

CFU Carers' Support Group



For carers and relatives of people with fronto-temporal dementia and semantic dementia

Newsletter

SEPTEMBER 2009

Welcome

Welcome to the September edition of our CFU Carers Support Group Newsletter! Thanks to everyone who made the journey to our carers' meeting on 30th July. Unfortunately our speaker was unable to make it so we took the opportunity to have an open discussion. Everyone who attended contributed very interesting points that have helped to make this edition of the newsletter. We have put together a very short newsletter just to highlight a couple of the things people mentioned that you might find interesting or helpful.

We hope you find the information useful and if you have any additional comments or questions, try the website, where you can find previous editions of the newsletter, summaries of other talks, and other useful information and links:

www.cerebralfunctionunit.co.uk/carers.html

Meeting Notes

Our meeting focussed on issues that were important to carers. Here are some of the points raised and suggestions / solutions we came up with during the discussion:

Community Support

A main problem experienced by carers of people with FTD and SD is the lack of recognition of the conditions by GPs and Psychiatrists in their own region. Many carers report initial difficulty getting help because of this and even when a referral to a specialist centre and diagnosis is finally achieved, support in the community can be difficult because of poor understanding of symptoms.

It is understandable that this occurs – due to the rarity of the conditions, many GPs may not have seen a person with FTD or SD before, so they are unlikely to recognise it, or to automatically understand the symptoms. To help with this, we have devised information leaflets especially for GPs and psychiatrists, and it is common practice for our consultants to refer them to our website in their clinic letters. Nonetheless, it is clear from carers' reports that sometimes the messages are not necessarily getting through, and that there is a lack of understanding in some areas. We will report this back to the department to see whether anything can be done to improve the situation, for example, formalising a new patient pathway, and/or training sessions for GPs and psychiatrists.

Encouraging your relative to engage in daycare

Even just a few hours of care a week can provide enormous relief from the constant pressure of being a carer. Many people report that these few hours are like a 'lifeline' to them, and that they could not live without it. Even so, there are often difficulties getting relatives to attend.

People with FTD and SD often dislike the idea of attending daycare. It disrupts their routine and takes them away from their familiar environment. Sometimes people can be

clingy and show reluctance to be separated from their carer. Some describe day centres as 'daft places full of old people' and consider that they are boring and not suited to their needs. In some cases, they are right. Not all places are suitable for people with FTD and SD, as they are often younger and have different problems to other people with dementia. It is important to get the right place for your relative – somewhere that they will enjoy going that will provide them with suitable activities that they can fit into their routine.

If your relative is reluctant to go, it is important to introduce the idea of a daycentre gradually. One way of thinking about it is the way you introduce a child to school – first time just go for a 'visit', next go with them and sit there for a short time, next time get involved and stay a bit longer, just continuing until you can leave them there on their own. Don't try and do too much at once – if they get an idea that they 'will not go on the minibus' to the centre, then don't try and make this happen, or they might end up never going to the centre at all. Remember – you are trying to make a VERY inflexible person work something new into their routine, so you might have to be flexible too!

Sometimes people with FTD and SD go along to daycare centres with the belief that they are doing it to 'help' the people who need to be cared for. Carers tell us that their relatives go along and make the tea, sweep the floor and so on, even though they don't do any housework at home! If they enjoy it and it has become part of their routine, then that's great, for them and you. The same can be said for anything they repeatedly do in the home – try and make things that they enjoy into 'their job'.

There are lots of different day care services available, and they vary from area to area. We cannot list them all here as the list would be far too long! In the meeting, Crossroads (<http://www.crossroads.org.uk/>) was mentioned as a helpful way of gaining individual care on a one-to-one basis. Crossroads is a national network of local charities employing over 5,000 trained professionals. They provide flexible services to people of all ages and health conditions. We also mentioned the befriending services of the Community Volunteers Service Mentoring and Befriending Services and Age Concern, which may help in situations where the person lives alone but potentially needs supervision to do certain activities. In the Trafford Area, there is a service called 'Away Day Care' that provides an excellent service to patients and carers.

Telling others about the diagnosis

As a carer of a person with a relatively rare disorder, it is not unusual to feel like you are 'on your own'. People with FTD and SD often come across as very well and perfectly reasonable to others, especially in the early stages, so your worries about their changes in personality and cognition might at first seem very subjective, both to you, and to those around you. It is of course your decision who to tell, but in our experience, telling others about the diagnosis can often help carers to feel less isolated and also relieves the burden of explaining their behaviour if and when the person does something 'out of character'.