

CFU Carers' Support Group



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

Newsletter

March 2009

Welcome

Welcome to the March issue of the Carers Support Group Newsletter!

Thanks to all of you who made it to the February Annual General Meeting. These meetings are really important to us as they give us ideas about how to progress with the group and what is really important to you, the carers. Without your input it would be difficult to keep the group going, so thank you. If you find it difficult to attend, but have any ideas or questions about future talks, please feel free to get in touch, as we are always willing to consider new directions for the group:

(Email: cheryl.stopford@manchester.ac.uk or write to Cheryl at the Cerebral Function Unit, Department of Neurosciences, Salford Royal Hospital NHS Trust, Stott Lane, Salford, M6 8HD.)

As the February meeting was the AGM, and mainly consisted of discussion about this year's talks, we have simply provided some housekeeping notes, a draft of the agenda and also some information about some of the subjects that came up during the meeting. We hope you find it helpful, and that we see you at some of the meetings this year!

Housekeeping Notes

The CFU carers support group website

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

As noted in the last newsletter, 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 discussed this at our February meeting, and there were differences in opinion. Some people said that 'dementia' was a useful term, in that they could use it to quickly excuse any embarrassing or inappropriate behaviours. However others find it to be problematic, in that as soon as anyone hears the word 'dementia', it is automatically assumed (by lay people and professionals alike) that the person has Alzheimer's disease, and therefore it can be difficult for others to understand the problems that they are facing.

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?
If you have any opinions on this matter, please let us know.

Shared Lives (formerly known as the 'Adult Placement Scheme')

One of our carers from the Tameside area mentioned this scheme at our recent meeting, so we decided to look into it further. In the case we are aware of, care is available on a kind of 'buddy-scheme' basis, for a few hours a week. Brenda has since contacted Salford social services about their version of the scheme and it is only available for people with learning disabilities, so there are obvious differences between boroughs. Nonetheless, we have found some information about it in case you would like to see if your area offers a similar scheme.

The Adult Placement Scheme provides an alternative and flexible form of support or accommodation with an approved carer, either within the carer's home or out in the community. It can provide a much needed break from the emotional and physical difficulties of caring for someone. The service user has the chance to learn new skills and follow their interests and hobbies in a safe and respectful environment.

Support is individualised and responsive to the changing needs of the service user and the approved carer. Volunteers from the local community apply to become approved adult placement carers to offer a consistent 1:1 relationship and support on a flexible basis. In order for a person to qualify as an approved carer, they must undergo a series of training and checks, including an enhanced Criminal Record Bureau disclosure, two personal references, a reference from a recent employer and an induction programme. In addition to this, training in first aid is administered. Once all of this has been completed, the prospective carer is put forward for approval which, if appropriate, is given by a panel of representatives from each area of health and social care.

A range of services are offered, from day support in the community to long term support. **Day support** can take place in the service user's own home or in the community, and can be used every now and again or for several hours each day. **Short term support** can be used for regular respite breaks or one off periods to allow the main carer of the service user an extended break or holiday. **Long term support** refers to a service user living with their approved carer in on a long-term basis and sharing the ordinary lifestyle of the approved carer and their family.

Charges (prices refer to Tameside only)

Day care: £5.30 per hour

Short term: £35.27 per night
£246.89 per week

Long term: The total cost for long term placement is £318.16 per week; £116.80 of this total is paid by the service user, £201.36 of this total is paid by the Adult Placement Scheme.

Contacts

National Association of Adult Placement Schemes (NAAPS)

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Website www.naaps.aco.uk

Tameside

Tameside Adult Placement Scheme
Hyde Town Hall
Market Street
Hyde
SK14 1AL
Tel 0161 342 5151
Email adult.placement@tameside.gov.uk
Registered manager: Gail Sutcliffe

The National Dementia Strategy

The topic of the government's new 'National Dementia Strategy' also came up during the meeting. This is a **5 year plan** outlined by central Government to improve various aspects of dementia care and the quality of life for people with dementia and their carers. It has been identified as a national priority and has been brought about through public consultation (around 50 events took place with a turn out of 4,000 people).

3 key steps have been forwarded to guide the strategy's implementation:

1. To increase understanding (professional and public) of dementia and remove stigma
2. To encourage early diagnosis, support and treatment where appropriate
3. To develop a comprehensive dementia service

To enable the above, GPs will work in partnership with mental health services and will be trained to spot dementia in its earliest stages. Hospitals will have one person who is directly responsible for dementia services to reduce fragmentation of services. Every person diagnosed with dementia will be provided with a personal **dementia adviser** to offer individualised support and information. Another general aim is to help people with dementia to remain in their own homes for as long as possible.

Several key objectives to help achieve the goals have been specified:

- Raise awareness and encourage people to seek early help/make early referrals. This will in turn, hopefully, reduce common misunderstandings of people with dementia and their needs.
- Provide quality, early diagnosis, support and treatment with an early specialist assessment and an accurate diagnosis which is properly explained to the individual and significant others
- Early access to care and advice following diagnosis from a personal dementia adviser
- Develop peer support to foster support between local people within communities and encourage people affected by dementia to take an active role in developing local services
- Improve personal, not just medical, support for people living at home by means of a range of flexible services

- Implement the New Deal for carers; provide support, advice and a proper assessment of their needs which includes breaks from caring
- Improve the quality of care in general hospitals which do not specialise in neurological disease
- Improve intermediate care and help people with dementia to remain in their own homes for as long as is appropriate
- Consider the effects on people with dementia and their carers when developing service planning, such as housing services
- Improve quality of care in nursing homes with clear responsibilities, care plans, checks and visits from mental health teams to ensure the appropriateness of services
- Improve end of life care with people with dementia and their carers being involved in the planning of care to be received
- Develop an effective and informed workforce with the right skills, training and a policy of further learning
- Making research into the causes and possible future treatments more accessible to the public

www.dh.gov.uk/dementia

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