

Communicating is one of the most important of human brain functions and one that progressively becomes a greater disability with FTD. It is an activity shared by a person with FTD and their spouse, carer, relatives and friends. But there are few sources of advice or tips to carers about how to communicate as the disease progresses.

FTD FrontoTemporal Dementia

Caregivers will be more successful if they recognize all dementias as a progressive form of brain failure and not simply a "memory problem." The brains of individuals with dementia are undergoing progressive deterioration which eventually affects nearly all areas of functioning –from the ability to recall events, exercise judgment, and control impulses, to the loss of language and field of vision.

With FTD, communication difficulties often occur concurrently with failures of planning and other executive functions. It is sometimes difficult to tell whether a particular problem is a "doing it" issue or a "talking about it" issue.

This document summarises tips for communicating more effectively. It is focused on WHAT to do, with minimal explanation about WHY you should do that (except where knowing some of the WHY might help with the WHAT)

TIPS

for communicating with a person with dementia.

Talk to the loved one (LO)

Not to the carer or a family member. Do not prejudge the LO's level of comprehension (because the LO may be insulted to be left out).

If communication of meaning with the LO fails, and you need the help of others, check afterwards with the LO that you have correctly understood the issue. "Albert, we think you are here to make your will, am I right?"

Speak Clearly to the LO

Make eye contact and face the LO directly. (All visual cues, even your attention, help to pass messages.)

Other conversations, background TV, radio or music all create distracting noise for the LO. The LO can become overstimulated or confused. Suddenly, getting some quiet for a few sentences becomes critical to communications. When you cannot control the environment... seek an escape. Enter the stairwell or other quiet space for a moment, saying "I can listen to you quietly here". When

listening, pay attention to the tone of voice and the body language of the LO, as these often convey more meaning than the faulty words.

Allow the LO time

Try to be patient. Thinking by LO takes a little longer. Urgency in your voice translates straight to anxiety in LO mind.

Break Down the Story

Smaller chunks are more readily understood. Reduce the complexity.

Say What. Do not bother to Say Why!

The short form we use is "Say WHAT, not WHY." Again, the object is to avoid unnecessary complications and avoid logical deductions or sequences. (When logic circuits are faulty, explanations of the logic are likely to cause confusion.) The objective of your communications changes to giving comfort to the LO. You retreat from your old objectives of discussion or peer debate.

While you can still have discussions,

talk during the best time of day for your LO.....when she is most rested, has just eaten, etc. Conversely, avoid talking to her when it is not the best time.

Keep Signs Clear in the house or Residence

"Undies". "Back Door". When declining cognition causes LO to be less well organised, signs can help for a while. Especially, direction signs can reduce confusion during temporary delirium such as after an operation.

Begin a Response with "YES!"

The "New Yes" is no longer an affirmation. It is a validation. It says 'I heard your question/suggestion and I understand'. It is used to keep open the communication when the use of a "No" will instantly close it. If he wants to visit a relative TODAY, answer "Yes, good idea. We have agreed with them we are going there for Thanksgiving."

Think "Yes, we have no bananas." This is very powerful medicine.

Many LOs adopt "No" as their habitual response. When they cannot process the options and consequences, "No" can appeal to them as a safe response. If that happens to you, then you will see profound results from your use of the New Yes.

Now!

LO urgency and impatience are common symptoms. Where the carer can accommodate a whim with spontaneity, that can be an ideal response. But when you cannot drop everything momentarily, then Yes We Have No Bananas is often your best option.

Semantic Dementia

Some patients remain fluent with normal phonology and syntax but increasing difficulty with naming and word comprehension (understanding of meaning), known as semantic dementia. They sound normal in their intonation, their conversational tone, but there are words wrong or missing. It is evident they struggle to find or choose the desired word, especially pronouns, nouns and names. Patients with these symptoms are said to have semantic dementia because these are the first evident symptoms of their failing cognition. If the semantic memory they seek to access contains the word "cat" and information about what a cat is, but they fail to find that, they might say "nice doggie". Neuropsych testing will also reveal deficits in picture naming with semantic errors being made e.g. "dog" for a picture of a hippopotamus.

An individual with dementia may, on average, miss one of every four words spoken to him. It's not that the individual can't hear what is being said: Auditory perception is one of the few brain functions to remain intact in the individual with dementia; however, the ability to comprehend language (a left temporal lobe function) is gradually lost. The part of the brain that controls the rhythm of speech (a right side function) remains intact.

Patients typically complain of a "loss of memory for words" involving, at first, less common words, especially nouns and particularly the names of people. They may complain of "hearing problems" when the real issues are difficulty with comprehension, or difficulty separating a conversation from the background noise. They may seek hearing aids, which provide little or no relief because they address the wrong disability.

The biggest issue in listening to such patients is deriving the intended meaning from what they say. A listener might be required to decode "that item". Or "the other man who helped us, you know!" The task is usually totally beyond anybody without 24*7 familiarity with the thinking of the LO. Success requires a lot of time, patience, trial and error and some intuition.

The biggest issue in talking to these LOs is having the message correctly received. You might get "But you said X!" when you had said "NOT X" and a critical word was missed.

When these patients become aroused, they may be quite unable to speak. Or might get out only "Come... !" Any kind of stress, emergency or emotion can bring on this symptom. The solution, when you have time, is to lower their arousal. The most effective available technique is to notice the breath out. It requires not just exhaling, but noticing the act of exhaling. Consider whistling a descending tone.

Very often, there is no time for such remedies. You might have to guess quickly. "Is there a snake?" "Yes!"

For these patients, context is important. So, for them, keep sentences simple, but not too short.

Progressive NonFluent Aphasia

Some LOs have a breakdown in speech fluency due to articulation difficulty (poor word production), phonological and/or syntactic errors but preservation of word comprehension, referred to as progressive nonfluent aphasia.

Progressive non-fluent aphasia (PNFA) is the least common form of Frontotemporal Dementia and affects the ability to speak fluently. Patients present with difficulty communicating due to slow and laboured production of words often with distortion of speech and a tendency to produce the wrong word.

Some patients have slurring of speech whereas others are able to articulate words but produce frequent near misses (e.g. they say "silter" for "sister"). Understanding of word meaning is preserved, but patients with PNFA have problems comprehending sentences and following conversations, especially if there are a number of speakers. Using the telephone and communicating with groups of people is particularly difficult.

In a rare, related aphasia, patients will substitute "arm" for "leg", produce novel words such as "sickser" for doctor and use complete nonsense words. This is Wernicke's Aphasia.

The biggest issue when listening to these patients is decoding meaning when the near miss is not so near. Or the listener has less familiarity.

The biggest issue with talking to them is knowing the message was received and understood. Very often, the carer assumes the LO's silence implies understanding when actually the LO is confused but seeks to avoid stating that. Avoiding background conversations is especially critical. Cafes often become impossible for any communication.

For these patients, brevity helps most. Subject and verb. Really keep sentences short.

The Aphasias, including Semantic Dementia

Collectively, these are branded "the language variants" of FTD. If a carer sees expression declining, for example a LO's range of nouns collapses so almost all things are described as:

"doggies" for all living things

"items" for virtually everything except

"crap" for those few things that must be dealt with...

Then the carer typically thinks the LO's comprehension is way ahead of the LO's expression. In fact, comprehension is close to keeping track with expression, but its losses are less noticeable. Then, telling him something becomes fraught with risk. You may more wisely choose to show him something instead.

Different patients may respond in different ways to their progressive failing in expression. Some may quickly tend towards mutism while others say many words very difficult to understand. With much effort and empathy, a listening spouse might successfully deduce a subject (though rarely will the spouse be able to discern the LO's view, except on a favourite subject or obsession).

Behavioral Variant

If the right temporal lobe is involved then patients (or carers) often notice problems recognising previously familiar people. It is not uncommon for patients to talk to people as if they were strangers only to discover later that were old friends.

Day-to-day memory is relatively spared but may appear poor due to difficulty with expression.

For these patients, the communication function is relatively unimpaired, at least until late stages. But communication may become unsatisfying, and even avoided. That is especially common if the patient's behaviour includes aggression or violence.

Then, smiles, body language, the Four Ds and “Yes, we have no bananas”: are especially important to defuse situations.

The Rage Stage

Some FTD patients encounter a “Rage Stage”. This can take numerous forms and the symptoms are typically a “stage” during the middle period of the disease, before or soon after diagnosis. But for some FTD patients, the symptoms remain for the duration of their journey.

The classic rage stage is marked by anger, aggression and violence. But in some patients, the predominant symptom exhibited is negativity, where everything is described in terms such as “disgusting” or “worthless”. Another outcome is accusations, typically against the spouse or principal carer because they are responsible for everything, therefore are to blame for whatever goes wrong. They are the only target always within range.

The rage stage can occur concurrently with lost inhibitions, for which the symptoms can be socially and/or sexually inappropriate remarks and judgements or a porn obsession. The combination leads to colourful events in which damage is difficult to contain.

The main objective for the carer is to maintain their unique relationship or to end it in separation or divorce. The outcome to be avoided is one in which the relationship is prolonged but in a permanently damaged state unsatisfactory to both. The challenge is huge. There are tools that are useful in all cases and they include “Yes, We Have No Bananas” and the Ds: Delay, Deflect, Distract, (lovingly) Deceive. Other tools are unique to the individual symptoms. They might range from more help with communications to less help, depending what works.

“I’m Sorry You Feel That Way”

Duck skirmishes. Decline to be the focus of his combativeness. If the LO takes exception to something you do or say, do not engage. The worst thing you can do is to snap and scream because the issue escalates. Either removed yourself physically or verbally from the equation leaving the LO nothing to fight about and no one to fight with. It rendered him helpless to continue his allegations. Often, silence is preferable to antagonism.

When you cannot get away, caught in a moving vehicle, you may be reduced to just repeating periodically. "Yes. I'm sorry you feel that way."

Body Language

Become comfortable with silence. Let her know that you are not anxious with "empty" time. It takes the pressure off of her. If she doesn't talk, don't feel the need to fill that space with your own banter. In these times, hold her hands, look into her eyes, enjoy quiet music, etc.

Use lots and lots of loving touch, eye gaze, and music. As language goes, touch, music, and eye gaze are the windows to the soul.

Pick Your Battles There are many things a carer may not like or may not want to have happen, but fighting them all is exhausting to impossible. Which are the fights you have to win to survive?

The loved one leaving a cooking element on, inviting a house fire?

Essential. Take steps. Porn viewing? Unessential, though unappetizing.

Not locking doors behind him and leaving the house vulnerable?

Essential, but YOU'll have to either run behind him and lock things up

or find a way to keep the house secure if you are not there to do it. For

'essential' things, try to find a way to use the "D's" to modify his behavior.

Beware that Deflection, if perceived by the LO to be taking him away from a perceived course, might be taken to be criticism. So Deflection

is safer if it is a wholesale change of subject. Glass beads to Amaze

The Natives is the ideal style for survival.

Logic is No Longer Your Friend

Your loved one's logic is destroyed along with those frontal lobe neurons which do planning and organisation and sequences. These failures take carers by surprise. Suddenly, skills become impossible.

Typing disappears. Doing up a seat belt becomes too complex.

Drawing a clockface or a childlike sketch of a house is too difficult.

Then you cannot succeed by logic to persuade the LO to do anything.

You might succeed by saying What you are going to do and declining to say Why. Using a carrot/bribe approach may succeed, or one of the D's.

Arguing or debating will not end well. These logical processes are now

to be avoided. Though it may seem from appearances or a lucid story

that he is capable of a reasoned discussion, he is not. It may be very

beneficial (producing a peaceful episode) to listen while not having an

actual discussion. Allow the LO to run with a thought/story/complaint

however repetitive (obsessions are common as are favourite

observations) Merely respond, if appropriate with a Yes We Have No

Bananas style when you need to avoid stating support for his proposal.

Use positive and encouraging conversational ploys but initiate nothing

of substance. When the carer must take charge of the couple's entire

lives, just do things without discussing them beforehand as you would

have done earlier in the relationship. The carer is now the only adult in

the marriage and needed to act like it. It takes a major shift in thinking

not to involve our loved one, but it is a necessary step.

The Carer must Change Attitudes or Actions. The LO can no longer Adapt. When we finally realize that, owing to the disease process our loved one is incapable of being different we then find a way to adapt our thinking. The LO cannot so the carer must. Everything is up to us now. Factor him out as a helpmeet, a partner, a sounding board. He will find your insistence on involving him in things annoying. They are YOUR things. Why should he care about YOUR issues, your appointments, your feelings, your anything? Your loved one is approaching or is already entrenched in the following mindset of want/don't want and like/don't like.

Lower Your Standards. Expect Little and you will be Less Disappointed

As the LO loses cognition the carer loses much of their relationship. Conversation becomes unfulfilling, dreams and future plans recede. Don't expect your loved one to care. Don't expect him to participate when he "isn't feeling it." Don't expect him to know anything. Don't expect empathy, humor, involvement, conversation or positivity. The carer cannot do everything that the couple could previously do. Forgive yourself some lower standards of entertainment, housekeeping, simpler meals, birthday presents.