

FTD support group small group discussions - Clinical Q&A

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Is there a diet for people with FTD? Does sugar make someone with FTD worse?

- *There is no diet for FTD, nor good evidence to suggest that diet changes the course of FTD or prevents it.*
- Research has shown that in FTD, a dramatic change in dietary preferences can occur. For example, people can develop a sweet tooth or 'food fads'. Less often, people can develop eating disorders such as anorexia and bulimia. If someone is eating inappropriately behavioural management can be helpful, for example controlling or preventing access to certain foods. Medication can be useful for some people. For example antidepressants can change the processing of certain brain signals to help manage the difficulties.
- A preference for sugary foods in FTD can be particularly problematic if someone is diabetic; diet and sugar levels are important. Therefore, it is essential to get the diabetes under control.
- It is often useful to get assessed by a dietician. It is important that people can enjoy eating, but this may need to be tempered. In the early stages FTD, the person with FTD sometimes may be more accepting of changes in diet and able to make informed decision.
- Weight gain can be an issue, especially if this is not checked by a healthcare professional, as it can lead to other health issues, such as heart disease or breathing difficulties.
- For issues with swallowing, adjust diet and see a Speech and Language Therapist and/or a dietician for advice.

Someone found using citalopram beneficial. Are there other medications?

- Citalopram is an anti-depressant.
- There are limited studies to show how much citalopram works in FTD.
- In general cases, it seems to be modestly effective but not life changing, and the effectiveness is only temporary. This links to FTD being changeable and people transitioning through different phases of the condition.
- It can be useful for a range of behaviours e.g. obsessional or irrational ones.
- Antidepressants in general should be tailored to the individual, e.g. if someone is having trouble sleeping, a medication which causes drowsiness may be more helpful.
- Using medication is a large, difficult topic. Someone needs to monitor progress when the person is trying different medications.
- General view is the fewer tablets someone is on the better, due to fewer side effects and how different medications interact with one another.
- Neuro tranquilizers are drugs used to calm someone, reduce anxiety and treat behavioural symptoms. It was advised to be wary of neuro tranquilizers because people living with FTD can be more susceptible to their side effects. Neuro tranquilizers are often given if behaviour is difficult to manage so there is a balance to be struck between managing the behaviour and side effects.
- Sometimes a small change in medication can make a difference to someone's life, but this is hard to generalise.

The use of sertraline for obsessional behaviour.

A person with FTD found sertraline to be very helpful for obsessional behaviours. They wondered about the benefit of trying to increase their dose.

- Individualised decisions for medication are vital. It was explained that there can be a different maximum dose depends on several factors. There is a cardiac risk with the medication, which means GPs may be reluctant to prescribe a higher dosage to older people.
- Discuss the risks and benefits with your GP, perhaps see if they can trial an increase in medication. This may need closer monitoring, for example follow-up appointments and an electrocardiogram (ECG).
- The National Hospital for Neurology and Neurosurgery (NHNN) can consult to help with the decision making.
- The decision comes down to a number of factors, and it is key to look at everything i.e. behaviour modification and combination of tablets. It is important to keep the risk at a minimum.
- Memantine and donepezil can be prescribed, which are used for symptom management in Alzheimer's disease but there is a very limited evidence for their effectiveness in FTD.

Side note: The overlap between FTD and Motor Neurone Disease (MND)

- There is a strong association between FTD and MND.
- MND affects the nerves (motor neurones) in the brain and spinal cord that control your muscles. It can lead to muscles weakening, stiffening and loss of movement.

- It is unusual to have FTD with MND, but not uncommon for people with MND to have FTD.

Are drugs in other illnesses helpful for people with FTD? For example Methylphenidate for ADHD

- The evidence is not there currently in relation to that particular medication's use in FTD.
- Professionals often prefer to prescribe drugs with which they are more familiar and confident, rather than ones from different specialities.
- One partner of a person with FTD said they had found strategies for managing behaviour in Autism helpful.
- The differences between FTD and Autism were highlighted, where Autism Spectrum Disorder is a neurodevelopmental disorder which is relatively static whereas FTD is primarily acquired and progressive. Therefore there are different trajectories and prognosis for the two conditions. Anatomically in the brain there is some overlap between the two.
- Although the ketogenic diet is thought to be beneficial in Autism, there is no strong evidence to show any benefits for FTD (see Diet section above).

Thoughts on antibody therapies/immunotherapies

- This has not worked well in Alzheimer's disease so far, despite it working well in initial trials with animals.
- They are still being developed.
- There is the view that there is a need to better understand the physiology of Alzheimer's disease (and other dementias) to effectively treat the condition.

Why is FTD hereditary in some people and not in others?

- Heredity is a bigger factor in FTD than in Alzheimer's disease. Roughly 20%-30% of people with FTD have some genetic link.
- Familial FTD is when someone is affected by the rare autosomal dominantly inherited frontotemporal dementia, which can be inherited and is caused by mutations in the tau, progranulin or C9ORF72 genes.
- When assessing to see if someone has the genetic form of FTD, you can look at someone's family history to see if it is possible genetic factors are involved. A consultant will talk to the family and allow them time to consider what they would like to do because having a diagnostic test has huge implications for relatives.
- The decision varies across families and must be individualised. Everyone involved is consulted before the person with FTD is tested to ensure everyone understands the implications. In clinic you would talk at the individual level and about the family system, as each family is different.
- If someone is living at risk they have 50% chance of developing FTD. To decide if they want to be tested they must have a period of genetic counselling, where they are also given a long time to make their decision. You must be over the age of 18 to

undergo genetic counselling. Less than 50% choose to have the test, often because there is no treatment currently.

- Decisions can depend on stage of life, one member said they felt if you did not have children yet but wanted children the test could be useful as there is the option of genetically modified IVF, which would enable a person with the gene related to developing FTD to have a biological child who did not have the gene.
- Currently we do not know how the gene translates into the protein. Recently gene silencing treatment is being tested, which involves effectively turning off a gene. This is very exciting as it will be striking at the mechanism of the disease, however it will not be suitable for everyone. This treatment is in the initial stages of being studied where it has recently started to be tested on humans.
- One person said a person with FTD had blood taken, so at a later date they can see if the gene is there. This was done with consultation.

How to get involved in genetic studies? For example the progranulin mutation trial

- Would need to look up the what the specific trial was about and the exact criteria to be involved, as they differ from study to study, but the main criteria is likely to be the genetic mutation. You can contact the team and ask about getting involved in research, for example with the [GENFI study](#).
- The genetic link allows FTD to be studied early on, because if someone is carrying one of the genes they will develop the condition, therefore we can study them early on to provide a clear understanding of FTD. Especially as there has been huge advances in genetics and our measurements. There will be the same protein involved in genetic and sporadic FTD, which can hopefully pave the way for treatment.

Can tests be done after the person with FTD has died?

- If someone has given their brain to a brain bank, for example the [Queen Square brain bank](#), this includes the option for genetic screening.
- If a blood sample is stored and available it may be able to be genetically tested. This needs to be done at a specialist genetics centre, for example there are ones in Cambridge, Manchester, UCL etc. We are happy to provide more information on this if needed – please send an email to Hannah at Hannah.carr@ucl.ac.uk

FTD in the media and forensic stories

- It is best to be wary of media stories.
- FTD and forensics is a massive topic. It can be an early manifestation of FTD, for instance where a previously law-abiding citizen suddenly commits a crime, such as fraud. Unfortunately the police force and legal professionals often are not aware this behaviour could be related to something being wrong in the brain, such as FTD, because they lack training and knowledge of this field. If someone who is under the care of NHNN becomes involved in forensics they will inform the relevant professionals, such as the legal team, about FTD.