

**Talking Point chat room 4 December**  
**Q&A session on 'Join Dementia Research' with Catherine (Helpline)**  
**and Jess (Research)**

|               |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
|---------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| HarrietD      | Hi everyone, and welcome to the Talking Point chat room, where we'll be hosting a Q&A session until 3pm :) Today, we're joined by Catherine and Jess from Alzheimer's Society's Helpline and Research teams, who have kindly agreed to answer any questions you may have about 'Join dementia research' including how to register as a volunteer, and what kinds of studies are involved. 'Join' is a new initiative which allows you to register your interest in participating in dementia research. |
| Ladybird23    | Afternoon                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Catherine J   | Hi everyone, great to be part of your chat session.                                                                                                                                                                                                                                                                                                                                                                                                                                                    |
| Jess_Research | Hello! :)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| HarrietD      | Thanks both :) To kick us off, could one of you tell us what JOIN Dementia Research is all about?                                                                                                                                                                                                                                                                                                                                                                                                      |
| Catherine J   | 'Join dementia research' is a new service which allows people to register their interest in taking part in dementia research through an online database. It will help match people to suitable studies in their area.                                                                                                                                                                                                                                                                                  |
| Ladybird23    | What are the studies?                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| Catherine J   | 'Join dementia research' contains different types of studies that people can take part in, ranging from clinical trials of new treatments to surveys about what works in improving quality of life for people with dementia and their carers.                                                                                                                                                                                                                                                          |
| Catherine J   | Anyone registered with JOIN can see a full list of studies available.                                                                                                                                                                                                                                                                                                                                                                                                                                  |
| Ladybird23    | I would take part in the survey but don't think I would be too much help as my Dad is now in a CH                                                                                                                                                                                                                                                                                                                                                                                                      |
| Catherine J   | Hi Ladybird, there aren't a lot of studies for people in a CH on 'Join dementia research' at the moment but the care home may be interested to get involved in a study called Enrich. I'll check out the link to that and post it.                                                                                                                                                                                                                                                                     |
| Catherine J   | You can also register yourself to take part in research. Anyone over the age of 18 can sign up to be a 'Join dementia research' volunteer as studies need healthy volunteers as controls but we are particularly keen to register more people with dementia.                                                                                                                                                                                                                                           |
| Grannie G     | Hello Catherine and Jess. Do you have any information about the clinical trials involving drugs for diabetes?                                                                                                                                                                                                                                                                                                                                                                                          |
| Ladybird23    | That's a good one. My Dad has that too.                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
| Jess_Research | Hi both - there are a few trials for diabetes drugs at the moment. One is through our Drug Discovery programme, and is testing a drug called liraglutide.                                                                                                                                                                                                                                                                                                                                              |
| Jess_Research | People can register to participate in that through 'Join dementia research', and you can also find out more on our web page (you'll need to copy and past the link): <a href="http://www.alzheimers.org.uk/liraglutide">www.alzheimers.org.uk/liraglutide</a>                                                                                                                                                                                                                                          |
| Ladybird23    | Thank you will look later                                                                                                                                                                                                                                                                                                                                                                                                                                                                              |
| Grannie G     | I didn't make myself clear enough Ladybird. I have been asked to take                                                                                                                                                                                                                                                                                                                                                                                                                                  |

|               |                                                                                                                                                                                                                                                                                                                                        |
|---------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|               | part in a clinical trial to see if drugs given to help diabetes can also help prevent dementia.                                                                                                                                                                                                                                        |
| Jess_Research | Is that the TOMMORROW trial, Grannie G?                                                                                                                                                                                                                                                                                                |
| Ladybird23    | My dad has been diabetic for many years, did all the right things and still got this dreaded disease.                                                                                                                                                                                                                                  |
| Grace L       | I've mentioned to my family that I would like my brain to be donated for research, but they are dead set against it, if I die before them, can they have the final say? Sorry if this post offends anyone                                                                                                                              |
| Ladybird23    | Think if it's in your will then they have to respect that. I admire you                                                                                                                                                                                                                                                                |
| Jess_Research | Hi Grace L - Thanks very much for your willingness to donate, it's very valuable. Unfortunately, similarly to organ donation, your family/next of kin will have the final say as your brain will need to be collected soon after you pass away (before the will is read). Worth more chats with them to explain why you feel strongly? |
| Grace L       | Yes, it's in my Will, but they are really religious (Catholic), I'm CoE, but not religious, never have been.                                                                                                                                                                                                                           |
| Jess_Research | Also, the people over at <a href="http://www.brainsfordementiaresearch.org.uk">www.brainsfordementiaresearch.org.uk</a> (Brains for Dementia Research) may be able to give you some more information about the process and afterwards if that would help you to answer your families' questions?                                       |
| Grannie G     | I don't know Jess. I'm waiting for the paperwork from Kings College, I was only told it is a clinical trial involving a diabetes drug and half the participants take a placebo.                                                                                                                                                        |
| Grace L       | They know why I feel strongly, husband died couple of years ago, he had Vad (early onset), I'd like my brain to go for research                                                                                                                                                                                                        |
| Grace L       | I've already had correspondence with the brains for research folks, thank you                                                                                                                                                                                                                                                          |
| Catherine J   | Going back to studies for healthy volunteers, if anyone's interested in taking part, there's a large 10 year study on 'Join dementia research' at the moment looking to recruit 5000 volunteers over the age of 50                                                                                                                     |
| Jess_Research | Thanks Grannie G. If it's a trial to 'prevent' dementia, it may be that one. They will give you either a common drug for type 2 diabetes (at a low dose) or placebo for a long time - they're testing to see if people taking the drug are less likely to develop dementia.                                                            |
| Catherine J   | Hi Grace L. Have you thought about other ways you might be able to contribute if you and your family don't agree on brain donation. There's things like trials for healthy volunteers that I mentioned earlier and sometimes there are studies for people who have been carers of people with dementia.                                |
| Grannie G     | Thanks Jess. I'll have to wait to hear more.                                                                                                                                                                                                                                                                                           |
| Grace L       | One thing I'd be concerned about is any Life Insurance Policies 'clauses' .... if you were taking part in research ...                                                                                                                                                                                                                 |
| Jess_Research | Ask them lots of questions, Grannie G! Do let us know how you get on.                                                                                                                                                                                                                                                                  |
| Catherine J   | I haven't heard of that being a problem Grace L. A lot of studies are observational and certainly for healthy volunteers would look at things like lifestyles so I can't see this would be an issue.                                                                                                                                   |
| Grace L       | I'd be willing to take part in a study (if there was one) as a former carer of a person with VaD/ dementia.... but I'm not keen on taking drugs                                                                                                                                                                                        |
| Catherine J   | That type of study wouldn't involve taking drugs. I'm not aware that there                                                                                                                                                                                                                                                             |

|               |                                                                                                                                                                                                                                                                                                                                                                                                                                     |
|---------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|               | are studies specifically for carers on 'Join dementia research' at the moment but new studies are being added all the time.                                                                                                                                                                                                                                                                                                         |
| Grace L       | I know some policies don't like to pay out if you haven't warned them about changes,                                                                                                                                                                                                                                                                                                                                                |
| Catherine J   | You're right Grace L but I don't think taking part in an observational study or a survey about your experience of caring will affect this.                                                                                                                                                                                                                                                                                          |
| Catherine J   | Going back to Ladybird's comment about studies in a CH - here's a link to the Enrich study I mentioned                                                                                                                                                                                                                                                                                                                              |
| Catherine J   | Oops :) <a href="http://www.enrich.dendron.nihr.ac.uk">www.enrich.dendron.nihr.ac.uk</a>                                                                                                                                                                                                                                                                                                                                            |
| Grace L       | Catherine, thank you... I was thinking more about taking drugs for research and informing insurance policies, so observational studies should be ok                                                                                                                                                                                                                                                                                 |
| HarrietD      | Thanks for your questions so far everyone, and for your helpful answers Catherine and Jess! To anyone who's just joined us, today's Q&A session is on our new initiative called 'Join dementia research' a place which lets you register your interest in participating in dementia research. Please feel free to ask any questions, and Catherine and Jess from our Helpline and Research teams will do their best to answer them. |
| HarrietD      | So could you tell us how would people be helping, by signing up as JOIN volunteers?                                                                                                                                                                                                                                                                                                                                                 |
| Catherine J   | One of the big difficulties researchers face is finding enough participants for their studies. By signing up as a 'Join dementia research' volunteer you will be helping overcome this.                                                                                                                                                                                                                                             |
| Catherine J   | If you do take part in a study, you will be helping others by contributing to future insights into dementia and its causes, as well as early diagnosis, better treatment, and quality of care.                                                                                                                                                                                                                                      |
| HarrietD      | Thanks Catherine :) If people are interested in taking part, can you tell us how they register with JOIN, and the process involved?                                                                                                                                                                                                                                                                                                 |
| Catherine J   | Yes, people can sign up on line at <a href="https://www.joindementiaresearch.nihr.ac.uk">https://www.joindementiaresearch.nihr.ac.uk</a> . Those needing help with the online registration can call our helpline on 0300 222 1122 and we will arrange a telephone appointment to complete the registration with them.                                                                                                               |
| Catherine J   | To register, you just need to provide some basic information about yourself, such as address and date of birth and some brief medical information.                                                                                                                                                                                                                                                                                  |
| creativesarah | what exactly would it involve My friend J has been coming to london for research (he is 41 with early onset Alzheimers) I went with him                                                                                                                                                                                                                                                                                             |
| creativesarah | I will have a look at the website address                                                                                                                                                                                                                                                                                                                                                                                           |
| creativesarah | I have taken part in the Breast Cancer research Tamoxifen project                                                                                                                                                                                                                                                                                                                                                                   |
| HarrietD      | Hi creatviesarah, and thanks for joining us :) Catherine just had some technical issues with the chat room, but she's back in now and will answer your question as soon as she can.                                                                                                                                                                                                                                                 |
| Catherine J   | Hello creativesarah, There are lots of different studies taking place at different centres across England. What it will involve depends on the study and the research team will tell you more.                                                                                                                                                                                                                                      |
| Grace L       | I've just had a quick look at the website, and can see that you can offer your help, even if you don't want to sign up. What kind of help do the researchers want?                                                                                                                                                                                                                                                                  |

|             |                                                                                                                                                                                                                                                                                                                                                                       |
|-------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Catherine J | Hi creativesarah, do take a look at the website, there are lots of Q & As there <a href="https://www.joindementiaresearch.nihr.ac.uk/help">https://www.joindementiaresearch.nihr.ac.uk/help</a>                                                                                                                                                                       |
| Catherine J | If you decide you want to go ahead and register and need some assistance don't forget you can call our helpline and we'll go through the process with you.                                                                                                                                                                                                            |
| HarrietD    | Just a reminder to everyone viewing this session that there's about five minutes left, so now's your chance to ask any questions you might have about JOIN.                                                                                                                                                                                                           |
| Ladybird23  | My dad took part in trials years ago with diabetes tablets, and still no further with research                                                                                                                                                                                                                                                                        |
| Catherine J | Hi Ladybird, that's why we need more trials and more people involved. The more research we can do the more chance we have of finding answers :)                                                                                                                                                                                                                       |
| HarrietD    | Ok, it's time to bring the session to an end unfortunately! A huge thanks to Catherine and Jess for your incredibly helpful answers and for telling us more about JOIN, and thanks to all of you who asked questions. I hope you found it useful. The links that Catherine and Jess included will also be in the transcript, along with other information about JOIN. |
| Ladybird23  | Yes but we are talking 10 or so years ago. I am quite put out that Dementia does not have the same cover as cancer                                                                                                                                                                                                                                                    |
| Ladybird23  | Thank you                                                                                                                                                                                                                                                                                                                                                             |
| HarrietD    | Thanks Ladybird - you're right, and that's something that JOIN is working to improve :)                                                                                                                                                                                                                                                                               |
| Catherine J | We're working on it Ladybird! :) Thanks for all your questions - hope it's been helpful. Bye                                                                                                                                                                                                                                                                          |

Thanks for reading the transcript for our chat room session on 4 December.

\*\*\*

Links referred to in the session:

- Testing the effect of the diabetes drug Liraglutide in Alzheimer's disease: <http://www.alzheimers.org.uk/liraglutide>
- Brains for Dementia Research: [www.brainsfordementiaresearch.org.uk](http://www.brainsfordementiaresearch.org.uk)
- Example of a research study conducted in a care home: [www.enrich.dendron.nihr.ac.uk](http://www.enrich.dendron.nihr.ac.uk)

Helpful resources:

- JOIN Dementia Research's website: <https://www.joindementiaresearch.nihr.ac.uk/>
- Sign up: <https://www.joindementiaresearch.nihr.ac.uk/beginsignup>
- FAQs for prospective volunteers: <https://www.joindementiaresearch.nihr.ac.uk/help>
- Alzheimer's Society website's general section on research: <http://www.alzheimers.org.uk/research>