

CFU Carers' Support Group



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

Newsletter

January 2009

Welcome

Welcome to the December issue of the Carers Support Group Newsletter, and Happy New Year!!!

Thanks to all of you who made it to the November meeting. The time that you give and the distances that some of you travel really mean a lot to us and make it worth our while. Unfortunately, we had to start our meeting with an apology. Due to unforeseen circumstances, our planned speaker, Sarah Page, was unable to make it on the day, but has agreed to come along in the new year to give her presentation to the group.

Because of this last minute change, the meeting did not follow the usual structure, and therefore the newsletter will be a bit different too. Rather than summarising the talk, we'll provide some minutes from the meeting, some general information about the group, and any other helpful information we can think of.

Minutes from the Carers Support Group Meeting 27/11/2008

1. First of all, we wanted to start by thanking people for sending back the postcards that were enclosed in the previous newsletter. As you know, the number of people on the mailing list has increased dramatically over the last four years. We therefore wanted to check that everyone who continues to receive the newsletters actually still finds them interesting and helpful, rather than thinking 'Oh no! Not that again!' We received a good response, and have sent this newsletter to all those returned the postcard. On this occasion only we have sent out the newsletter to those who have not returned the postcard (in case you have forgotten). If you would still like to receive the newsletter, please let us know, either by using the postcard, or by email (cheryl.stopford@manchester.ac.uk). If you have lost the postcard, feel free to send an informal note to Cheryl Stopford at:
Cerebral Function Unit
Department of Neurosciences
Salford Royal Hospital
Stott Lane
Salford
M6 8HD
2. We had a short discussion about the development of the group. We are aware that we have followed the same pattern (i.e. formal talk – group discussion – newsletter based on the talk) for a long time now, and this has proved very successful for some people. We have a number of people who come to every meeting (who we don't want to lose!!!) but we would like to encourage newcomers into the group. We discussed some of the following ideas:
 - a. Possibility of splitting the group into 'newcomers' and 'regulars', either before or after the formal talk

- b. Basic 'training sessions' for newcomers to teach them about the syndromes (although this may stretch beyond our resources)
- c. Splitting the group by diagnosis (i.e. FTD vs SD) so that we do not alienate certain groups (again, this may stretch beyond our resources)
- d. Making sure that we are all welcoming to newcomers and sensitive to their needs
- e. Ensuring that we go round the group and introduce ourselves at every meeting
- f. Asking 'regulars' to talk to newcomers about their own experiences in the early stages. This would give newcomers the chance to ask questions to people who have been through the same thing, perhaps 'normalising' their situation, making them feel that they are not on their own.
- g. Developing a 'buddy scheme' whereby people are able to swap contact details with another person in the same situation, enabling them to have telephone / written / face-to-face contact (as desired) with someone to share experiences and gain support. Most carers at the meeting felt that this was a good idea and would welcome such a scheme being facilitated. However it was noted that carers would need to be well matched in terms of their relative's symptoms and stage, and also the coping style and personality of the carer.
- h. Keep the rolling programme of talks but suggestions for new/popular talks included:
 - Recent scientific advancements and new genetic findings
 - The new mental capacity act
 - The role of the Psychiatric team and prescription of antipsychotic drugs in FTD
 - The brain and behaviour
 - Imaging of FTD and SD – What we can see on a scan
 - Communication (contact someone from speech and language therapy)
 - Physical aspects of FTD and SD
 - An update on benefits and allowances

If you have any other ideas or thoughts about topics that might be interesting or helpful, please let us know by letter/email. We are always happy to hear your suggestions and would welcome your input, even if you find it difficult to make it along to the meetings.

The CFU carers support group on the web

Just to remind you, it is easy to access any previous newsletters on our webpage by following the link below:

www.cerebralfunctionunit.co.uk/carers.html

Our site also provides summaries of talks, carers questions and answers from previous meetings, links to useful resources such as Citizens Advice and Crossroads, and factsheets produced by the Alzheimer's Society that provide information about legal matters and looking after yourself. There is also a link to the general CFU website, where you can find information about our research and publications. There is also an 'Information for Clinicians' section produced specifically for doctors who may have limited knowledge of the conditions.

Your Opinions

Differing opinions of the word 'dementia' have been expressed and the topic has become increasingly debated over the last few years. At the recent International FTD conference, use of the word dementia was a hot topic of discussion amongst clinicians and caregivers.

We are interested to know your opinions. Do you find the word 'dementia' to be offensive or inappropriate? Or do you find it helpful when describing symptoms to others? Are there alternative words that you tend to use? Do you think the word 'dementia' increases your access to services? Do you think a change of name would change the way people view the disorder? How strongly do you feel about this issue?

We will have a short discussion about this at our next meeting, as we are interested to know your thoughts on the topic. If you would like to write in with your views, please do, and we will publish them in the next edition of our newsletter.

Information for carers: Advice from the Directgov website

Since we haven't got a talk to summarise, we thought it might be a good idea to just pass on a few helpful facts from the government website (<http://www.direct.gov.uk/en/CaringForSomeone>). This gives lots of advice on benefits, carers rights, carers assessments, and support services available.

Did you know...?

- Your right to a carers assessment, and to the services and support you may receive, is not linked to your income or capital (savings and property). However, after the assessment your local council will look at your income and capital to decide what care services you may be charged for.
- You may qualify for a 'Warm Front' grant (i.e. help paying for heating and insulation improvements) if you are in receipt of attendance allowance or disability living allowance.
- As a carer, you may be entitled to reductions in council tax. Also, if you leave your own property to live with someone you are caring for (e.g. a parent/friend), you could be exempt from paying it altogether on your unoccupied house.