such as a carer support worker
- ☐ C_Q104_7_inc. Other (please specify)

C_Q104_7_oth_inc

C_Q105_inc. Did any of these kinds of help your relative/friend was receiving stop due to coronavirus?

- ☐ Yes
- ☐ No

Which ones stopped due to coronavirus?

- ☐ C_Q106_1_inc. Home care/home help/a support worker
- ☐ C_Q106_2_inc. Meals on wheels (including Wiltshire Farm Foods etc.)
- ☐ C_Q106_3_inc. An incontinence laundry service
- ☐ C_Q106_4_inc. A cleaner/cleaning service
- ☐ C_Q106_5_inc. Has there been someone to stay with your relative/friend so you can have a break/respite
- ☐ C_Q106_6_inc. Has there been someone to support you

C_Q106_7_inc. Which of these "other" services stopped due to coronavirus?

Please write only those that have stopped

C_Q106_7_oth_inc

C_Q107_inc. Have any started again now?

☐ Yes

☐ No

Which ones have started again now?

☐ C_Q108_1_inc. Home care/home help/a support worker

☐ C_Q108_2_inc. Meals on wheels (including Wiltshire Farm Foods etc.)

☐ C_Q108_3_inc. An incontinence laundry service

☐ C_Q108_4_inc. A cleaner/cleaning service

☐ C_Q108_5_inc. Has there been someone to stay with your relative/friend so you can have a break/respite

☐ C_Q108_6_inc. Has there been someone to support you

C_Q108_7_inc. Which of these "other" services have started up again?

Please write only those that have started up again

C_Q108_7_oth_inc

C_Q109_1_inc. Did your relative/friend get any extra help at home during the coronavirus outbreak that s/he was not having before?

☐ Yes

☐ No

C_Q109_2_inc. Please write about the extra help that your relative/friend had at home during the coronavirus outbreak that s/he was not having before.

C_Q110_1_inc. Has this extra help continued?

- ☐ Yes
- ☐ No

C_Q110_2_inc. Which extra help has continued?

Now we would like to know about the health care and support services that your relative/friend may have used recently.

C_Q111_inc. In the **last 3 months** has your relative/friend been in contact with his/her GP?

- ☐ Yes
- ☐ No

Has s/he:

(Please click all that apply)

- ☐ C_Q112_1_inc. Seen a GP at the surgery?
- ☐ C_Q113_1_inc. Seen a GP at home?
- ☐ C_Q114_1_inc. Spoken to a GP on the telephone (including where you have done this on his/her behalf?)
- ☐ C_Q115_1_inc. Seen a nurse at the surgery?

C_Q112_2_inc. In the **last 3 months** how many times has your relative/friend seen a GP at the surgery?

What was the reason(s) s/he saw the GP at the surgery?

C_Q113_2_inc. In the **last 3 months** how many times has your relative/friend seen a GP at home? What was the reason(s) s/he was seen by a GP at home?

C_Q114_2_inc. In the **last 3 months** how many times has your relative/friend spoken to a GP on the telephone? Include any instances where you have spoken to the GP on their behalf. What was the reason(s) s/he and/or you spoke to the GP on the telephone?

C_Q115_2_inc. In the **last 3 months** how many times has your relative/friend seen a nurse at the surgery?

What was the reason(s) s/he saw a nurse at the surgery?

Now we would like to know about some community health and care services that people can make use of.

In the **last 3 months** has your relative/friend seen a:

(Please click all that apply)

- ☐ C_Q116_1_inc. Community Nurse or District Nurse?
- ☐ C_Q117_1_inc. Community Psychiatric Nurse (CPN) or Community Mental Health Nurse?
- ☐ C_Q118_1_inc. Psychiatrist
- ☐ C_Q119_1_inc. Social worker or care manager
- ☐ C_Q120_1_inc. Psychologist
- ☐ C_Q121_1_inc. Physiotherapist or Occupational Therapist
- ☐ C_Q122_1_inc. Dentist
- ☐ C_Q123_1_inc. Optician
- ☐ C_Q124_1_inc. Specialist nurse (e.g. Admiral Nurse, palliative care nurse, respiratory nurse)?

C_Q124_1_oth_inc. Please write which specialist nurse your relative/friend saw in the space provided:

C_Q116_2_inc. Why did your relative/friend see a Community Nurse or District Nurse?
How many times?

C_Q117_2_inc. Why did your relative/friend see a Community Psychiatric Nurse (CPN) or Community Mental Health Nurse?
How many times?

C_Q118_2_inc. Why did your relative/friend see a Psychiatrist?
How many times?

C_Q119_2_inc. Why did your relative/friend see a Social worker or care manager?
How many times?

C_Q120_2_inc. Why did your relative/friend see a Psychologist?
How many times?

C_Q121_2_inc. Why did your relative/friend see a Physiotherapist or Occupational therapist? How many times?

C_Q122_2_inc. Why did your relative/friend see a Dentist? Dental work done, check up, fillings etc. How many times?

C_Q123_2_inc. Why did your relative/friend see an Optician? Regular check up or emergency work etc.

How many times?

C_Q124_2_inc. Why did your relative/friend see a specialist nurse?

How many times?

C_Q125_1_inc. Did your relative/friend avoid seeking help for any health issues because of the coronavirus?

- ☐ Yes
- ☐ No

C_Q125_2_inc. Why did your relative/friend avoid seeking help for any health issues because of the coronavirus?

C_Q126_1_inc. In the **last 3 months** has your relative/friend been to hospital as an outpatient or day patient to see a specialist, attend a clinic or go to A&E?

- ☐ Yes
- ☐ No

C_Q126_2_inc. What was the reason for using the service?

How many times did your relative/friend attended the service?

How long was the stay?

C_Q127_1_inc. In the **last 3 months** has your relative/friend had to stay in hospital as an in-patient overnight or longer?

☐ Yes

☐ No

C_Q127_2_inc. What was the reason for going to the hospital?

How many times (or days/nights) did your relative/friend attended the hospital?

C_Q128_1_inc. In the **last 3 months** has your relative/friend had to stay in a nursing home or care home?

☐ Yes

☐ No

C_Q128_2_inc. What was the reason for staying in a nursing home or care home?

How many days did your relative/friend stay in a nursing home or care home? If they now live in care write "all"

Now we're going to ask about any prescribed medications that your relative/friend is currently taking, so if you have a prescription handy that would be really helpful.

C_Q129_inc. How many different **prescribed** medications does your relative/friend take?

☐ 0

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

☐ 6

☐ 7

☐ 8

☐ 9

☐ 10

☐ 11

☐ 12

☐ 13

☐ 14

☐ 15 or more (Write number in box)

C_Q130_Meds_*_*_inc. Please write the names of these medications (i.e. Donepezil), dosage (i.e. 10mg), and how often your relative/friend takes each medication (choose from the drop down menu i.e. once daily) in the specific boxes below. If the frequency doesn't fit these options please write this information in the dosage section, i.e. "10mg four times a week".

If your relative/friend takes the same medication but in different dosages or frequencies, i.e. Donepezil 10mg once a day and Donepezil 5mg twice a week, please add these as separate entries.

	Medication name	Dosage	Frequency
	Medication name	Dosage	
1	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
2	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
3	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
4	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
5	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
6	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
7	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
8	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
9	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
10	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
11	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
12	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
13	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
14	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>

C_Q130_Meds_ *_*_inc. Please write the names of these medications (i.e. Donepezil), dosage (i.e. 10mg), and how often your relative/friend takes each medication (choose from the drop down menu i.e. once daily) in the specific boxes below. If the frequency doesn't fit these options please write this information in the dosage section, i.e. "10mg four times a week".

If your relative/friend takes the same medication but in different dosages or frequencies, i.e. Donepezil 10mg once a day and Donepezil 5mg twice a week, please add these as separate entries.

	Medication name	Dosage	Frequency
	Medication name	Dosage	
15	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
16	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
17	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
18	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
19	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
20	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
21	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
22	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
23	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
24	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
25	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
26	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
27	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
28	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>

C_Q130_Meds_*_*_inc. Please write the names of these medications (i.e. Donepezil), dosage (i.e. 10mg), and how often your relative/friend takes each medication (choose from the drop down menu i.e. once daily) in the specific boxes below. If the frequency doesn't fit these options please write this information in the dosage section, i.e. "10mg four times a week".

If your relative/friend takes the same medication but in different dosages or frequencies, i.e. Donepezil 10mg once a day and Donepezil 5mg twice a week, please add these as separate entries.

	Medication name	Dosage	Frequency
	Medication name	Dosage	
29	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
30	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
31	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
32	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
33	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
34	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
35	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
36	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
37	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
38	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
39	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
40	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
41	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>
42	<input type="text"/>	<input type="text"/>	<input type="text" value="v"/>

C_Q131_1_inc. Were your relative/friend's healthcare needs affected by the coronavirus outbreak – for example, appointments postponed or planned operations delayed?

- ☐ Yes
- ☐ No

C_Q131_2_inc. In what ways have your relative/friend healthcare needs been affected by the coronavirus outbreak?

C_Q132_1_inc. Did any healthcare services your relative/friend was already receiving stop due to coronavirus?

☐ Yes

☐ No

C_Q132_2_inc. What healthcare services that your relative/friend was receiving stopped due to coronavirus?

For instance what services stopped, when they stopped, etc? Were they replaced by phone services?

C_Q132_3_inc. What impact did these healthcare services stopping have on your relative/friend?

Thank you for answering all these questions and telling us about your experiences. The main aim of the study is to develop resources that can help to support people in the future as we learn to live with coronavirus.

C_Q133_inc. Is there anything else you'd like to tell me about, that we haven't covered?

Please close the survey by closing your browser, and thanks again for answering these questions.

A researcher may contact you in a few days to ask about any missing questions or ask for clarification, if needed, with some of your responses.

As mentioned earlier in the survey, here is the Dementia UK webpage that contains information about carers assessment: <https://www.dementiauk.org/get-support/legal-and-financial-information/the-carers-assessment/>