FTD Annual Seminar - Q&A

Facilitator: Professor Nick Fox

Note taker: Hannah Carr

Key:
Q = Question from audience
N = Nick's response
J = Jon Rohrer's response
CFA = Comment from audience

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Q1) Where we live, we are struggling to get a diagnosis and they keep saying it is Alzheimer's. Is there somewhere we can go or someone who can help us to get the diagnosis support we need? And when it progresses how do we get the right kind of support?

N: You highlight a problem everyone here will probably echo. It is very difficult to get appropriate support particularly with an unusual dementia. Not everyone can travel in the various stages of the dementia. We know there are many who would like to come to a meeting like this but who cannot.
It's easiest if you have already come through our service so you can say "contact them". We get lots of emails about asking to support applications for continuing care and asking to tell some professional what condition a person has. So we can try to do that at a distance but our resources are limited.

CFA: GPs can't diagnose FTD so I think you have to insist to see a neurologist.

N: That is absolutely right – ask for a specialist. GPs often feel the only person they can talk to is the patient whilst the most relevant information often does not come from the patient but their family. Here they are worried about confidentiality. So write a letter to tell them what is happening – not four pages but just brief points of what is happening and what you think they should know.

CFA: I had to speak to my own doctor about it and they said to bring my wife in with me.

N: If you say “I want you to tell me what’s wrong” then there is alarm bells but if you say “I think you need to know the following…” or you can say to your loved one that you need to go to doctor and will they come with you?

CFA: Make yourself a carer and report that to the GP and this almost helps to get you in the back door.

Q2) How do we persuade GPs to refer earlier than they do? By the time it gets to diagnosis valuable time is long lost.

N: There can be an agony of not knowing. And you can be palmed off with answers such as depression, anxiety or their behaviour is down to marital/relationship problems. Some get told that the behaviour of the person they have loved for decades is their fault and not a because of a disease. So there is nothing wrong in feeling relief when you get clarity over a diagnosis.
One of the prime things we need to do is educate GPs better and we are starting to do that. We are going to improve our website and run courses for GPs. We want to do these courses by, with and for you. We want them courses to involve people who have looked after someone living with FTD.

CFA: I don’t think you are going to get anywhere just offering courses and websites. You need to work with a governing body to require that this is part of their learning. They are not going to voluntarily take this up.

N: You are right, ideally people would have a certificate to say they have done this. GPs do need to complete their continuing professional development (CPD) so we are hoping to provide these courses to give them points towards their CPD. So it would be in their interest to get them.

CFA: If you are going to train GPs then you need to be holistic; it is not just about the patient but also the families.

N: You make a good point about the need for a carers needs assessment. So, yes, GPs need to recognise the other members of the family also.

CFA: From my perspective, I think my family was just lucky that I had a loud mouth and was pushy and pushed and asked for things. No GP I have come across knows about FTD. So I think if you want to make something happen in the short-term you can help your loved ones by not accepting no. Put something in writing and they have to answer you.

N: Writing letters is powerful. If you have problems in the hospital system, then there is a service called PALS that you can write to. If someone in senior management receive a letter from you then it can up your priority. You can also write to local MPs and this can also be successful.

CFA: Medical students at our GP practice have followed us to make a case study on my husband's illness. So at least the next generation of doctors may have more awareness.

J: The handbook for junior doctors 15 years ago had just one page called dementia and it said there is no need to make a diagnosis of which dementia it is because it would not help. We are now in a much more enlightened age and I get emails from medical students all the time who have heard of FTD. There is a societal change and a change in medical training.

Q3) If you get a diagnosis of FTD does that include information on what abnormal protein you have in your brain, whether it's genetic or sporadic and is it reasonable to expect that those answers are available to you if you ask them?

N: At the moment, we are relatively limited if you have a non-familiar form of FTD as to knowing for sure what abnormal protein is the cause. There are some specific syndromes that we know more of than others. Semantic dementia, for example, is one form where we can have a pretty good guess that it is caused by TDP rather than tau. If you have a genetic form of FTD, we can know with certainty which form is causing the disease. With non-genetic forms, the only way we could really tell what abnormal protein is at play is if we could look at a piece of brain tissue under the microscope – so thank you to all who have signed up to the brain bank donation as you are helping to move this research forward.
So what else could you reasonably ask for? If you are at a non-specialist centre, then getting the diagnosis of FTD is probably the best they can offer. In a specialist centre, they may be able to say what variant they think it is. But does it really matter? Well it will matter in the future in terms of new therapies – some therapies may be only suitable for certain form of FTD like cancer therapies are. So what you can ask for is whether this is genetic and you can expect a discussion about your family history, whether you would or would not want to know and if you would like to get referred for genetic testing if they cannot do it.

Q4) How can you manage sugar cravings?

Tips from the audience: grapes and toothpaste.

N: You could lock the cupboard or provide a diversion.
There are many fixations one can have such as a sugar craving or alcohol and they can put on weight from this. In some situations, the understanding of taste can alter so watered-down alcohol doesn't seem to be minded and for sugar cravings saccharine sugar or artificial sweeteners as opposed to sugar.

A comment on having a child with FTD:
N: I think there are different needs whether you are the child, partner or parent of someone with FTD. What does this mean for intimacy? What does this mean for my risk? We need people with similar positions banding together so they do not feel on their own or isolated.