

CFU Carers' Support Group



January 2012

Newsletter

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

Summary of Meeting 13th October 2011

General discussion

There were no speakers at the October meeting instead we held an open forum to allow free discussion. Since a great deal of the information discussed at the meeting was highly personal, only general topics of discussion will be recorded in this newsletter. One topic that recurred during the afternoon was the difficulties carers face when they can no longer cope with the burden of looking after a loved one at home. In particular, the lack of information about choosing the best care home for a loved one and gaining continuing NHS healthcare. Brenda and I thought that this may be a good topic for the newsletter in particular focussing on care homes.

Care Homes and Continuing NHS Healthcare

Deciding that you are no longer able to care for a loved one independently is always an exceedingly difficult decision. It is made more difficult when your loved one has a disorder that is not widely recognised and is associated with unusual symptoms such as changes in behaviour and personality. Many people who attended the group in October were not yet looking at care/nursing home, but they were aware that it might be needed in the future. Several people at the meeting had begun to look at care homes and for places for their loved ones to go for respite care and had faced difficulties. One attendee described her difficulties choosing the correct care home for her husband and she explained how she had to move her husband because of serious issues with the first care home he went to.

Problems our carers commonly encounter

There seem to be several problems that people frequently encounter:

- Firstly, there is a lack of understanding of what FTD and SD are. Care home staff members tend to see the term 'dementia' and assume that the patient has memory problems, like patients with Alzheimer's disease. They are then unable to manage challenging and unusual behaviours that occur in FTD and SD because they do not understand the cause of these behaviours. This can in part be improved by trying to help teach the care home staff about the disorders, if they have time and are willing to listen. At the CFU we have leaflets that provide brief descriptions of FTD and SD and we are happy to give copies of these to you, or send them to the relevant care home if requested. There are also information sheets on the CFU website (<http://www.cerebralfunctionunit.co.uk/information sheets.html>) and copies of previous newsletters (<http://www.cerebralfunctionunit.co.uk/newsletters.html>). Some of the previous newsletters include summaries of talks tackling how to manage challenging behaviours and communication difficulties that sometimes occur in FTD and SD, which can be particularly helpful.
- Secondly, the costs of putting someone into long term care are considerable. In addition, there is significant variation between the costs of different care homes and there are clear regional differences in care home costs. Paying for long-term care will be described in a bit more detail below.
- Thirdly, care homes appear to be better in certain regions and having a loved one in a care home that is a distance from where you live is not ideal.

Paying for long-term care

At the moment, the amount of money the government will subsidise towards getting residential long-term care depends on the amount of income and savings a household has, i.e. it is means-tested. If someone has savings greater than £23,250 they are expected to pay for the costs of care themselves. If the person is living alone then the value of their house is included in their amount of savings. When the value of their savings drops below £14,250 only their income goes towards residential care costs.

The costs of keeping a loved one in a care home or a nursing home are high. If there is not sufficient money to cover the entirety of someone's stay in a home then the local authority offers some funding. However, since that funding is capped family members may have to make up the difference between funding and costs. If family members do not have the funds to do this then they may have to move their loved one to a cheaper home. This could be particularly difficult with patients with FTD and SD who are easiest to manage when there is continuity and routine. Many people seek advice about financial matters from their local government but it is better to seek independent financial advice at the earliest possible stage. Independent financial advisers (IFAs) should have professional qualifications awarded by the Chartered Insurance Institute and when going to them for advice on funding for long-term care they should also have a 'CF8' qualification. They may also have additional qualifications from the Society of Later Life Advisers.

There are two types of benefits that can be claimed by self-funders in care homes:

- 1) Attendance allowance: for residents over the age of 65 who require help with activities of daily living. This is £49.30 per week and increases to £73.60 per week for residents who need round the clock support.
- 2) Registered Nursing Care Contribution: for all residents who need nursing care. This is directly paid to the care home by the primary care trust. The amount differs slightly according to which area of Britain you live in but is typically over £100 per week.

The Dilnot Report (published August 2011)

The Dilnot Report was written following a government-backed analysis of long-term care. It determined that people were not provided with adequate information about the available 'financial options and products'. The report suggests that local governments should highlight that IFAs should be visited by a higher proportion of people making long-term care decisions, and make suggestions of trustworthy IFAs.

Care homes in the North West

Each local authority has a list of care home in the area and, if contacted directly, they should be happy to provide this list. There is also some constructive information on the website www.scie.org.uk. Brenda and I have discussed how we could find out other useful information about care homes and nursing homes in the North West. Since Brenda is not directly involved with advising people about care homes she only has limited knowledge. We thought about trying to contact care homes, but without actually going to them it is difficult to provide any useful information. We really need all of your help with this; if you have had any experiences with particular care homes, good or bad, we would very grateful if you could tell us about it, either by email (jenny.harris@manchester.ac.uk) or post (Jenny Harris/Brenda Reah, Cerebral Function Unit, Hope Hospital, Stott Lane, Salford, M6 8HD).

Continuing NHS Healthcare

If someone has gained funding for continuing NHS healthcare they are not responsible for the healthcare and residential costs. This policy is for the entire United Kingdom, it is not region specific. However, gaining continuing NHS healthcare is a challenging and ongoing. It may be useful to read the May 2010 and June 2011 newsletters which summarise talks given by Caroline Butlin-Worrall, Community Care Legal Advice Service Manager for the Citizens Advice Bureau, about continuing care, and by Margaret Reid, a carer who attends the group, about gaining continuing care for her husband who has semantic dementia, respectively. One main difficulty faced when trying to get continuing NHS healthcare for patients with dementia is that because their illness may involve changes in behaviour, communication or memory rather than sickness or weakness (in effect cognitive rather than physical illness) they may be deemed to have sufficient behavioural and management needs to need continuing NHS healthcare. The ins and outs of continuing NHS healthcare are quite complicated and it is worth

looking directly at the official documents for 'the National Framework for Continuing Healthcare and NHS-funded Nursing Care'. These can be found at <http://www.dh.gov.uk/> under 'Publications' (search for the National Framework for Continuing Healthcare and NHS-funded Nursing Care).

If you have any questions about care homes or continuing NHS healthcare don't hesitate to get in touch.