

Managing The Rage Stage

The worst of a frontotemporal dementia (FTD) journey is nothing anybody wants to see. It's rage. Spouses or principal carers of a person with FTD rages see every episode of rage behaviour. Other family members see few. Medical practitioners often see no rages, or one. Carers often cannot even convince members of family that it is sometimes really that bad.

The major websites for dementia resources have two major omissions.

- Remarkably, the words "terminal" and "fatal" do not appear. The major associations avoid being the sources of this important bad news. If you need to demonstrate to your insurance company or your hospice provider that FTD is fatal, you may need your medical practitioner.
- There is little advice to help family members manage the most difficult symptoms of FTD. The major associations try to not be the cause of frightening new carers. They do not provide tips for communicating with dementia patients even though failing communications may be the major cause of fading family relationships. And they omit advice for managing rages which are common dementia symptoms.

Brain failure with FTD is not like Alzheimer's Disease (which is about ten times more common and better known). The first sign of Alzheimer's is memory loss. FTD is first noticed because of strange behaviours and unusual, bad decisions or word loss.

It is very hard to get resources that help manage FTD. There are summaries on the web. There are articles for doctors and medical researchers. Deep in medical publications, there are statistics for aggression and violence from dementia patients. But until now there is little "news from the front lines" or practical tips for the family members of a person with FTD.

Violence in people with dementia is more common than is widely published. The statistics for violence in Early Onset Alzheimer's Disease report that 17% exhibit severe aggression in the first year after diagnosis and 20% exhibit violence during their journey. Carer observations of hundreds of patients resident in nursing homes suggest that the numbers are probably similar for FTD.

Family members faced with an "FTD rage stage" need to know more. They need facts, strategies, advice and tips. This disease threatens the health, welfare and sanity of all family members involved in the care of their person suffering rages. Rages often cause family members to be no longer able to care for the person with dementia.

Family members need to know that they aren't the only ones. Carers need to know there are survivors who are ahead of them on the FTD road, there are lessons learned that can be passed on. There is a way through this. There are resources providing real support to carers.

What Causes the Rage Stage?

Dementia is progressive brain failure resulting in death. In FTD, the frontal and temporal lobes of the brain gather excesses of proteins. These are proteins present in a healthy person, but which accumulate in greater quantity in the brains of people with FTD. (to read more, see FTD Biology below.) The proteins clog the brain and cells die progressively.

The behaviours of the rage stage are caused by fading or failed inhibitions. The social filters no longer work to keep words and actions acceptable. Planning, organising, decisions and sequences are done in similar parts of the brain but each fail at different times and rates.

The fading inhibitions which trigger the rage stage are likely to cause related behaviours in some patients. Those behaviours may include socially inappropriate remarks, unwelcome intimate touching, porn obsessions, sexual abuse, excessive irrational spending, physical abuse, compulsive swearing and emotional abuse. The caregiver is often deeply shocked and embarrassed at the reactions of others who do not understand and take offence.

When Does The Rage Stage Occur?

Anger and aggression are most likely to develop in the middle stages of a person's FTD journey. This is also typically around the time that most persons with FTD reach diagnosis. Before diagnosing dementia, doctors require poor cognition and declining abilities and behaviours. It takes time to observe these changes as trends.

CASE EXAMPLE 1

Support is required when help and guidance is needed, when cause is in doubt, not when a stranger issues a diagnosis. "I wish I had access to this 10 years ago when, like many here, dementia hadn't been mentioned and I wondered why our marriage was heading for the rocks. I wish when I was wondering 'what now?' I knew which resources to seek and trust and which ones were an insulting waste of time and money. I could do it all so much better now."

Mostly, the rage stage happens in midstage. But every journey is individual and there are families who suffer rages right through their journey and families who see none. Some patients who are violent or who do sexually inappropriate acts may later have less extreme behaviours. They may moderate to an occasional push of another Nursing Home resident or physical and verbal resistance to personal care. A prediction for FTD rages is: "your mileage may vary". Just trust your judgement of your own experience, because each patient's past is their own best predictor. Each family builds their own history of developing FTD behaviours.

CASE EXAMPLE 2

My husband is now obsessed with a favourite sex act. He has filled the memory of his phone with porn pictures of it. He talks about it loudly in stores. He wants it every day, sometimes more often. I comply because if I don't, his mood is negatively impacted, and it leads to episodes of rage. I have not received the support that other victims of the rage stage might receive, in part because I haven't been open about what's happening.

What Forms Can the Rage Stage Take?

Some people living with FTD remain pleasant and easy-going throughout their journey of progressive brain failure. Others experience anxiety and may develop intense behaviours of anger, aggression and violence and paranoia.

A carer first experiences rages when a person with dementia lashes out at them for seemingly no reason or becomes obsessive. The rage may be verbal or physical or both. The carer is first severely shocked. It is normal to feel surprised, discouraged, hurt, irritated or angry. Learning what causes anger in dementia, and how best to respond, can help you cope.

CASE EXAMPLE 3

'I asked a question about the shopping list while my husband was tying his shoes. He had an instant rage. This was the first time I had to be quick to dodge a punch. His anger was so intense that my survival instincts kicked in. It was completely out of character from the man I married. It was shocking.'

When persons with dementia become angry, they may raise their voice, throw things, become combative. Behaviours include hitting, kicking, pushing, yelling and screaming at you or even trying to physically attack you. They may swear vehemently, even if they've never uttered a foul word before.

CASE EXAMPLE 4

'If I give him my hand, he will try to crush it. He uses all his strength.'

Sometimes, there are warning signs such as a deep frown, a loud voice, an angry scowl, or a swinging of the arm at empty space. But other times, it can be difficult to see the anger coming. It may seem to rise out of the blue. This "no-warning", "out of blue sky" anger can be the hardest to manage because of its unpredictability. It catches carers with their guard down. It is extraordinarily wearing for the carer to be constantly walking on eggshells.

CASE EXAMPLE 5

'My energy levels (physical, emotional, psychological, spiritual) while he was still living at home were, well, let's just say I was running on empty for years, and aware of it.

FTD taught me not to try to predict the future at all. I had to live in the moment. One day at a time.

I now realise that much of his violence and hostility toward me was caused by fear, fear that I could not provide him what he needed. He was right, I couldn't! It takes a village, a three-shift team of professionals with a secure facility to take care of someone who is physically able yet has lost their marbles.

He hit me on five or six occasions, a couple of times resulting in broken ribs.

It took a year or so after his placement for me to start emerging from FTD-land. A lot of my energy now goes towards trying to repair the damage that FTD has caused to our family.'

When warning signs of a rage stage show in advance, they often are not recognised by the carers. Carers may hope the behaviours will pass, or simply lack the experience to respond. In prior months leading up to the first rage event, a person with dementia may exhibit "playface" or a certain tone of voice when maltreating pets or children. He may raise his arm, shake his fist, kick out, come close to another person physically and get 'in their face'. His face may twist and get progressively uglier as the impulse-controlling neurons die and inhibitions fade. These are observable hints of harm he wants to do. But inexperienced carers tend to discount those signs of approaching physical confrontation.

CASE EXAMPLE 6

'There were times I would fear for the grandchildren, as he loved thumping them and pushing them as he did with the dogs. I tell my children he mustn't swing the 5 year old by his ankles upside down. That he must not be allowed to rap the dogs or the grandkids on their skulls or under their chins, that he mustn't be allowed to roughhouse with them. That he shouldn't be alone with them because of some past inappropriate behaviors.

I told him in a forceful tone, "Don't kick the dog !!!!!" I got back, "I WILL too !" I told him not to do that again and this time he came toward me with one hand in a fist. I backed away. Foul language and an order to go over there ! (the couch) brought more aggression. I stood my ground and he struck out and got my forearm 3 times.

I have a plan to flee. I have notified the 800 number for Home Health and his home health nurse. I have left an urgent message for his neurologist. I have told all family members. I have packed a bag and my purse. The phone and laptop are easily accessible. The house has 4 exits...'

The rage stage may or may not be accompanied by an obsession with pornography. Deteriorating language can signal imminent rages. A person entering rage stage will become critical, accusatory, blaming. Everything is described as "worthless",

“disgusting”, “futile”, “horrible”. Disinhibited language includes rampant swearing even by people who never did when they were whole.

Dementia affects emotions. Carers of persons with dementia will observe progressively that patients’ emotions are being affected by the disease. Dementia affects the brain, and the brain is responsible for storing and retrieving memories, words and names, making decisions and storing our values. The brain also controls our emotions and behaviours. So, depending on where the damage occurs in the brain, emotions may be affected as well. Typically, only carers with 24*7 experience will initially recognise the events, the patterns and the trends of these early changes in emotions and behaviours. The trends initially are not apparent in a twenty minute medical consultation in a clinic, delaying diagnosis. Other family members at this stage with less than 24*7 contact find the FTD person very normal and believable as s/he still “looks FINE to me!”

Rage reactions can occur in response to a carer’s actions. A person in rage stage is very easily triggered into becoming agitated. Their obsessions and delusions can be tripped into irritation and anger. These catastrophic rages can arise from a misunderstanding of a carer’s expression or action, from jealousy or “out of the blue”, from an FTD obsession or accusations. This "over-reaction" in emotions can cause anger and aggression.

CASE EXAMPLE 7

Marjorie Grayson, 84, fatally stabbed her husband Alan Grayson, 85, three times at their home in Orgreave Lane, Sheffield on 13 September 2018, before calling 999 and stating: “I’ve just stabbed my husband, I think I’ve killed him.”... The judge said it was only after an investigation began that the family realised there had been “noticeable behavioural changes in the recent past”....He said that neuropsychiatric experts decided that Grayson had behavioural variant frontotemporal dementia (FTD).

<https://www.yorkshirepost.co.uk/new...-following-tragic-sheffield-killing-1-9847884>

<https://www.yorkshirepost.co.uk/new...of-highly-unusual-murder-of-husband-1-9356360>

It is very important that the carer communicates to others (doctors, family members etc.) their justified fears. One effective way to do this is to record (audio or video) the sufferers rages as proof of what they are trying to deal with. This may have to be done without the sufferer knowing, which seems initially like an invasion of privacy, but can turn out to be life-saving.



In the Rage Stage, calm can become distress in seconds and without warning.

Dementia can cause paranoia, delusions, and hallucinations. Distortions of reality can be another result of the disease process in dementia. These symptoms can present as confabulations (where the person can't remember something, and invents a false story without intent to lie, actually believing it), anxiety or depression. Not everyone with dementia develops these symptoms, but they can make dementia much more difficult to handle.

The rage stage sometimes presents as jealousy and/or accusations. It is “the disease talking”. But the language is very personal and hurtful to the carer and it takes great understanding of the disease for the carer to restrain from reacting. It is very difficult for the carer to understand that you are only the target because you are the one always in range, the one who does everything.

CASE EXAMPLE 8

‘She was paranoid about “cheating”. They were both in the kitchen bickering about it and she turned around and sprayed him in the face/eyes with a bleach cleaner and while he was stunned and incapacitated she beat him severely with a kitchen pot. It was the moment he realized she wasn't her old self. The violence led to her diagnosis (behavioural variant of frontotemporal dementia). She could not recognise anything was wrong (anosognosia). She divorced him.’

Accusations are a recognised FTD symptom, closely related to the 'rage stage' and obsessions. It is the disease talking, through fading inhibitions. Knowing that is very little help, except that you can blame the disease and forgive the person.

Your defences, imperfect as they are, are the Four Ds, Yes We Have No Bananas and being agreeable. They are described here below.

Can the Rage Stage be Treated with Medication?

Your doctor may suggest SSRI or SNRI medications which may be helpful in moderating symptoms. (These are medicines that are usually used for depression.) Atypical antipsychotics are often used for more extreme cases. (You may have read that antipsychotics are risky. This is true, but atypical ones are less risky than others.) The goal is to lessen the more severe behavior and mood problems; the goal is to make things more steady, not to "sedate" or "zombify" the patient. The choice of medication to suit a particular person is difficult and can involve trial and error. If a suitable medication can be found, it can make a huge difference in quality of life for the patient, as well as allowing others to better care for them. While medication can help some persons with dementia, it usually only takes the edge off anxiety. It may not always avoid a meltdown on the patient's part when a rage pops its cork and a volcano erupts. Medication of dementia at home does not always stop the worst behaviours from happening. Meds do not help much with rages except in residence and under constant professional supervision to adjust them.

A person with dementia often has anosognosia. They honestly and emphatically insist they are "fine" and are prevented from recognising their own symptoms and changes. They often refuse medication and decline to attend doctor's appointments. Alternate methods may be tried to get the person to take the medication, which can feel deceitful to the carer. The doctor may help by changing the medication form (e.g. from pills to liquid medication or transdermal patches). Sometimes, all attempts at medication are refused.

Tips to help prevent agitation and manage rages

1. Create a calm environment. Remove sources of stress.
2. Avoid environmental triggers. Noise, glare and background distraction (such as having the television on) can act as triggers.
3. Monitor personal comfort (temperature, fluid intake, clothing)
4. Simplify tasks and routines.
5. Provide an opportunity for exercise.
6. Avoid saying "No", especially as the first word of a response.
7. Decline to argue. Logic is no longer your friend.
8. Be ready to down tools and act on a whim. Take a drive together. Have a picnic.

There are carer strategies that are relevant in communications. Short, broken sentences for simplicity. Subject. Then statement. Or Question.

Some people with FTD tend to miss logical steps in a discussion. It happens because their logic circuitry in the frontal lobe is suffering intermittent faults. We notice their tendency to hear the first point of a reply and, if it is not pleasing, they stop following. The strategy we have slowly developed in response is one that seeks to keep them listening.

We try to make the first words a recognition of their request or viewpoint.

Especially, avoid contradicting them. E.g. resist asking them to "stop it". Try to avoid starting any response with "No" because it will stop them from understanding what follows. Instead, start every response with a "Yes". It keeps them listening.

The "New Yes" means something different from agreement. It is a validation, saying 'I understand your question or request'. It is a strategy we have come to label: "Yes, we have no bananas".

Implementing this is not easy and takes a little practice. The best tip is to try to start each response with a "yes", especially if you suspect any tension or anxiety in the subject.

Avoid arguments. Avoid confrontations. Calmly look directly at a person with dementia. Even your attention is a signal of respect and openness. If you get an early opportunity to nod in understanding of the patient's message, do so.

Logical discussion, debate and argument are no longer effective communication tools when logic has become a disability in a person with dementia. Logic is no longer your friend. You will not "win" a logical discussion and you are likely to trigger a rage from frustration in the person with dementia.

Change your attitudes or actions. The person with dementia can no longer change theirs. 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. He CAN'T so WE 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.

WANT/DON'T WANT....LIKE/DON'T LIKE. Understand that this is the only thing important to him from now on. Using this mindset to your advantage is all you can depend on. Make everything about him, cater to his every want or need. Lose your personality when around him. Agree with everything that isn't flat out dangerous. The deeper in the disease process, the easier for you it will be to subjugate your desires to his. At first he "looks FINE to me !" That stage is very difficult for us. We tend to think he can control what he does, that he is doing these things, whatever they are, on purpose. This 'phase' lasts a very long time. The loved one will "look fine!" to everyone else but us for quite a while. After a certain point the disease dictates, not the loved one's former personality, morals, ethics, or reason.

NO MATTER WHAT, ARGUING OR DISCUSSING WILL NOT END WELL.

Don't ever do it. Though it may seem like he is capable of a reasoned discussion, he

is not. Keep this ever present in your mind. Listening to him while not having an actual discussion is very beneficial. In response, use frequent positive and encouraging conversational ploys but bring up nothing of substance.

LOWER YOUR STANDARDS. EXPECT NOTHING FROM HIM AND YOU WILL NOT BE DISAPPOINTED. 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.

'YES. I'M SORRY YOU FEEL THAT WAY.' Decline to be the focus of his combativeness. The person suffering a rage stage may perceive that you can do no right, even when you are trying. Remove yourself physically or verbally from the equation then the person in rage stage has nothing to fight about and no one to fight with. It renders him helpless to continue his allegations. If unable to leave, such as when travelling, keep repeating periodically: "I'm sorry you feel that way." If you have to live in silence, that may be preferable to living with negative, angry rage reactions.

ANY SUGGESTION THAT TRIES TO DEFLECT HIM FROM HIS PROPOSED PATH WILL BE PERCEIVED TO BE CRITICISM. It is not reasonable. It is not logical. But it IS all these things to him. If you continue to suggest anything that does not wholeheartedly agree with his choices you will be the enemy. You need to avoid that at all costs. You have a unique relationship to protect, so you should choose to deflect blame elsewhere. Some authority is responsible for the cancelled driving licence or the impounded guns. Some medical practitioner is responsible for diagnosis and medication. You take his side in discussions between you on these matters. You praise his achievements. There may come a time when you can go so overboard into praise that a normal person would gag. A person in FTD rage stage will often purely 'eat it up'. Unless advised in advance, most carers miss the opportunity to calm FTD behaviours with praise and appreciation. By the time praise works, overpraise may be even better.

LEARN TO CONTROL THE DISPLAY OF YOUR NEGATIVE EMOTIONS. Allow only positive or neutral expressions on your face, no matter what the provocations. Know that things can escalate quickly when the loved one perceives you disapprove of an action or you are upset in some way.

URGENCY. A person in a rage stage will often exhibit urgency and impatience. Where you can, be ready to act on their whim. If they are 'smokin' their tires', try suggesting a leisurely event. "How about we go to a movie?" Or "Would you like to have a picnic and walk the dog?" Where you cannot, use Yes We Have No Bananas : "I want to go to my sister's NOW." Yes, good idea. We have arranged with her that we are going for dinner on Saturday. She is a great cook. Shall we take a bottle of wine?

CARER SAFETY. Making the environment safe is a must. Weapons need to be removed, knives locked up, power tools disabled or locked away. Once a carer

expects or experiences a rage event, an escape plan must be created. A 'go bag' should be ready with some emergency cash and placed where it can certainly be retrieved, perhaps with a friend or neighbour. The carer's phone should be backed up and consideration given to a 'burner' phone.

Western societies all have legislation for the emergency treatment of a person with dangerous behaviours. This may involve involuntary placement for assessment, while ensuring the safety of the patient and others. The code for this in UK is "sectioned" (after the section of the Mental Health Acts in each part of the UK), in Canada it is "formed" (after the prescribed form), in California it is "5150" etc. Periods and processes vary by jurisdiction, but with similar objectives. Emergency Departments, police, social workers and Justices of the Peace can direct you and you will know when you need to learn more.

FTD Biology

The body's production of proteins is a normal function of genes. Most researchers expect that the accumulation of proteins in the brains of people with FTD is caused by over-production. But there is a possibility that it is caused by a failure of the brain's lymph system to flush excess proteins to waste.

The presence of excess proteins initially causes intermittent failure to transmit an electrical signal from a neuron to a synapse. Like a spark plug misfiring. Because the symptom is intermittent in the early stages of the disease, the signal can sometimes succeed after more time and effort permit a successful attempt. As a result, a FTD symptom (such as difficulties in wordfinding, inability to perform sequences or rage behaviours) may sometimes be present and sometimes absent in the same person during the early and mid stages of the disease.

There is a further complicating factor. The brain seeks an alternative path for the message. Like going from NY to Boston via Canada. This is termed plasticity and it too takes more time and lowered arousal. And initially that will sometimes get the signal delivered and result in finding the word, fact, name or other memory sought. For the carer, this variable performance causes self-doubt that the declining trend is really happening. Other family members with less contact have greater doubt. With progression and buildup of excess protein, the neuron chokes, signals never succeed, the neuron fails, dies, and atrophies. The brain's plasticity continues to seek and often find alternative routes. Via Georgia. Via Tijuana. Or not quite to Boston but somewhere close. "No, not John. The other man who helped us, you know!"

Performance deteriorates and is measured in declining results in neuropsych tests. Relatives observe more frequent failure of executive function. Some tasks, planning, sequences, memory retrieval, inhibitions, dexterity, balance etc may deteriorate. But it is only when masses of neurons fail, die, decay and dissolve that the results are visible as atrophy on a MRI scan. The patient's path to reach a stage of visible atrophy may take years or even decades from the exhibition of the first symptoms. The increased availability of scans has resulted in increased reliance on their use to confirm a diagnosis of FTD. It is a very conservative approach which often delays diagnosis. It may reduce diagnostic errors, but at the cost of long delay and doubt for patients and relatives who are left seeking alternative diagnoses and treatments.

There are many devastating consequences for the patient's driving, employment, insurance, welfare eligibility, and the family's planning and wellbeing.

About 40% of FTD cases occur within people who have one or more genetic defects (mutations) which are known to be associated with FTD. There are a handful of such defects identified and it is widely expected that more will be found. However the presence of the genetic defect alone is not sufficient to trigger FTD (or the prevalence of the disease would be much higher than it is). Some people with one of the known genetic defects may never contract the disease. There may be a trigger mechanism, such as a concussion or delirium. There may be a genetic antidote mechanism which has not been identified (though researchers confirm that people with a protective PLCG2 mutation, the rs72824905-G allele, not only enjoy heightened protection from Alzheimer's disease, but also from frontotemporal dementia (FTD) and dementia with Lewy bodies).

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