

CFU Carers' Support Group



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

Newsletter

DECEMBER 2006

Welcome



Welcome to the December edition of the carers' support group newsletter.

Many thanks to all of you who came to our open meeting in October, it was great to catch up with carers and welcome newcomers into the group. We talked about what kind of talks carers would want for next year's meetings. You can see a list of meeting dates and invited

speakers for the coming months in the Diary section of the newsletter. We would also like to say a big thank you to all of you who completed our carers' questionnaire. It was great to get feedback about the support group as well as suggestions for future meetings. We've included a summary of your impressions on the support group in this newsletter.

We very much hope to see you at our next meeting in January. In the mean time, best wishes for the festive season and 2007!

Contents

Welcome	2
Your feedback on the Carer Group	3

Carers' Feedback on the CFU Support Group

Why and for whom was the carer group set up?

The CFU Carer Support Group was set up in September 2004 to provide help and advice to carers and relatives of people with fronto-temporal dementia (FTD) and semantic dementia (SD). Caring for someone with dementia is never easy but caring for someone with one of these conditions can be particularly isolating. People with FTD or SD are affected at a much younger age (usually in their 50s or 60s) than most dementias, so the burden of caring for a partner with FTD or SD may come at a time when people are still working, bringing up a family or already caring for elderly parents. In addition, the symptoms of FTD and SD are very different from those seen in other degenerative conditions, such as Alzheimer's disease. The sufferer undergoes a profound personality change, with loss of empathy for loved ones, self-centredness and challenging

behaviours. In the face of all this, carers have very few support options to turn to. At the moment, most support groups available in the North of England are set up specifically for carers of Alzheimer's disease. Many carers feel isolated in such contexts as other carers' personal situations are very different from their own. Because FTD and SD are relatively new clinical entities, understanding of the condition is still poor and carers have difficulty accessing information about symptoms and prognosis. Poor recognition of the condition in the health professions may also impact on carers' ability to access appropriate support. Carers may also fail to get adequate support from their own families and friends, who, because of their lack of understanding of the condition, may interpret the behavioural changes as wilful.

What do we do?

The support group is open to carers and relatives of people diagnosed with fronto-temporal dementia and semantic dementia who attend the CFU clinic. We currently have 65 carers on our mailing list. We hold quarterly meetings to provide advice and social support in an informal setting. Professionals are invited on a regular basis to talk about the clinical, social and legal aspects of care.

We also hold open meetings where carers can meet up on an informal basis. We send regular newsletters to all carers, keeping them up to date with meetings and providing detailed summaries of carer talks. Details of our meetings and past talks are also posted on our website at:

www.carers.cerebralfunctionunit.co.uk

Carers' feedback

As the support group has now been running for just over two years, we

wanted to gain a clear idea of how effective the group has been in meeting

its targets and how beneficial its services have been to the carers involved. We asked carers to give feedback on the support group by completing a simple questionnaire. Carers were asked to rate

on a scale of 1 (not at all) to 5 (greatly) how much the carer meetings and newsletters had benefited them in the following areas:

1. Clinical understanding of their relative's medical condition (i.e., frontotemporal dementia or semantic dementia).
2. Confidence in communicating and informing others about the condition (e.g. allied medical professionals, family).
3. Management of relative's mental and behavioural problems.
4. Understanding of legal and financial aspects of caring (e.g. Power of Attorney).
5. Access to local support services (e.g. respite care)
6. Coping with the emotional burden of caring for someone with dementia.

Carers were also encouraged to supplement quantitative judgements with qualitative comments and examples.

Results

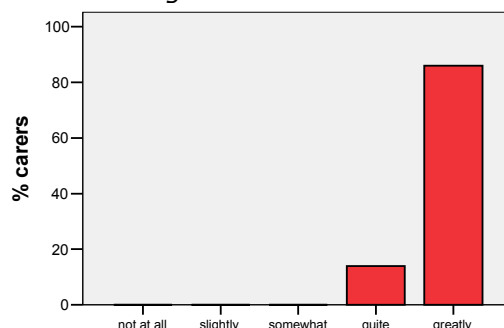
The questionnaires were sent out to all carers on our mailing list (65). We received completed questionnaires from 24 carers (37%). Carers had been attending the CFU clinic with their relative for an average of 4 years. Most carers had been involved in the group for the past 1 to 2 years and had attended

an average of 3 meetings. Two carers had joined the group in the last 6 months. 35% of carers had been unable to attend any meetings, either because they lived too far from Salford or because they were unable to arrange an alternative carer for their relative.

Clinical understanding of frontotemporal dementia and semantic dementia

Over 80% of carers felt that the meetings had greatly improved their understanding of FTD and SD. Many carers commented that they had gained a better understanding of the brain areas involved in these conditions and how changes in the brain could cause symptoms such as alterations in personality and loss of communication.

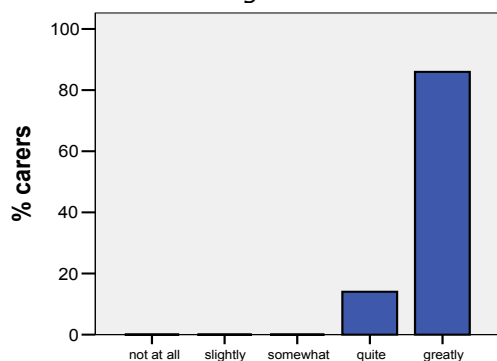
Understanding of FTD and SD



Confidence in communicating and informing others

Similarly, over 80% of carers felt that the group had greatly improved their confidence in informing others about their relative's condition. This ranged from explaining symptoms and discussing reasons for changes in behaviour with friends and family to informing GPs and care workers about the condition. Many carers felt more confident and comfortable when discussing these issues, and in several cases, this had led to increased cooperation from family as well as health professionals.

Confidence in informing others

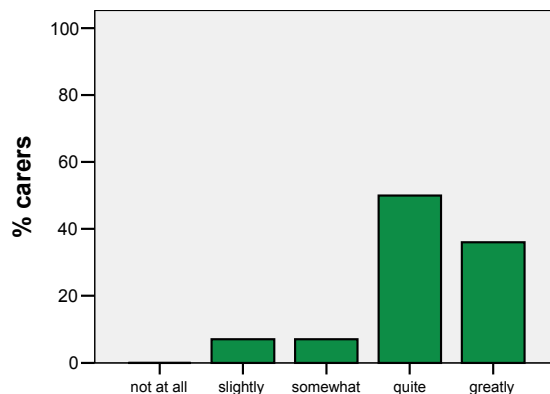


Management of cognitive and behavioural problems

Over 80% of carers felt that the meetings had improved their ability to manage their relative's everyday mental and behavioural problems to a significant degree. Many carers commented that they were less frustrated by their relative's behaviour because they were better able to appreciate the causes of behavioural change. Certain carers had also attempted to implement behaviour management strategies, such as establishing clear routines and avoiding

direct confrontation. However, many carers still felt they would benefit from more direct advice on coping with challenging behaviours.

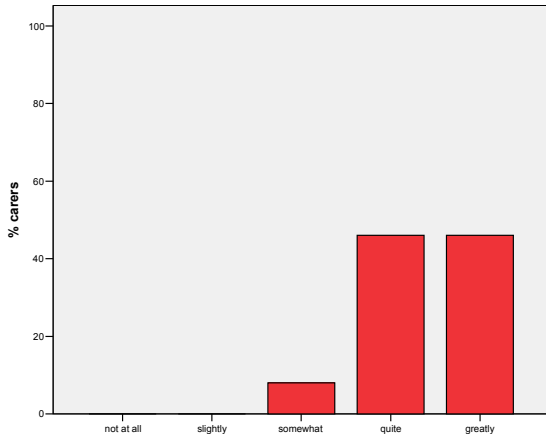
Managing cognitive and behavioural problems



Understanding legal and financial aspects of caring

Over 80% of carers felt the meetings had significantly improved their understanding of legal and financial matters. In particular, many felt that being advised on Power of Attorney and when to take action with their relative's finances had been very beneficial to their family, enabling them to secure investments and plan for the future with the minimum of distress. Some carers reported that a better understanding of the benefits system had enabled them to secure carer allowances, however many welcomed more detailed talks on the subject as they found it a very complex and confusing area.

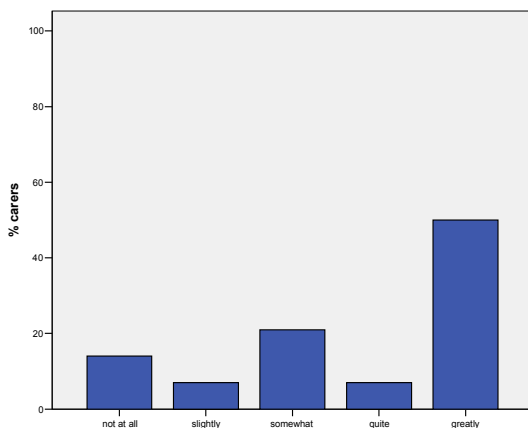
Understanding legal and financial issues



Access to local support services

Over 50% of carers felt that the meetings had greatly helped them to access local support services, such as respite care and day care. Many carers commented that the meetings had increased their awareness of support alternatives and contact points for accessing these services. However, several carers had encountered difficulties in securing these services in their local area, mainly due to poor recognition of their relative’s condition and support needs by local authorities.

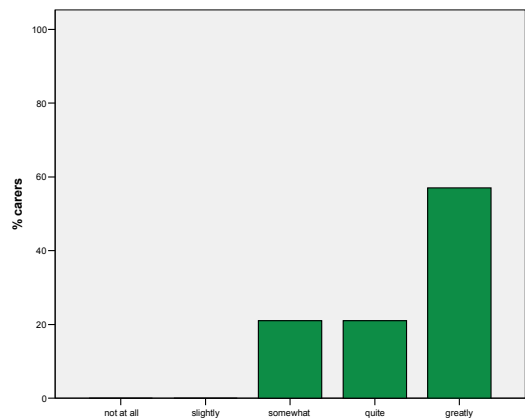
Access to support services



Coping with the emotional burden of caring for someone with dementia

Over 50% of carers felt that the meetings had greatly improved their ability to cope with the emotional aspects of caring for someone with FTD or SD. Many carers commented that they now felt less isolated and more supported, knowing that others had been through similar experiences.

Coping with the emotional burden of caring



Carer newsletters

Carers also gave positive feedback about the newsletters. They felt that reading through the summaries of talks at home helped them to clarify and retain what they had learnt in the meetings. They also found the newsletters were an effective tool for communicating with others and regularly made copies for family, GPs and care workers. Carers who were unable to attend meetings felt that the newsletters were an effective way of keeping informed and up to date with the group. Whilst carers who attended regular meetings focused on the benefits of personal contact for emotional coping, those who lived too far to attend meetings appeared to rely on the newsletters for emotional support.

Aims for the future

Our aims are to:

- Continue to inform carers about FTD and SD by establishing a rolling program of talks from clinicians who are specialists in this area.
- Increase understanding of legal issues by inviting solicitors to give updates on legal matters.
- Increase understanding of financial matters by contacting professionals from the social services and benefits agencies to speak to the carers.
- Invite speakers who are able to give practical advice on dealing with challenging behaviours (e.g. clinical psychologists).
- Continue to raise awareness of FTD and SD. Many of you have reported difficulties in accessing facilities due to a general lack of understanding of the conditions within health and social care support services. We are currently looking into the possibility of producing information sheets aimed at medical professionals.