

# CFU Carers' Support Group



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

## **Newsletter**

**JULY 2009**

# Welcome

Welcome to the July edition of our CFU Carers Support Group Newsletter! Thanks to all of you who made the journey to our carers' meeting on 11<sup>th</sup> June. As part of our rolling programme of talks, Dr Julie Snowden, Senior Neuropsychologist at the Cerebral Function Unit clinic gave a very informative presentation about the behavioural symptoms related to frontotemporal dementia and semantic dementia. These changes often cause lots of problems and can be extremely embarrassing for carers, so we thought it was important to invite Dr Snowden back to provide advice to both existing and new members of the group. We've provided a short summary of the talk and also some of the questions and comments that group members contributed. We hope you find the information useful and if you have any additional comments or questions, try the website, where you can find previous editions of the newsletter, summaries of other talks, and other useful information and links: [www.cerebralfunctionunit.co.uk/carers.html](http://www.cerebralfunctionunit.co.uk/carers.html)

## Understanding behaviour in frontotemporal and semantic dementia

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### Introduction

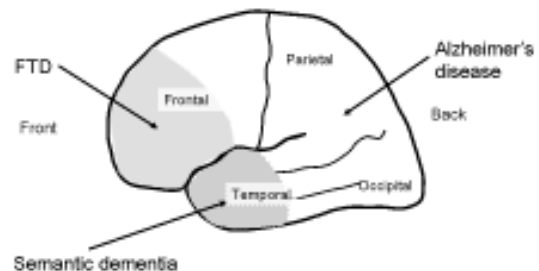
Behavioural, social, and emotional changes in fronto-temporal dementia (FTD) and semantic dementia (SD) are often the most problematic and upsetting aspect of the condition for carers and families. The changes in behaviour are often difficult to understand and come to terms with, and can have a major impact on daily life. As with mental symptoms, behavioural changes are inherent to the disease and are not voluntarily caused by the sufferer. This talk describes how degenerative brain disorders can cause behavioural symptoms, how behaviour is typically affected in FTD and SD, and how such behaviours can be managed more effectively.

### How can the brain affect behaviour?

To get a good understanding of these changes in frontotemporal dementia and semantic dementia, it is important to look at the brain and the way it functions (see diagram). The areas at the back of the brain (the 'parietal' and 'occipital' lobes) process the information that comes in through our senses, and are important for functions such as vision. In contrast, the 'frontal' and 'temporal' lobes act as a control centre, and help us to integrate and make sense of this information. This is very important in our understanding of the

meaning of things. It is these parts of the brain that are affected in FTD and SD. They cover the largest area of the brain in humans, and develop later in childhood. It is therefore unsurprising that you might have noticed that the person you care for acts in a 'childlike' fashion – the parts of the brain that have not yet developed in children are the same as those that are not working in people with these conditions.

For a more detailed overview of brain functions and dementia, please see Prof Neary's talk 'Frontotemporal dementia: An overview' (Newsletter February 2005).



## Frontotemporal dementia

When the frontal lobes don't work as they should, the system of control begins to break down. This can affect behaviour in a number of ways. As people with FTD are typically unaware of their problems, they are not able to reflect on changes in their behaviour, nor do they have insight into how they might have behaved before.

### *Planning and foresight*

People with FTD may lose the ability to plan future actions and anticipate the consequences of their actions. This may occur in the long term (i.e. failing to exercise to achieve/maintain fitness), or short term (i.e. when planning future shopping, failing to buy more milk before the existing pint runs out). Inability to anticipate the consequences of actions may lead to poor judgement and decision-making.

Being able to foresee the consequences of our actions is a huge motivator in daily life (e.g. we get out of bed early because we want to get to work on time). As people with FTD often lose the ability to 'look ahead', there is no real drive for them to engage in activities, resulting in apathetic behaviour. Alternatively, people with FTD may be overactive, carrying out seemingly pointless actions. The reason for this purposeless activity is that it is not 'goal-driven' – the person cannot see why something needs to be accomplished, so continues actions without an endpoint.

### *Organisation*

Frontal lobe dysfunction may also result in disorganised behaviour. FTD sufferers may attempt to carry out activities in a rather unusual, illogical manner. For example, when dressing, they might put on a jumper before a shirt, simply because they see it first. Even a simple task such as making a cup of tea might present problems, as there are several components involved, and the order in which they are carried out affects the outcome. Difficulties occur because the frontal lobes play an important role in our ability to sequence and organise our thoughts and actions.



### *Attention*

People with FTD may also have impaired attention. They are often easily distracted by irrelevant information (e.g. noise outside a hotel room) and can not control what they pay attention to.

### *Checking/Monitoring*

As mentioned earlier, there can be a loss of motivation and subsequent failure to anticipate the consequences of actions. People with FTD tend to have little insight into the effects of their behaviour and fail to 'check' their conduct. Thus, they tend to make mistakes and often appear oblivious to their errors.

In addition, they may display impulsive behaviour, with no concern for the social consequences of their actions. They may have immediate 'wants', like a child, without insight into the difficulty that this might present for the carer. They are typically unable to inhibit these immediate demands.

### *Abstraction*

People with FTD may demonstrate 'concrete' or literal thinking. For example, a figure of speech such as 'over the moon' might be interpreted literally as having something to do with outer space. The frontal lobes play an important part in our ability to understand abstract concepts, meaning that people with FTD may interpret things differently, often with reference to their own personal experience. Thus, they may appear self-centred, with little interest in others' viewpoints.

### *Flexibility*

A common symptom is a loss of flexibility in behaviour. The frontal lobes are very important in

allowing us to adapt our behaviour according to a novel situation. For example, if we were to plan a picnic, but then had to change these plans because it started to rain, our frontal lobes enable us to understand that a change of plan is reasonable, and help us to plan an alternative activity. People with FTD often lose this ability, and become quite rigid in their thinking. They may be unable to adjust their actions in unfamiliar situations, and thus behave inappropriately. For example, they might 'sulk' or throw a tantrum because they are stopped from doing something in their routine. Also, they may 'perseverate' (do/say the same thing over and over again). This is because their brain fails to tell them that the action/information is no longer relevant to the current situation.

#### *Emotions and social behaviour*

The frontal lobes also play a key role in our emotions. Indeed, one of the most difficult factors that carers encounter is their relatives' loss of feeling towards them and their family. People who may have once been very affectionate towards their loved ones may become 'cold' or 'blunt' in manner. There may be a loss of sympathy and empathy, and people may no longer respond appropriately to situations, such as the death of a family member or a happy occasion such as the birth of a new grandchild. Also, in contrast to this 'loss' of emotion, it is also common for people with FTD to show inappropriate demonstration of emotion. People may become 'disinhibited' and tactless, for example they may laugh loudly or swear inappropriately. They are typically unembarrassed by their behaviour, and are not aware of the repercussions of their actions.

Related to this is the fact that people with FTD often show a loss of self-care and reduced hygiene. This may occur for several reasons, including apathy and poor planning, but is also due to the fact that they lose awareness of social norms and taboos.

#### *Sensory information*

People with FTD are able to *feel* normally, but it is our experience that sometimes their *responses* to stimuli are abnormal. For example, there may be no response to painful stimuli such as scalding hot water. The reason for this behaviour is yet to be clarified, but it is possible that there may be a relationship with impaired attention. There is evidence to suggest that how we behave is governed by attention, for example, a runner focussed on winning a race may complete the circuit without feeling the pain of a sprained

ankle, simply because they are not attending to it. Impaired attention may therefore influence FTD sufferers' reactions to stimuli.

#### *Repetitive behaviours*

It is very common for people with FTD to show repetitive behaviours. These might be simple mannerisms such as tapping, humming the same tune, or repeating the same phrases or words. Carers also commonly report more complex repetitive routines and rituals, such as pacing, wandering, and hoarding.

### **Semantic Dementia**

There is some overlap between the behavioural changes of FTD and SD patients, and some of you caring for people with SD may have already recognised several of the symptoms described in the previous section. However, there are some subtle differences.

The temporal lobes play a vital role in integrating information from our senses to produce our understanding of the world. One of the first symptoms of SD that relatives tend to notice is that of impaired comprehension of words and inability to name things. The 'tools' of language (i.e. the sounds and grammar) are well preserved, so speech is fluent and effortless, however the meaning of individual words and concepts is reduced, resulting in non-sensical speech and odd behaviour.

Although problems in language are prominent, there are effects on other aspects of functioning, for example, recognition of the following may be impaired:

- Visual stimuli - faces and objects
- Auditory stimuli - non-verbal sounds
- Olfactory stimuli – smells
- Tastes
- Tactile stimuli

The actual *perception* of the information is normal – it is the person's ability to understand the meaning of the information that is impaired. For example, they might see a person they know perfectly well, and be able to pick out individual features, but they may be unable to recognise the meaning and consequently name the person.

Similarly, the properties of items may be lost – for example, when shown a picture of fruits they may

be unable to state which one is soft or hard, or sweet or sour.



#### *Preservation of ability*

The loss of meaning is not uniform. There can be variance in understanding of visual information versus verbal information, relating to right/left emphasis of problems in the brain. Also, there are some areas in which there is preservation of function, such as understanding of number – it is common for patients to enjoy number games and quizzes. Also, personal experience has a strong effect upon what is recognised – things that are frequently experienced and are highly relevant to their daily life are more likely to be understood than things that are not. For example, a person who owns a budgerigar may be more likely to recognise, use, and understand the word ‘budgerigar’ than the word ‘hamster’. Similarly, people with SD can often recognise and name their own items (e.g. kettle), despite being unable to recognise another example of the same item.

The loss of meaning that occurs in SD influences behaviour in a number of ways:

#### *‘Odd’ or inappropriate use of words and objects*

As people with SD often lose the meanings of words, they find it hard to discriminate between words with different meanings, and may therefore use a word in an inappropriate context. Carers often report that patients will use a noun indiscriminately (e.g. using the word ‘chips’ for all types of food). Likewise, if a person does not recognise an object correctly, they might use it in an incorrect manner (e.g. using a toothbrush to brush their hair or toothpaste to clean their shoes).

#### *Loss of sense of danger*

Additionally, their lack of understanding might lead to dangerous situations, such as scalding themselves as they do not recognise the properties of boiling water from a kettle.

#### *Obsessional behaviour and routines*

As the world around them is beginning to lose all sense of meaning, people with SD often stick to things that they know, and become suspicious of non-routine things.

#### *Narrowed behavioural repertoire /preoccupations*

Again, this is likely to be due to their preference of ‘known’ things. As people lose their knowledge of the world around them and find it more difficult to understand topics that they were previously interested in, they become less inclined to engage in activities.

#### *Rigid routine, clockwatching*

This may be due to preserved number concepts – people with SD may recognise time as meaningful, thus providing a tangible sense of meaning for their life.

#### *Self-centredness / inappropriate behaviour*

Like people with FTD, it is common for people to fail to recognise others’ needs and emotions. This may be due to their basic comprehension problems (i.e. they might ignore a friend simply because they don’t recognise them and cannot discriminate them from a stranger; or alternatively they might be overfamiliar with a stranger for the same reason).

#### *Hyper-reactivity*

Unlike people with FTD, who show reduced reaction to sensory stimuli, people with SD may show hyper-reactivity, with excessive response to even the slightest touch. As SD sufferers are able to attend to stimuli, but have impaired understanding of its meaning, they may find it difficult to react appropriately to things. Also, they may have difficulty adapting to and accepting novel stimuli – they are unable to ‘filter out’ things that have little relevance e.g. background noise.

## **Dealing with behavioural problems in FTD and SD**

### *Dealing with members of the public*

Coping with people with FTD and SD in public situations is often difficult and can sometimes be embarrassing. One way of dealing with awkward situations is to let other people around you know exactly what is causing the person's odd behaviour. Carers typically report that members of the public tend to feel more at ease when they know there is a definite 'cause' for the person's actions. For example, a shop assistant may be intimidated by a person with FTD who is talking loudly and swearing in a disinhibited fashion. Telling the shop assistant that the patient has a degenerative brain condition (by means of a 'quiet word' or handing over a 'carer's card' – see p.8) may reduce embarrassment for you, the carer, and also may reassure the stranger that the person is not dangerous and cannot 'help' their actions.

### *Personal hygiene and self-care*

As mentioned earlier, people with FTD and SD are often lacking in motivation or don't understand the social significance of personal hygiene. In FTD, it is often essential to prompt people to wash and dress. However sometimes that is not enough. Carers sometimes report that their relatives refuse to wash, and in those circumstances it is important to try to use the way in which the person behaves as a mechanism for improving the situation. For example, if a person is very 'fixed' in their routines and shows ritualised behaviour, it might be useful to try and incorporate washing and dressing into their daily routine. An example from one carer was that she developed a diary in which a list of activities was drawn up for each day. Activities (including a shower) were planned at the same time each day, and the person was asked to work through each activity and tick them off when they were completed. Thus an order was enforced for the person to stick to – they were not required to plan their activities and developed a simple, repetitive daily routine.

Similarly a patient with FTD who refused to change his underwear was encouraged to do so simply with the provision of a clean pair of exactly the same colour and type.

In SD, refusal or reluctance to wash may arise from a basic lack of understanding of the activity

involved. Some carers report that their relatives are fearful of the water and in particular, the shower. This may be because they do not understand the very concepts involved – the feeling of water falling down upon them may cause distress because they do not understand it. It may therefore be less frightening for the patient if they were to have a bath, or a handwash.

Another example that one carer gave was that their relative would not shave when admitted to hospital. Eventually it was realised that he did not recognise the hospital razor, and when his family brought his own razor the next day, the problem was resolved.

### *Eating behaviours*

It is common for people with FTD to demonstrate odd eating habits. There is often a preference for sweet foods, such as biscuits and chocolate. People may become gluttonous, eating everything that is put in front of them (sometimes including food on others' plates). This relates to a lack of ability to inhibit behaviour, and also a tendency to respond indiscriminately to environmental stimuli (this is called 'utilisation behaviour'). In addition, people with FTD may even seek out food, and also may 'cram' food into their mouths instead of chewing and swallowing one item at a time. This may relate to problems in sequencing, or may reflect a 'repetitive' behavioural routine.

For those patients who are gluttonous and seek out sweet foods, it may be helpful to set boundaries and rules as part of a routine (i.e. you can only have your dessert after your main meal and not between meals). One carer whose relative tended to steal food from others' plates found it helpful to put a line of tape around their place setting and instruct them that they were only allowed food within that area.

If such tactics do not work, it may be necessary to simply remove temptation (i.e. don't keep biscuits or sweets in the house, or lock such foods in a cupboard).

In contrast, some patients may refuse to eat, in which case it may help to introduce routines and keep mealtimes as regular or routine as possible. Additionally, it may help to always use the same plate and cutlery.

### *Reasoning*

Reasoning with the person about their behaviour will only have a limited effect as one of the main

difficulties for people with FTD and SD is thinking about the consequences and repercussions of their behaviour. For example, if a sufferer repeatedly starts drinking a cup of tea when it is still scalding hot, explaining to them why they should wait till the tea has cooled down will probably not stop them from doing the same thing again next time. Many carers have found that using rational arguments only serves to increase sufferers' irritability because they are unable to use reason to guide their actions. The best way to cope with challenging behaviours is to adapt your lifestyle to accommodate them. For example, one way of stopping someone from scalding themselves would be to remove the cup of tea and only hand it to the person when it is cool enough to drink.

### *Driving*

People with FTD and SD often have strict routines and like to do the same things at set times. Certain routines are so fixed that sufferers get very frustrated when these need to be changed. A common problem is resistance to stop driving: people with FTD and SD can become very irritable and may even continue to drive despite being told they shouldn't. This can be a particularly contentious subject as their practical driving skills are actually preserved, it is their behavioural changes (e.g. impulsivity, lack of planning, poor sequencing) and understanding (e.g. of road signs or rules) that is impaired.

The best way to tackle this problem is to do so gradually, and also early on in the course of the disease so that the change of routine is less of an issue. Suggesting that the person perhaps only drive locally at first or that taking the bus or train to a certain place might be more enjoyable will be more likely to result in positive action rather than suddenly explaining to the person that they are no longer allowed to drive. It is good to introduce alternative routines such as walking or using public transport, even if it means using an excuse (e.g. free bus passes, price of petrol etc). If all else fails, carers of particularly rigid, inflexible relatives may find it necessary to actually remove the problem altogether by selling the car.

### *Dealing with comprehension problems in SD*

It is a good idea to retain some consistency in naming. For example, even if there are variations (e.g. if you have a daughter 'Elizabeth' who goes by the various names of 'Liz', 'Lizzie', 'Beth' etc) it may be helpful to always use the same name. Similarly, it can be helpful to put words into context. For example, rather than saying 'Where are your glasses?', say 'Where are your glasses that you use for reading?'. This extra information can help aid understanding.

Understanding of objects can be aided by always keeping items in the same place. People with SD have preserved visuospatial abilities and often demonstrate a good 'spatial map', therefore keeping things in the same place helps them to understand what they are used for. For example 'the bottle in the shower is what you use to wash your hair'.

### *Taking care of yourself*

In the midst of all these changes, carers often forget to look after themselves. However, you're the one who's constantly under pressure and being asked to adapt, so it's important to make sure that you make time for yourself, both emotionally and physically. Some carers often feel that they should shoulder the burden by themselves and be entirely responsible for their relative. As a consequence, they often end up isolated from others and physically worn out. It's important to be open to others and to seek support from your family, friends and neighbours, telling them about the disease and the problems you have to deal with on a day-to-day basis.

# Carer's Questions

*My wife never seems to show any emotion. Do you think she is unhappy?*

It is most likely that she is perfectly happy in mood. Typically with these disorders, it is the family that suffer more than the patient themselves. The patient often doesn't realise that there is anything wrong, and is not aware of the changes that the carer is seeing.

In some cases (particularly in FTD) people can seem excessively clingy and anxious. This is sometimes part of the repetitive and stereotypical behaviour that occurs in the disorder, rather than a genuine depression or state of anxiety. In such cases, it may be helpful for the doctor to try medications to alleviate the situation.

*My husband has a strange relationship with food. He eats it very quickly and would eat non-stop if he could. Why is this happening and what can I do about it?*

People with FTD commonly overeat and show a preference for sweet foods. This may reflect a problem of inhibition (i.e. as soon as they see food in front of them, they cannot stop themselves from eating it), although some people actively seek food out, suggesting this is not always the case. It is possible that these people are having difficulty recognising and interpreting normal hunger and satiety cues.

*A lot of symptoms were covered in the talk. Is my relative likely to develop them all?*

No. The symptoms depend entirely on which area of the brain is affected. There are symptomatic differences among people with the same disease according to where the degeneration is taking place. Some people tend to present with problems in motivation, whereas others are restless and difficult to manage. People with the former 'apathetic' type tend to remain the same. Those with an 'overactive' restless presentation typically become more apathetic as the disease progresses, thus making them easier to manage.

*Is there an overlap between FTD and SD?*

Although the two diseases are related, most people's symptoms stay the same and remain well circumscribed. There are some commonalities between the two and occasionally, people may develop certain features characteristic of the other disease. For example, FTD sufferers may develop mild difficulties in understanding word meaning or SD patients may become a little apathetic in their behaviour as the disease progresses. However, these changes are relatively mild and there is never a complete crossover between diseases. That is, FTD does not change into SD and vice versa.

*What are the legal implications of inappropriate behaviour in the disorder?*

Most people with FTD and SD do not break the law. But it is easy to see why they might: if they cannot understand what they are doing wrong, or fail to plan ahead and consider the consequences of their actions, it would not be surprising if they did something wrong.

Since this is the case, the person is thought to lack mental capacity for what they are doing, and therefore cannot be held entirely responsible for it. Of course, every situation is different, but undoubtedly a diagnosis of FTD or SD should be taken into account in such a scenario. It would be important to contact the doctor that you see here at the CFU as they would be able to support you by writing any necessary letters to explain the diagnosis and symptoms.