

## **7<sup>th</sup> May Carer's Meeting – FTD Discussion group led by Seb Crutch**

Note taker: Hannah Carr

The information in this document reflects the content talked about at the FTD small group discussion at this rare dementia support meeting. The content discussed reflects people's personal accounts and opinion and we would like to stress that everyone is different. People's experiences of dementia and their dementia journey vary hugely. People may or may not find the information helpful.

### **Stages**

#### **Q: What are the stages of FTD and what should you expect to see in the early stages?**

Some people gave their accounts of what they believed to be the early stages of FTD from their experiences. Some noticed instant changes in behaviour and personalities becoming more florid where as others did not notice a behaviour change (especially with semantic dementia) and some said that their behaviour became more passive.

One member pointed out that she finds it more meaningful to focus on what is here rather than what does it mean or what is next.

Another member wanted to have a sense of stages and what to expect so they could tell others such as children and so that the symptoms to develop will not come as a surprise (they can prepare for them).

The group realised, however, even from the accounts given in the discussion group that the stages and the behaviours in those stages can vary massively from person to person.

### **Diagnosis**

The group also discussed how to go about getting a diagnosis and the experiences they had with this.

Members mentioned the issue of changes in consultants at their GP surgery and a range of diagnoses that were originally given such as alcoholism or orbitofrontal impairment. Others mentioned issues with mental health and their family members being sectioned into mental health facilities due to their behaviour to later be discharged and told they were fine.

It was mentioned how a referral to a neurologist seems to be the best way to either confirm a diagnosis of FTD or to rule it out. This can be made via the GP.

One member stressed how important it is to get a diagnosis confirmed so that access to support and benefits is then available (some of these are not available until a confirmed diagnosis and a certificate from the GP can be obtained).

### **Support**

The group then went on to discuss what support there is in greater detail.

Members stressed how useful they found organisations such as Age UK (particularly in helping to fill out forms for benefits), Alzheimer's Society and RDS.

One member mentioned Last Power of Attorney (LPA) and stressed how important they found this to be.

Benefits that were mentioned included:

- Attendance allowances
- 25% council tax discount

It was asked if there can be any support for physical aspects such as dressing and washing. Some members mentioned that they address this by paying for their own home care. Though a care needs assessment may also enable some to get support in the home.

Admiral nurses were also mentioned but one member noted that they were not able to access the admiral nurse service as there was not one in their area. It appears that admiral nurses are restricted by geographical limits, but this will hopefully be addressed with the help of the new RDS centre. The RDS centre will work closely with the admiral nurses and will employ an admiral nurse to support members regardless of their geographical location.

### **Communication**

The final point that was discussed was communication and how to communicate with someone with FTD.

Members provided the following suggestions:

- Tap into their interests. Talking about something they are interested in may spark conversation and more communication. For example, sport or music.
- Speech and language therapy: members said they found this NHS service very useful both for the individual with FTD and for the family member or carer. This can be accessed via a referral from the GP.

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