

CFU Carers' Support Group

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

Newsletter

OCTOBER 2004

Welcome

We'd like to welcome you to the first issue of our newsletter, which is being sent out to all of you who expressed an interest in our support group. As most of you know, we held our first support meeting on the 23rd September. A big thank you to all of you who could make it, we were really glad for your encouragement! You really made it a success with your enthusiasm and openness. The atmosphere was warm and lively and everybody seemed at ease and keen to share their feelings and experiences with

each other. As this was our first meeting, we discussed what carers wanted from the support group, how they wanted the meetings to be structured and what kind of issues they would like to be addressed. In this newsletter, we've summarised the main points that were made during the meeting. We hope you'll find this useful, please feel free to write in with any comments or queries about the support group or meeting and we will be pleased to reply to them. We very much look forward to seeing you at our next meeting!

Contents

Welcome and contents	page 1
Purpose of support group	page 2
People involved	page 2
A few ground rules	page 3
Organisation of future meetings	page 3
Some suggestions for future sessions ...		page 4
Next meeting	page 5
Discussion forum	page 5

Purpose of the CFU support group

The CFU support group has been set up for carers and relatives of people with fronto-temporal dementia and semantic dementia. We understand that caring for someone with dementia can be very stressful and emotionally difficult. Support groups for dementia carers can offer some relief by providing the opportunity to meet other carers who understand their situation. At the moment, most support groups available in the North of England are set up specifically for carers of Alzheimer's disease. However, in our experience, people with early onset dementias have very different needs from sufferers of Alzheimer's disease. Many of you have told us that you often feel

isolated in such contexts as other carers' personal situations are very different from your own. Following our initial letter about the support group, we received a large number of favourable replies from carers who felt there was a strong need for a support group which would bring together carers of people with fronto-temporal dementia and semantic dementia. Many of you felt the purpose of the support group should be both social and informative and that through sharing your own experiences you could learn more about these conditions and how others cope, as well as find out what practical help is available to carers.

People involved

At the moment there are three of us running the support group: Brenda Reahe, Cheryl Stopford and Camille Julien. Brenda is the social worker at the CFU and advises carers on legal, financial and social matters. Many of you will have talked to her at the follow-up clinics. Cheryl and Camille are research

assistants and carry out psychological assessments of patients who come to the clinic. Running a support group requires a lot of organisation and time so if anyone would like to get involved in the organisation or facilitation of support meetings, we would greatly welcome your help.

Ground Rules

Some people may find talking about their life as a carer quite difficult and uncomfortable. In order to develop a caring and trusting atmosphere within the support group, we agreed on a few ground rules during the meeting:

CONFIDENTIALITY:

everything that is said during meetings will remain confidential and should not be discussed outside of meetings.

RESPECTING EACH

OTHER: carers coming to the support meetings may want to talk about many different issues, some of which may be very sensitive. We ask that every member of the group listen sensitively to other carers' opinions and concerns and respect what they have to say without judging them.

ENJOY IT!

we hope that you'll enjoy meeting new people and sharing your experiences with carers who are going through similar situations.

Future support meetings

General organisation

We hope to hold the meetings every 2 to 3 months. Meetings will take place on Thursday evenings in the Cerebral Function Unit at Hope Hospital, where you come for your clinic appointments. We aim to start meetings around 5pm, however, if several of you would like to come to a meeting but can't make that time, we could always arrange to have some of the meetings at earlier times. Please let us know if you would like this to be arranged.

The majority of responses from our initial letters about the support group showed that most people were interested in attending meetings that involved both formal talks and informal discussions.

Consequently, we will try to arrange a short, informative talk for each meeting, with time for a follow-up discussion, when you will be able to ask questions, offer opinions or advice to others, or simply chat to people in the same situation as

yourself. We hope that this will prove to be a useful way of ensuring that people gain both practical and emotional benefits from the support group as a whole.

Some suggestions for future sessions

At the first meeting, we asked for suggestions for future topics of discussion, and themes for invited speakers. Here are some of the issues that were raised as possibilities for forthcoming meetings:

Invited speakers for:

- Legal information – power of attorney, wills
- Financial information - benefits advice, attendance allowance etc
- Access to services – e.g. Crossroads, daycare, respite, carers' organisation
- Information about the illness – prognosis and explanation of the disease
- Explanation of behaviour and personality changes

- Dealing with sensitive issues – bathing, hygiene, changing clothes, sexual matters etc
- Coping strategies – e.g. laughter therapy

Potential discussion topics:

- Specific behavioural problems, for example, coping with food fads, collecting/hoarding behaviours, stubbornness and rigidity of thinking, habits and repetitive behaviours, paranoia
- Dealing with attitudes of others – family members, general public
- Constant feeling of pressure and anxiety
- Personal methods of coping

We will invite a different speaker to each meeting, to try to cover all potential areas of interest. We will let you know the topic of each session in the preceding newsletter, so that you can decide whether you are interested in attending the

meeting. If you have any other suggestions for the invited speakers, or for the discussions please let us know.