

CFU Carers' Support Group



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

Newsletter

OCTOBER 2006

Welcome

Welcome to the latest edition of the carers' support group newsletter.

In July, we were visited by Jackie Kindell, a specialist speech and language therapist, who came to discuss the problems in communication that carers and their loved ones may face. Jackie has long been

associated with the Cerebral Function Unit, and retains close links with the department. She has a wealth of experience in the area of dementia and gave invaluable information and advice on the problems of communication and how to deal with them.

Contents

Welcome	2
Language and Communication	3
Communication in frontotemporal dementia	4
Communication in semantic dementia	5
How to deal with communication problems	6

Language & Communication

Speaker: Jackie Kindell, Specialist Speech & Language Therapist, Stockport, Pennine Care NHS Trust

As you will know, communicating with a person with frontotemporal dementia (FTD) or semantic dementia (SD) can be difficult. Conversation is a two-way process, requiring both generation of speech and understanding of what the other person is saying.

Meaningful communication also requires some kind of 'social understanding' and rapport between the people involved.

What are the main problems?

Carers commonly report problems such as:

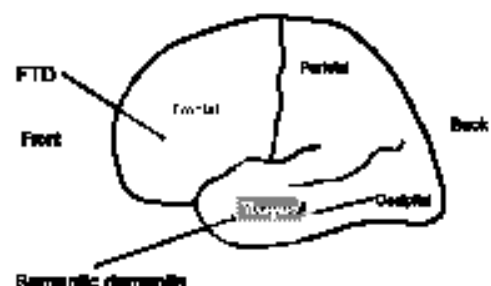
- ⇒ Using the wrong word
- ⇒ Using 'filler' words, such as "thingy" or "whatsit"
- ⇒ Getting information in the wrong order/piecing facts together incorrectly
- ⇒ Reduced speech, no initiation of conversation
- ⇒ Minimal response to questions, no elaboration
- ⇒ Inappropriate comments, causing embarrassment in social situations
- ⇒ Routinely used jokes or stories produced regardless of situation
- ⇒ Repeated comments or themes
- ⇒ Set monologues produced, without real interaction
- ⇒ Inappropriate emotional responses to others' comments
- ⇒ Poor understanding of single words and/or concepts

What are the underlying reasons for these symptoms?

The frontal and temporal lobes play an important role in our ability to communicate. In essence, the frontal lobes are responsible for our **control** and **regulation** of communication, and also the **social** and **emotional** aspects of our interaction with others. The temporal lobes are more concerned with our **knowledge** and **understanding** of

words and **concepts**. This means that the 2 syndromes can lead to different problems in communication.

Brain areas affected in frontotemporal dementia and semantic dementia



The frontal lobes and frontotemporal dementia

Inappropriate comments

In communication, it is important to consider not just what you say, but also what you say to whom and in what situation. We regulate and modify what we say according to the social context. For example, we act differently in formal (e.g. interview, church, wedding, funeral) and less formal (night out with friends, at home) situations. The frontal lobes are very important in regulating our behaviour in this way. Whereas we might think something internally, our frontal lobes are able to 'stop' us from saying it. People with frontotemporal dementia in particular are unable to do this. They fail to inhibit their innermost thoughts and do not modify their comments according to the situation.

Social norms and turn-taking

Similarly, they might fail to observe social norms and rules of conversation. For example, they might interrupt or talk over other people's comments, and talk too much in a conversation. Conversely, they might not initiate conversation or respond to others at all. This failure to initiate or produce speech is again related to the frontal lobes, which are essential for motivation and generation.

Sequencing

It can sometimes be difficult to follow the train of thought of a person with a frontal lobe disorder. The frontal lobes play a large part in organising our ideas and thoughts, and if damaged, can disrupt a person's ability to communicate in an ordered and meaningful way. There may also be problems in attention, meaning that a person might become easily distracted, and have difficulty maintaining a single topic in conversation.

Social difficulties

Degeneration of the frontal lobes also affects a person's skills of social understanding. You might have noticed that your friend/relative can no longer pick up on hints and subtleties in conversation, meaning that you have to make direct statements and give specific instructions. Interpretation of humour, sarcasm, and abstract sayings can be poor (for example 'a piece of cake' might be interpreted to mean a slice of dessert rather than something easy). This failure to 'abstract' non-literal language, or to see the funny side of jokes or humorous comments is common in frontotemporal dementia.

Emotion

Failure to act with and recognise appropriate emotion is also common in frontotemporal dementia. Some carers comment on the change in their relative/friend's ability to express emotion, and to understand and appreciate the feelings of others in a conversation. For example, people are often described as 'cold' towards their family members and close friends, with little interest in their feelings or wellbeing. Also, they might not react appropriately when given good/bad news. This is due to the fact that the frontal lobes play an important role in our appreciation of the emotions of

others and our ability to see things from others' point of view.

Rigidity/Repetitiveness

Carers also commonly report the use of repetitive and stereotyped speech. This can be manifest in not only the use of repeated words and phrases, but also the production of mannerisms and use of intonation. As you may remember from previous articles in the newsletter, the frontal lobes are vital for mental flexibility. Repetitive, stereotyped output can reflect inability to switch mental set, or to spontaneously generate a new idea.

Temporal lobes & semantic dementia

Comprehension

The temporal lobes are responsible for our ability to understand the meaning of the world around us. This can affect numerous domains, for example:

- ⇒ Words (e.g. "Bush? What does 'bush' mean?")
- ⇒ Objects (e.g. "What is a thimble?")
- ⇒ Smells (e.g. cannot recognise the difference between the smell of bacon and the smell of burning)

- ⇒ Tastes (e.g. mistaking sugar for soap powder or vice versa)
- ⇒ Sounds (e.g. not answering door/telephone because of failure to understand what the sound means)
- ⇒ Visual stimuli (e.g. poor understanding/recognition of pictures or faces)
- ⇒ Pain (not recognising pain, leading to injury, or in contrast, oversensitivity to touch)

⇒ Gesture (failure to respond to physical gesture e.g. waving)

This failure to understand inevitably makes communication difficult, particularly when multiple domains are affected. There is also potential for danger, as patients may eat inedible substances, or fail to respond to warnings such as the smell of gas or the sound of a fire alarm.

Routines

People with semantic dementia also tend to prefer fixed routines, and are often resistant to change. This can impact

upon their communication skills in several ways. Firstly, if routines are narrow and fixed, there are fewer topics to talk about, so attempting to engage them in a meaningful conversation can be difficult. Secondly, if their routines are fixed in time (for example, if they go out for a walk at 3:15pm every day), they are likely to be less communicative at this time, simply because they cannot alter the notion that this is the time of day that they go out for a walk.

How to deal with communication problems in these disorders

Dealing with inappropriate comments

- It can be difficult to share a diagnosis of dementia with other people, particularly when the dementia is rare and difficult to understand. However, family members and friends often do understand once a condition is explained to them and this helps them to know how to respond and be tolerant of difficult or unusual behaviour and communication. Changes in emotional response are common and can be put into context once the dementia has been explained.

- For day-to-day situations with strangers, showing a carer's card can be a quick and easy way of explaining and excusing odd or inappropriate behaviours. These cards are available from the CFU support group (see end of newsletter).
- Try to think about things from their point of view – their understanding of the world will be narrower than your own, so they may interpret situations wrongly.
- Deal with disinhibited and inappropriate behaviour in a matter of

fact manner and encourage others to do the same. Explain clearly to others that this arises from their dementia.

- It is important to recognise your own needs – if taking your relative/friend out has become too difficult because of their behaviour, it is okay to avoid taking them out.

Dealing with inflexibility

- If a person is very fixed in their routines and time conscious, it can be helpful to explain this to others, for example, visitors or members of a care team. If someone is due to arrive at 1pm, arriving at 1:30pm will only lead to agitation. Try to make sure that people are aware of the importance of the routines.

- Others will need very detailed information about a person's routine in order to care for them successfully, as a change can be very upsetting. In a different place, they may not be able to do the same things they can do at home at first, but the more familiar items that they have around them and the more they follow their usual routine, the easier life will become for them.

- If a person has a fixed (but incorrect) idea about something, for example, if they are convinced that their problems arose as a result of a brain scan, it is

likely to be fruitless to try and change their mind. Although their insight is clearly compromised, this self-induced notion gives them a reason for being the way that they are.

Dealing with poor motivation

- Sometimes it is easier to find something to say if you do something together, for example, go for a walk. Activities stimulate conversation – either at the time or afterwards. Try to converse on topics that interest them, for example new or old hobbies, or attendance at a club or day centre.

- The person may have preserved skills and this can be used when planning activities (e.g. good understanding of numbers – number games; good visual skills and hand-eye co-ordination – copying/painting).

- Sometimes a person with dementia 'perks up' when with visitors/other people. However, sometimes family or friends offer to sit with or visit the person, but are at a bit of a loss what to do or say. You may need to give them some direction, for example, looking through old photos or books with pictures, doing a jigsaw, or being prepared to talk about certain topics.

- If someone else is going to look after the person you care for, try to provide as

much information about them as possible, including details of their social history, previous jobs, family etc. If you can include photos, this is even better. This helps others think of topics to talk about and helps them build a relationship with you relative/friend. It also helps them to see the person behind the dementia.

Dealing with poor comprehension

- Reduce competing distractions/background noise if you need to talk.
- If the person fails to understand, if possible try to show them what you mean by using other forms of communication, for example, gesture.
- To help understanding, try to give a little more contextual information if necessary. The extra words give meaning to help understanding. For example:
 - o "Mary – your older sister"
 - o "Little Rachel"
 - o "Blackpool – where we have the caravan"
 - o "The dentist – who does your teeth"
 - o "Curry – that we get from the takeaway"

Being consistent in how you refer to people or places in this way is important. If possible, use the person's own

words/vocabulary, and try and make it as personally relevant to them as possible.

- For some people, tying a word or concept to a time frame or location can help, as often people have good memory and spatial skills. For example:
 - o "Tatton Park – where we went on Monday"
 - o "Suzie – she comes on a Thursday"
 - o "Strawberries – in the garden under the frame you made"

Dealing with poor naming

- Try not to correct word finding errors if you know what the person means. For example, if you know that when the person says "can we go to Blackpool to get some chips?", they actually mean "can we go to the shop to buy some oven chips?", there is little benefit in attempting to correct the errors. If you understand the meaning from your knowledge of the person and context, respond as though they have said the words correctly.
- You may need to explain common word errors (such as in the example above) to help others interpret such situations.
- If someone is struggling to find a word:
 - o Give them time to think.

- If they are struggling and it is obvious, complete a sentence naturally in a conversational style (i.e. "oh, you mean.....").
 - If it is not obvious, try to narrow the options by asking simple questions (e.g. "Is this about Paul?").
 - If possible, ask them to try and show you what they mean (i.e. gesture/demonstration).
 - Have a 'give in gracefully' phrase in case you both get frustrated, for example "don't think about it now – it might come back to you later", and then distract onto something else.
- In the early stages, some strategies and practice may help, for example word lists, small photo books etc.

Taking care of yourself

It is not possible (nor is it advisable) to constantly provide stimulation for people with dementia. Overstimulation is just as problematic as no stimulation, and feeling a need to provide activity to 'keep their mind working' can be exhausting alongside the daily tasks of caring.

Consider your own needs as a carer, and always remember that they are just as important.

- Communication is a two way process, so when problems occur, the carer's opportunities for communication are also affected. This is particularly relevant when the carer is a spouse. It is important to try and get time out of the caring situation to take care of yourself and talk to others.