

CFU Carers' Support Group



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

Newsletter

May 2006

Welcome

Hello and a warm welcome to the May edition of the CFU Carers' Newsletter! Apologies for the long delay between newsletters. As we had two carer meetings relatively close to one another (February and April) we thought we would wait and combine summaries of both talks into one bumper edition. Many thanks to all of you who came to the last two meetings, it was great to see so many people come and enjoy the talks. The first meeting was held on the 9th February and focused on carers' rights and needs. Joan Martin, a Carer Support Worker from the Carers' Centre in Salford gave an excellent talk on the legal and practical support available to carers. Many carers at the meeting were surprised to find out how much help was actually

available to them and we have since had reports of carers who have managed to secure extra support and assistance as a result of this talk. Our 2nd meeting on April 27th focused on physical problems in FTD and SD. Dr Richardson, a Consultant Neurologist at the CFU gave a very clear and concise talk, highlighting the problems that can appear in the late stages of these conditions. In the following pages, we have provided a summary of both talks, which we hope you will find interesting. We very much look forward to seeing you at our next meeting!

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February 2006: Caring for Carers

Speaker: Joan Martin, Carers Centre, Princess Royal Trust, Salford

As you will know, caring for someone with dementia can be a challenging experience. According to the national carer's organisation, there are approximately 5.7 million adult carers in the UK, of whom, an estimated 1 million care for someone for over 50 hours per week. The fact that this work is unpaid means that carers save the government an estimated £57 billion per year. Recognition of this has led to the development of a number of legal acts, organisations, and provisions to support carers in their often difficult and full-time roles.

Legal Rights

Two acts have been crucial in providing carers with rights of their own, independent of the person for whom they are caring:

- **Carers and Disabled Childrens Act 2000:** This gave carers the right to have a community assessment of their own needs regardless of whether the patient requests support or not. In some areas, the patient and carer are assessed together; in others, assessments are done independently. The carer assessment should be reviewed every 6 months, and acts as

your opportunity to tell social services about your needs.

- **Carers Equal Opportunities Act 2004:** This act states that local authorities must make carers aware of their rights to an assessment, and also must take into account carers' employment, leisure, and lifelong learning wishes. Other organisations, such as the Primary Care Trust and the Hospital Trust must work together in responding to requests from social services in support of carers.

Support in the Community

Provisions vary across different regions. However there are several organisations that might be able to help you:

- **Carers Centre:** You can search for your local centre at www.carers.org. The carers centre is an independent organisation supported by donations and expertise from health and social services. It is designed to support carers, giving advice and information. It is not a service provider – it simply gives access to information about various topics such as:
 - Getting the best from other services
 - Local support groups
 - Training in caring

- Help and advice on returning to work/managing commitments
- Introduction to educational, training, or leisure activities
- Advocacy in cases of breakdown with social services
- Opportunities to help others from your own experience.

The carers centre also plays a role in the health and social community, by helping to train health professionals, and working on committees to challenge services in the area and improve service providers. In doing so, they are responsive to carers' needs and requests.

- **Local informal support groups**: In each area, there are likely to be a number of informal support groups, unattached to a national organisation. These groups may be informative, or purely social. Your local carers centre should be able to give you relevant contacts.
- **Age Concern**: Again, your local carers centre should be able to point you in the right direction. Age concern can offer independent advice concerning all aspects of care, and plays both a social and informative role.
- **Crossroads**: This is a national federation, with each scheme being

independent within its own area.

Crossroads has a licence to provide care on behalf of the local authority. It is a care provider, and gives carers the opportunity to have some free time. It costs approximately £1.50 per hour, with a maximum of £12 per week. The type of care depends entirely on patients' needs and requirements. For example, someone could be employed simply to stay in with your relative/friend, whereas others might prefer to go out walking together.

Flexibility in Care Provision

There is some flexibility in the way that you deal with your rights and benefits.

Direct Payments are a good example of this. Basically, each Local Authority has a pot of money to provide services for carers. By using Direct Payments, your entitlement to financial support can be allocated to you in cash so that you can pick and choose the services that you need. In effect, you can use the money to 'buy in' services from your chosen organisation(s). Inevitably, there is some paperwork involved, but the Direct Payments scheme should be able to help you to complete it. The scheme has its own management system, and can advertise for carers for you. It is now also possible for a relative to act as a paid carer.

Benefits

It is important to state that benefits advice is a highly specialised area of expertise. Rules and regulations are constantly changing and every case is different, meaning that it is difficult to give generalised advice on the topic. Joan maintains that the only safe way to talk about benefits is on a one-to-one basis with a qualified expert, from either the Welfare Rights Organisation or the Citizens Advice Bureau (CAB). There were a couple of issues on which she was able to comment:

Council Tax

If you own a property and care for someone who lives in that property who has lowered mental capacity, it can be possible to get your council tax band lowered to a certain degree. The confirmation of lowered mental capacity typically requires a letter from a doctor involved in your relative/friend's care. The lowering of council tax bands is independent of council tax benefit. Speak to your local Council Tax Office for details.

Carers and Attendance Allowances

Unlike some of the other benefits available, neither carers nor attendance allowance are means-tested. Their purpose is to help carers to look after

people who may need help with their personal care as a result of physical or mental disability. Attendance allowance is available for persons aged 65+. Disability Living Allowance may be an alternative for the under 65s.

Means-tested benefits

Even if you are refused means-tested benefits (e.g. Council Tax/Housing benefits), it is still useful to apply for them. In attempting to claim for such benefits, you become accredited as a carer, and this is recorded in your pension records. This can subsequently lead to an increase in your pension benefit.

Useful contacts

Carer's centres: www.carers.org

Age concern: www.ageconcern.org.uk
(0800 009966)

Crossroads: www.crossroads.org.uk
(0845 4500350)

Direct Payments/Council Tax:
www.direct.gov.uk

Citizens Advice Bureau:
www.adviceguide.org.uk

April 2006: Physical Aspects of Frontotemporal Lobar Degeneration

Speaker: Dr Anna Richardson, Consultant Neurologist, Hope Hospital, Salford

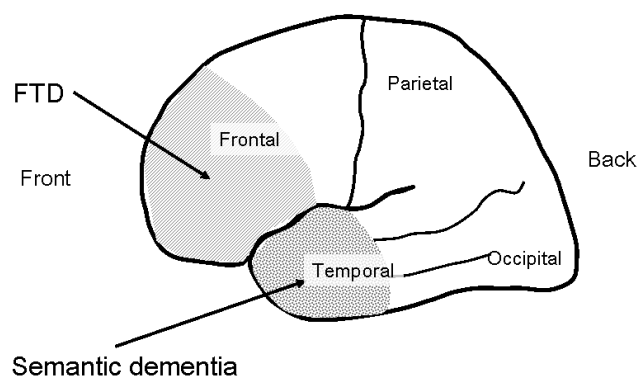
Talking about physical problems in frontotemporal dementia and semantic dementia may at first seem a rather surprising topic as it tends to be more people's mental health rather than their physical health which is affected in these conditions. However, physical problems do become apparent in the later stages, as well as in rarer forms of the disease.

Brain functions and scientific terms

First, a brief recap on scientific terms and brain functions! The term 'frontotemporal lobar degeneration' is an umbrella term for the unifying disease process which causes a number of disorders, such as frontotemporal dementia (FTD) and semantic dementia (SD). We've mentioned in previous newsletters that different areas of the brain are responsible for different psychological functions. For example, the occipital lobe (at the back of your brain) processes visual information, the parietal lobes are responsible for spatial navigation, the temporal lobes (behind your ears) support language and memory functions, whereas the frontal lobes (at the front of your brain) are responsible for planning, strategic thinking and social judgement (see diagram).

Frontotemporal lobar degeneration is a brain disease which generally affects the front parts of the brain (the frontal and temporal lobes). In most people, FTLD affects either the frontal or the temporal lobes of the brain. If it affects mostly the frontal lobes, this gives rise to the syndrome of frontotemporal dementia (FTD), associated with personality and behavioural change. If the temporal lobes are mostly affected, people develop the syndrome of Semantic dementia,

Diagram of the brain showing areas affected by FTD and SD



associated with a loss of understanding of the meaning of words and objects. In some cases, FTLD may affect both frontal and temporal lobes, and people will exhibit

a mixture of both FTD and SD syndromes. In the following sections, we will use the term Frontotemporal lobar degeneration (FTLD) to talk about the disease in general.

This is just a very brief recap of notions that have been covered before in previous support meetings. If you want to refresh your memory or are interested in finding out more general information about FTD and SD, then please feel free to download our previous newsletters which are available on our carers webpage at the following address:

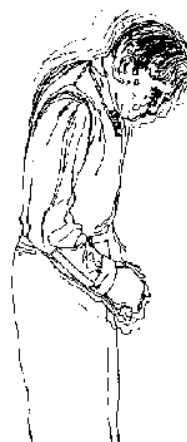
www.carers.cerebralfunctionunit.co.uk

Physical problems secondary to behavioural disorder

People with FTD generally undergo a marked change in personality and behaviour for which they show little insight. In terms of behaviour, they generally fall into one of 2 types: disinhibited or apathetic. People with a 'disinhibited' type of behaviour are generally overactive and restless, tending to pace around a lot. People with an 'apathetic' behavioural change show a decrease in physical activity, will tend to sit or lie down for large parts of the day and are often quite difficult to persuade to go out. In both subtypes, people remain physically healthy.

However, these behavioural changes may be misinterpreted as a physical problem. For example, a person's loss of mobility due to their apathy and lack of motivation may be interpreted as a physical problem, even though, in reality, the person is fully able to walk. Some people may develop repetitive behaviours, such as repetitively rubbing their hands or legs. Again, this is not because their hands / legs are hurting them physically but is all part of their behavioural change.

Repetitive behaviours in FTD



Incontinence

Incontinence can affect certain people with FTLD although it by no means affects everybody. Incontinence is not due to a physical or neurological problem but can arise as part of the behavioural change. For example, people who become very apathetic can exhibit a certain lack of self-

care, and neglect their personal appearance. Incontinence may arise because they are no longer embarrassed of their personal appearance in public. Although incontinence in this case is not a physical problem, it can be helped by taking the same medication that is used to treat people with physical bladder problems.

Later stages of the disease – parkinsonism

People in the late stages of FTLT generally experience some physical problems, such as stiffness and slowness. These are called ‘parkinsonism’ by clinicians, because they resemble in some way the symptoms seen in Parkinson’s disease. People with parkinsonism develop problems in the control of movement. Their movements become slower, their limbs stiffen (this can also affect the neck and trunk) and they sometimes develop a tremor (shaking) of the limbs (although this is less common in FTD). Relatives generally notice that the person is walking more slowly, with a stooped posture or that their face is less expressive than before. These symptoms emerge in the later stages of the disease because the disease process is spreading deeper into the frontal lobes to parts of the brain that are responsible for the control of movement. Unfortunately, giving people

the same medication used for Parkinson’s disease does not improve symptoms as both diseases have different mechanisms.

The following problems are *not* seen in FTLT:

- Epilepsy
- Muscle jerks
- Sudden changes in physical state: physical symptoms appear and develop gradually

FTDP-17

Most cases of FTLT are sporadic. Only a small number of cases are inherited and passed on through families. In these families (who carry the FTDP-17 gene), it is often common to see movement disorders associated with FTD, either in the same individual or in different members of the same family. Although small in number, these families have been extensively investigated by scientists who believe that unravelling the genetic basis of the disorder in these families may help us to understand the underlying basis of all forms of the disease, including sporadic ones.

FTD-MND

Motor-neurone disease (MND) is a rare but well-known disease of the nervous system. Some rare FTLT patients may

develop features of MND and present with prominent physical problems in addition to FTD or SD. Changes in physical capacity may be noticed by carers and can be confirmed through neurological examination and neurophysiological tests, where needles are inserted into the

muscles to check how well the nerves in the muscles are working. In some cases, people develop MND first and then later acquire symptoms of FTD or SD.

Questions

Q. My husband has frontotemporal dementia and seems to have a rather 'selective' memory. Is this part of the illness?

A. It is understandably frustrating to live with and care for someone who seems only to remember things that are important to them, and to forget things which are important to you. This type of 'selective memory' does occur as a result of the illness, and is not so much a problem in memory as it is a problem in behaviour and attention. As you will know, one of the symptoms of frontotemporal dementia in particular is that people can become more self-centred, and less interested in matters that do not specifically relate to them. They lose insight into others' wishes and feelings. Also, there can be problems in concentration and attention to information. All of these things can affect the way that information is 'encoded' and processed. You will know from personal experience that if you are not interested in something, you are less likely to take it in and remember it. This is exactly what is happening here, but on a much broader scale.

Q. Will routines improve motivation?

A. People with frontotemporal dementia and semantic dementia do typically respond well to routines. There is a tendency for reduced flexibility in thinking processes, and as part of this, patients seem to prefer rigid and structured schedules.

Q. Can head injury cause the dementia?

A. The simple answer is no. In almost every type of neurological illness, there are studies that suggest a positive link with head injury. However, there is overwhelming evidence to suggest that this is not the case.

Q. You mention a decline in brain cells and loss of function. Is this a continual process?

A. Unfortunately, yes, the conditions are degenerative and do worsen over time. In fact it is likely that a lot of cells are lost even before the symptoms of the disease become noticeable.

Q. Are there any known triggers?

A. No, there are no known environmental triggers which can be avoided. The only cause that is currently recognised is familial inheritance, but this is only relevant in a small number of cases.

Q. My husband recently suffered a severe and prolonged period of hiccups? Is this related to his diagnosis of frontotemporal dementia?

A. Nobody knows exactly what triggers hiccups. However, this is not a feature of the disease, and there is no link between frontotemporal dementia and hiccups.

Q. Do the conditions shorten a person's life span? Is dementia something you die with or die from?

A. Inevitably, a decline in brain functioning leads not only to mental, but also to physical decline. As the physical decline progresses towards the end of the disease course, patients become more immobile, and are increasingly prone to infection. It is these physical changes, rather than the mental decline per se which eventually cause the sufferer to die. The fact that these changes are inevitable means that a diagnosis of 'dementia' does indicate a shortening of lifespan. The progression of the disease varies widely between individuals, but the estimated prognosis is approximately 10 years.

Q. My wife has semantic dementia, and has great problems in understanding simple words. Despite this, she can type letters to copy without any difficulty. Why?

A. This type of observation is common. Semantic dementia results in a very specific problem in understanding, with relative preservation of other linguistic skills. Patients can often repeat, write, and read words, without understanding what they mean. Furthermore, spatial and motor abilities remain intact, so there is no reason why a person should be unable to continue to perform basic skills of typing, particularly if this was a skill that was well practised before the onset of the illness.

Q. My husband, who has semantic dementia, has started to swear on a regular basis. He has always been a mild mannered man, and never used to use bad language. Is there any reason for this change?

A. There is no 'scientific' explanation for this, but interestingly, it is a common phenomenon in other neurological disorders, for example in patients who have had a stroke. In semantic dementia, there are a number of possible explanations:

- A loss of understanding of the significance of the words
- Lowered inhibition for the use of the words
- Reduced vocabulary – using the first word that comes to mind

Q. My husband complains that he is tired all of the time, and would stay in bed all day if he could. Is this normal?

A. This is quite common in these types of dementias. It is likely that reports of 'tiredness' actually reflect apathy and lack of motivation.

Unfortunately, this is something that is rather difficult to overcome. A loss of interest in familiar hobbies is a common feature, and relatives often find that suggesting activities that were previously enjoyable is unsuccessful. Carers use different methods to try and motivate, depending on the wants and needs of the individual. For example:

- Visiting relatives – sometimes interaction with others (e.g. grandchildren) can help
- Being involved in different activities. When people come to the clinic to be tested, they often engage in neuropsychological testing without question. Relatives can be surprised by this, as it is a stark contrast to what their behaviour is like at home. If possible, try to become involved in some simple, novel activities outside of the home – there may be a difference in motivation in different environments