



Chat from Rari-tea webinar

21 April 2021

14:30:59 From Amanda R to All panelists : Hi all my name is Amanda and am carer to my husband with young onset

14:31:47 From Tanya W to Everyone : Hi Tanya Where from Alzheimer's Society Richmond & Kingston, very excited to be joining.

14:32:04 From Jane H to Everyone : hi

14:32:17 From Kate Fallows to Everyone : Welcome Tanya, so pleased you are able to join us today!

14:32:26 From Carolyne T to All panelists : Hi Carolyne from Dementia Together in Suffolk :)

14:32:42 From Jacqui D to All panelists : Hi Tanya, Geraint and I live I Kingston, I expect we will meet you IRL soon

14:32:53 From Karoline B to Everyone : Hi interested in the session today as my nephew is 42 with FTD

14:33:04 From Julia S to All panelists : Hi Julia S from Alzheimers Society too! delighted to join really looking forward to this - thank you

14:33:13 From Bethany C to Everyone : Hello all, Beth C here, Up until last week I was the Lead Dementia Nurse. Looking forward to learning more on rarer types of dementia in younger people

14:33:43 From Tanya W to Everyone : Are the slides available afterwards?

14:33:46 From Katie W to All panelists : Hello - Katie W here too

14:34:13 From Kate Fallows to Everyone : Hi Tanya, yes, we're recording the webinar and will share a link to it and the slides in the coming days.

14:34:14 From Georgia P to All panelists : Sorry everyone I am Leila not Georgia just to let you know

14:34:23 From Tessa Gutteridge to Everyone : yes, slides will be sent to you

14:34:35 From Tessa Gutteridge to Everyone : hello Leila, welcome!

14:35:37 From Tessa Gutteridge to Everyone : Welcome everyone - we will also share the chat with you all after

14:35:44 From Chris N to Everyone : Looking forward to this webinar. Rarer dementia needs to be discussed more as it always seems to be Alzheimer's when people consider dementia. I am living with FTD.

14:36:08 From Jane H to Everyone : hi I'm Jane Harris from Plymouth working for age uk in a dementia day care centre.

14:38:07 From Alison to All panelists : hello, this is Alison from Singapore

14:38:36 From Tessa Gutteridge to Everyone : Hello Alison, thank you for joining us!

14:38:52 From Deborah L to All panelists : Hi I manage a younger people with dementia day centre (Alzheimer's Society) Sheffield. We have over the years experienced people with the rarer dementias. Very complex and needs real understanding.

14:39:43 From Tessa Gutteridge to Everyone : yes, hope this helps...

14:59:00 From Julie H to Everyone : As well as noting the disabilities it would also be good to outline the abilities that have been retained

14:59:44 From Tessa Gutteridge to Nikki Zimmermann(Direct Message) : have you picked up the message asking for abilities retained

15:01:16 From Julie H to Everyone : In my own case from early symptoms to diagnosis took around 5 years

15:02:21 From Tessa Gutteridge to Everyone : Julie, isn't that too long and lets hope we can reduce that time to diagnosis

15:04:26 From Julie H to Everyone : Way too long, which is why I join in with campaigning for more timely and accurate diagnosis

15:06:40 From Julie H to Everyone : Do we know if the familial genes are the stronger or weaker type (sorry for inaccurate ters as I now have word finding difficulties sometimes

15:06:44 From Bethany C to Everyone : Thank you so much for sharing Paul, keep playing the game. Wonderful to see how you are both adapting with the use of technology. I hope more becomes available to continue keeping you well and safe. Thank you again

15:08:55 From Kate Fallows to Everyone : Thank you Paul and Pippa. You were both so open and full of positivity as well as lots of good ideas around how to adapt.

15:09:05 From Tessa Gutteridge to Everyone : MCI - mild cognitive impairment...

15:13:25 From Julie Hayden to Everyone : Fantastic talk Martina

15:14:46 From Marcel F to Everyone : Well done Martina - remain positive its so important and love the new acronym for PCA!

15:15:04 From Chris N to Everyone : What a common phrase we all hear "There's nothing wrong with you" if you seem to be coping!

15:16:52 From Julia S to Everyone : Martina, thank you so much - brilliant presentation

15:17:26 From Tanya W to Everyone : The art gallery is so beautiful. Thank you Martina.

15:17:42 From Agnieszka D to All panelists : It's a privilege to hear you all! Thank you!

15:17:56 From Alison L to All panelists : Martina, you are such an inspiration

15:17:58 From Kate Fallows to Everyone : Positive Capable & Adaptable. Martina you so personify those words. Wonderful talk. Thank you.

15:18:28 From Tessa Gutteridge to Everyone : oi, whats wrong with Sam Smith?!

15:19:33 From Bethany C to Everyone : Thank you Martina. Amazing to hear your story and see your positivity. I am so sorry that you closed your business, the artwork is beautiful. High hopes for the future for society to adapt, we need to support people in staying independent and not let society, government etc cause further disability

15:20:40 From Elaine P to Everyone : I'm amazed at the amount of insight you all have and by your ability to express yourselves. it just shows how different these diseases are for everyone

15:20:57 From Julie H to Everyone : Always great to hear stories of people being seen swiftly and being well supported

15:22:47 From Louise D to All panelists : Thank you all so much for taking the time to share your experiences. I am so impressed with all your humour as well... the Sam Smith quip had me laughing out loud!

15:23:00 From Chris N to Everyone : Clinicians believe people with FTD lack Insight but today's panel proves this is not the case.

15:23:31 From Julie H to Everyone : Very good point Geraint. Which of our changes are due to dementia and which to lockdown?

15:23:53 From Lesley B to All panelists : I am so blown away by all your attitudes. The way that you can express the difficulties that you have had. I could listen to you all, all day long! Thank you for sharing.

15:24:49 From Mairi W to All panelists : My Dad has both variants of FTD, behavioural and language, and he has never had any insight into his condition. I think it varies from person to person.

15:25:11 From Bethany C to Everyone : Its a difficult time to be diagnosed Geraint. I would agree that symptoms are difficult to differentiate between dementia, social isolation and lockdown issues. I wish you many years of working (and enjoying D&D!!). Thank you so much for your insights.

15:25:54 From Julie H to Everyone : So many people I know are complaining of chronic fatigue, myself included. I wonder if this is exacerbated by lockdown

15:27:32 From Carlyne T to All panelists : Haha brilliant !

15:28:19 From Tanya W to Everyone : I'm so impressed at the way people are reinventing themselves and creating manageable lives. It's also intriguing that the diagnosis can feel like a relief after such uncertainty.

15:28:20 From Lesley B to All panelists : Would love to see your carvings and I am sure you will be a great success.

15:28:27 From Deborah L to All panelists : Hi I have really enjoyed today's webinar, I have to go as have a staff meeting. I will be in touch and thank you

15:29:39 From Jacqui D to All panelists : We are hoping to get SLT, that is a great question

15:29:45 From Jessica H to All panelists : You have all been so inspirational, I tend to work with advanced dementia in care homes, but having an insight to how your diagnosis effects your day to day life and emotions, as you are able to all express it so clearly, is amazing for me and I feel that I can take so much of this into my practice. Thank you for all sharing :)

15:30:31 From Chris N to Everyone : Geraint, as always, you make me laugh and well done for yours and Jacqui's cheerful approach to life.

15:31:51 From Lesley B to All panelists : I agree so much, I have felt for a long time it should not be under OPMH. I am a Dementia Adviser.

15:32:16 From Katie W to All panelists : Thank you for all of you to give us info - was lovely!

15:32:38 From Lesley B to All panelists : I would love to know about anymore webinars.

15:32:51 From Liz S to All panelists : Thank you all so much for sharing your personal insights.

15:33:12 From Samantha Y to All panelists : Thank you very much .

15:34:06 From Lesley B to All panelists : How can we find out which are the most advanced geographical area with the best results. We could all learn from them.

15:34:45 From Jacqui D to All panelists : Thanks Pippa, that is a good insight

15:36:37 From Kate Fallows to Everyone : Thank you Nikki and all the wonderful panellists for sharing your knowledge, experience, thoughts and ideas. What a fascinating webinar.

15:36:37 From Jacqui D to All panelists : Agree with Martina, we were diagnosed quickly because I played the system.

15:37:20 From Kate Fallows to Everyone : This checklist is what Nikki is talking about for people who have concerns about signs and symptoms. <https://www.youngdementiauk.org/personal-checklist>

15:37:40 From Alison L to All panelists : thank you Gerant. Happy to finally meet Jacqui, whom I absolutely adore and respect. So lovely to watch you both working together and strategising

15:37:48 From Mairi W to All panelists : Very good point Martina. It was an absolute nightmare getting a diagnosis for my Dad, purely down to the fact his GP just didn't listen to us and countless misdiagnoses of stress/personality disorder etc

15:37:48 From Liz S to All panelists : PSPA has red flag posters for GPs <https://pspassociation.org.uk/information-and-support/for-professionals/resources-for-professionals/>

15:38:00 From Julie H to Everyone : Brilliant webinar folks xxx

15:38:02 From Lynsey H to All panelists : Absolutely fantastic session - thank you so much

15:38:11 From Bethany C to Everyone : I have learned so much. Thank you all for your insights and expertise and I wish you all the best

15:38:13 From Kate Fallows to Everyone : The Young Dementia Network has also created a checklist for GPs which you may find useful. <https://www.youngdementiauk.org/gp-guide>

15:38:23 From Catherine K to Everyone : Thank you so much to all of the panelists. It has been really inspiring listening to you.

15:38:38 From Tanya W to Everyone : Thank you this has been so inspiring and informative

15:38:45 From Tamas T to All panelists : Thank you all for sharing your stories. I could learn quite a lot from you. You are very inspiring.

15:38:48 From Sue N to All panelists : Excellent, thank you so much fir sharing your personal stories.

15:38:49 From Gill L to Everyone : Thank you so much for a very informative webinar and for being so honest about your experiences! :)

15:38:54 From Carlyne T to All panelists : Thank you for sharing your experiences guys, will really help lots !

15:38:56 From Amanda R to All panelists : Thank you 🙏 excellent 😊 our first time

15:38:57 From Rachael C to Everyone : thank you for your inspiring stories and strategies you use

15:39:39 From Lisa P to All panelists : Really great webinar, inspiring & educational.

15:39:51 From Mairi W to All panelists : Thank you everyone!

15:40:02 From Debbie W to All panelists : Thank you very much, very interesting and inspiring.

15:40:53 From Dany B to All panelists : Thank you all, this was so informative.