



CFU Carers' Support Group

M

A

Y

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

2

0

0

5

Newsletter

Welcome

Welcome to the new edition of our bulletin, following the fourth meeting of the carers' support group in early April.

Yet again, the meeting was a big success, with a large number of people attending. We would like to thank everyone for coming – it's great to see both familiar faces

and new recruits at each meeting. For those of you who were unable to attend, the session was devoted to the behavioural changes that can take place in FTD and SD as well as possible ways of managing them.

Speaker

Dr Julie Snowden, the Senior Neuropsychologist at the Cerebral Function Unit, gave a fascinating talk about the relationship between brain and behaviour. She described the behavioural changes in both fronto-temporal dementia and semantic dementia in detail, explaining the problems that many of you will have encountered in daily life.

As with previous talks, we have summarised the main points and have included some of the questions that were asked by carers at the end of the session. We hope that the information is useful to both you and your families in understanding the problems you may experience.

Inside this issue:

Welcome	1
How does the brain affect our behaviour?	2
FTD—The frontal lobes	3
Emotions and social behaviour	4
SD—The temporal lobes	5
Behavioural consequences	6
Management of behaviour	7
Coping with behaviours in SD	8
Carers' Questions	9
Dates for your diaries	10

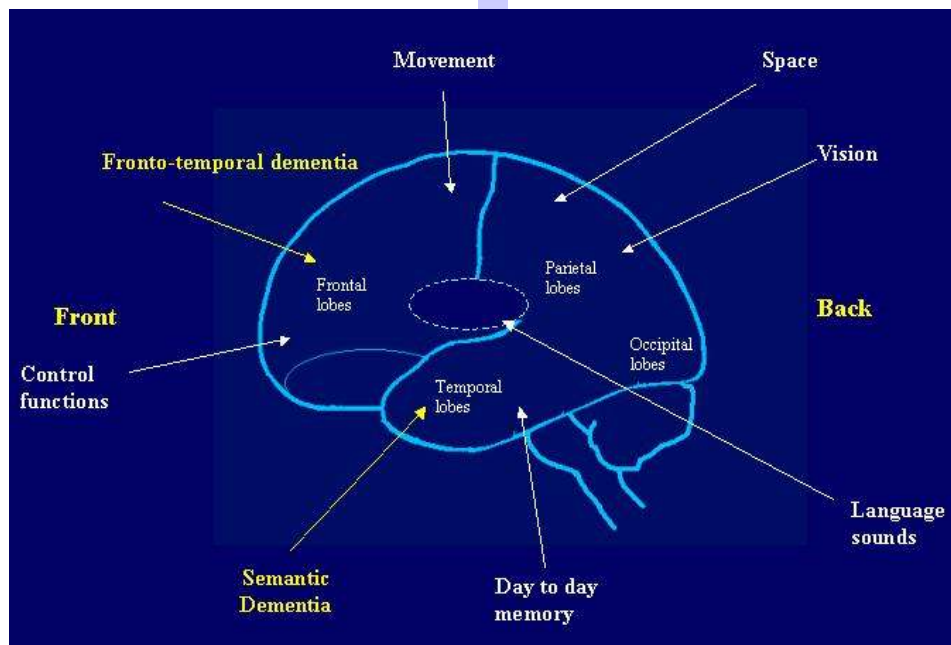
How does the brain affect our behaviour?

In order to understand the link between behaviour and the brain, it's useful to know what the main areas of the brain are responsible for. You may remember from our previous newsletter that different areas of the brain play different roles in our daily functioning. As you can see from the diagram below, the areas at the back of the brain (the 'parietal'

and 'occipital' lobes) are very important in terms of processing what comes in through our senses.

In contrast, the areas at the front (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, such as words, objects and faces.

Fronto-temporal dementia and semantic dementia form part of the same disease, known as '**fronto-temporal lobar degeneration**'. The underlying disease process is the same. It is the **location** of the disease that determines the symptoms and the corresponding name that is given to the dementia. As you can see in the diagram, in fronto-temporal



dementia, the disease primarily affects the frontal lobes, whereas in semantic dementia the disease selectively affects the temporal lobes. Since

the back part of the brain remains unaffected, there are no problems in visual or sensory function. However, the affected frontal areas are responsible for controlling behaviour, meaning that there are often profound changes in personality and social behaviour.

FTD - The frontal lobes

The frontal lobes develop later in maturity. They help to control incoming information from the environment, and to guide our actions and behaviour.

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.

Planning and foresight

People with FTD may lose the ability to plan future actions and anticipate the consequences of their actions. You may have experienced some of the following:

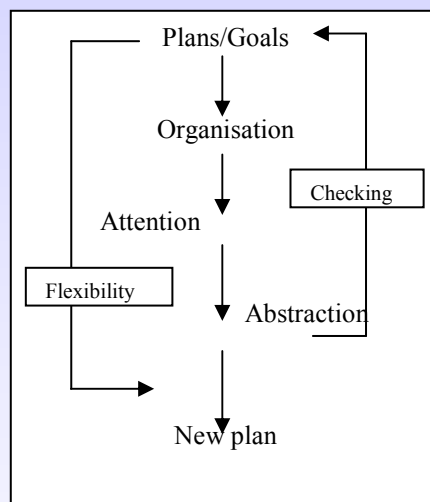
- Inertia, apathy, lack of motivation - people with damage to the frontal lobes can become less proactive.
- Purposeless activity, impulsivity - sometimes people act quickly without thinking things through.
- Neglect of self care and personal responsibilities - lack of motivation to carry out simple tasks.
- Behaviour governed by immediate wants - lack of foresight may result in inappropriate judgments about things such as money or eating behaviour.

Attention

People with FTD may also have impaired attention. It may be difficult to engage them in tasks and they may fail to complete activities because they are easily distracted by something else.

Organisation

Frontal lobe dysfunction may also result in disorganised behaviour. You may have noticed that your relative fails to complete tasks, or that they attempt to carry out activities in a rather unusual manner. 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.



Checking

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

Abstraction

People with FTD may demonstrate 'concrete' or literal thinking. For example, a figure of speech such as 'too many cooks spoil the broth' might be interpreted literally as having something to do with cooking. 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.

Emotions and social behaviour

The frontal lobes are not only important in cognition. They also play a key role in our emotions. Often, 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' in manner. There may be a loss of sympathy and empathy, and people may no

longer respond appropriately to situations. In contrast to this picture of a '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 tell jokes at a funeral. They are typically unembarrassed by their behaviour, and lack insight into the effect it has on others.

Repetitive behaviours

It is very common for people with FTD to show repetitive behaviours and mannerisms such as humming the same tune, or repeating the same phrases or words. People often develop repetitive routines and rituals, and it is common for carers to report behaviours such as pacing, wandering, and hoarding.

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 re-

spond 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' behaviour as discussed above.

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.

SD - The temporal lobes

As you may remember from Professor Neary's talk in February, the temporal lobes play a vital role in our understanding of the world.

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. However, there are some subtle differences.

Language

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.

Perception

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 the person in this photo perfectly well, and be able to pick out individual features, but they may be un-



able to recognise the meaning and consequently name the person. Similarly, the properties of items may be lost - for example, when shown a picture of fruit 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 under-

standing 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.

Behavioural consequences

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

Using the wrong words

People with SD often use inappropriate terms, such as calling a cow a “dog”. They may also sometimes use words in an over-inclusive fashion (e.g. using the word “milk” to refer to any type of drink). This is because they have lost the precise meaning of what words and objects refer to.

Narrowed behavioural repertoire

People with SD can become focused on a narrowed range of activities. This is likely to be due to their preference of ‘known’ things.

Obsessional behaviour

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.

Rigid routine and 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.

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 their 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.

Inappropriate object use

Lack of understanding may lead to poor recognition of objects and poor discrimination between objects.

Self-centredness

Like people with FTD, it is common for people to fail to recognise others’ needs and emotions.

Loss of sense of danger

People with SD may lose sense of the properties of things, for example, hot oil.

	FTD	SD
Interests	General loss	Narrowed
Activity	Lacks persistence	Persistence
Eating	Indiscriminate	Food fads
Sensory response	Reduced	Hyper-reactivity
Repetitive behaviour	Simple	Complex, compulsive

Su

Management of behaviour

The following section provides some advice on how to manage challenging behaviours. This is really something that we've gleaned by talking to carers over the years. This is really an area where you can help us, as you're the ones being asked to cope with caring for someone on a day-to-day basis. So if you have any ideas, then please let us know

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 conse-

quences 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.

so that we can share them with other carers. Firstly, it's important to recognise that changes in behaviour are an integral part of FTD and SD and that sufferers are not being deliberately difficult. Carers shouldn't feel that they are to blame for their relative's emotional or behavioural changes, it is simply part of the disease process.

Rigid behavioural routines

Certain routines are so engrained that sufferers get very frustrated when these need to be changed. A common problem is stopping driv-

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. 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.

ing: people with FTD and SD can become very irritable and may sometimes continue to drive despite being told they shouldn't. The best way to change routines if they do need to be altered is to do so gradually. 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.

Coping with behaviours in SD

The following section focuses on changes in behaviour that are more specific to people with SD and are a direct result of their inability to understand the meaning of things.

Communication

People with SD have difficulty in understanding the meaning of individual words. It can often help understanding if words are put into context: speaking in complete sentences is better than communicating in short phrases or by single words. For example, sufferers might have difficulty understanding the meaning of the word "chicken", but their understanding will improve if it is linked with a specific ex-

perience they can remember (e.g. "chicken that you had for your tea on Monday"). Similarly, a sufferer may not recognise the name "Lizzie" but might recognise "Lizzie who lives next door".

It may also help to use the same vocabulary that the sufferer uses on a day-to-day basis as they may not understand words that are no longer familiar to them.

Using names and words in a consistent manner may also boost communication. For example, if a relative is always referred to as "Aunt Claire", sufferers may not understand that other names (e.g. "Claire Townsend", "Our Claire") also refer to the same person. Similarly, if a person always talks about their pet as a "budgie", they may not understand that "budgerigar" also means the same thing.

Object recognition

Loss of understanding is not just restricted to words, people with SD can also lose their understanding of the meaning of objects. This can result in them using the wrong object, for example, washing their hair with bath cleaner instead of shampoo. A good way to get round this is to always keep objects in the same place. People with SD are generally better at remembering *where* things are as opposed to *what* things are. If they remember that the last time they washed their hair

they used the bottle on the shelf next to the bath, then they will be more likely to go back to that place the next time round. Similarly, it's important to keep objects with different functions in separate places. Putting the bath cleaner in a separate place would reduce the risk of it being confused with the shampoo bottle. Putting distinctive labels, such as a red sticker, on objects that are regularly used may also help to get round this problem.

If a person goes into respite care or leaves their home, it is important to remember that they may not recognise novel objects, even if they have similar ones at home. For example, one patient in our unit would stop shaving every time he went into respite care. The staff eventually realised that this was because he didn't recognise the razor he had been given because it wasn't the one he was used to. Sure enough, once he was handed his own razor, he was able to shave as normal.

Carers' Questions

A number of questions came up in the meeting about how to deal with changes in behaviour. Thank you for all your suggestions, we've included them below. This is an area that we don't really know much about as we're not

the ones caring for someone with dementia. You are the real experts here, so if anyone has any experience about these issues, please write in with your suggestions and we'll include them in the next newsletter.

How can you deal with changes in eating pattern?

Overeating can be a problem for people with FTD and SD and they may develop what seems to be an insatiable appetite. This can add to the demands on a carer's time and energy. You may be able to limit overeating if you:

- Try giving five to six small meals per day.
- Have low calorie snacks, such as apples and carrots, available.
- Consider whether other activities - such as walks - may help.
- Lock some foods in cupboards, if necessary.

Some people also develop excessive cravings for sweet foods and become very irritable if they are deprived of them. One possibility is to try milk shakes or low calorie ice creams.

How do you deal with odd behaviours in public?

One of the characteristic features of FTD and SD is that people lose their ability to judge how to behave appropriately in a social setting. People may become disinhibited and behave in a rude or inappropriate manner towards friends or strangers; other people may be overly affectionate or familiar with people they hardly know. This may cause the carer to feel embarrassed and unsure of what to say. Many carers have said that they usually try to have a quiet word with the people involved, quickly explaining the nature of their partner's impairment. Another suggestion, which many of you thought would be useful, was for the carer to keep on them a few cards (about the size of a business card), explaining that their partner has dementia, which can be handed unobtrusively to any people involved.

I have been trying to get a professional to come to our home and spend a few hours with my partner so that I can have some respite, but my partner refuses to stay with them on their own. Is there any way round this?

A sudden change in routine may be very disruptive for a person with FTD or SD. Introducing a new person gradually and staying with your relative till they feel comfortable on their own with the new person may be a less stressful way of introducing change into the person's life style.

Carers' Questions (continued)

How can you manage incontinence?

Physical incontinence is associated with FTD in later stages of the disease, however the changes that occur in a person's brain can interfere with a their ability to:

When caring for someone with dementia, incontinence may seem like the last straw. However there are measures that can be taken either make the problem less stressful. It is important to seek professional help at an early stage and not to try and struggle on your own. It may also be helpful to observe the person's toileting patterns and suggest they use the toilet at regular times that follow that pattern.

- Recognise the need to go to the toilet
- Be able to wait until it is appropriate to go to the toilet
- Leave enough time to go to the toilet
- Recognise the toilet
- Use the toilet properly.