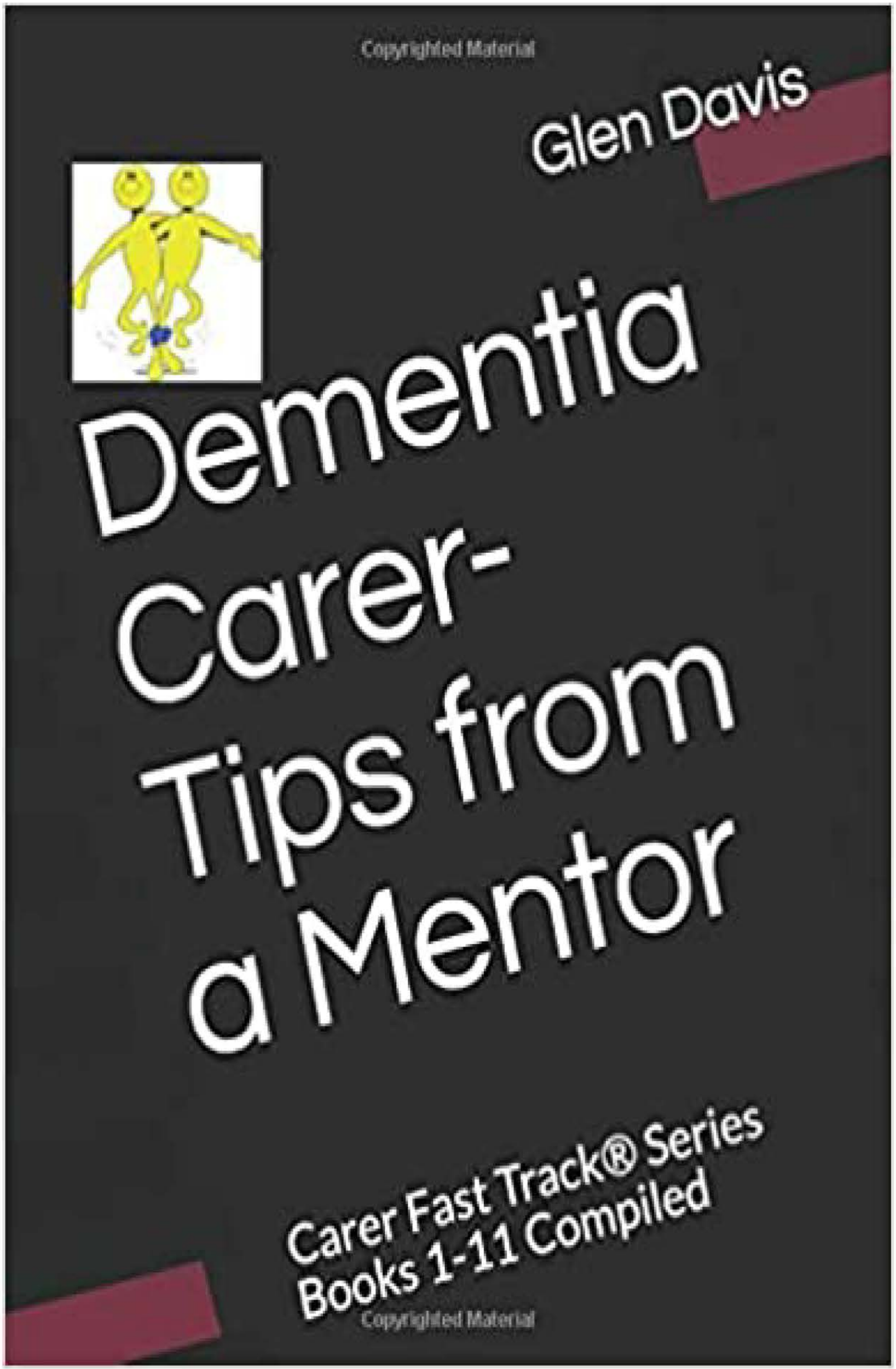

Glen Davis

Dementia Carer- Tips from a Mentor

Carer Fast Track® Series
Books 1-11 Compiled

Dementia Carer- Tips from a Mentor **Carer Fast Track® Series Books 1-11 Compiled**

Preface ISBN: 978-0-6488198-9-9

This series of eleven booklets presents new perspectives on being a carer for a person with dementia. These are practical tips and insights not published before. Each 10-minute booklet is designed to fit within the limited time resources of busy carers.

> **REVIEWS:**
> **"...some really cool booklets...Short, Sweet, Concrete"**
> **Rita A. Jablonski, PhD, CRNP, FAAN, FGSA**
> **Professor, School of Nursing**
> **University of Alabama.**
>
> **"These practical tips have been road-tested by many other carers... I commend them to you."**
> **Professor June Andrews RMN, RGN, FRCN, OBE**
>
> **"your booklets are brilliant. Really informative, and you write so logically making everything easy to read." Christine, UK.**

Professor Rita Jablonski, University of Alabama has endorsed my booklets and has adopted "Yes We Have No Bananas" into her courseware: https://makedementiayourbitch.com/2...-dealing-with-dementia-rage-in-ftd/#more-2700

Professor June Andrews, University of Stirling, UK, has endorsed "Managing the Rage Stage" and "Tips For Communicating": https://juneandrews.net/blog/post.php?s=2019-09-09-frontotemporal-dementia " These practical tips have been road-tested by many other carers." https://juneandrews.net/blog/pos t.php?s=2019-09-09-frontotemporal-dementia

Karen Tyrell CDP, CPCA, Canada has licensed "Tips For Newbie Dementia Carers" for all students enrolled in her dementia courses.

Most helpful January 31, 2020 USA
"This is immensely useful to a person who takes care of a loved one with FTD. It gives solid suggestions for how to deal with rages. Most

of these modalities I have never seen explained in other publications or on official websites. I wish I had known these things when we were just starting out after diagnosis. When my husband's behavior did deteriorate into anger, rages and finally blows, I was happy to have this resource to help me."

Excellent help! January 30, 2020 USA
"This book gives an excellent look at an aspect of FTD rarely discussed openly. This could truly be a life saver for the caregiver!"

Dementia Carer- Tips from a Mentor
The information you need to have is here April 23, 2020, USA
"Like most people with a spouse with dementia I have an entire bookshelf full of books on it, The 24 Hour Day, What if it's Not Alzheimer's, Stop and Smell the Garbage, Where's Alice, etc etc. This little set I happened on is by far the most educational, informative and helpful of them all.
Instead of just telling you what you can expect or someone else's story it gives you black and white steps on how to deal with it. What to do, or not do, what to say, or not say.
It is my #1 recommendation for anyone looking for help."

This book compiles all of the most innovative practical measures for managing the most challenging behaviours encountered from a person with dementia. Subjects encompass violence, aggression and accusations exhibited by persons in the Rage Stage as well as new techniques for communicating, including "Yes, We Have No Bananas". Caregiver wellbeing and survival is addressed. Diagnosis, anticipated symptoms, genetic testing are covered from a carer perspective.
This series of eleven booklets presents new perspectives on being a carer for a person with dementia. These are practical tips and insights not published before.

This compilation, primarily for use in nursing courses, is a warehouse of discrete parts, each presenting novel perspectives on aspects of care. This compilation does not present the continuous story of a journey with dementia as there are many such books.

That brings me finally to a confession and a disclaimer I must make. This compilation looks deceptively like a book. But it is not, it is a collection of booklets. To be brief, they are blunt. This compilation sits within a cover only because that is my only available option in print.

by Glen Davis (Author)

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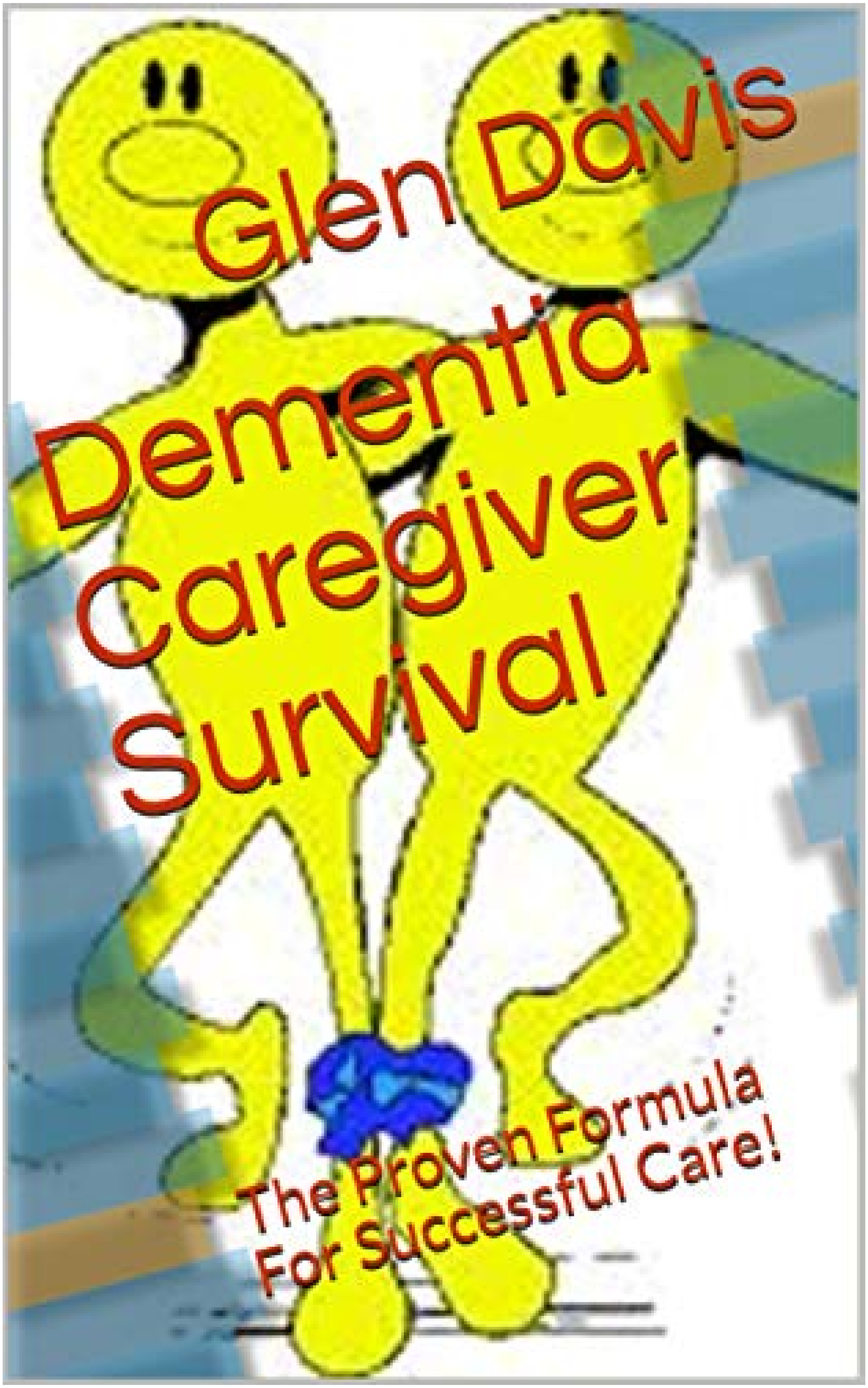

Glen Davis
Dementia
Caregiver
Survival
The Proven Formula
For Successful Care!

Dementia Caregiver Survival:The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 1)

YOU are a carer or nurse for a person suspected of suffering dementia. You are seeing the symptoms, the losses in cognition, the memory troubles, the behaviour quirks, the obsessions, the faded empathy. You know this person is not truly 'a jerk'. But what other surprises lay in store for you? How do you get through this? Dementia will take one life. Don't let it take two.

The Carer Fast Track® Series of books is about you, the carer. Along the trails I travelled for twenty years as a carer, I befriended over 200 people with dementia. I learned their stories, met their families, understood their behaviours, attended many funerals and distilled the lessons.

I want you to survive this. To do so, you must accept that you are at risk. Take seriously the early signs of fatigue, depression, and caregiver burnout and follow our formula. Your health and your survival are at stake. This series of booklets is designed to cut the following risks and avoid having you become a victim:

Caregiving as a risk factor for mortality:The Caregiver Health Effects Study
Richard Schulz, PhD; Scott R. Beach, PhD, *JAMA.* 1999

> After adjusting for sociodemographic factors, prevalent disease, and subclinical cardiovascular disease, participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than non-caregiving controls.

If you are a spouse, relative or friend of a person with dementia, your relationship is personal, one-to-one and your focus is the welfare of that one person. The role is intense and consuming. While the person with dementia is living at home, you can be on-call, on duty 24*7. The frequency of your caring duties increases as the disabilities increase of the person with dementia.

If you are a carer, social worker or nurse, your relationship is with a number of patients, one-to-many (or one-of-several-to-many). During your working day, you care for the welfare of all patients in your charge. This is your vocation or your career. It is demanding work for the whole duration of your shift, involving incidents and emergencies which intrude into routine caring duties. The stresses of this work are very significant and must be countered with off-shift relief.

ABOUT Us

I was principal carer of my wife Carole. Our journey together with dementia started in 2000. I retired from my work to care full time for Carole in 2010. In 2015, Carole was admitted to a nursing home as her care required three-shift expertise. I visited daily and befriended many other residents and families, learning their stories. Carole died in 2019, aged 79, from organ failure caused by her advanced dementia.

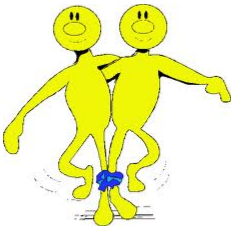
Along our journey, Carole survived over 50 ‘excursions’ from home in five weeks, three of them involving police. She suffered a fall, pulling on her pyjamas. A fractured hip required a prosthetic joint and the anaesthetic caused delirium. Her placement journey was traumatic for us both, but was ultimately successful. Four months before she died, I successfully relocated Carole by Royal Flying Doctor for her safety and wellbeing.

My own health cracked after four years as full time carer. I underwent surgery for prostate cancer, incurring lymphoedema as an outcome. Then, I snapped an Achilles tendon when running at night to Carole’s aid.
Some of our story is published here:
https://palliverse.com/2016/04/27/glens-story-i-am-the-principal-carer-for-my-wife-carole/comment-page-1/

I help carers behind me on the FTD road, just as others help me. The resources published here as the Carer Fast Track® Series are designed to present insights not previously well covered by published literature. These practical tips have been road-tested by many other carers. There are millions of people in need of support and strategies. They include nursing home staff, nurses and professional carers as well as family caregivers, people exercising Power of Attorney and guardians.

Now in 2020, deep into the First Year after Carole’s death, my grief has turned a corner. The New Year offers the time for renewal and I am accepting the offer.

But that’s enough about us. These booklets are about you.



Caregiver Survival:

What is different about caring for a person with dementia is that we lose the person and our relationship progressively with fading cognition, therefore our grieving starts during the caregiving journey.

By the time you get to suspect "dementia", you have been living with your Loved Ones's (LO's) symptoms for years, probably a decade, and have suffered misunderstandings, relationship damage and you have reacted and maybe responded. These relationship changes have hit you by surprise. They occurred as you reacted to the failing empathy and changed behaviours of the person with dementia. Your response may have been emotional detachment in self defence. But suddenly with diagnosis (dx) comes a new opportunity to see the bigger picture, to recognise that your past has dealt with neurological disease and to see where degeneration will take you. Carers need more **validation** at this time and they typically don't get it from doctors. Doctors deal with patients, not carers. Doctors typically think dementia starts with dx (I have had a doctor specialising in dementia patients say that to me in writing). That is the start of a doctor's role and the first opportunity to participate in patient wellbeing.

Caring for a person with dementia is stressful. The same may well be true of other fatal diseases, but it is very significant when your LO does not know who you are. And it is that stress which raises the carer mortality by 63%. This says risks are real and severe and require conscious management and a **superior strategy**. This statistic is probably greater than being a circus performer. On par with going to war (the US 16th Infantry leading the D-Day invasion lost 31%). It's as risky as playing in the NFL.

Can we improve our odds? This is what NIH says about surviving grief:

https://mailchi.mp/nih.gov/taking-care-of-yourself-while-grieving?e=1087ccce67

https://www.nia.nih.gov/health/mourning-death-spouse?utm_source=NIA+Main&utm_campaign=17f6681b17-20200130_caregivingmourning&utm_medium=email&utm_term=0_ffe42fdac3-17f6681b17-18468599

In summary:

- Practice self-care
- Exercise regularly
- Eat well
- Sleep well
- Get company and understanding. Get out and about.
- Seek solace in prayer, music or library
- Check out any new health concerns
- Consider counseling
- Get legal and financial planning done
- Beware making big changes (house, job) while grieving

Which of those make a significant difference in survival? How do we know which are the right strategies for us? NIA and NIH offer no information. I can tell you which of these made most difference for me, but I know from my discussions with many other carers that the answers are different for each individual. You have your own unique combination of issues, not only from that NIA list. Your LO has other medical conditions. You may have your own unique disabilities. There may be guns or drugs in the house. The way to survive is to use this as a checklist to identify what is troubling you, and use your friends and mentors to make improvements. You need your own unique custom survival strategy and it needs to be effective for you. Your mission is to identify, plan and execute those "somethings" that you are going to do to avoid becoming a burnout statistic.

The solutions promoted by the Alzheimer's Assoc. are respite or placement, but respite is often declined by the person with dementia or unacceptable on grounds of behaviours. Even permanent residential placement is not an end of the caring and advocacy roles.

Way back in 2012, the assessor asked me "How do you cope?" I misunderstood the question and started to describe the things I did... "But... HOW do you cope?" I said "We lower our standards" and I think she immediately regretted asking. But it was true. Cleaning happened less often. Some objectives were abandoned. We choose our battles. We lower our standards. We abandon some retirement plans. And we forgive ourselves some of our limitations. These are necessary adjustments for carer survival and the tolerance of the loads that otherwise result in carer burnout.

A big tip for carer survival is to have dreams of a future ...it is healthy to dream about "life after dementia". And later, to plan that. A good friend of mine, another caregiver to his wife resident in a nursing home, was very despondent about the impending death of his wife. I made him a scrapbook with pockets, inserted pics of him and his wife, his kids, his grandkids, his siblings and a few of his hobbies. I called it "My Life After Dementia" and encouraged him to fill in the blanks and show his family. He told me that these activities literally saved his life. And he drove eleven hours each way to visit me and tell me again.

I used to find a relief by starting to nourish ideas of "life after dementia". When I put my head down, I would give a minute to think of hobbies, trips, or friendships to be renewed. I found it my kind of sanity therapy. You can choose a primal scream instead, whatever works for you as an escape valve.

Your Survival Strategy does not end with the death of your LO. It has to extend at least as far into the grieving period as the **turning point at which renewal starts** (Book 11). Grieving presents risks of depression, isolation and giving up. Some of your dreams of Life After Dementia have to develop into plans and progress before you can feel you have survived.

Divorce?

Following years of changed behaviours, lost empathy and eroding relationships, many couples are driven to consider divorce. This question frequently arises before diagnosis is reached, but also after dx. And the initiative can come from either the partner with dementia or from the carer.

The carer who observes the degenerating cognition and the changing behaviours (Ref: Managing The Rage Stage) will most commonly remark “This is not the person I married.” In many cases, that is almost literally true, when obsessions and rages have changed the personality of the patient and simultaneously eroded the couple’s relationship.

Often, the same behaviours go un-noticed by other family members who see the patient infrequently, for short periods, when on their best behaviour (“show-timing”). Similarly, the patient’s doctor, with short consultations, has no opportunity to assess the trends (Ref: Diagnosing Dementia). The carer, as a result, becomes increasingly isolated or alone in this perspective, often concluding the patient has become a complete jerk and is left unvalidated.

The patient most commonly has no insight into their own degraded behaviours (this is anosognosia, wholly involuntary and not to be confused with denial) but can observe the results of the failing relationship, the harsh words, the time sought apart. So the patient too is likely to initiate divorce, blaming the carer and perceiving no fault in him/her-self.

Divorce is not necessarily a bad outcome and is not necessarily avoidable. When divorce is initiated by an undiagnosed patient, the carer may not be motivated to contest the matter and may be constrained by privacy considerations from providing complete evidence. After diagnosis, medical records become subject to further privacy constraints.

In some western jurisdictions, divorce can provide a separation of the partners' assets so as to protect the carer from becoming liable for the future care costs of the patient. The advice of an elder care attorney should be sought immediately if divorce is contemplated. Financial liability may be able to be simplified and reduced.   A divorced spouse will not subsequently be next of kin to the person with dementia and will not be able to make decisions for the patient's medical care.

Your Ease of Mind

You are overwhelmed. You have extra work. You have duties outside your normal role. And you are grieving the progressive loss of your relationship. This load is heavy and the emotional load that comes with it has some unfamiliar elements.

Typically, by the time a patient reaches a diagnosis of FTD, the disease has reached the midstages of its progression. Diagnosis may come ten or twenty years after the onset of the disease because symptoms are slow to develop and become recognised as trends. It is not only the symptoms of dementia which become more apparent over this time. The relationship with the caregiver suffers damage concurrently, for reasons not correctly recognised or understood until diagnosis provides some explanation. Sometimes the caregiver's response undergoes an emotional detachment done for survival. That relationship damage may not be wholly reparable. The damage occurs incrementally, by surprise, as a spouse reacts by withdrawal from incidents of failing empathy and changed behaviours within the undiagnosed person with dementia.

You are on a journey you did not seek. It may have come wholly as a surprise to you when you first learned that the person you care for has dementia. The emotions of grief, sadness and loss may exceed any such emotions you have previously experienced. That burden will so overwhelm you that you will become an emotional casualty of your journey with dementia unless you can find a survival strategy.

There are opportunities that differ in every individual journey. But there are some that are common. The first is to recognise that, for you, there may be a life after dementia. As soon as that sinks in, you will ask yourself its shape and a dream is born. There is little opportunity during your caregiving journey for that dream to evolve into anything like a plan, but in that dream there is hope and hope is nourishing.

The second may surprise you as it did me. A diagnosis of dementia contains an element of relief. There was nothing you could have done to avert the onset of the disease and there is nothing you can do to stop the inevitable degeneration. Your burden carries no element of blame or shame. Recognition brings a balm.

The third is your journey offers you opportunities for happiness and pride. You might discover you have an unsuspected Mother Teresa gene. You may have memories of happy times as you sit with the person for whom you are caring. There are moments of intimacy in acts as simple as helping them to eat or drink. These emotions may not have come your way had you not taken this dementia journey together.

Fourth is that you are not alone in adversity. You will meet other carers and, in some, you will find a kind of comradeship that comes from facing the same challenge. You will encounter some dedicated people and you will see them under strain, when they reveal much character. If you make the time to acknowledge them, you can make lasting friends. Find your tribe, your support group. It may lie online or be an in person support group, it may be family or friends. You may be surprised who is still with you at the end of this journey… and who is not.

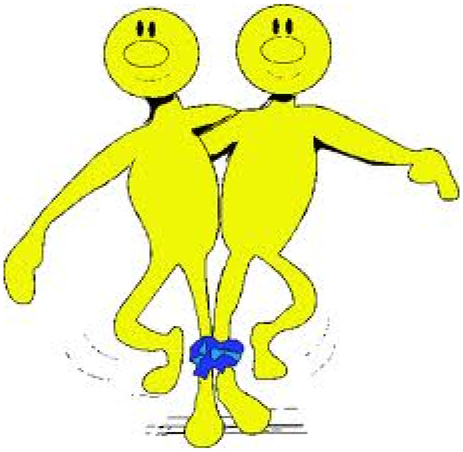
One Day at a Time:

You will encounter much advice urging you to not get too far ahead of yourself. When caring duties are onerous, survival becomes a daily issue and looking ahead can be overwhelmingly depressing.

Along similar lines is the advice “Apply your own oxygen mask first.” The 'oxygen mask' anecdote is a reminder that the carer is the one in charge now (and it was not always like that). The LO can no longer make quick, correct decisions, and the carer must do that every time and be ready to do it again tomorrow if necessary.

But the caring journey is unlike an airplane emergency. Caring is a marathon. I am not enamored of analogies like 'oxygen mask' or 'parachute'. But they serve a purpose when a carer may otherwise panic and not find a solution. There is help available. There are strategies that make the caring journey survivable.

To be around for your LO in the future, you must survive every crisis. To do that, you have to take care of yourself, all the time. You are now the only responsible, capable adult in this relationship. It is not selfish to look after yourself. If you are run into the ground, you cannot effectively care for your LO.



The other books in the Carer Fast Track® Series:

Tips For Newbie Dementia Carers: The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 2) Kindle Edition

This is a ten minute introduction designed to fit within the limited time resources of Newbie Carers. It is brutally brief in introducing subjects avoided by the major associations. This book links to the Caregiver Survival Guide.

Tips For Communicating: The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 3) Kindle Edition

One most important symptoms of dementia is failing communications within a family afflicted with fronto-temporal dementia, FTD. Much can be done to improve the journeys of each family member by learning better communications.

Alzheimer's disease typically begins with cognitive problems resulting from memory loss. But the onset of FTD is marked by changes to the individual's personality, social behaviour or language abilities. This is due to the specific functions performed by the areas of the brain affected by FTD. The frontal lobe has roles in mood, personality, emotional expression, self-awareness, logic, sequences and judgment. The temporal lobes, which process sound, also play a key role in understanding and using language, and in the management of sensory input, including pain, sensory stimuli and emotion. Damage first to the left temporal lobe results in disabilities concurrently in comprehension and expression, but also to the processing of details and sequences. Damage first to the right temporal lobe sees disabilities in context and big picture issues, behaviours, obsessions, empathy for others. All these different varieties of dementia incur communications impairments which can be better managed with the toolkit of skills uniquely published in this book.

This important document describes ways to communicate with a loved one who suffers from FTD. It includes critical proven tips for carers to ease their path on this FTD journey. This is information unavailable on the main dementia websites or in published resources.

Diagnosing Dementia: The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 4) Kindle Edition

What carers need to know.

What diagnosis is and what it is not.

When to say "Stop !"

Who needs to know and how should they be informed?

What next?

Take Genetic Testing? The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 5) Kindle Edition

Why get genetic counselling first?

What is learned?

What is not learned?

Who needs to know and how should they be informed?

Who should decline genetic testing?

"I'm FINE!" Coping with Anosognosia. The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 6) Kindle Edition

Never heard of "anosognosia"? Nor have many health professionals.

It is your understanding of the concept that is important. Many people wrongly think this is "denial". But this is involuntary. Lost cognition prevents the patient having self-awareness.

What should you do, and what should you not do?

Managing The Rage Stage. The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 7) Kindle Edition

When dementia attacks the frontal lobe, fading inhibitions and rising obsessions are frequent outcomes. With these emotional filters not working normally, rages are frequent outcomes. Anger giving way to violence is a symptom in more than 20% of people with FTD. These symptoms are most often a feature of the midstage of the disease, sometimes the symptoms causing a person to be diagnosed with FTD. When the symptom is a temporary feature, it dominates the caring relationship. Then it is called "The Rage Stage".
These behaviours are among the most difficult for carers to understand and manage. This book is uniquely dedicated to the management of rage.

REVIEWS:

"Great" …"I must say that I was profoundly moved by your descriptions of what people have to live with, and the style and content of your practical advice. Very few people are aware of the extent to which a family caregiver must at times subjugate their entire personality to the person that has been created by the FTD, in order to keep the peace and stay safe. Most people would give up at a very early stage and I salute those who persevere from love and duty. You have made a very good description of it, that I am sure will be helpful to many people."

Professor June Andrews RMN, RGN, FRCN, OBE

"It is so valuable. When you have it published would you let me know where so I can send others to read it?"

Barbara Karnes, RN, Award Winning End of Life Educator, 2015 International Humanitarian Woman of the Year

Selecting a Dementia Residence. The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 8) Kindle Edition

Selection Criteria

What to look for

What to ask

What you should ignore

Managing Dementia Placement. The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 9) Kindle Edition

Here's the plan

Backup plans

Choosing your help

You, afterwards

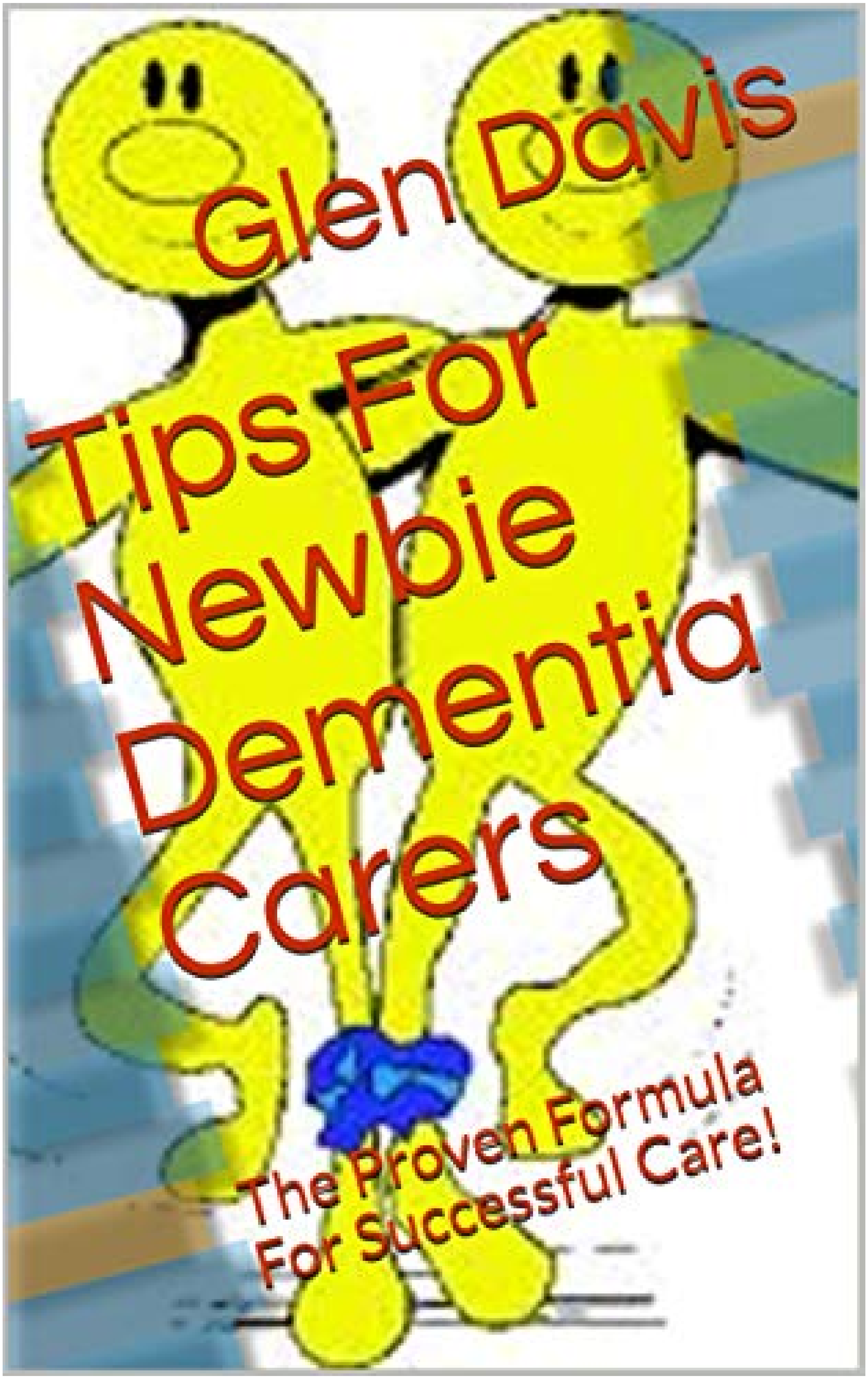
Coping with End of Life. The Proven Formula for Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 10) Kindle Edition

For this subject, there is a lot of published help. The issue is finding the right material to read.

Grieving starts early on the dementia journey. But there is more to come, including your own personal surprises.

Picking Up The Pieces. The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book11) Kindle Edition

There is a way to start your renewal and to get that under way.


Glen Davis
Tips For Newbie Dementia Carers
The Proven Formula For Successful Care!

Tips For Newbie Dementia Carers:

The Proven Formula for Successful Care! (Carer Fast Track® Series Book 2) Kindle Edition

This is a ten-minute introduction designed to fit within the limited time resources of Newbie Carers. It is brutally brief in introducing subjects avoided by the major Associations. This book links to the Caregiver Survival Guide (Book 1).

Tips for Newbie Dementia Carers is deliberately a dangerous venture. Every dementia journey is different in the symptoms portrayed, the rate of progression, the time of diagnosis and the stage of the journey at which a caregiver reads the Tips.

In my wife's 20-year journey with dementia, I got to know over 200 people with dementia, their stories and their caregivers. Many times, I have felt (or other carers have said) "I wished I had known THAT a couple of years ago". "Tips for Newbie Dementia Carers" attempts to touch briefly on the many subjects each caregiver will/may encounter. ***The idea is to help you choose what things you do first and to prepare you for those subjects you choose to leave for later.*** For each subject raised, there are hints and references for where to learn more. This is a portrait done with a six inch brush. No subject is addressed here in detail.

Your Journey with Dementia

Dementia is a term used to describe a global malfunction of the brain, which causes memory loss and changes in behaviour and personality for the affected person.

There are numerous variations of dementia symptoms and causes. All affect three functions of the brain — language, memory and decision-making. All are fatal, degenerative diseases with no cure. For some, including the most common which is Alzheimer's Disease, there are medications which can slow or moderate progression. For all of the Fronto-Temporal Dementias (FTDs), the only available medications are to moderate symptoms and there are no drugs effective in slowing the progression of the disease.

A caregiver embarks on the dementia journey with the person with FTD (sometimes referred to as "the patient" or "the loved one (LO)"). Many caregivers are the spouse or a relative of the LO. As the LO loses some mental faculties and aspects of their personality, the carer loses and grieves aspects of their relationship. "Anticipatory grief" and "Living bereavement" are real, hurtful, and difficult to address. So is carer burnout (see Book 1 in this Series).

Diagnosis and Symptoms

There is no pathological or other objective test for FTD before autopsy. FTD is diagnosed by the recognition of symptoms and a trend of degeneration.

Each person with dementia exhibits symptoms when different portions of their brain come under attack by the disease. With each of the variations of FTD, the gaps between neurons and synapses become clogged with accumulated, misfolded proteins. The neurons misfire, causing intermittent symptoms, then die and dissolve. Parts of the brain atrophy and are replaced by fluid so that the brain, seen on a scan, appears to shrink.

When the left temporal lobe is the first part of the brain affected, the first symptoms observed are difficulties with expression. Wordfinding and comprehension suffer concurrently. This is termed Primary Progressive Aphasia or Semantic Dementia.

When the right temporal lobe is first affected, the first symptoms noticed are mood and behaviours and lost empathy. This is termed Behavioural Variant (bvFTD).

When the frontal lobe is first affected, it is inhibitions and executive functions that are damaged. Obsessions may arise. Difficulties are experienced in daily tasks and in following sequences. Household products may be confused. Objects may be wrongly thought to be food.

Every FTD patient experiences their own unique combination of symptoms depending on the particular functions of their brain damaged. Some symptoms are intermittent because neurons may sometimes fire and sometimes not. In addition, the brain has “plasticity”, the ability, in time, to find another pathway to a sought memory. These intermittent symptoms mean the patient’s disabilities are not always evident to others. Trends may not be recognised. Diagnosis is likely to be delayed.

Later in the FTD Journey

Typically, by the time a patient reaches a diagnosis of FTD, the disease has reached the midstages of its progression. Diagnosis may come ten or twenty years after the onset of the disease because symptoms are slow to develop and become recognised as trends. It is not only the symptoms of dementia which become more apparent over this time. The relationship with the caregiver suffers damage concurrently, for reasons not correctly recognised or understood until diagnosis provides some explanation. Sometimes the caregiver's response undergoes an emotional detachment which, consciously or unconsciously, is done for survival. That relationship damage may not be wholly reparable. The damage occurs incrementally, by surprise, as a spouse reacts by withdrawal from incidents of failing empathy within the undiagnosed person with dementia. An intimate spousal relationship may develop into a caregiver role. Divorce may have occurred at the instigation of either party.

A person with FTD is losing some abilities to think. At the same time, emotions are unimpaired and run at full strength. That combination causes confusion, disorientation, mood changes and apathy. Over the course of the journey with dementia, additional portions of the brain come under attack. Eventually the symptoms experienced tend to merge across the different variations of FTD.

Eventually, if the patient survives the many risks and hazards which arise from their failing cognition, their brain loses the ability to maintain the most basic bodily functions. Their speech deteriorates and they may become mute. They lose continence. They lose the ability to rise or walk. They have difficulty swallowing which may trigger aspiration pneumonia. Eventually, vital organ failure brings death. That sounds awful. But there are worse ways to die than with no cognition, therefore no fear.

For Newbie Carers- First Steps

- Once a physician (having undertaken neuropsychological testing) suspects FTD, undertake only one more appointment, for an MRI (a magnetic resonance imaging scan). This will identify any injury that may be operable. Do not bother with more "expert" attempts at diagnosis as they are stressful. If the MRI shows "atrophy consistent with age" or "no significant abnormalities", stop! You have achieved the objective, there is no operable condition. If the MRI shows "significant/material atrophy of frontal/temporal/parietal lobes", stop ! You have achieved sufficient evidence confirming a diagnosis of FTD. Yes, a PET scan can allow a superior distinction between different dementias but it is likely to produce no actionable information. A diagnosis of FTD is 'only' an opinion formed from observing symptoms. There is no definitive test prior to autopsy.
- Your journey with dementia started years ago. Onset occurs typically more than ten years prior to diagnosis. There was nothing you could have done to avoid it, slow it or change it. Now you know the cause is

this disease, you are free to blame the disease and forgive the patient. All those symptoms you observed are now explained. It is important to note that you are already in the mid stages of your journey with dementia.

- The important information varies greatly with individual cases. Where anosognosia characterises the case (when the patient insists “I’m Fine” and is unable to recognise his own disabilities), there is no point describing the disease or symptoms to the patient and all advice needs to be couched as "typical precautions at your age and stage". Where the patient is uncooperative and combative, there is no point offering any advice to the patient. In other cases:
- Use the opportunity immediately to get your insurances, will, advance care directives and powers of attorney in place. A delay may cause your patient's wishes to be later challenged on the ground that he/she lacked competence.
- Get support. Involve other family and friends in the caring role early in the journey so they learn the behaviours of the person with dementia and the appropriate responses. If you leave it until later, the gap becomes too daunting. Consider joining an online forum. Consider whether you would benefit from counseling.
- Scan and share with relatives the important documents including advance care directive and powers of attorney (and the location of the originals of very important documents like deeds and wills).
- Learn the techniques for getting reluctant patients to attend to Powers of Attorney/PoAs. Be willing to brief an attorney in advance. Consider seeking the advice of an elder lawyer regarding notifying the patient’s employer. Some have to stop working immediately because serious errors in judgment may put the employer at risk. Notifying the HR department avoids unfair dismissal and can help watch for the patient’s interests.
- Learn a long list of technical skills, including
    - loving deception (one of "the D's")-- is partly along the lines of white lies to make things go more smoothly. It is also partly along the lines of not saying / explaining everything so as not to get some new problem going. You can think of this technique as “therapeutic responses” designed to avoid escalation of emotions. Our LO's with FTD no longer process as they did; the kinds of discussions one has had in the past (or could have had in the past) cannot happen now. So, sometimes it is just not saying everything -- not bringing up things that are important in regular life. You tell the FTD person or DON'T tell him whatever it is that is necessary to get him to do what is best for him and gives you the least amount of blowback.
    - The "Ds" are delay, distract, defer, deflect, (lovingly) deceive.

- The New Yes, and "Yes We Have No Bananas". **The New Yes is a validation instead of an affirmation.** "Yes" is now not necessarily an affirmative, it is more like an acknowledgement that you heard him. It says 'I understand your comment or request and will address it'. It is used to keep a communication channel open when a "No" will instantly close it. **"Yes We Have No Bananas"** goes hand in hand with "the D's." The basic idea is, never say NO -- always give an answer (no matter how unreasonable the demand) that sounds like YES. LO: "I want to do X /We need to do X/You must do X." Sometimes it is "Do it NOW!" You: "Yes, we will see what the doctor says at the next appointment." "NO" shuts him down and he hears nothing past "NO". The two strategies are really important for **avoiding confrontations**! for example -- your person with dementia wants to do something unwise (buy something; get driver's license back; move to a new place; etc.), and you say: "Sure! Let's look into that right after X happens!" Or, "That's interesting, let's look into that. Look over here!" Don't say NO. Put it off. If push comes to shove, **Deflect** Blame (another D) away from you, onto someone else in authority -- because you are probably being blamed for everything already. If it doesn't work the first time you employ this technique, there will come a time when it will be effective owing to progression.
- How and Why to Lower Arousal
- When to get close
- What to write and why, dealing with failing comprehension (Ref: "**Tips for Communicating"**)
- Why to say What and not bother to say Why. How to keep communication simple.
- How to be the patient's advocate.
- How to minimise confrontations. Do not assume you can converse any longer as peers. You listen and respond in an agreeable manner or a neutral one. Never disagree or give a contrary opinion. (Ref: "**Managing The Rage Stage**")
- Why to often be ready to down tools and respond with spontaneity. If your person with dementia is "all about me", they genuinely see no other priority. When you are able to go along with a whim, it will help avoid conflict. Your flexibility is key.
- Responses to obsessions**.** Reasoning absolutely will not work, with FTD. When logic circuits are broken, logical explanations fail. Switch over to the "Ds" and the New Yes.
- Keeping family members involved in caregiving. Invite them to be involved in the care of LO. Bring their understanding along to keep pace with progression, avoiding a gulf too wide to bridge.

  - Dealing with family Backturners. Make specific requests: “Please take him bowling Tuesday at 2pm for two hours while I get the shopping done."
  - Dealing with failing personal hygiene including showering, cleaning teeth, changing clothes.
  - Dealing with incontinence.
- Assess your particular risks and exposures to:
  - uncontrolled spending by patient. (Use a single account with a regular allowance, debit card access, and no overdraft protection.)
  - patient falling for scams
  - patient giving away money and possessions
  - patient falling for "girlfriend" scams
  - patient succumbing to porn
  - sexual obsessions
  - inappropriate behaviours
  - accusations and other non-physical rage stage symptoms
  - walkouts and getting lost
  - aggression and violence
  - driving with FTD
  - social isolation
  - physical isolation
  - "a broken thermostat". FTD patients are notorious for lessened tolerance of ambient temperature fluctuations.
- Understand that this disease is fatal and is characterised by progressive cognitive decline. As your person with dementia loses identity, you both will lose your relationship. Individual responses must differ.
- Very few carers are able to continue to provide care at home. As the workload increases, the 24*7 role generally becomes too great for one or two carers. You are likely to need a three-shift residential placement with skills matched to the demands of your patient. Much guidance is needed in identifying a suitable residence and is available from online forums.

"Tips for newbie carers" is a huge topic, very scary for real newbies. When your eyes are glazed by fresh diagnosis (dx), there are so many subjects coming up at once. Each newbie has different issues, concerns and values which are not addressed by the plethora of superficial brochures thrust upon them.

Overview

Dementia is a progressive deterioration of cognition. It causes disabilities in logic, intellect, memory, learning and social skills interfering with normal activities and relationships.

There are various types and causes of dementias, all of which are fatal diseases. Alzheimer’s disease and vascular dementia are the most common, with various frontotemporal dementias being more rare. Some patients have combinations, termed “mixed dementia”.

There are good government and academic websites with more information. While there is no cure, there are techniques that help greatly to manage symptoms and there are medications which can help moderate anxiety and some common behaviours. Beware of scammers pushing proprietary cures.

Addressing Confusion:

My whiteboard reminders (inside the pantry door) for Carole and me read:

[Carole]
Be aware of exhaling to lower arousal. This allows brilliant Right Side to do sequencing and word finding tasks. (Ref: Tips For Communicating)
Trust.
Avoid frustration and anger which cause speechlessness.
Write notes as well as speak.
Touch. Get close.
Say what. Don't bother to say why.
Be ready to down tools and act on whims and spontaneity.
Allow LO time to process.

These tips helped us often. But failures of understanding and even complete misunderstanding still happen. "But you said... [the exact OPPOSITE of what I said and repeated]" Complete misunderstandings seem to arise when the subject is understood by the person with dementia but one or two critical words of context are missed, allowing the message to be fundamentally reversed. Writing notes is designed to counter that. The message can be read in slow-time and re-read. But there is no opportunity for writing notes when you are driving the car or managing a crisis...

Confusion is a very common symptom:
Losing your mind is nothing compared to the terrible effort of holding on to it.

In many of our LOs, I think this effort is a struggle to understand. The wish to understand crashes into the inability to understand. The result can go in many different directions... confusion, distress, anxiety, refusal, rage, fear/terror, resignation.

These emotions are heightened by a move into residence. And the very persons with dementia whose behaviours at home are so extreme as to necessitate urgent placement are the same persons whose responses to the change of environment are most extreme. It can be very distressing for carers and family to watch their loved ones live through this confusion.

Responding to Urgency:

Urgency is a symptom of the disease. The description "A whim of iron" is accurate.

I found it helped to think "This is the dementia talking". After consulting with the head of our Neuropsychology Dept, Robert Moss, I would lower Carole's arousal (ref: Tips For Communicating Book 3 in this Series) and respond with spontaneity whenever possible.

Faced with anxiety, resist asking her to "stop it". Try to avoid starting any response with "No" because it will stop her from understanding what follows. Instead, start every response with a "Yes" or "Sure", "Certainly", "Good idea". It keeps her listening.

Apathy

Apathy is the most common neuropsychiatric symptom of dementia, with a bigger impact on function than memory loss -- yet it is under-researched and often forgotten in care.

The clinical literature talks about this symptom exclusively as "apathy". But the symptom is most commonly "entropy" where the person with dementia loses not only interest, enthusiasm (apathy) but energy (entropy). They lose the ability to walk far or fast. They would rather sleep than be bothered with activity. As a result of diminishing exercise, they may suffer other health issues, have disturbed sleep, wander without objective.

Apathy is the most common symptom of dementia. Lack of activities is troubling for some (but not all) patients and for all carers. It is poor for the patient's overall health. But there is only so much encouraging that a carer can give before it turns to negative nagging.

The activities best suited to dementia patients range with personal taste from quite active to very passive. What surprises most carers is the degree of simplicity of activities that suit a person with dementia. It is a big shock to find that a person who was, a year ago, keen on driving country trips now wants to care for a cloth doll. Or a man who did household chores who now wants to play Patience or Solitaire or stack blocks. Simple outings such as a walk to a coffee shop often suddenly become the most satisfying activity to choose.

Failing Empathy

The loss of empathy is often an early symptom of all the frontotemporal dementias. Because it occurs before the other symptoms which cause family members to seek diagnosis, lost empathy is often not identified correctly by family members. The first thought is typically that the patient is being a "Jerk!" or "Bitch!"
If these behaviours are raised with a medical practitioner, they will too commonly be mis-diagnosed, frequently as "marital problems". Many couples are referred for counselling which, of course fails because it seeks to address the wrong issues.

Eventually, as other behaviours attract attention, the diminishing empathy may become recognised as a symptom of dementia. Like other symptoms, there is no way to postpone nor achieve more empathy if the pFTD is already on that road. It begins early and hits us hard. In many cases, the damage done to the relationship is so severe that it is irreparable once the problem is finally recognised as "dementia".

As a patient loses empathy and aspects of their personality and identity, the carer loses their relationship. By the time that other symptoms of dementia arise and trigger neurological investigation, it can be 10 years after brain changes and loss of cognition and neurons occur. By that time, the carer will have been responding to the patient with irritation, judgement, withdrawal, anger or a host of other emotions and responses. Had we realized at inception that lost empathy was a disease symptom, a circumstance beyond the patient's control we may have been able to avert the negative responses and the damage of years' duration.

Several aspects of lost empathy add to the issues for carers. Like other dementia behaviours, the symptoms are intermittent for two reasons. Neurons fail intermittently before they die. And the brain's plasticity sometimes finds other ways to find the answer. Examples of lost empathy are observed frequently only by the spouse who has 24*7 contact. To other family members, to friends, to medical practitioners, the symptom is rarely seen and is not perceived as a trend. Hence they tend to conclude the patient looks “Fine”, “Normal”. And the spouse lacks support for the observations, so can become isolated.

The thing that will most help us counteract loneliness and social isolation is to find a community of carers of FTD patients, a support group, others who are with us on this road to realization and discovery of ways to cope with the unimaginable. These people will listen to us as we reveal what behaviours we now live with. They can assure us we are not crazy and that no matter who else does not see what we see, our fears, concerns and observations are valid. The more people we can find whose loved ones are similar to ours, the more experiences we will hear about and the more varied ways of dealing with things will be discussed. We will be validated and no longer so alone in this.
Failing that, we need a firm friend who believes us implicitly simply because we say these things are happening. This friend can be a sounding board, a way for us to bounce ideas off them in order to come up with a game plan, a blueprint of what to do and how to respond going forward as we choose to stay and care for our beloved family member.

The carer must overcome the notion that lost empathy is something the person with dementia can control. It is another very real case of our having to change our mindset and reactions or responses because our loved one cannot. When we are accustomed to logical and caring actions from a spouse, and then we are confronted with unexplained lost empathy, it is very difficult for us to really internalize how impossible it is for the person with dementia to behave differently. The lost empathy can come and go for years before eventually becoming evident to infrequent observers.

Faced with failed empathy, a carer can best respond by changing themselves. At a minimum, the carer must lower their expectations for normal, caring attitudes from a person with dementia. Usually, other standards must also be lowered, for behaviours, for hygiene, for social interaction. Some carers cannot continue an intimate relationship and morph, either by default of by design, from spouse to live-in caregiver. Many spouses choose to sleep apart. Some divorce. The following notes may help guide your actions in dealing with lost empathy:

- It is a frontal lobe function, closely related to inhibitions and often accompanied by inappropriate social interactions or sexual actions. The loss of empathy is a very early symptom and may predate other more recognisable dementia symptoms. For example, the first noticed inappropriate social interaction may come 5 to ten years later.

Carers typically react first to lost empathy and intimacy by hurt feelings and anger, suspecting their former solid relationship, or

- imagining they are crazy when the person with dementia surfs in and out of behaviours. A diagnosis of dementia may yet be ten or more years in the future, far ahead from first, sporadic, unrecognized symptoms. Once diagnosis is reached, the lost empathy may, in retrospect, be recognised and placed in perspective as an early symptom of dementia. For many carers, that understanding comes too late to repair or undo the relationship damage.
- It really helps to have family members who understand, but that does not always happen. An online forum for support and understanding may help somewhat. Throw a pity party? It is possible that counseling with the right person might help, but generally we would be informing the therapist of behaviors and the disease in general. When dementia is yet to be diagnosed, counseling can be only of general support.

By the time we realize it is caused by a disease with no cure, empathy has generally been lost for years. The main cost of lost empathy occurs with the people living with the person with dementia, usually the spouse or close relatives. Some carers struggle to know when they should hold a person with FTD accountable. "How much is he responsible for?" "Are there any normally functioning pathways or have they all become corrupted by the disease?" " Are these behaviours 'Assholery' or dementia?" Eventually, they learn to let it go. There is no way to tell, and trying is pointless. Reaching diagnosis can be cathartic. It is possible then to blame the disease for all past troubling symptoms. But that will not necessarily restore family relationships damaged along the way. You will encounter well-meant advice about things you can do to "reduce your risk" of contracting dementia or of "delaying the onset" of dementia.

Dementia and Driving At the same time that you are pursuing a diagnosis of dementia, the difficult subject arises : when should a person with dementia stop driving? The same behaviours and symptoms that caused you to search out diagnosis are affecting driving performance.

The ability of a person with dementia to drive is determined not by their skill. The determining factor is their ability to make correct decisions in an emergency. The brain when affected by dementia can 'get around wrinkles' when it has time and when arousal is within the required band. (This is termed 'plasticity', the ability of the brain to find another way.) But the brain with dementia freezes in an emergency and arousal instantly elevates. Denied the time and conditions it needs to perform, the brain with dementia makes no decision or the wrong decision in an emergency.

The person with dementia can typically not perceive the problem. Their inability to recognize their own symptoms (called 'anosognosia') means they struggle to accept why they should not drive. Their response looks like 'denial' but is different, they really cannot see the issue. The subject becomes very challenging for them. It is more than their driving that is at stake. It is more than their independence. Their license is seen as a validation of their ability and identity and its threatened withdrawal is a devastating loss.

Managing this subject is likely to be a great early test of the carer. It will call for great empathy (think Mother Teresa scale). It will be a protracted process calling for patience. The carer has to manage the risk and keep the person with dementia safe. There are consequences for other road users, legal and insurance issues. Emotions run high. All of these demands fall upon a carer at a time they are just learning the skills of the trade.

The same principles apply to this subject as all others. The carer should avoid becoming the person blamed, because the carer has a unique long-term relationship to protect. The carer should ask the doctor to refer the decision to the driving license authority, who will conduct an assessment. It is the authority which makes the decision. The carer's sympathy and allegiance can remain wholly with the person with dementia. The communication skills required are described in Book3 of this series. The management of any rages is described in Book7.

There are very many hypotheses, from living further from main roads (for better air quality) to improved diet, supplements, exercise (mental and/or physical), social activity, volunteering and spiritual activity. Little harm is done by these recommendations for better health, except they imply that if you have dementia, it is your fault and you could have done better.

You are reading this book because you are dealing with symptoms suspected of being caused by dementia. If so, the onset of the disease occurred many years ago, the progression of symptoms was slow, intermittent and subtle.

Exercise, diet and the many proposed activities may well improve your health but may do nothing at all to the course of the disease.


Glen Davis
Tips For Communicating
The Proven Formula For Successful Care!

Tips For Communicating:

The Proven Formula For Successful Care! (Carer Fast Track® Series Book 3) 2nd Kindle Edition

One most important symptom of dementia is failing communications within a family afflicted with fronto-temporal dementia, FTD. Much can be done to improve the journeys of each family member by learning better communications.

Alzheimer's disease typically begins with cognitive problems resulting from memory loss. But the onset of FTD is marked by changes to the individual's personality, social behaviour or language abilities. This is due to the specific functions performed by the areas of the brain affected by FTD. The frontal lobe has roles in mood, personality, emotional expression, self-awareness, logic, sequences and judgment. The temporal lobes, which process sound, also play a key role in understanding and using language, and in the management of sensory input, including pain, sensory stimuli and emotion. Damage first to the left temporal lobe results in disabilities concurrently in comprehension and expression, but also to the processing of details and sequences. Damage first to the right temporal lobe sees disabilities in context and big picture issues, behaviours, obsessions, empathy for others. All these different varieties of dementia incur communications disabilities which can be better managed with the toolkit of skills uniquely published in this book.

This important document describes ways to communicate with a loved one who suffers from FTD. It includes critical proven tips for carers to ease their path on this FTD journey. This is information unavailable on the main dementia websites or in published resources.

REVIEWS:

> **"some great content here!" Dr Elissa Campbell,**. President of Palliative Care Western Australia and Chair of the ANZ Society of Palliative Medicine's Special Interest Group in Palliative Care for Older People
>
> **"I want to congratulate you on the astonishing insights and thoughtfulness of the booklets, as well as the immensely practical approach. It is clear it comes from a place of deep experience."** Dr Jennifer Philip, Professor of Palliative Medicine at University of Melbourne & St Vincent's Hospital

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). This is known as semantic dementia.

These people 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 they 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 will then escalate. Either remove yourself physically or verbally from the equation leaving the LO nothing to fight about and no one to fight with. It renders 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 will 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 "Ds" to modify his behaviour.

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 "Ds".

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 needs to act like it. It takes a major shift in thinking not to involve our loved one, but it is a necessary step.

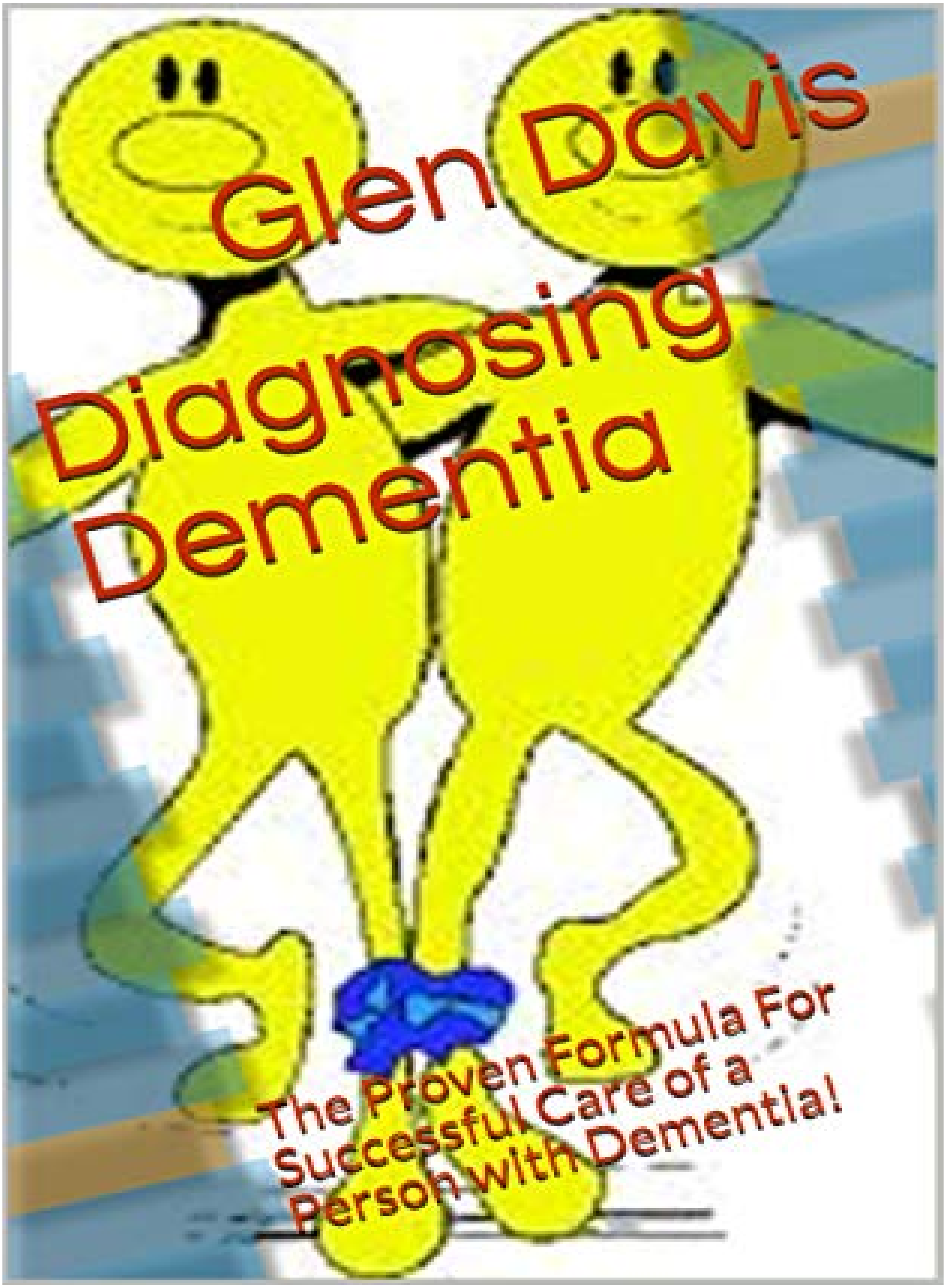
The Carer must Change Attitudes or Actions. The LO can no longer Adapt. When we finally realize that owing to the disease process our loved one is incapable of being different, we then find a way to adapt our thinking. The LO cannot so the carer must. Everything is up to us now. Factor him out as a helpmeet, 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.

Take the LO’s side when they are agitated about an issue.
'Take her side' in any issue. Say things like "I'll help you get started." Give her jobs like stirring pots or watering plants or packing the dishwasher. Focus on what is left rather than what is gone. "We've still got us!" "Together, we can do it." "I need you to do this while I do that over there." If his driver’s license is threatened and the LO thinks that unfair, support the LO’s position. Let the authority be the ‘bad guy’ because you have a unique relationship to protect.
But take this idea further and literally take their side. Teepa Snow did a video reconstructing an incident where she literally took the side of a frightened dementia patient among too many strangers. The lesson stuck because I had done something similar with Carole in hospital in the middle of the night. What Teepa Snow did beautifully is capture the symbolism. You stand alongside to show you jointly face an issue. When oral communication is failing, that kind of symbolism speaks volumes with low risk of being misunderstood.
And it has lots of application, once understood. If he is seated at a desk, you don't speak from the other side of the desk. You walk around and stand alongside.
If she is mixing salad on a bench, you stand alongside making the burgers. Practice the skill and it comes easily when things go sour.

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.


Glen Davis
Diagnosing Dementia
The Proven Formula For Successful Care of a Person with Dementia!

Diagnosing Dementia:

The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 4) 2nd Kindle Edition

- What carers need to know. What dementia is and how it is diagnosed.
- What diagnosis is and what it is not.
- When to say “Stop !”
- Who needs to know and how should they be informed? What next?

Your Journey with Dementia

Dementia is an umbrella term used to describe a global malfunction of the brain, which causes memory loss and changes in behaviour and personality for the affected person.

There are numerous variations of dementia symptoms and causes. All affect three functions of the brain — language, memory and decision-making. All are fatal, degenerative diseases with no cure. For some, including the most common which is Alzheimer’s Disease, there are medications which can slow or moderate progression during the early stages. For all of the Fronto-Temporal Dementias (FTDs), the only available medications are to moderate symptoms and there are no drugs effective in slowing the progression of the disease.

A caregiver embarks on the dementia journey with the person with FTD (sometimes referred to as “the patient” or “the loved one (LO)”). Many caregivers are the spouse or a relative of the LO. As the LO loses some mental faculties and aspects of their personality, the carer loses and grieves aspects of their relationship. “Anticipatory grief” is real, hurtful, and difficult to address. Typically, the carer will not receive validation for their loss of relationship nor their anticipatory grief from friends and family who do not see them daily. Comments such as “You still have your spouse/dad/mom” can cause lasting hurt.

Recognising Symptoms

There is no pathological or other objective test for FTD before autopsy. FTD is diagnosed by the recognition of symptoms and a trend of degeneration.

Each person with dementia first exhibits symptoms when different portions of their brain come under attack by the disease. With each of the variations of FTD, the gaps between neurons and synapses become clogged with accumulated, misfolded proteins. The neurons misfire, causing intermittent symptoms, then die and dissolve. Parts of the brain atrophy and are replaced by fluid so that the brain, seen on a MRI scan, appears to shrink. On a PET scan, brain activity in response to a selected stimulus, is characteristically different in a brain with FTD. The onset of the disease may have occurred many years before brain abnormalities appear on a scan as material departures from normal. Scans years after the onset of the disease may be inconclusive or show minor change which is dismissed as being within the range of individual differences. **Symptoms may reach severely troubling levels before scans provide confirming evidence.**

The first abnormal behaviours of FTD:

- Errors of judgement, excessive spending, gifts or lawbreaking;
- Misreading non-verbal cues. Failing to comprehend irony or subtlety;
- Vacant stare and daytime naps;
- Falls, failures of balance or coordination;
- Lost dexterity, “all thumbs”;
- Word-finding trouble, especially nouns. Pronoun errors (he for she);
- Junk food binge;
- Disregard for the emotions of others (lost empathy).

When the left temporal lobe is the first part of the brain affected, the first symptoms observed are difficulties with expression. Wordfinding and comprehension suffer concurrently. This is termed Primary Progressive Aphasia or Semantic Dementia.

When the right temporal lobe is first affected, the first symptoms noticed are mood and behaviours and lost empathy. This is termed Behavioural Variant (bvFTD).

When the frontal lobe is first affected, it is inhibitions and executive functions that are damaged. Obsessions may arise. Difficulties are experienced in daily tasks and in following sequences. Household products may be confused. Objects may be wrongly thought to be food.

Every FTD patient experiences their own unique combination of symptoms depending on the particular functions of their brain that are damaged. Some symptoms are intermittent because neurons may sometimes ‘fire’ and sometimes not. In addition, the brain has “plasticity”, the ability, in time, to find another pathway to a sought memory. These intermittent symptoms mean the patient’s disabilities are not always evident to others. Trends may not be recognised. Diagnosis is likely to be delayed.

The Long Path to Diagnosis

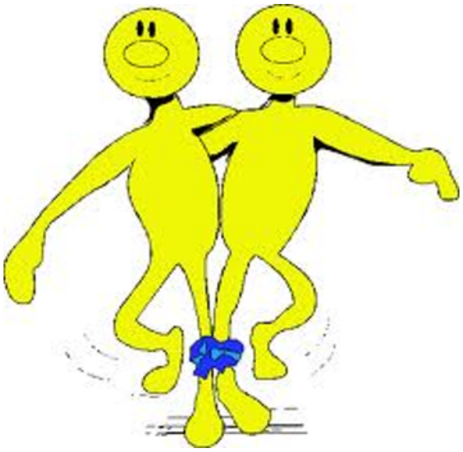
As a carer for a person who may have dementia, you may not need to be able to diagnose the disease. You do need to know why it is difficult, time-consuming, uncertain, likely to be delayed. You do need to know how to gain the cooperation of your LO in the diagnostic process, perhaps repeatedly. It will help greatly if you know how to present to the diagnosing practitioner the symptoms and trends you have experienced. You do need to know what the results mean.

The majority of carers start the path to diagnosis by complaining to their doctor about observed symptoms of their LO. It might be a change in their behaviour towards some new obsession, increasing apathy, lost ability to find their words, no empathy for their family members… for some reasons, you think they are just not themselves. You probably do not suspect a neurological disease. The doctor may see signs sufficiently disturbing that they refer your LO to a specialist, possibly a geriatrician, perhaps a neurologist or a neuropsychologist.

A few carers may have some experience of dementia or cognitive disabilities, or have some friends or family with experience, or they do some research of symptoms by themselves. They may come to an appointment with some suspicion about the likely outcome.

I present below the clinical diagnostic criteria (two pages) that are recommended practice for medical practitioners. (This sample applies explicitly to the behavioural variant of FTD but similar issues for the carer arise from the clinical criteria for other variants.)

I will then explain some of the issues that arise for you, the carer, and suggest the practices you can best adopt.



DIAGNOSTIC CRITERIA

Criteria for Behavioral Variant FTD

In 2011, an international consortium developed revised guidelines for the diagnosis of behavioral variant frontotemporal dementia based on recent literature and collective experience. The following chart delineates the present criteria for bvFTD.

International consensus criteria for behavioural variant FTD

I. Neurodegenerative disease

The following symptom must be present to meet criteria for bvFTD

A. Shows progressive deterioration of behaviour and/or cognition by observation or history (as provided by a knowledgeable informant).

II. **Possible bvFTD**

Three of the following behavioural/cognitive symptoms (A –F) must be present to meet criteria. Ascertainment requires that symptoms be persistent or recurrent, rather than single or rare events. A. Early* behavioural disinhibition [one of the following symptoms (A.1 –A.3) must be present]:

A.1. Socially inappropriate behaviour
A.2. Loss of manners or decorum
A.3. Impulsive, rash or careless actions

B. Early apathy or inertia [one of the following symptoms (B.1–B.2) must be present]:

B.1. Apathy
B.2. Inertia

C. Early loss of sympathy or empathy [one of the following symptoms (C.1 –C.2) must be present]:

C.1. Diminished response to other people's needs and feelings

C.2. Diminished social interest, interrelatedness or personal warmth

D. Early perseverative, stereotyped or compulsive/ritualistic behaviour [one of the following symptoms (D.1 –D.3) must be present]:

D.1. Simple repetitive movements

D.2. Complex, compulsive or ritualistic behaviours
D.3. Stereotypy of speech

E. Hyperorality and dietary changes [one of the following symptoms (E.1 –E.3) must be present]:

E.1. Altered food preferences
E.2. Binge eating, increased consumption of alcohol or cigarettes
E.3. Oral exploration or consumption of inedible objects

F. Neuropsychological profile: executive/generation deficits with relative sparing of memory and visuospatial functions [all of the following symptoms (F.1 –F.3) must be present]:

F.1. Deficits in executive tasks
F.2. Relative sparing of episodic memory
F.3. Relative sparing of visuospatial skills

III. Probable bvFTD

All of the following symptoms (A –C) must be present to meet criteria.

A. Meets criteria for possible bvFTD

B. Exhibits significant functional decline (by caregiver report or as evidenced by Clinical Dementia Rating Scale or Functional Activities Questionnaire scores)

C. Imaging results consistent with bvFTD [one of the following (C.1 –C.2) must be present]:

C.1. Frontal and/or anterior temporal atrophy on MRI or CT
C.2. Frontal and/or anterior temporal hypoperfusion or hypometabolism on PET or SPECT

IV. Behavioural variant FTD with definite FTLD Pathology

Criterion A and either criterion B or C must be present to meet criteria.

- A. Meets criteria for possible or probable bvFTD
- B. Histopathological evidence of FTLD on biopsy or at post-mortem
- C. Presence of a known pathogenic mutation

V. **Exclusionary criteria for bvFTD**

Criteria A and B must be answered negatively for any bvFTD diagnosis. Criterion C can be positive for possible bvFTD but must be negative for probable bvFTD.

- A. Pattern of deficits is better accounted for by other non-degenerative nervous system or medical disorders
- B. Behavioural disturbance is better accounted for by a psychiatric diagnosis
- C. Biomarkers strongly indicative of Alzheimer's disease or other neurodegenerative process

*As a general guideline 'early' refers to symptom presentation within the first 3 years. Table reprinted from *Brain*; permission granted to AFTD from Copyright Clearance Center.
Rascovsky K et al. *Sensitivity of revised diagnostic criteria for the behavioural variant of frontotemporal dementia*. Brain. 2011 Sep, 134(pt9): 2456-77. Epub 2011 Aug 2.

BENEFIT OF DIAGNOSIS

There is an unexpected benefit that comes with a diagnosis of FTD. You can be sure this is not your fault, there is nothing that you did wrong and nothing that you could have done would avert or defer the onset of dementia. You can also avoid inappropriate medications.

TIMING OF DIAGNOSIS

Diagnosing dementia earlier would be a great help to many people, especially to carers who incur great delay and expense seeking an explanation and treatment in the hope of a cure.

There are screening tests (ACE-R, MBI-C and others) which seek to detect dementia earlier. These are helpful when dementia is suspected or when carers report symptoms which are recognised by a practitioner as perhaps being caused by dementia.

There are signals which might trigger the concern of an alert carer or their doctor. Those signals can be hard to spot because they are highly diverse, such as a change of gait, a change of the LO’s mode of expression towards indefinite word choice such as “thing” in lieu of many nouns, “horrible” or “disgusting” in lieu of many adjectives, or lost inhibitions such as excessive spending, frequent gifts, porn or sex obsessions and many more.

For another category of carers, the problem of delayed diagnosis takes a different path. At the time I retired from work, all I could say about the reason was that "Carole needed more help at home". There was no thought that a fatal disease was the cause, and I had never then heard of FTD. For us, the issue was not initially even a search for a cause. Later, a relative likened some of her symptoms to Alzheimer's. By the time Carole was eventually tested by a neurologist, I had a well-rehearsed description of her symptoms (which turned out to be typical of svPPA (Semantic Dementia). But that was about twelve years past onset of the disease.

ISSUES ARISING FROM A DX OF FTD

There are two things I want to kick and scream about the practice of diagnosing FTD.

First, the Diagnostic Criteria Chart accurately reflects the most common current practice. Notice that it requires for a dx of ‘Probable bv FTD’ that all three mandatory conditions A,B and C are met? Notice that C requires imaging results consistent with bvFTD? The problem is that magnetic resonance imaging (MRI) does not portray damage until neurons dissolve in a significant volume and that can be long after symptoms are present. This modern, increasing reliance upon scans is a conservative practice which considerably delays dx.

Second, all practitioners and carers know there is no objective test for FTD until autopsy. The best diagnosis of FTD presently possible is symptomatic. When cognition and behaviours are impaired and the trend shows decline, carers should accept that treatment and care should proceed as if FTD is diagnosed. But if a practitioner states only "behaviours are consistent with a dx of FTD" then carers are unreasonably denied a diagnosis. This practice compounds the problems of families suffering FTD. It denies them proper validation, leaving family disagreements about care unresolved. It denies them grounds to have driving licenses reviewed. It denies them eligibility for some insurance, veteran and welfare support. It does harm to the patient and that is inconsistent with the practitioners' duty.

I will always urge carers to challenge practitioners who delay diagnosis by these practices. My wife Carole's dx and eligibility were delayed by a year before I learned enough to advocate effectively. It would have been delayed longer if I had not learned to be effective.

Doing more scans has been the response to reduce the error rates in diagnosing dementia, yet outcomes are still poor. Later and poor. I sympathise. Nobody wants to issue a dx of a fatal disease and be found wrong. But much damage is being done to vulnerable patients and their families by the current, worsening, delays.

Bilingual Patients

Dementia-related language symptoms differ in Italian and English speakers, study finds.
University of California - San Francisco

Neurologists had long assumed that brain diseases that impact language abilities would manifest in essentially the same way in patients around the world. But recent discoveries have begun to question that assumption. For instance, Italian speakers with dyslexia tend to have less severe reading impairment than English or French speakers due to Italian's simpler and more phonetic spelling.

English and Italian speakers with dementia-related language impairment experience distinct kinds of speech and reading difficulties based on features of their native languages.
The new study, published January 10, 2020,... focused on patients with non-fluent PPA...
English speakers had more trouble pronouncing words -- the traditional hallmark of nonfluent PPA -- and tended to speak less than usual. In contrast, Italian speakers with the same disorder had fewer pronunciation difficulties but tended to produce much shorter and grammatically simpler sentences...

The results are important for efforts to ensure accurate diagnoses for patients with PPA across different cultures: in the current study the Italian speakers do not match the established diagnostic criteria for nonfluent PPA as closely as the English speakers, since the criteria are based on studies of

English-speaking patients.

"This means that there are probably many people around the world -- including non-native English speakers… who are not getting the right diagnosis because their symptoms don't match what is described in clinical manuals based on studies of native English speakers," said Gorno-Tempini.
https://www.eurekalert.org/pub_releases/2020-01/uoc--sbd010820.php

Testing for Symptoms

Frequently, the go-to test for patient cognition is the Mini Mental State Examination, MMSE. It takes about twenty-five minutes, is easily scored on the spot and it produces a score out of thirty. That score is compared against a scale of results for a given population.

MMSE is a blunt instrument when used as a test for dementia. A person who is really smart can pass it despite having dementia. A person who is not so clever might fail it without having dementia. So, its accuracy is poor, even if it is used as an initial screen.

MMSE compares to a population average. As you already know, that is not the recommended way to diagnose dementia, which is to compare a patient's present results with previous results to detect a declining trend.

And MMSE is better at detecting Alzheimer's Disease than it is at detecting other dementias including vascular dementia and the FTDs (for which it is very poor).

MMSE is so commonly used because it is quick. For the most extreme contrast, a full battery of neuropsychological test instruments selected for a particular case can take days, requires very rare expert resources, requires the cooperation of carer and patient (which cannot be presumed). Even then, a battery of neuropsych tests produces only results which are compared with a population average. It needs at least two such batteries to produce a patient trend. Sometimes, a score sufficiently below the expected range will persuade a testing physician that it should be read as "decline".

The world has many innovative tests. Several, including ACE-R, are more effective than MMSE when used as a screening test for cognitive dementia. The Addenbrooke's Cognitive Examination – Revised (*ACE*-*R*) is a brief cognitive dementia screening *test* battery.

You can download ACE-R at:
http://www.stvincents.ie/dynamic/File/Addenbrookes_A_SVUH_MedEl_tool.pdf

Another superior short screening test is the ACLS Allen Cognitive Level Screen.
Here is a site on the ACLS. https://allen-cognitive-levels.com/...t-levels-of-allen-cognitive-test-results.html

Problems:

1 Conducting psychometric testing first requires SUSPICION of cognitive or behavioural abnormality. By the time suspicion is aroused, damage from the onset of the disease has already caused symptomatic decline in the health of the patient and probably in the family relationships.

2 Testing requires COOPERATION. Patients with anosognosia (most) and those with some obsessions (few) are likely to not cooperate. There are caregiver skills which will often gain cooperation, discussed later.

3 Testing requires REPEAT(s) to establish a trend of declining patient symptoms, necessary to meet the cognitive diagnostic criteria. You get to do all this fun again !

“We diagnose Alzheimer’s Disease too late,” Dr. Stephen Rao at Cleveland Clinic’s Lou Ruvo Center for Brain Health. “For most people, the disease is probably going on for ten, 15 years before they’re diagnosed.”
https://www.beingpatient.com/worrie...are-the-questions-you-should-ask-your-doctor/
And "ten, 15 years" from onset to dx is for Alzheimer's Disease!

Alzheimer's Disease is effectively screened using MMSE, but the other dementias including the FTDs are not detected effectively by MMSE. The other dementias are further delayed before dx.

When to say “Stop”?

How do you settle into a diagnosis and stop looking for another answer?

When you track the symptoms long enough, eliminate other possibilities and research the diagnosis until you reach personal satisfaction. A diagnosis of

FTD is an opinion based on the observation of the symptoms. It requires reduced cognition and progressive decline over time.

Can there be no sign of damage on the scan and still be FTD?

Yes. FTD symptoms are exhibited when neurons first start misfiring because of intermittent interruption by protein accumulation. Only after blockage becomes permanent, and many neurons die and dissolve is atrophy eventually evident with a MRI to an extent inconsistent with normal aging.

They want to do a PET or SPECT scan. Should we?

These new scans illustrate brain activity in response to a known, recorded stimulus. A profoundly diseased brain will exhibit unusual and distinctive activity patterns different from "normal". It is increasingly common that these scans are recommended as ways to "confirm" a diagnosis of a particular variant of dementia. There is no guarantee that the result will be conclusive because the activity patterns may not appear abnormal until the disease reaches the middle stages of a dementia journey.

Abnormal behaviours will usually be exhibited well before PET or SPECT scans illustrate marked variation from normality.

There is no one answer to the question of whether you should proceed. Some patients are much more tolerant of appointments and tests than others. The most important factor in your decision is your own confidence in the diagnosis or tentative diagnosis. If you have done a battery of neuropsych tests which indicate FTD and you have reached satisfaction that the symptoms you have experienced are consistent with FTD and you have done an MRI to rule out any operable cause, it is perfectly reasonable to stop pursuing more tests.

What the carer can do to advance diagnosis:

https://www.youtube.com/watch?v=aJOVj5nEWuc

Carers seeking to discover what is wrong with their LO are often frustrated, not knowing whether they are dealing with anxiety, depression, a mental health issue or something else. You set off in search of something you expect can be cured.

Diagnosis of dementias requires clinical evidence of reduced cognition (measured by neuropsychological tests) and a declining trend (if you do not present evidence of a declining trend, they will likely seek to observe it themselves in a subsequent appointment, so it pays to have a document listing typical behaviours in a Was/Is contrast). Your objective is to best present the long term observations of the patient's family over a long period of time~~,~~ to provide examples of the symptoms and to draw out illustrations of the trends. And to devise some way to get the patient to participate.

The practitioners you consult lack your history and perspective of LO’s trends. Your first and greatest task is to quickly outline that history. Because your LO may be greatly offended or embarrassed to have these stories discussed in his or her presence, it should be done in writing in advance of an appointment. Your letter needs to contrast the before and after symptoms, with a time frame.
You need to address several categories, behaviours, memory, language, apathy and relationship changes. If there are changes in diet, energy etc, include a category for each.
Try to hold the total description to one page, not too tightly packed.

When you have an opportunity to present them to a diagnostician, you are likely to need to make a good, quick first impression.

Keep up a journal of LO behaviours. Keep it daily if possible, but with brief examples.

Getting your LO to an appointment

Some people with FTD resist cooperating in attendance at medical appointments.

The NIA.NIH has tips for attending appointments:

https://www.nia.nih.gov/health/doctors-appointments-tips-caregivers?utm_source=NIA+Main&utm_campaign=0012a66e46-20200213_caregivingdocvisits&utm_medium=email&utm_term=0_ffe42fdac3-0012a66e46-18468599

but they assume that the presence of dementia is known and they do not well deal with a patient’s failure or refusal to cooperate.

Reasoning with a person with dementia does not work. Because of their fading communication skills, they are likely to feel they are being persuaded or manipulated. That may set you up for complete refusal which would make your task even harder. Many carers have had difficulty getting their LO into an appointment or to a care place and have had to use ‘loving deception’ to get cooperation with getting in the car and to the facility. This activity is difficult for a caregiver to accept. Essentially, it makes for greater peace, less anxiety and better health outcomes for the LO. (The subject is discussed in Book 3 Tips For Communicating.)

A common example is to attribute the appointment to another reason, possibly another health condition that the LO is keen to address. Possibly a blood test/pathology might be the working ploy (loving deception) proffered to get cooperation for the tests that actually need to be done.

Your own communication tone should be pleasant and matter-of-fact, avoiding any suggestion this is a big deal. Say whatever you have to do to get cooperation.

Choose your timing to discuss the subject. Pick a time when the cooperation fairy has left a fresh sprinkling of magic pixie dust.

Consider using your allies. Can another family member(s) get a better a outcome for this task? Consider sharing your problem with clinic staff It is typical that hospital staff underestimate the difficulty of getting patients to venues for more testing and getting their cooperation, but you could get lucky, or perhaps they have a social worker who can help?

In the most extreme cases, it would be impossible to convince an uncooperative spouse to go to any such appointment using any direct approach. Then, don't even try. Use an indirect approach for nearly everything. Anything that flatters the LO or fits in with his worldview that he is fine. It may be to help you, or to help with research, or perhaps just as a routine checkup, to get a baseline from a doctor who works with your GP - any of those allow the LO to hold onto his narrative that he's fine. Desperate to gain LO’s cooperation with testing, some carers offer to undergo testing themselves.

Reaching Diagnosis of dementia

“Your spouse has (…) Dementia.” What next?

This will probably be said in front of your spouse who may understand little, but some. Whatever you can do to provide reassurance and restore normality is your first priority.

Soon, your mind will turn to who needs to be told, and how. This will be difficult if, as often happens, family members have become divided about the behaviours and the care of your spouse.

You will have your priorities and there will be people who need to be told personally or by phone. But when it comes to the facts and details, I am an advocate one email to everybody, multi-addressed. Then they all know at the same time, they all know the same information and they all know which others know. It can save a lot of confusion and conflict later in the caring journey.

Later in the FTD Journey

Should your LO be diagnosed with dementia, you need to know what is in store. Some diagnostic specialists may tell you, but some do not.

Typically, by the time a patient reaches a diagnosis of FTD, the disease has reached the mid stages of its progression. Diagnosis may come ten or twenty years after the onset of the disease because symptoms are slow to develop and to become recognised as trends. It is not only the symptoms of dementia which become more apparent over this time. The relationship with the caregiver suffers damage concurrently, for reasons not correctly recognised or understood until diagnosis provides some explanation. That relationship damage may not be wholly reparable. An intimate spousal relationship may develop into a caregiver role. Divorce may have occurred at the instigation of either party.

A person with FTD is losing some abilities to think. At the same time, emotions may be inappropriate but some run at full strength. That combination causes confusion, disorientation, mood changes and apathy. Over the course of the journey with dementia, additional portions of the brain come under attack. The symptoms experienced tend to merge, with progression, across the different variations of FTD.

Eventually, if the patient survives the many risks and hazards which arise from their failing cognition, their brain loses the ability to maintain the most basic bodily functions. Their speech deteriorates. They lose continence. They lose the ability to rise or walk. They have difficulty swallowing which may trigger aspiration pneumonia. Eventually, vital organ failure brings death.

PROGRESS?

This is small progress, but in the right direction, I think:
https://www.mdmag.com/peer-exchange...ommendations-for-diagnosing-alzheimer-disease
Is there a conceptual framework that you use to approach the diagnostic process that you would recommend?
Bradford C. Dickerson, MD: "Yes...
Currently, I think we advocate for a 3-step framework that starts by

describing the person’s overall cognitive functional status. What we mean by that is, does the person have mild cognitive impairment? Does the person have dementia? Maybe they don’t even have mild cognitive impairment. Maybe they have some subjective cognitive decline that they feel they’re experiencing. And when Dr Shaughnessy tests them, they perform normally on neuropsychology tests. So in the beginning, we don’t always need neuropsychology. What we really need to do is interview the person ***and, ideally, an informant***, and find out what they are lacking in terms of independent functioning. What have they lost? What do they need help with?

“... if you, as the care partner, can leave the person and go on a trip for a weekend or a week, would they function independently in daily life? If the care partner says, “No, I would never do that,” you can pretty comfortably say that the person probably has crossed the threshold into dementia. I think that’s the starting point, No. 1.

“No. 2 is, what’s the particular cognitive behavioral syndrome that the person is experiencing? ... Is the main problem executive function? Is the main problem language? Are there multiple problems? A lot of times we see, I think, this common presentation of a person who has memory loss. They’re just not holding on to information, and they also have executive dysfunction. They’re not able to reason. They’re not able to perform tasks to the level that they used to be able to in order to get the job done to reach goals in a valid way.

“And then the third level is, what’s the brain disease that is the cause of the problem?”

PREVALENCE

How prevalent is dementia in Australia? Australia does not have national data that can provide reliable prevalence estimates of dementia. Internationally, less than 40% of OECD (35 major industrialised nations in Europe, the Americas, and the Pacific) countries have national rates of dementia diagnosis, and only two countries—Denmark and the United Kingdom—have specific targets to improve the rates of dementia diagnosis....
About 0.1% of the population under 65 years of age has dementia, compared with about 5.2% of the population aged between 65 and 70, and 28.8% of the population aged 85 years or older. The prevalence increases to 41% for those over 90 years of age....
While acknowledging the lack of national data, the Australian Institute of Health and Welfare estimated that, in 2018, about 376,000 Australians had

dementia and 61% of people with dementia were female. Dementia Australia commissioned research from the National Centre for Social and Economic Modelling which suggested that in 2019, 447,115 people live with dementia, with the majority of these people being women....

https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-3.pdf

The paper cites estimates (conducted by the University of Washington) of prevalence of dementia in Australia by age and gender but the estimates have very large accuracy intervals at 95% confidence because the quantity and quality of comprehensive data is poor. This is not uniquely an Australian problem. We have only a crude idea of how many people we are trying to care for.

Our Royal Commission knows and reports (2020):
"Australia’s population is ageing and there are increasing numbers of older Australians living with dementia."
Quite simply, we die more often from dementia which has no cure than we did in the past because cancer, heart disease, tuberculosis, whooping cough etc were greatly cured in the 20thCentury.
What is hard to measure is whether the age-specific rates of dementia are changing. That is only hard because dementia is not yet accurately diagnosed nor reported.

Pledge to 'detect cancer and dementia BEFORE symptoms'

https://www.express.co.uk/news/uk/1...o-general-election-dementia-cancer-brexit-spt
This is a Great British objective, though funding is scant.

We have heard researchers talk before about a new approach to advance the diagnosis of dementia.
This is the first time I have heard the idea endorsed by a prominent politician. And it is done in the circumstances of a closely contested election.
Of course dementia is currently diagnosed by analysis of the symptoms, so it currently must await the development and recognition of symptoms and the diagnostic queues, overcome patient non-cooperation etc. The attempt to diagnose dementia before symptoms appear is radical and requires a wholly different mindset examining biomarkers in an exploratory way in people who are not symptomatic.

Until now, our best advice received and given has been to be alert to the early warning signs of dementia. Memory lapses, wordfinding difficulties or errors, odd behaviours out of character. That is, we carers were advised and we advised others to understand and be alert for the exhibition of early symptoms.

Of course we are almost always unfamiliar with the symptoms of dementia, so we are poor observers and poor judges. We discount our observations as being isolated examples. Until they become patterns and trends and we hear the observations of friends, family, doctors etc and we pursue dx.

In all of these endeavours, we have been seeking to identify dementia after its onset by the observations of symptoms and trends.

In the article linked above, Professor John Bell said: “The Accelerating Detection of Disease programme will ... research ... early diagnosis and help us shift the standard in healthcare forever. We have a vision to live in a world where you ***prevent disease rather than treat it too late***."

I have to say, having watched for about 20 years in a world of little effective treatment for dementia, administered too late, the vision is highly appealing. This particular program involves a lot of genome sequencing and artificial intelligence. It will mean the analysis of biomarkers in people who are not symptomatic. There are troubling implications and not only for the maintenance of privacy.

Should an apparently healthy young person allow the intrusion involved in a sub-molecular investigation of their person? Will they be allowed a choice? Given the option of participating in screening, for cancer or dementia, some would opt out on grounds including they are not confident in the accuracy of results, they would refuse the treatment if they are found susceptible, or they would rather get on with living and not hear bad news.

Is there a better way to pursue the vision of preventing dementia? Not yet. We do not know nearly enough about the biology of the disease. We know little about how or why genes mutate. We know little about what mutations and repeats produce which proteins and misfolds. We don't know what other biological triggers are involved, only that some of them (diet, exercise, strokes, concussions, TBIs etc) appear to not be genetic.

The World Dementia Council is intended to be a coordinator of these issues. But it is now painfully aware that time is running out and progress is lagging. It has not found the vision, focus or discipline to get on track to achieve its goals.

Is genome sequencing and artificial intelligence the only way to pursue the vision of preventing disease?

No.

Is it the best way to pursue progress? Other researchers are pursuing alternatives (protein formation, folding, clumping and others) and those would be very welcome.

Genetics of dementia raises many issues including privacy.

It is a fascinating and favourable development that the avoidance of dementia has reached a political prominence sufficient to become an electoral pledge. That is new and I believe a welcome development, regardless of which political candidate raises the subject. We have long begged for more government attention to those suffering this disease.

FTD- case examples of a journey

Most dementia carers are spared the worst of rages and accusations. These following stories are recounted here because there is much to be learned from the experiences of others, but FTD carers typically are isolated from other carers.

These stories do highlight the positives of their respective journeys and yes, those are the perspectives that the major association sites are keen to publish.

We all must find our own course through the particular challenges we encounter. The wide range of carer experiences sampled here provide precedents for most carers, but there is something unique about every single story.

There are many who experience delayed diagnosis. The extent of the delays and the problems caused to families are very great.

With Anne by his side, Geoff spoke to doctors, GPs and specialists about his symptoms and it took 14 years before he was formally diagnosed with frontotemporal dementia in 2005.
‘Doctors dismissed my husband’s dementia as anxiety and depression’
https://startsat60.com/health/healt...ry-misdiagnosed-frontotemporal-dementia-carer
This is not just a story of a diagnosis, but a carer journey too.

Another individual dementia journey. This story from an Australian daughter.
"...it is profoundly underestimated just how much burden lies with a carer. It is very isolating and demanding"
www.dementiadaily.org.au/family-story-shared-by-dementia-advocate/?utm_source=eNEWS&utm_campaign=f922cc025a-EMAIL_CAMPAIGN_2019_10_14_12_43&utm_medium=email&utm_term=0_1e20c6d0c3-f922cc025a-123063321

Another individual account published, this by a son dealing with the degeneration of his father from FTD.
https://bowdoinorient.com/2019/10/25/the-descent-into-the-abyss/
This journey shares a troubled, protracted course to diagnosis.

A nurse, bride, wife, and the mother of a baby boy. At 29-years-old, Kara Kirby of Paris, Illinois looked to have it all.
https://www.wthitv.com/content/news/FTD-Beyond-the-Reflection-Part-1-564104931.html
After more than a year and a half of testing, doctors diagnosed Kara with FTD. At 29-years-old.
I am grateful to the brave families who publish their stories to help others.

"the truth of the matter is - she already had the illness"...at 29yo.
https://www.wthitv.com/content/news/FTD-Beyond-the-Reflection-Part-2-564176741.html
Part 2 of the Kara Kirby story.

Barbara Bamford, mum of two daughters, diagnosed with FTD, and placed in residence in mid stages, aged 35 !
https://www.mirror.co.uk/news/uk-news/family-heartbreak-mum-diagnosed-dementia-20796965

"Dear editor ..." How a letter about one family's dementia plight helped millions
In 1979, a reader wrote to the Observer about a 'sad, quiet, epidemic' that had destroyed her family. Her plea led to the foundation of the Alzheimer's Society
/2019/nov/03/alzheimers-society-40-years-old-dementia-needs-more-funding

At 66, Bob Karger was losing language. It was not the tip-of-the-tongue feeling that melts when you recall a sought-after word. He had lost the connection between sounds and meaning — the way *ba-na-na* recalls a soft, yellow fruit or *ea-gle* calls to mind a large bird of prey. In a recent conversation, he had thought acorns grew on pine trees.

Mr. Karger did not know how to use items around the house, either. When he picked up a can opener, he would not realize it could remove the top from a tin. If he held a hammer, he might grasp it by the head, turning it around in his palm, not knowing he could swing it into a nail. His world was filled with incomprehensible items.
https://www.nytimes.com/2019/11/07/well/mind/frontotemporal-dementia.html
Since brain areas that dictate personality are often the first to suffer, most people/carers end up on a therapist's couch long before finding their way to a neurologist.
For Ms. Karger, most days feel like a dress rehearsal for widowhood. People with frontotemporal dementia sometimes live a decade after their diagnosis, so caregivers experience years of progressive mourning. "This grief is not official," Ms. Karger wrote in a speech she gave to fellow caregivers. "Casseroles do not appear at the front door, flowers are not delivered, condolence letters are not received."

"We got married in 1991 and we have two amazing kids together," Scharper said.

In 2008, Nash started to change.

"We started to see some personality changes, along with some behavioral changes. We didn't know what quite was going on. We thought it was going to be severe depression and we were treated with medication," Scharper said.

But Nash's symptoms only got worse. It wasn't until 2015 when they finally got an answer.

"We were diagnosed with frontotemporal dementia," Scharper said.

"It's primarily a personality change," said Dr. Brad Boeve, a neurologist at Mayo Clinic in Rochester.

"It's really a devastating illness. And to have no therapies that are even remotely effective has been very disappointing," Boeve said.
https://www.kimt.com/content/news/The-Battle-Against-FTD-564581401.html

It started with minor verbal slip-ups. Forgotten names. Rambling sentences. Gradually, the little things became long voicemail messages and persistent confusion.

I haven't heard my grandfather say my name in a few years. He knows me as 'that girl in that city.'

My grandfather has **Primary Progressive Aphasia** (PPA), a type of frontotemporal dementia. Degeneration of the frontal or temporal lobes in the brain include brain tissue that is crucial for speech and language.

The first symptoms of PPA are subtle difficulties with communication. The type or pattern of the language deficit differs from patient to patient. https://usmfreepress.org/2019/11/18...hers-battle-with-primary-progressive-aphasia/

Olive Munro, 69, who was diagnosed in 2015, and her husband Ronnie tell their story in a film for the Dementia Uncovered campaign.

Olive, 69, who lives in Ardtalnaig on the south side of Loch Tay (Scotland), says she knew little about **Vascular Dementia** when she was diagnosed.

She is helping raise awareness of this form of dementia which occurs when blood vessels in the brain are damaged, reducing blood flow to brain cells and affecting how they work. https://www.thecourier.co.uk/fp/new...ent-she-was-diagnosed-with-vascular-dementia/

She's always been happy, cheerful, friendly, social. Fun-loving. A little bit ditzy but I found that adorable," George said. "Probably 10 or 12 years ago, she started developing these compulsions like compulsive gambling, compulsive shopping, compulsive spending, compulsive eating."

He said he thought she was going crazy, but found information on FTD and realized it fit.

"Stephanie's case is really unique in that it's brought out this personality. This really kind and caring and loving personality that she probably always was but it's really exaggerated."

"She'll go around giving people money or she'll go around telling people that she loves them, revealing this underlying compassionate personality."

https://www.fox5vegas.com/news/loca...cle_1e6ea798-0cbd-11ea-b502-b7d2d72b6aff.html

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David Baddiel opens up about his father‵s dementia ordeal
His father‵s brash personality – which David adds always included a lot of swearing – has been heightened to a degree that has proved uncomfortable for David.

This has resulted in sexually inappropriate remarks that he doesn‵t want his children, Dolly, 15, and son Ezra, 12, in particular to hear – and so temporarily stopped them from seeing him.

‵I‵m always trepidatious about going to see my dad, particularly with anybody else,‵ he explains about Colin‵s difficulty meeting people.

‵He says a lot of sexual stuff, it’s inappropriate, we can’t take the children, they don’t want to go anyway.
https://insiderfinancial.net/david-baddiel-opens-up-about-his-fathers-dementia-ordeal.html

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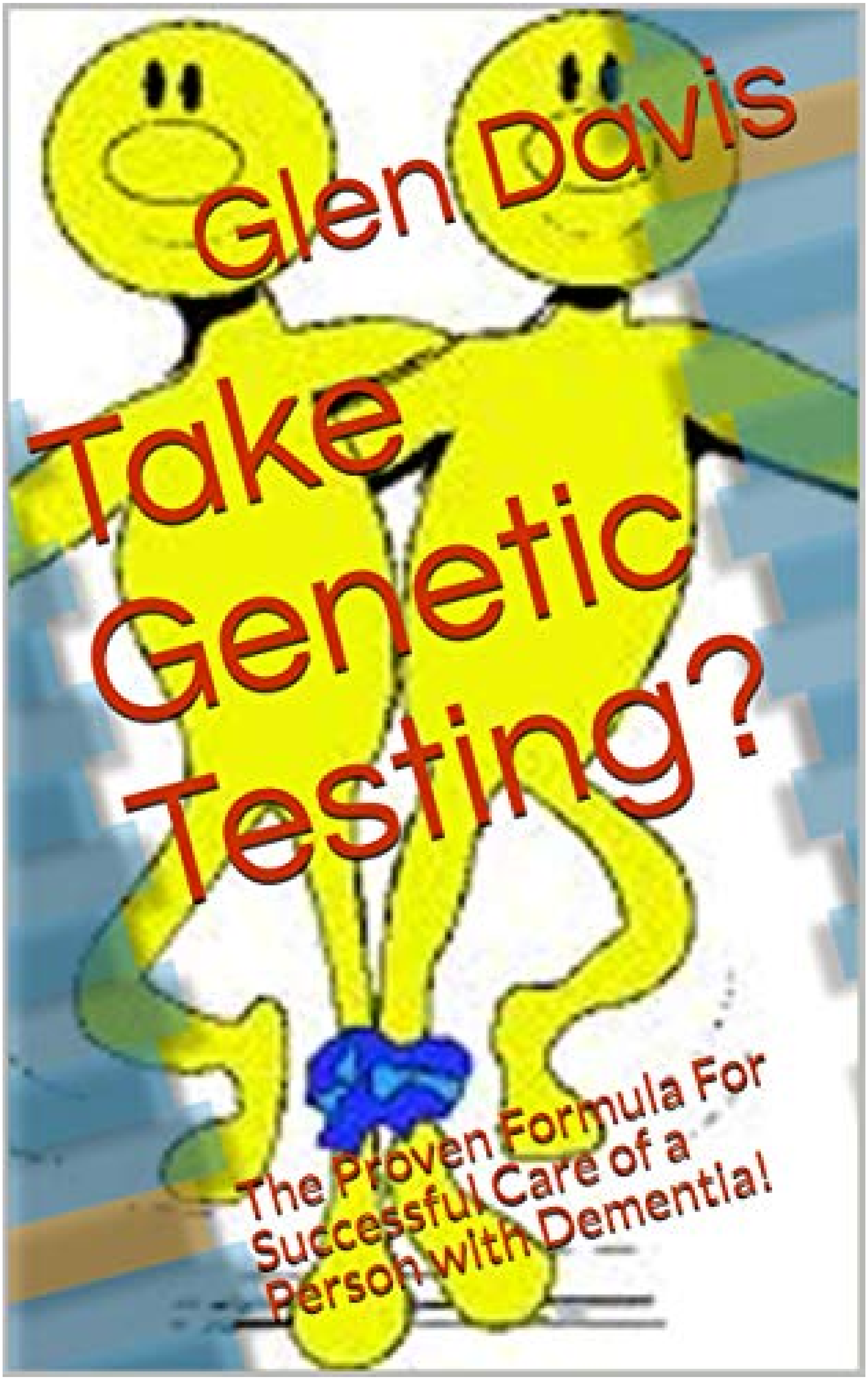
STOLEN FUTURE
Some published case studies for FTD. St Louis Post-Dispatch, 2019.

A pamphlet UCSF prepared for health care providers; at page 3, it describes the *diagnostic process.*


Glen Davis
Take Genetic Testing?
The Proven Formula For Successful Care of a Person with Dementia!

Take Genetic Testing?

The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 5) 2nd Kindle Edition

This guide is not intended to influence your decision whether or not to take genetic testing. That is a choice you should make after taking expert genetic counselling and carefully considering your own objectives and circumstances and the other people who may be affected by your decision. Its purpose is to ensure you take an informed decision, knowing the facts and consequences.

Why consider genetic testing? Genetics has no part in the diagnosis of dementia (see Book 4, page 3 for the Diagnostic Criteria). But there are several of genetic mutations that have been discovered to increase the risk that a person may contract dementia. That previous sentence is very carefully accurate because there are too many statements published on this subject that are careless and irresponsible. Let me emphasise that the discovery of a genetic mutation known to be associated with dementia in a person (or that person's parents, children or siblings) does not infer that the person will get dementia. What it does mean is that the risk is greater than in a person without that genetic mutation.

At the time of writing in 2020 there are a handful of genetic variations linked to heightened risk of dementia. The three most often discussed are C9ORF72, MAPT or GRN. Rarely, risk arises from an illness-related **mutation** in one of other **genes**: TARDBP, VCP, CHMP2B, SQSTM1, UBQLN1 or TBK1 and it is widely assumed that more will be discovered. That is important because it means that any tests currently done can search only for the presence or absence of one or more of that known list of mutations. So no current test can assure you that you do not have a genetic variation which heightens your risk of dementia. It also means that a test done which searches for the presence of any of the known list of mutations related to dementia may have its results superseded by the discovery of a new mutation.

Some people consider genetic testing because, for example:

1. they have reason to inquire about a particular gene. For example, they may have a parent whose autopsy revealed a C9orf72 mutation, and they wish, having taken comprehensive genetic counselling, to determine whether or not they inherited that particular feature. In that case, their question is more closely aligned with one that good quality genetic testing can answer; or
2. they have the behavioural symptoms of bvFTD, but the atrophy pattern displayed by MRI scan does not match the classic expected

pattern. Genetic testing might then add a clue to help determine a diagnosis. Such an outcome can be very beneficial for families because it can end their long search for answers if a diagnosis can be supported.

3. They have reason to inquire about a particular gene which is undergoing trial for gene therapy aimed at slowing or stopping the progression of dementia. One such current trial examines the ALS side of C9orf72. Another seeks to deliver a healthy GRN gene which, when mutated, produces reduced level of progranulin, a protein critical for lysosomal function, neuronal survival, and normal microglial activities.

A function of human genes is to produce proteins for use elsewhere in the body. Different genes produce different proteins. When the genes mutate, varying from their normal sequence by repetitions, they can produce proteins that vary from their normal shape (said to be 'mis-folded'). Whether the mutated genes do or do not produce misfolded proteins depends on other unidentified biological factors (sometimes referred to as triggers) which may or may not be genetic.

If and only if a trigger is activated, misfolded proteins are produced by the mutated genes. Those misfolded proteins take shapes that more readily aggregate in clumps or 'tangles. They are carried in the bloodstream and cause no problem until they reach the brain. Within the brain are very narrow intervals between neurons (nerves) and synapses which carry electrical signals to other parts of the brain. Those signals find words, recognise shapes and sounds, trigger emotions, make judgements, apply inhibitions, and all the other processes that control our actions. Those narrow intervals between neuron and synapse can be interrupted temporarily or permanently by aggregations of misfolded proteins.

When misfolded proteins are present, certain parts of the brain come under attack in the form of blockages of neurons. Different proteins have a disposition to attack first in different parts of the brain, so there is a correlation between certain genetic mutations and related types of dementias. The correlation is not perfect for reasons that are not wholly understood but include the likelihood of multiple genetic mutations complicating the outcomes.

The action of the misfolded clumped proteins is first to interrupt the electrical signal emanating from the neuron, like a sparkplug misfiring. That might lead to a delayed decision, a word not found or many other imperfect outcomes. Initially, the errors are rare, the behaviours are intermittent and mostly go unnoticed.

In time, which varies greatly from months to decades, the proteins permanently block some neurons which then die and dissolve. The brain seeks other routes to send its messages and initially it often finds them. This is termed 'plasticity'. It takes longer and its performance is variable for reasons including the person's state of arousal. Sometimes the brain succeeds in a millisecond and the outcome is perceived as normal. Sometimes it takes longer and the outcome may be perceived as 'thoughtful' or 'deliberate' or 'ponderous'. Sometimes, a person in heightened arousal may be quite unable to communicate or decide and they become prone to dangers arising. And sometimes the brain fails. The person loses the thought or cannot execute the action.

Only when masses of neurons have totally failed, died and dissolved is the result of the dementia visible on an MRI scan. It may be years or decades after the onset of dementia that the scan first produces evidence inconsistent with normal ageing. Different dementias tend to produce different characteristic shapes of brain atrophy, recognisable by practitioners.

What is the motivation for genetic testing? People arrive at this question from different directions and those reasons are important for the decision process of whether to undergo genetic testing and whether to be informed of the results (two separate questions).

What will genetic testing tell you?
If you choose to be informed of the results, genetic testing for dementia can answer one of two possible questions. They are:

1. **Do I have a mutation of a specific gene** (e,g. C9orf72). This might be relevant if, for example, a parent or sibling died of dementia and a genetic test established the presence of that particular mutation.
2. **Do I have a mutation of any of the genes known to present a heightened risk of dementia?** This might be relevant if, for example, there is a family history of dementia and either no genetic testing or genetic testing with different outcomes.

Genetic testing can establish additional information, including, for example, the number of repeats of certain genetic variations. That additional information may be useful in quantifying the presence of certain heightened risks.

What genetic testing will not tell you?
These are some of the possible questions you may have which current genetic testing cannot answer:

1. **Do I have any genetic factors which increase my risk of dementia?** Testing can only look at specific genes. Because the complete list of genes which affect dementia is unknown and more are expected to be discovered, genetic testing cannot answer.
2. **Will I contract dementia?** Genetic testing cannot determine whether or not a biological trigger is present which is necessary to cause the onset of dementia. Those triggers are not identified and may or may not be genetic.
3. **Will any of my first-degree relatives (parents, children or siblings) contract dementia?** Each of your relatives inherits different combinations of genes from the same parents, so your testing cannot answer for any of your relatives. Genetic testing cannot determine whether or not a biological trigger is present which is necessary to cause the onset of dementia. Those triggers are not identified and may or may not be genetic.

Should I get genetic testing done?

Genetic testing answers only the question whether a specific gene mutation is present. It does not answer the patient's most common questions which are whether you and your relatives will contract the disease.
Genetic testing produces data which are extremely sensitive from privacy perspectives and which can produce untold grief in the wrong hands~~,~~ or if interpreted from a perspective of little knowledge.
There are people who have benefited from conducting genetic testing, even when the results confirm the presence of a genetic mutation associated with dementia. An example is a case where a person showed the distinctive symptoms of bvFTD. However, the MRI scan did not closely correspond to the classic pattern of atrophy and the family could not be certain of the cause of the symptoms. Genetic testing confirmed C9orf72 mutation consistent with bvFTD and allowed the bvFTD diagnosis to be confirmed.
The first benefit arising for the family was they no longer had to research other possible causes. Knowing the cause allowed their efforts to be focused on coping with behaviours and preparing for degeneration. A second benefit arising is that C9orf72 is also a cause of a related disease, ALS. There is research being conducted seeking to halt the progression of ALS by means of gene therapy. There is value in the opportunity to participate and benefit if the research succeeds.

Whether or not genetic testing is advisable depends greatly on whether the answer to this question is valuable to the person:
"Is there present one of the genetic mutations known to be associated with dementia? If so, with what repeats and penetrance?" Because these are the only questions truly answered.

Whether to undertake genetic testing is a choice you should make after taking expert genetic counselling and carefully considering your own objectives and circumstances and the other people who may be affected by your decision.

WHO, WHERE, WHEN? Quality Counselling Privacy Risk of leaks. Genie out of bottle.

Should I choose to be informed of the outcome of genetic testing?
If the question did not occur to you to ask, consider this : 65% of people who had genetic testing done chose subsequently to not be informed of the result. Some changed their minds. Others always intended to not be informed because they wanted the results stored for use by others, typically their children or siblings, but did not want to be informed because they did not want the results to influence how they lived their lives.

REPORTED EXAMPLES OF GENETIC TESTING

"A young mum was left feeling 'kicked in the stomach' when told she has inherited a rare form of dementia.
"Thirty-five-year-old mother-of-two Hannah Mackay underwent tests when both her father and grandfather were diagnosed with the same form of the disease - frontotemporal dementia - in their mid 50s.

"Now it has been confirmed that Hannah, who lives near Haywards Heath, will also develop the disease."

https://www.midsussextimes.co.uk/ne...heath-mum-35-devastated-by-dementia-1-8999649

Of course the result of the genetic tests merely concludes that Mrs. Mackay has inherited the genetic mutation from her paternal line. That is not a sufficient cause to predict that she will develop dementia.

We must hope that her genetic counselling is more competent than this report. The report was based on a release from the Alzheimer's Society which, among other things, states:
35-year-old Mum from Haywards Heath unites with Alzheimer's

Society to find dementia cure after being told she will develop the condition

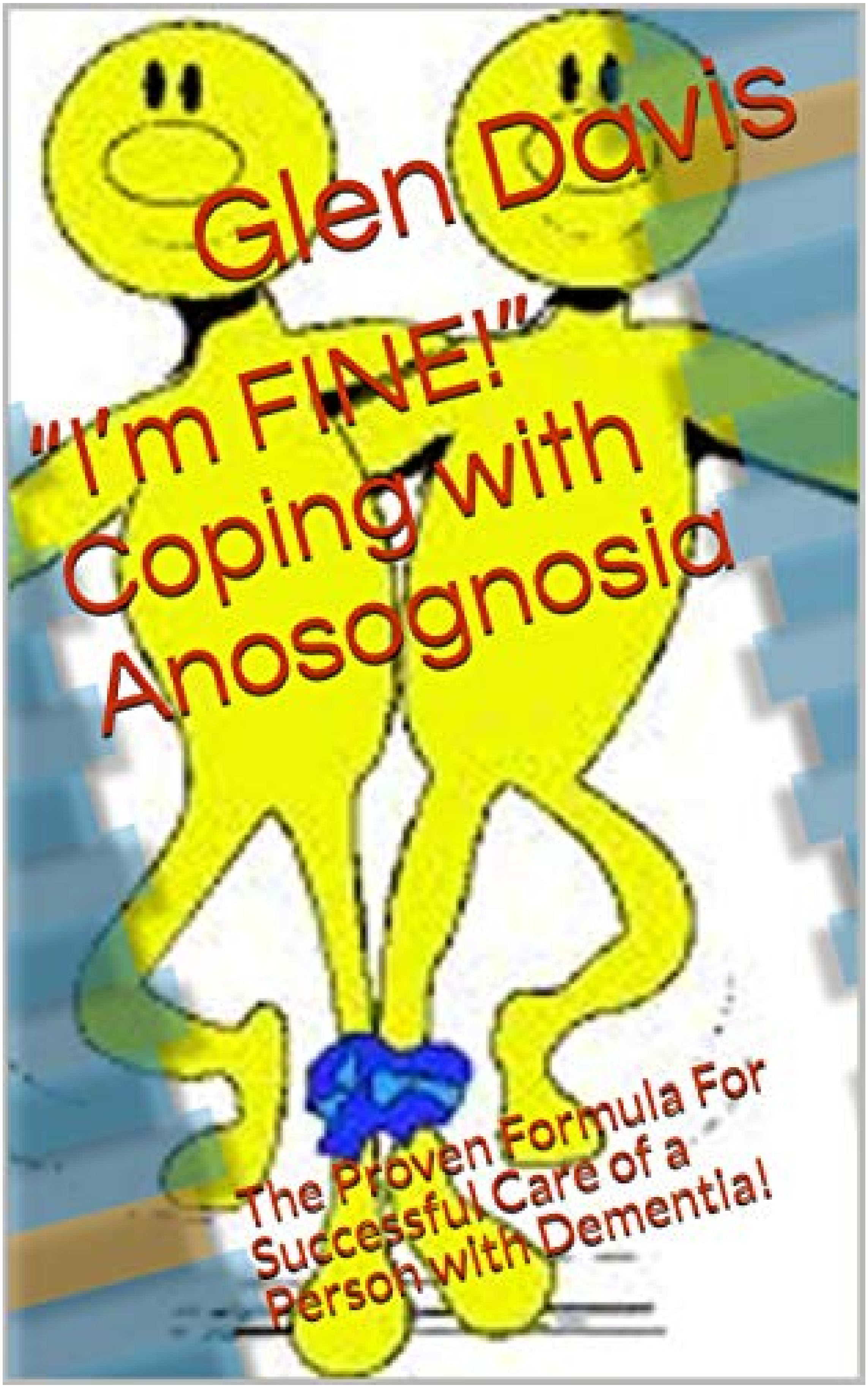
A 35-year-old mother of two young children has united with Alzheimer’s Society by joining their Memory Walk campaign to raise vital funds to beat dementia, after learning she will develop a rare inherited form of the condition.

My response :
"Genetic testing answers only the question whether a specific gene mutation is present. It does not answer the patient's most common question which is whether you and your relatives will contract the disease.
"The relationship between genetic defect and the incidence of FTD is poorly understood. It is not causally deterministic~~,~~ or the disease would have a much greater prevalence than it does. There is some trigger mechanism at work which may or may not also be genetic.
"Genetic testing produces data which are extremely sensitive from privacy perspectives and which can produce untold grief in the wrong hands, or if interpreted from a perspective of little knowledge.”

[Harvard neurologist Dr. Rudy Tanzi] said he receives between a dozen and two dozen emails a day from people who took a direct-to-consumer genetic test and tested positive for the APOE4 variant. He tells them the gene doesn’t guarantee that they will get the disease and that many other risk factors can protect or increase one’s risk. “There are enough people doing these consumer genetic tests that you know that many more are finding out their APOE status than ever before,” Dr. Tanzi said. “The question is, is it useful? If knowing your e4 status is going to stress you out, well, stress is a risk factor. You have to think about the effect of the stress of knowing. It’s also important to consider the consequences of family members inadvertently learning they may have the e4 gene variant, too~~,~~” he noted.
https://www.wsj.com/articles/should-you-find-out-if-youre-at-risk-of-alzheimers-11563196415

This booklet is not supposed to be about whether or not to undertake genetic testing. That contentious issue always comes up and grabs everybody's attention ! There is no one answer. You must navigate to your own decision using your history, these facts and comprehensive genetic counselling.

This booklet is supposed to be about “If you get genetic test results, for heaven's sake get to understand exactly what they mean !”


Glen Davis
"I'm FINE!" Coping with Anosognosia
The Proven Formula For Successful Care of a Person with Dementia!

“I’m FINE!” Coping with Anosognosia:

The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 6) 2nd Kindle Edition

Persons with dementia often have anosognosia. They honestly and emphatically insist they are “fine” and are prevented from recognising their own symptoms and changes. This is a hallmark FTD symptom. It is not confined to bvFTD but is present also in the language variants, aphasia and semantic dementia. Anosognosia is not present in all cases of FTD, but is a very common symptom. The characteristic statement is: “I’m FINE !”

Anosognosia **is a deficit of self-awareness, a condition in which a person with a disability is unaware of its existence. It was first named by the neurologist Joseph Babinski in 1914.**

The person with dementia may be able to tell you that he or she has FTD and even to list some of its symptoms, but refute the eventual outcomes.

“It says I won’t be able to drive. I’LL know when it is time to stop.”

“ It says I’ll die in 10 years. That’s silly.”

Persons who have anosognosia are unaware of their new deficits or the progressive decline in their abilities to manage tasks and self-care. These persons are not in denial. They have limited awareness or are wholly unaware of the decline.

When people with anosognosia confabulate, (they fabricate imaginary experiences as compensation for loss of memory) they believe what they are saying; they are not lying. Their remarks should be treated with respect, followed by a smooth transition (using the 4 “Ds”, see Tips For Communicating) to whatever tasks or activities need to occur next. Regular help for the home and family, planning ahead and working with a positive, partnership approach will help with the long-term daily care management.

AFTD publishes an article: “What to Do About Anosognosia?”
https://www.theaftd.org/what-to-do-about-anosognosia/

The AFTD article presents important points about recognising and understanding anosognosia, but it does not well answer its headline question: “What to do about anosognosia?” Carers need advice that can be more practically implemented.

- There is no approved treatment nor cure
- The patient is unable to perceive his/her own symptoms so sees no need to change, learn, recognise or adapt. "I'm FINE!"
- Any attempt to educate the patient is likely to be met by non-cooperation. Any attempt to change or contradict the patient may result in frustration and hostility.
- Answering "What to do about anosognosia?" is best started by addressing what not to do. Don't attempt to educate, change or contradict the patient.
- Anosognosia is not present in isolation. It is one of numerous dementia symptoms present simultaneously in a person. Each patient presents their own characteristic, unique combinations of symptoms.
- It is common that anosognosia is present in combination with other FTD symptoms in ways that require custom strategies for patient care.
  - People with anosognosia often show a lack of concern about their disease ("I'm FINE!") and its emotional impact on their family members. Those patients are likely to decline or resist medical appointments, deny their diagnosis, refuse to take medication.
  - If anosognosia is present with failing inhibitions, the person with dementia will exhibit emotional extremes. They may be consistently "loving" everybody, they may bounce between extremes of highs and lows and they may have characteristic anxious accusations or rages.
  - A combination of anosognosia with antisocial behaviours can produce rare and difficult issues for carers. Such patients may show little regard for risk or hygiene. They may develop obsessions about guns or machines. They may make inappropriate personal remarks in public or may make unwelcome sexual advances. Obsessions with sex, porn and/or affairs may develop.
  - Other common obsessions may be present with anosognosia. Spending obsessions may arise around favourite subjects such as computers, guns, tractors, cars. Vast amounts of family resources may be wasted on multiple purchases, scams, gifts.
  - Confabulations are common. The person may be misunderstood by family or by professional carers to be a compulsive liar. Those with little experience with the person may well believe his stories. But the stories are not deliberately false. They are the result of a damaged brain's attempt to make sense of the world.
  - With cognitive decline and the progression of time, the patient's behaviours often escalate and tend towards blame. Spouses and family members are ever-present targets so are the people most commonly blamed. The patient's perception is that he is not to blame, so it must be the carer and family members who cause

    the disagreements. The expressions of accusations are typically uninhibited and are very personal, so it is difficult for family members to remember “it is the disease talking” and to remain unhurt by these expressions of blame.

    - In a significant number of cases (over20%), behaviours escalate to aggression, rage and violence.
- Though anosognosia is a common element in all these combinations, compounding the issues for the patient’s care, there is nothing that can be done to treat, cure, change this symptom or to moderate the resultant behaviours. The person’s lack of self-awareness prevents any recognition of their need for change.
- There are, however, carer strategies that address all the combination symptoms of the patient. And there are survival skills that a carer may adopt. The carer response to anosognosia is to change aspects of the environment and to change aspects of the carer’s response. In particular, the most effective strategy is to change communications interactions to avoid triggering the patient’s behaviours*.
- In dealing with anosognosia, the demeanor of the carer is a critical factor influencing the responses from the patient and the outcome of incidents. Indeed, the carer’s choices of behaviours and communications are exceedingly important in keeping the patient on an even keel and minimizing the frequency of incidents. Carers managing these symptoms have noticed that the patient’s mood is often an exaggerated form of the carer’s mood: if she showed irritation, he became angry. If she displayed anger, he would be furious and may fly off the charts into physical aggression. When the carer is calm and accepting, the LO responds better and life is easier. In the US, carers commonly refer to this as the Stepford Wives syndrome (for reasons that escape me…).

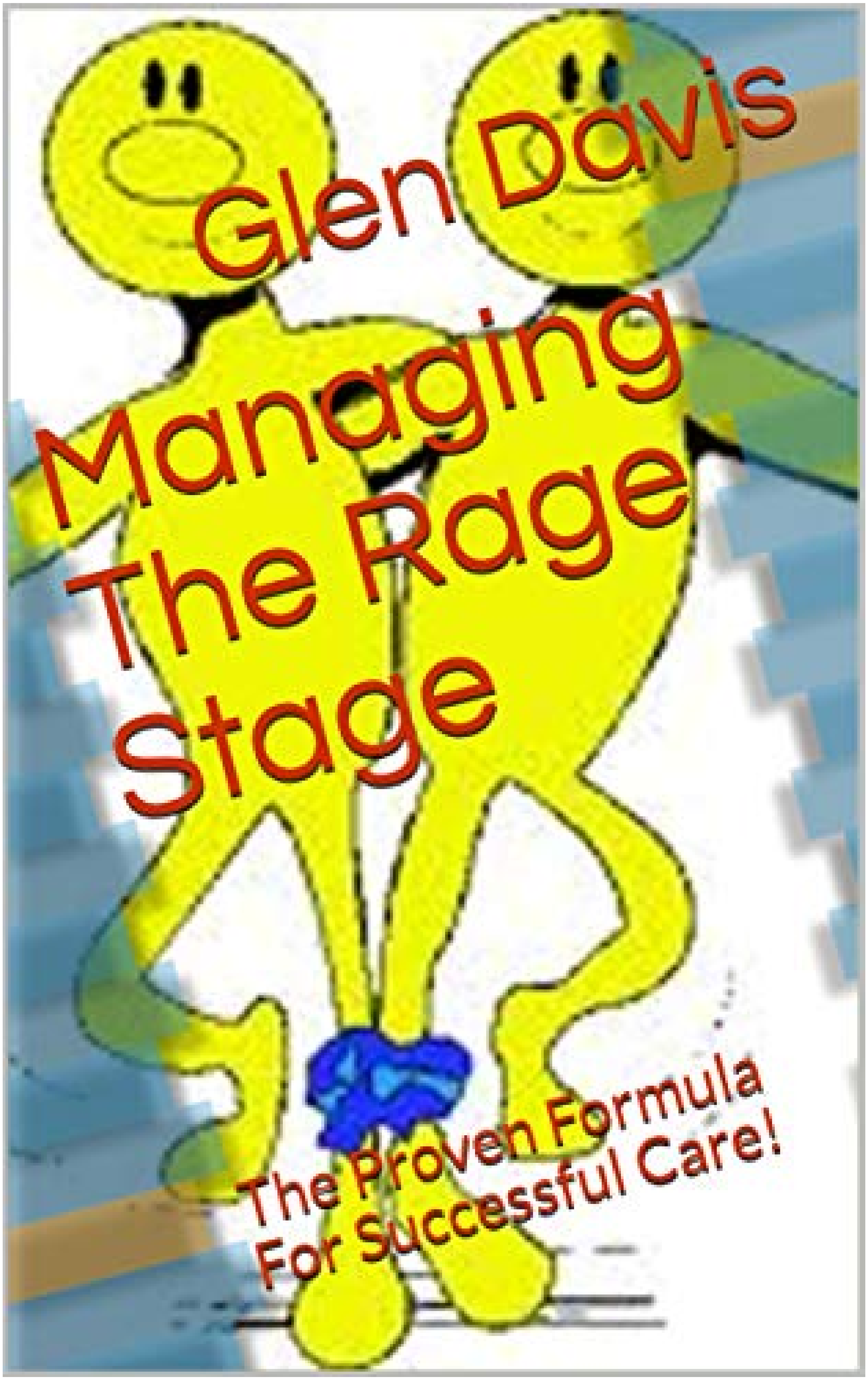
The more complete answer to the question: “What to do about anosognosia?” is “nothing!” Accept it because you cannot change it. Survive it by not fighting it. Live in the FTD person’s reality since he can no longer live in yours. Learn the survival skills in “Tips for Communicating”. Manage the obsessions. Be prepared for violence using “Managing the Rage Stage” whenever behaviours suggest aggression is imminent or present.

*see:Tips For Communicating: The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 3) 2nd Kindle Edition

One most important symptom of dementia is failing communications within a family afflicted with fronto-temporal dementia, FTD. Much can be done to improve the journeys of each family member by learning better communications.

Alzheimer's disease typically begins with cognitive problems resulting from memory loss. But the onset of FTD is marked by changes to the individual's personality, social behaviour or language abilities. This is due to the specific functions performed by the areas of the brain affected by FTD. The frontal lobe has roles in mood, personality, emotional expression, self-awareness, logic, sequences and judgment. The temporal lobes, which process sound, also plays a key role in understanding and using language, and in the management of sensory input, including pain, sensory stimuli and emotion. Damage first to the left temporal lobe results in disabilities concurrently in comprehension and expression, but also to the processing of details and sequences. Damage first to the right temporal lobe sees disabilities in context and big picture issues, behaviours, obsessions, empathy for others. All these different varieties of dementia incur communications disabilities which can be better managed with the toolkit of skills uniquely published in this book.

This important document describes ways to communicate with a loved one who suffers from FTD. It includes critical proven tips for carers to ease their path on this FTD journey. This is information unavailable on the main dementia websites or in published resources.


Glen Davis
Managing The Rage Stage
The Proven Formula For Successful Care!

Managing The Rage Stage.

The Proven Formula For Successful Care! (Carer Fast Track® Series Book 7) 2nd Kindle Edition

When dementia attacks the frontal lobe, fading inhibitions and rising obsessions are frequent outcomes. With these emotional filters not working normally, rages are frequent outcomes. Anger giving way to violence is a symptom in more than 20% of people with FTD. These symptoms are most often a feature of the mid stage of the disease, sometimes the symptoms causing a person to be diagnosed with FTD. When the symptom is a temporary feature, it dominates the caring relationship. Then it is called "The Rage Stage". These behaviours are among the most difficult for carers to understand and manage. This book is uniquely dedicated to the management of rage.

REVIEWS:

"Great" …"I must say that I was profoundly moved by your descriptions of what people have to live with, and the style and content of your practical advice. Very few people are aware of the extent to which a family caregiver must at times subjugate their entire personality to the person that has been created by the FTD, in order to keep the peace and stay safe. Most people would give up at a very early stage and I salute those who persevere from love and duty. You have made a very good description of it, that I am sure will be helpful to many people."

Professor June Andrews RMN, RGN, FRCN, OBE, Professor Emeritus of dementia studies at the University of Stirling, Scotland

"It is so valuable. When you have it published would you let me know where so I can send others to read it?"

Barbara Karnes, RN, Award Winning End of Life Educator, 2015 International Humanitarian Woman of the Year

"I want to congratulate you on the astonishing insights and thoughtfulness of the booklets, as well as the immensely practical approach. It is clear it comes from a place of deep experience."

Dr Jennifer Philip, Professor of Palliative Medicine at University of Melbourne & St Vincent's Hospital

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 living 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 mid stage. 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 his 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.

Once 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 sufferer's 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.

CASE EXAMPLE 9

Michigan State Troopers found the suspect with a gunshot wound to his left hand. The wife was found with a gunshot wound to her hand and hip, and the daughter was found dead in the basement with numerous gunshot wounds to her torso.

Troopers say the wife told them her husband was in the early stages of dementia and was upset they had taken away his car keys.

https://www.9and10news.com/2020/03/16/charlevoix-county-man-arrested-for-murder/

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, try repeating periodically: "I'm sorry you feel that way." (This is well accepted by some Los but not others.) 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.

Neurons produce results 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).

WHERE TO GET HELP

If, as a carer, you want head-patting, the rosy glow brigade will carefully avoid telling you that dementia is terminal, carefully avoid discussing rage and violence and refer you to hotlines where these issues are treated as if they are exceptions. One outcome is that you and other such carers are isolated with no peer support from the big organisations.

The National Institutes of Health and the National Institute on Aging have produced a booklet "for Patients, Families and Caregivers" on FRONTOTEMPORAL DISORDERS.
The introduction sets our expectations: "NIA leads the federal government effort conducting and supporting research on aging and the health and well-being of older people."
https://order.nia.nih.gov/sites/default/files/2017-07/ADEAR_FTD_508.pdf
I read it through and it contains some useful information and no obvious errors but I was uneasy.
There was something missing. I ran my word search through it:
"terminal"? No hits.
"fatal"? No hits.
"death"? Only in reference to autopsy...
Sure enough, this leading publication from this leading research and support agency was shying away from the truth ! Eventually, on page 25, we find this gem of politically correct evasion:
"End-of-Life Concerns
"People with frontotemporal disorders typically live 6 to 8 years with their conditions, sometimes longer, sometimes less. Most people die of problems related to advanced disease."
Eh? Come again? "Concerns"? "Most people die..." ? The NIA has shied away from telling us the truth.

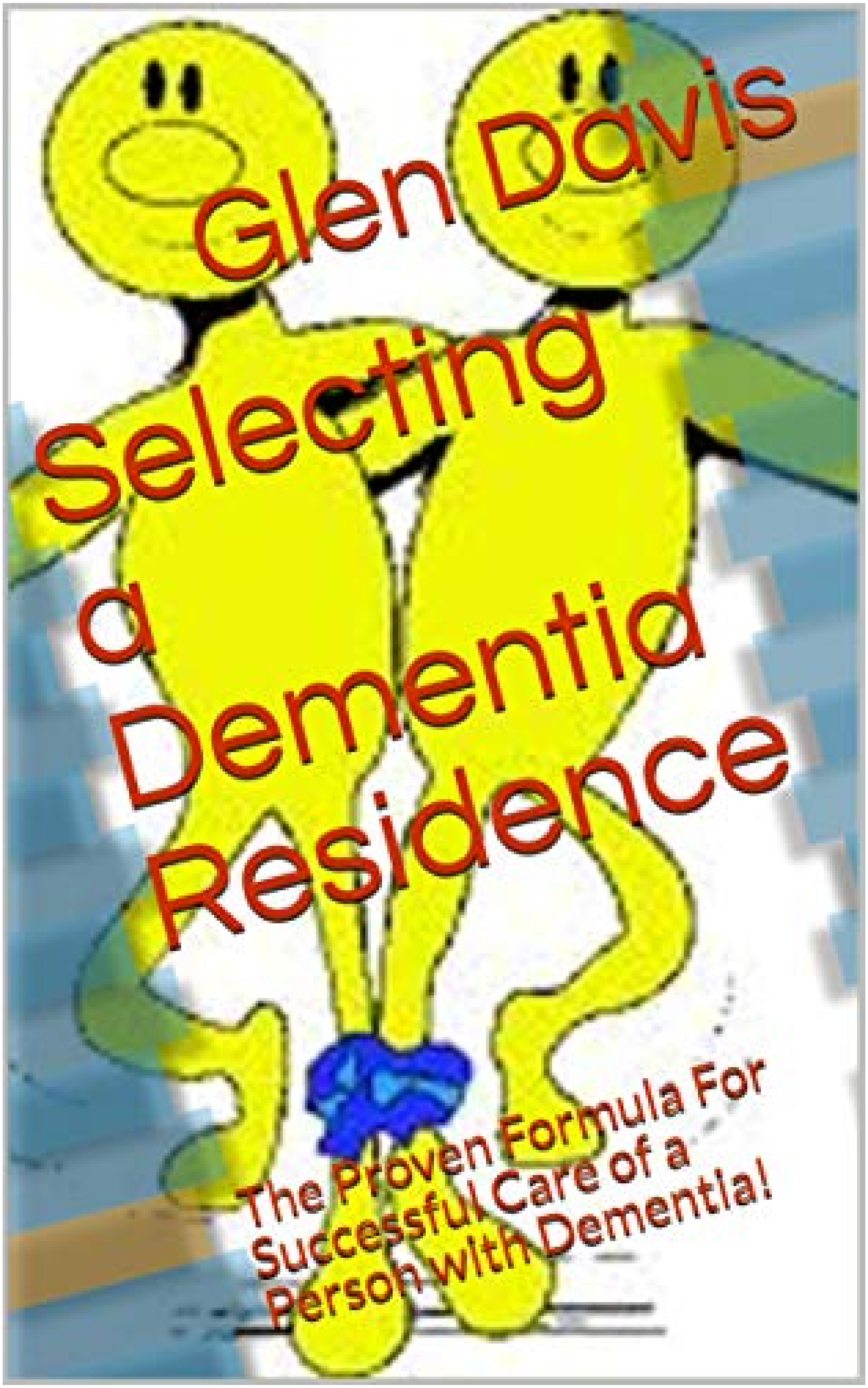
The truth is that death by dementia occurs when the brain loses so much control over swallowing or breathing that aspiration pneumonia or organ failure cause death, or mobility failure causes injury resulting in death. Dementia is invariably fatal and there is no cure.

Prof June Andrews calls this kind of deception "toxic positivity"… "condescending and trivialising their situation... It is harmful... I can see the post traumatic stress disorder developing in the carers, from diagnosis all the way to the funeral."

Trivialising the consequences of dementia, underplaying its significance, disguising its consequences for relatives and carers, these are mainstream activities for agencies.

We expect truth from leaders and we get spin. We expect support and instead resources are diverted towards deception such as "Living Well With Dementia".

For further real help, see Book 1, the Caregiver Survival Guide. You will need your own personal survival plan and your own peer group of other carers, mentors, friends and family.


Glen Davis
Selecting a Dementia Residence
The Proven Formula For Successful Care of a Person with Dementia!

Selecting a Dementia Residence.

The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 8) 2nd Kindle Edition

"Is Dying at Home Overrated?" …the complex realities of dying at home, and the unintended consequences of making it a societal priority.
"As a palliative care physician, I regularly ask my patients, or their family members, where they want to die... Having asked this of hundreds of patients, I have come to expect most will tell me that they want to be at home."
https://www.nytimes.com/2019/09/03/well/live/is-dying-at-home-overrated.html
Yes, that is what we answer. Most of us, when asked, say we want care at home and we want to die at home. And yes, as Dr Leiter describes, that preference is often ill-informed and not always realistic.

"It takes a village" to provide 24*7*365 care for a person with dementia. And yet many carers struggle on alone in the earnest belief that they alone care more and try harder and love their relative with dementia ("Loved One" or LO)... and can do better than a three-shift professional, trained, rested operation in purpose-built premises. We often kid ourselves too long, to our detriment, and the detriment of our LO. Their opportunity to bond with carers and other residents is deferred, sometimes too long. Caring for a loved one with dementia takes a village with a mechanic, plumber, electrician, food hygienist, occupational therapist, speech therapist, personal hygienist, emergency nurse, an auditor... or a very handy wife!

https://www.latimes.com/opinion/sto...xN_2BXGuknySo2oNHNHA6_hZhKNHpr6_oJgLjnaCm4ZNk

The decision to place an LO in residential care is notoriously difficult. We carers tend to delay letting go, delay deciding. Any move is going to take our LO out of his routine and his comfort zone. The outward appearance of a disrupted routine is confusion, lost cognition and competence. But a move (or two) is usually going to become necessary. "Placement guilt" is a very common phenomenon and I felt it very badly. All the studies and publications about it emphasise that the guilt is misplaced and it is, but it is hard to shake. Our LO with dementia declines in his ability to remain independent. His care is usually going to take a three-shift professional staff, whether or not he becomes a wanderer, whether or not his behaviours include violence.

There are exceptions in which, for good reasons, a person with dementia receives care at home for the whole journey. A village with relief and respite services are built around them. But for the great majority, the decision is made to place them in residential care. This booklet is a guide to selecting a residence.

TIME OF PLACEMENT

The time for placement is when the caregiver(s) is/are no longer able to provide proper care and keep the patient safe from harm. Proper care encompasses complete nutrition, hygiene, health and safety. The best time for placement is not determined by when a person with FTD reaches a specific stage. (There are various good descriptors of the stages of a dementia journey and there are some typical milestone events which are sometimes said to be indicators of the time for placement. Those indicators miss the point, because they focus solely on the characteristics, behaviours and abilities of the LO.)

The time for placement arrives when the home caregiving environment is stressed and stretched to cope with a bad day. These signs are unmistakable and are apparent as near-calamities in nutrition, hygiene, health or safety. A caregiving team that barely scrambles to avert a disaster on a bad day may fail next time, when the problem may not be just a little bit worse.

In my experience (of hundreds of cases), the great majority of carers leave the time of placement until later than ideal. In waiting too long (and I include myself) they took unnecessary risks with the wellbeing of the person with dementia and those with whom they interact. Those risks include the real risk of injury to the person with dementia and those innocent bystanders with no knowledge of their condition or the best ways to interact with them. In waiting too long, they also deny the person with dementia the best opportunity to forge meaningful relationships with the staff and other residents.

CHOICE OF RESIDENCE FOR PLACEMENT

Families need to carefully deliberate the choice of residence.
The task demands extensive research, expert evaluation and calm selection. But the task comes at a time that families are under maximum duress, are often divided in direction, choice and timing. Too often, placement decisions are delayed until they are driven by a caretaking emergency. The choice of a dementia residence is very far removed from all our pre-dementia retirement plans. We work and plan all our careers for a comfortable retirement. Images of relaxation, travel, hobbies, families and fun fill our

heads. And we are blindsided when faced with an alternate reality in choosing a residence for a person with FTD and challenging behaviours. Our selection criteria are rarely well matched to the new needs of the patient. Many of us are seduced by potted palms, architectural features, a grand entrance like a London hotel. We are usually at great risk of making a poor choice initially, until time, errors and adjustments occur.

There are issues to be unpacked here. The first is facility ignorance about the behaviours they are facing in a potential resident with FTD. They often have too little experience. The second is that some conduct appraisals to assess the 'suitability' or 'match' of a prospective client with their community or facility, but the appraisal is brief, not conducted in residence and often fails. The biggest risk falls not on the residential facility conducting the assessment, but on the carer or family that must manage the horrors of a poor assessment.

The commercial vultures circle, knowing families are easy prey. It is the families who are taking the biggest commercial risks and risks of stress and relocation. Contracts are written to commercially favour the supplier, not the client. The problem is not confined to residential placement but applies also to in-home care.

Families need better advice. Even the best advice available is not yet good enough. The scoresheet advice from Alz Assoc is a failure.
http://www.agis.com/Document/2/default.aspx

Families need time and counselling and they are instead in emergency stress.

Families need to not be fraudulently misled. There are websites of facilities making claims which mislead families.

Choosing a residence is a very important subject affecting all but a handful of FTD carers. I feel I was very badly advised at the time of Carole's extreme and urgent need. We survived and succeeded only because I knocked on the door of every facility within two and a half hours' drive and asked questions and made inspections until I learned enough to ask the right questions and make the telling observations.

Then, when I identified the right home for Carole, the system which meters and prioritises access got in the way. I was desperately searching, advocating and negotiating through January 2015. Carole entered residence in Bill Crawford Lodge 3 Feb 2015.

When I sold the farm in 2016, I burned a wheelbarrow full of brochures, directories, guides and advice about choosing residences. Mostly it was correct, but it was incomplete and not useful.

The best facilities are scarce resources. Demand exceeds supply. The task of the carer is very difficult because the right sort of residential facility for your LO at the time of placement bears no resemblance to anything you imagined in your dreams of your retirement.

The needs of dementia patients upon first placement with very few exceptions must deal with behaviours and disabilities that require specialised staff and purpose-built facilities. In late stage, when a LO can no longer walk or exhibit aggression, the needs change. Then, the care for a dementia patient becomes much closer to those of a person in hospice in an aged care facility.

There are published checklists such as
http://www.agis.com/Document/1/adult-day-care-center-checklist.aspx
I found them all unhelpful as they omitted real priorities and included factors of low significance.

I remember writing questions for other carers. They included things like:

What percentage of your present patients have a dx of dementia? (You want to hear >80%. You need a specialised residence, not an aged care residence with a few dementia beds. You want all staff trained and experienced in the management of patients with dementia, not some staff or a minority. You want a place where dementia is the rule and not the exception.)

Are any of your caring staff unfamiliar with any of the behaviours of dementia? (There will always be some new staff in training. But within one month, the answer should be nil.)

What are the ratios of caregiving staff to residents for each of your daytime shifts? (exclude cooks and meal preparation) Check the answer by your own observation and ask about any apparent discrepancy.

What are the most difficult behaviours to manage of your present residents? (Just to flush out their stories to explore how they go about coping)

What behaviour would you not accept? (That will give you an idea of the conditions under which they might trigger eviction.)

What percentage of your residents die in residence? (You want to hear very close to 100%. That is the outcome of Aging in Place.)

How many residents have transferred elsewhere in the last 6 months? (You want to hear : only those hospitalised.)

"What is the ratio of PRN administration?" If it is over 50% , the culture regarding the use of extra medications at the discretion of nursing staff is dubious.

What performance statistics for the residence do you track? Are stats shared with carers?

Is there an adequate outdoor area and garden which is supervised by staff and available to residents in daylight hours? (check by observation that it is actually used actively.)

How many residents have been outside the secure area in the last month and for what reasons? (outings are good. escapes are bad)

The question of whether the carer should relocate nearer to family members or stay in your chosen environment will be an early decision. In some cases, that decision precedes the decision to place the LO in residence.

The question of affordability of a residence ranks very high for USA carers owing to the health care system differences which expect people to save and insure individually for the whole costs of residential care. Prices like $US $7-9k/month for years are common there, with extra costs for incontinence, laundry, grooming, outings...

The price of residential care is most strongly correlated to the staff-patient ratio.
Night-time staff ratios is one of my criteria in choosing a NH. It is never as good as you would like. Carole's nursing home has a 2:30 ratio overnight, which sounds inadequate, but the backup is pretty good. Being part of the Ballarat Hospital and being within a large hospital precinct, it shares access to the Hospital Medical Emergency Team Alert system. It puts the right sort of resources on the spot for medical emergencies in minutes. It is not as good as being on-site, (Emergency staff have no familiarity with individual patients) but is next-best. The MET resources are not dementia-specific, but they see enough delirium cases to have some insight. So they effectively improve the ratio to the equivalent of 3:30 and I think that is acceptable.

Proximity to carer is often a big issue. Locked dementia wards, known in US as memory facilities, are scarce~~,~~ so finding one with a vacancy often means long travel for some family members.

Early in your search you will encounter aged care residences with some "dementia beds" or even a "dementia wing". No doubt there are some easygoing dementia patients who are suited to these facilities. What I found however is that the few patients tend to have a very limited environment, little variety of contact with different people, limited or no outdoor access. I just went "Nope". It was not a satisfactory way of life.

You will find other facilities who have assessment systems designed to filter out residents with needs greater than they can manage. Your question for these places is "Where do you refer or transfer the people you cannot accept or manage?"

The place you need will say "We do not turn away anybody. We take residents for the whole journey. This is what we do, we manage dementia behaviours." Finding it and getting access take time and you really do not want to be doing that in a rush, like somebody you know.

Your critical selection criterion is expertise and competence in the management of the behaviours of patients with dementia. Look for calm professionalism in the staff, and question them closely on 'challenging behaviours' they have handled. Bear in mind that sometimes you will have to opt for the least worst solution.

It is tempting to favour appealing architecture, manicured grounds, potted plants, fancy décor and polished piano. A better choice may well have worn linoleum and peeling paint. In the brochures, activities look very attractive at a residence. They may be classed as those which are good for the mind and those for the body. But rare is the resident who participates fully or takes advantage of these activities on his or her own. If you can find an opportunity to observe other residents during an “activity” session, observe who participates and who does not. Because participation rates are low, benefits expected are rarely realised. It is a huge change of circumstances from the retirement that you may long have planned and is not an adjustment that carers make quickly or easily.

What are your sources of help and advice?

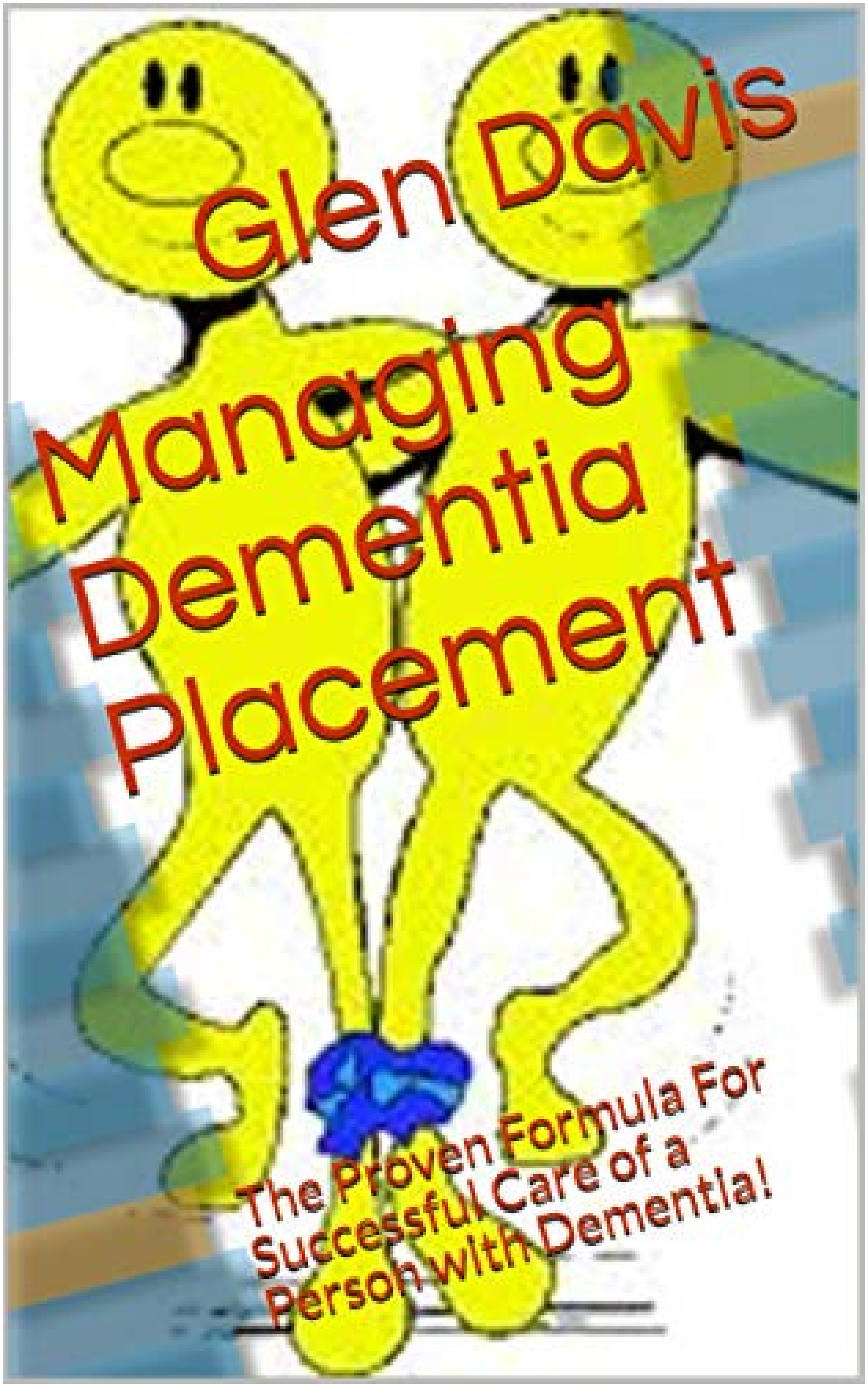
Do you have any nurses or doctors in the family?

Which of your friends can best assist?

Try the reception at your local hospital and ask "Who deals with the placement of dementia patients with challenging behaviours?" Try the same question with the help line at the Alzheimer's Association. Somebody knows what you need to know and they are hard to find.

There are commercial agencies which can be useful. One in USA is "A Place For Mom". But they can at best give you a good short list and final selection is yours.
One that I used in regional Australia was a service called Direct2Care :
http://dpp.grampiansml.com.au/ongoing-management-and-care/recommended-referrals-post-diagnosis/direct2care/
It has its counterparts elsewhere.

Do not settle for one source of advice unless you are very sure your choice is correct. This is a time that you need all the filters you can find to help you come to a good decision.


Glen Davis
Managing Dementia Placement
The Proven Formula For Successful Care of a Person with Dementia!

Managing Dementia Placement.

The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 9) 2nd Kindle Edition

We carers tend to hang onto the better days of our journey with dementia and think of them as the new normal.
Then some new shock loss occurs and we have to reset our expectations lower again.

The big trick in all of that is that it is the bad days that need to be the focus when it comes to the big decisions, like stopping working, stopping driving, assessing the need for extra in-home support, and assessing the timing of placement. Because when you only just survive a bad day, you know the next one can be a whole lot worse.

When is the right time to place one's spouse or loved one (LO)?

I am a veteran of only a few placements. I have heard a lot of other carer stories, so I have accumulated a little learning-by-proxy. There are several ways to answer this question.

First, you set "lines in the sand". They are all individual and depend on the damage the carer has suffered on the trip, the carer's experience of the patient's behaviours.
Most people assume or hope there will be a clear trigger. "Fecal incontinence" or "Fatally dangerous incident" or "Next time the cops bring him home".

This is one example of a carer’s thinking which sought to anticipate multiple possible triggers : **"when he is a danger to himself or others and I can't manage it, when I can't manage his personal care, or when he gets lost constantly. "** These triggers are more subjective than most, but still they seek an event, some sign that the carer cannot manage. My points are these:

- you cannot predict all the triggers and you are likely to miss the critical one that gets you; and
- you can continue to adapt, compensate, become inured until some disaster strikes and somebody gets hurt.

When at-home respite has not suited him and, for such patients who find it difficult to accept help from strangers (or even to have strangers in their home) there is not going to be any source of in-home help which defers the date of placement. In-home help might let you do some shopping while he stays home. That's all you can expect from it.

Successful placement happens before somebody gets hurt or killed, before family wealth is substantially squandered, before family members are sexually abused or relationships ruined, before carer health is needlessly sacrificed.

I did not reach that success and nor did many other carers I know, while others did.

Here is the problem. If you deserve the medal for successful placement, you don't get a Purple Heart for taking injury. You don't get the satisfaction of thinking "I went right to the wire."

Let me tell you very clearly that Success is far better, and I have seen both up close. To achieve Success, you don't cross one of those lines and nobody gets hurt.

Let us take the case of a LO who is not one of those patients who exhibits aggression or violence. He is not yet incontinent, and you still trust him to walk home safely. Then, you are not about to hit one of those objective hard lines. But you are run ragged trying to be 24*7 sole carer and you are worn out by it.

So you need to keep reassessing how much is gained by struggling on. Placement is going to happen, either in time or too late. The longer you delay it, the less cognition he will be able to apply to adapting. Only you can judge this. The doctor can recognise his degree of dependency, but has (s)he placed a LO in a dementia residence? Assessment agencies can estimate his need for care. But you, the carer, are not their patient and they are merely drive-by agents in this decision.

But a move (or two) of residence for your loved one (LO) is going to become necessary. "Placement guilt" is a very common phenomenon and I felt it very badly. All the studies and publications about it emphasise that the guilt is misplaced and it is, but it is hard to shake. He is declining in his ability to remain independent and the questions you ask yourself show that you are sensitive about the risks and will be hurt. You have no choice. When you can no longer keep him safe at home, when you have survived risky situations which are going to recur, you can no longer safely provide care at home. His care is going to take a village with a three-shift professional staff, whether or not he becomes a wanderer, whether or not he becomes accusatory or violent.

The time for your husband's placement is often expressed by health workers to be related to his behaviours and condition. That is true for broken ribs and it is not true for FTD. The time for placement of an FTD patient has nothing to do with the patient's age or stage. It is when the carer says : "On the worst day, I cannot cope with the behaviours or cannot keep everybody safe". "Everybody" is not just the spouse and kids, it is other road users, checkout chicks, cops, neighbours, shoppers, anybody he interacts with. Residential placement is necessary when the load of caring becomes too great for the family resources available. It is appropriate when the load ***once*** becomes too great, not when the load is on average too great, or always too great. On your worst day, if you cannot cope, you are at risk of injury to patient, carer or both or to unsuspecting bystanders.

Many of us hung on beyond when it was safe. I did, and colleagues (ahead of me on the dementia trail) despaired for me. Everybody tries to identify their own lines in the sand, but I encourage you to not risk crossing them because there is no rewind button if an incident or an accident happens. You might, for example, draw your line at the threat of physical violence. As long as violence is avoided, you say the line has not been crossed and you can continue. But once violence occurs, the line has comprehensively been crossed, events and their consequences cannot be erased, and there is no going back. You cannot keep everybody safe any longer. These are the things to say immediately to the social worker and put on the record if you must.

FTD forces us to play our hand

We have to take awful risks at this stage, when LOs have some mobility and retained abilities, but flawed judgement and cognition and behaviours. I drove colleagues to distraction with my wife Carole's “outings” (wanderings alone, day or night) and risks before placement. Looking back, I am not at all sure I could have done better. Mental Health Services were still trying to invent reasons and means to delay placement when I insisted Carole could no longer be kept safe at home. As it turned out, she could not be kept safe in residence either.

I have come to understand, years later, from learning the stories of many other dementia journeys, that the acceptance of terrible risks is 'FTD-normal'. There is no way to avoid the increased probability of harm of some sort. Protect them from wandering and they are at heightened risk of anxiety, depression, increased medication load and induced behaviours. Place them in residence and they may suffer insufficient activities and stimulation and harmful interventions from other residents.
"Scary" is par for the course, whatever decisions a carer takes.

Placement, like the rest of an FTD journey, varies a lot case by case.
Your needs are very individual. As an illustration, let’s take a case in which the distinguishing features are young onset, slow progression and awareness of the patient’s own diagnosis and disabilities. In such a case, the search for an eventual placement residence will be unlike most others. And it is more likely to start early, which is unusual.

I worked very hard, very urgently, to identify Carole's first permanent residence. I knocked on the door of every residence within two hours' drive (and a couple beyond that) and kept asking questions until I learned the right questions to ask.

When I found the place, I discovered the other carers had much better search techniques and had asked friends until they found an expert somewhere in their network.

There are organisations who will search for you, at a price. Here is one, and you might learn something from their website:
https://www.aplaceformom.com/

Here is our story.

What a day!

We had a visit from the psych nurse early this morning to monitor Carole's progress and symptoms. There has been no change in her meds in a week. And the valium has not reduced the frequency, duration or severity of walkouts or rages (it simply made her more unsteady and at risk of falls).

I explained that when Carole's brother Jack goes home to USA Sunday, I cannot any longer acquit my duty of care to keep Carole safe at home. I would be stressed right out with Carole at home and unstable and unsafe...

Lunch time, I took a phone call that Carole is to be admitted to the psych ward of the Regional Hospital today. It is a 10-bed facility specialising in mental illness and has a reputation for succeeding with interventions to stabilise behaviours.

Carole was busy making sausage rolls with her friendly home care worker. I told the worker who immediately offered to take Carole for a one hour drive while I packed her bag. Carole heard me take the call and her antennae were jangling. I said I had to go to the city to get my psa results. It is true, but not today. When they got back from their drive, we loaded Carole straight into the back seat, child locks activated, her case out of sight in the boot (trunk). Carole slept most of the one hour drive.

Jack and I had discussed strategies. The A Plan was to all stroll in, allegedly to get my psa pathology results. The B Plan if we had dramas on the trip was to call ahead five minutes and have psych ward female staff out of uniform meet us at the ambulance pad. The C Plan if Carole resisted at the door was for me to go get staff while Jack stayed with Carole in the car. As things unrolled, Carole did not want to get out of the car and we went for the C Plan. It worked like a dream thanks to staff and Jack.

The female nurse let Carole take her arm (a clever gesture reeking of experience), showed her around the lounge, her room etc. Carole did not notice the locked entry door door to the unit. Carole slowly developed an inkling that she was to stay… but was still shocked when Jack and I prepared to leave. The nurse remained very calm and distracting. The staff were great.

Carole became teary and depressed after we left. The duty psych put her on venlafaxine (effexor) a SNRI anti-depressant. I hope it works better than the mirtazapine which provided no relief for a long seven weeks. But she ate her soup, dessert and drink. I am not worried that she left her main course because she ate a truckload of sausage rolls for lunch.

Such a hard day! I had to lie to succeed. Admitting her felt like breaching her trust. It had to happen. It is the only way to have her safe while her meds and behaviours are stabilised. My head says it is right but it breaks my heart anyway.

I hope there is an idea here that helps somebody else dealing with a placement nightmare.

This placement was interim and just for the purpose of stabilising meds and behaviours. They discharged Carole when that was achieved, or they reach a limit they cannot pass.

My plan was to take Carole home if she would be safe and happy at home.

But if she is not safe and happy, I had run out of resources I could call on for serious help. Long term placement had to be a contingency plan, so I continued to work on it, without much success.

Through three emergencies this year, the official respite systems have failed us. We have kept Carole safe at home only with the help of family members who have travelled for the purpose. Before that, I travelled (at least 11 hours each way) to them. But the outbreak of the rage stage and walkouts have made me reassess my ability to keep Carole safe. We now need rages and walkouts permanently behind us for Carole to live safely at home. These are the decisions I face when Carole is discharged.

One week later:

Carole is continuing to go really well! It is astonishing that she can be constantly calm and happy a week after the dramas we had.

I have just come home from visiting. Carole is to be discharged into the locked dementia unit of a nursing home Wednesday for probably a few weeks (temporary respite), depending on how she progresses.

A psychiatrist will continue to supervise her meds which will continue for now at current doses.

2mg diazepam (valium) twice a day (a BIG mistake)
0.5mg risperidone/day
37.5mg venlafaxine (effexor)/day.
I meet with him tomorrow, Monday at 11am but expect no change.
The respite position is available to 12 Jan.

Two weeks later:

Carole's meds have been jerked around by a GP and by the NH's use of PRN meds and they wonder why she has become destabilised !

QUOTE

[Psych Nurse],
At [facility] yesterday, XYZ showed me Carole's med chart. She has been put back on venlafaxine. But the dose of valium has been increased to 5mg twice daily.

Eventide has reported to me that Carole has had four falls since Sunday including one yesterday in the presence of a staff member who was unable to save her. (the falls were the result of the Valium, a benzodiazepine strongly contra-indicated for FTD patients).

I ask please that the psychologist consider cutting the dose of valium (benzidiazapine) back to 2mg twice daily to reduce psychomotor skill damage~~. W~~ with no PRN discretion for more benzos.

I provided the official US Govt NIH latest report:
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC181170/

QUOTE
Benzodiazepines can cause significant behavioral disturbances in dementia patients in addition to **increasing the risk of falls, fractures, and worsening cognition.** 87,88 Benzodiazepines are inappropriate especially if used for behavioral disturbances that are secondary to medical problems. Nonetheless, there is a high prevalence of inappropriate use of benzodiazepines in

frail, older adults in nursing homes and in the community. Best practice recommendations for benzodiazepine use in patients with dementia include (1) emergency or short-term (few days) use; (2) use of short half-life agents, preferably metabolized through phase 2 (e.g., lorazepam, oxazepam); and (3) avoidance of other central nervous system depressants. In long-term care facilities, it is recommended to follow the criteria set forth by Beers 89: **benzodiazepine use is inappropriate (1) if it includes any use of flurazepam, diazepam, or chlordiazepoxide and (2) if the following recommended dosing limits per 24 hours are exceeded:** lorazepam (3 mg), oxazepam (60 mg), alprazolam (2 mg), temazepam (15 mg), triazolam (0.25 mg), and 5 mg for the nonbenzodiazepine hypnotic zolpidem.
UNQUOTE

It is so inappropriate that carers have to be the guardians of medication. Yet carer experience and my own near misadventures have proven this so necessary.

Three months later:

I grieved miserably at placing Carole in the Nursing Home (NH) on 3 Feb. My head knows it was the only possible decision for her safety and we have the most suitable (dementia-specific) NH available, but my heart is slow to follow. For Carole and for me, this has been a crucial long term step, and much harder than the temporary placement accomplished in December. The "living bereavement" that is a part of every FTD journey continues. I have mourned all the specifics, but I continue to grieve what we have lost, what we had planned and the sadness of Carole's journey with this wretched disease.

Carole has not yet accepted her placement in the NH. She can barely express an intelligible thought, but she wants me to take her home every time I visit. I have discussed this with the manager of the NH and I have cut my visits to one every three days because of the stress that follows my departure. I had hoped to take Carole to the wedding of a friend and former neighbour, a 6'4" strapping young farrier we nicknamed "Stumpy". But I eventually agreed with the NH manager that the return from the outing would be too unsettling. It was very sad to go to the wedding without her.

The issue for both of us is grief. For her it is about living in a NH. For me it is complex. I had wanted to see her through the whole journey at home. But her progression, medication failures and my health failures last year beat me. Carole is always happy to see me, but gets very stressed when I leave. After three months, there is no sign that she is coming to acceptance of life in a NH. She is the only resident (of thirty) in this category.

I have finished remaking Carole's MovieMaker movie using clips from the stories that I recorded in 2013 in her own faltering voice. It reawakened my grief to replay those tracks and the tears tumbled. But the job is done now and I take pride in it.

I am still suffering the consequences of the prostate surgeries last year. I have swelling from lymph node removal (the biopsy proved them to be clear of the prostate cancer) and the swelling seems to be delaying the recovery from the Achilles tendon repair in September. I am only just starting to do the first physical work since last May, so I feel desperately unfit. I need to toughen up.

The 'good news' is I have a bit less stress and a lot less work since I placed Carole. Her safety is assured. That seems little comfort until I remember her broken hip from a fall and her risks on the road during walkouts. My family and Carole's family have done everything possible. So I am blessed and count my lucky stars. It reminds me that so many other carers must travel this rough road without the unconditional support of their families. My heart goes out to them all.

A few days later:

Carole's medication continues to be risperidone and venlafaxine. The psychiatrist and the NH manager are convinced both remain necessary. It seems to me that overall, she is better with this medication than without. It is just enough to slightly moderate her anxiety and it has ended the violence (kicking and swinging at staff).

But her anxiety is still awful to experience. I visited today and the first minute was the usual joy and surprise at my presence. Then, her sole thought and request was for me to take her away. I quickly took her to the cafe for a cappuccino. She would frequently stop in tears and I had to change the subject to her boys or her grand daughter or her dog to try to get a smile or just to interrupt her distress. Back in the NH, she only wanted to leave. Staff struggled to distract her so I could leave and Carole realised immediately and wailed.

Staff tell me she settles. But into what state of depression and despair I can only imagine. Staff also tell me she is often teary and inconsolable.

I can find no better response to improve Carole's life. It is very frustrating to see her so unhappy and to be powerless to relieve the cause. Both her boys will visit concurrently in a month. We are calling it her Canadian Mothers' Day. But a month is an interval Carole can no longer understand, so to talk about the event now serves no purpose but a momentary distraction.

My visits seem to be becoming less successful at improving Carole's mood for longer than the

first minute. The only opportunities to choose an event to coincide with my departure are meal times or bathroom breaks. The only half-suitable mealtime is lunch because leaving at the evening meal would get me home too late to feed the animals. Carole does not care enough for either of those events to be successfully distracted.
UNQUOTE

It is "one day at a time", very unsatisfactorily.

The early months of placement can be heartbreaking. The process of acceptance and adjustment can be very long. Almost unendurable for both LO and carer. "Haunting" is an accurate description.

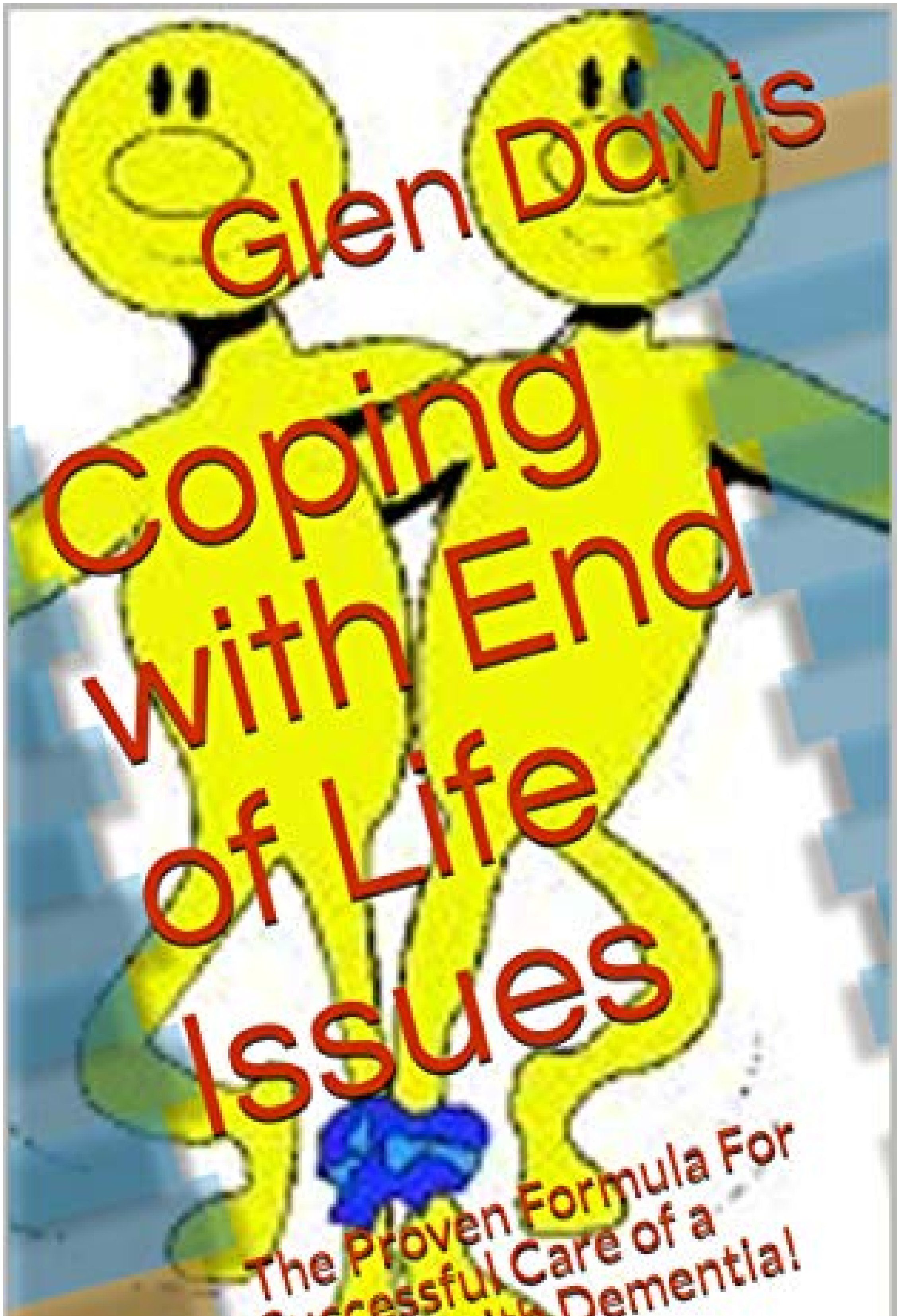
We should talk a little about carer guilt. For me, this came about because Carole had been able to express her opposition to placement in residence.

But we never did discuss before FTD what she wanted for my life.

Patients with FTD have broken logic and lost empathy. Yet they still have and express emotions. Forcefully and without inhibition.

I did not adapt to those changes very quickly. As time passes, I guess I get better at distilling these messages. The LO does not think about the carer's wellbeing because they have lost that ability. Empathy is gone. It is no longer a factor and their judgement is flawed. They express emotions and we have a long practice, habitual, learned ways of responding. Learning a whole new set of responses evaded me too long. We carers need to acknowledge to ourselves that our LO can no longer feel or express empathy for us. That ability became a disability with anosognosia and those functions of their brain died.

There are some important (and perhaps unexpected) benefits that arise from placement. The care environment changes from one or two family members to a three-shift team of trained professionals. Those family members get improved rest, so their caring activities (during visits or outings) can be better planned and receive attention and focus. The LO gets a more sociable life and more people, both staff and residents, with whom to interact. (At home, they are prone to “self-institutionalise” and spend much time alone or in bed.)


Glen Davis
Coping with End of Life Issues
The Proven Formula For Successful Care of a Person with Dementia!

Coping with End of Life Issues :

The Proven Formula For Successful Care of a Person with Dementia! (Carer Fast Track® Series Book 10) 2nd Kindle Edition

Death by dementia does not follow the usual ‘rules’ of a slow death. There are many paths to the end, by injury, by infection, by other diseases and complications.

What can be said about it is that, if all other accidents and illnesses are avoided (which is rare) then death by dementia is not as terrifying generally as the journey before it. Carers and family members are prepared by the progressive loss of cognition, by grieving, by the deaths of others, and the lost cognition means the person dying of dementia suffers no terror.

The principal carer of a person with dementia often wonders what signs to watch out for, so that other family members may be warned as death approaches.

Specialist Clinical Advice- Late Stage Dementia.

The following section summarizes generous clinical advice I received from a specialist in the behaviours of people with dementia. I have permission to share this with you. I will break it up into subject headings.

I offer Health Warnings that the subjects range from difficult to morbid.

In places, my questions or comments are interspersed in italics to provide context.

1 EATING AND DRINKING

Specialist: Family carers, I find, are the best informants about the condition of their loved ones and the best at taking on recommendations because they are generally more invested and often see changes in their loved ones more practically/intuitively.

Carole [my wife who died in 2019] is clearly in the end stages of her disease. This stage can still go on for some considerable time. Especially whilst she continues to take some food/ fluids. The taking of food is not always a reliable indicator of awareness/ will to survive however. For many people at end stage disease, they open their mouth in a reflexive way to the spoon rather than seek food. Without feeding assistance they would not be able to sustain themselves.

2 VOCALISING (WAILING)

Specialist: Vocalising (wailing) in a residential facility is perilous. Of course, it is not purposely orchestrated by the person with dementia to disrupt staff and other residents, though that is often its effect. This would have to be one of the most misunderstood of all dementia related symptoms/ behaviours.

I agree with your point of view that vocalisation is not particularly amenable to psychotropic medication. The exception would be the use of sedation only at night to provide rest for those who would vocalise 24/7 otherwise.

In addition, there are now prescribing restrictions in this State on psychotropic drugs use in aged care facilities to prevent their prolonged use without regular review of efficacy.

At the end of the day, these drugs will do nothing to respond to the underlying causes.

Vocalisation (the wailing) is generally multi factorial.

When it is repetitive, constant and unable to be stopped or interrupted by the presence and attention of another person, then this is directly related to brain damage and the disruption to circuits which allow us to shift gears/ tasks and apply breaks to our behaviour. A bit like a needle getting stuck on a scratch on a record, the sound gets stuck on repeat. The needle may sometimes be able to be bumped temporarily (often by asking questions, playing music and getting the person to sing (which uses a different pathway to speech). However, if the record is sufficiently scratched (i.e. there is sufficient brain damage), it won't be long before they get stuck on repeat again.

The fact that you indicate that this is not yet happening every day and can be diverted for longer periods, suggests that perhaps the damage has not fully progressed to the most severe stage of constant vocalisation. However, I suspect that this may yet escalate to that point and so the nature of her brain damage is probably one contributing factor.

The fact that the needle can still be bumped with some periods of peacefulness also suggests some modifiable factors. The most important being external environmental stimulation.

It is important for staff to understand that she cannot fully control the vocalising without an external stimulus to interrupt the circuits and inhibit them.

We also need to remember that in FTD, it is the frontal lobes/ adult brain functions that are being lost. The frontal lobes of the brain are not fully developed in children.

What does a child or baby do when they are awake and are alone without attention for prolonged periods? They cry.

What does the cry signify? I am alone, I am afraid, I am in pain, I am wet.

Glen: *I say many similar things to other carers about Carole's wailing when they ask what it expresses. It is like a 6-month old baby. It says "something is not right with my world. You find it and fix it please."*
Of about eighty residents I have known in Carole's nursing home (NH), all mid and late stage

dementia patients, four including Carole have habitually vocalised in some way. Carole's expression is the most like crying and therefore perhaps the most distressing.

3 IMMOBILITY AND PAIN

Specialist: For someone with severe end stage dementia, who has lost the ability to move about, shift their own body position to get more comfortable, get to the toilet when they need to, get a drink when they are thirsty or communicate their needs in words; what do they have left but to wail to express their need for care/ attention?

Therefore, we have to start responding to vocalisation in this context as an expression of unmet need and try and anticipate what the unmet need might be, just as we would a child/ baby. i.e.: through a process of problem solving and elimination of potential causative factors.

Any rational person would come running if a child was left to wail. Yet for some reason people become annoyed at the cries of an adult who is equally powerless to meet their needs and self sooth. These people get unfairly labelled as disruptive, manipulative etc and this is why staff reach for the psychotropics to keep them quiet. In fairness, vocalising is hard to be around 24/7. However often staff are ill informed about the causes, strategies they could try and also don't always look at their role or the role of environment in the behaviour.

4 SENSORY DEPRIVATION

Specialist: Sensory deprivation is a significant contributing factor to vocalisation, hallucinations and delusions in end stage dementia. If the brain lacks sensory input, it will create its own with internal imagery (day dreaming or hallucinations), memory regression (living in memories from the past), internal dialogue about fears and insecurities (delusions) or sounds (chattering to one's self/ vocalising if language has been lost). We know that sensory deprivation is rife in residence care settings. Facilities are under- resourced and task focused so there is lack of time/ focus on stimulation. Residents also often have communication deficits, hearing and vision impairments that add to social isolation and sensory deprivation. Yet there are ways to provide sensory stimulation even to people in terminal/ vegetative states.

As you say, Carole often improves with her vocalising after a period of interaction with you.

Glen: *The residence is all hard surfaces and reflected sound and it helps immediately to be outside. Birds, sky, clouds, sun and fresh air and the absence of nursing home sounds and voices do a lot of good. A drive to the cafe for "PRN Hot Chips" with salt and vinegar, "much more effective than Risperidone"...*

5 SENSORY STIMULATION/ENGAGEMENT

Specialist: People in end stage dementia are operating at a more reflexive stage and so care, activities and environmental strategies need to focus on engaging the senses.

Hence to meet unmet needs and provide environmental stimulation, possible strategies could include:
- regular scheduled toilet and pad check/ change
- regular position change to reduce pain, pressure area care
- regular offers of food/ drink when staff are passing by in between meals
- chew toys attached to string or necklace to provide alternate oral distraction/stimulus to divert vocalising and help with saliva production to reduce dry mouth
- fiddle mats or aprons if she is able to manipulate objects with her hand
- squeeze balls or padded dumb bells to ease hand contracture, physio should be able to assess and provide these
- baby dolls/ teddies to cuddle. Ones that talk, make noise or have heart beats provide additional stimulus. This may also help ease contracture severity
- limb stretches/ massage/ hand massage with aromatherapy oils
- heat packs and intermittent use of a portable chair massage pad for tactile stimulation, blood circulation, pain and muscle tension relief
- intermittent use of an iPod or MP3 player loaded with her favourite music with noise cancelling headphones. This might stimulate singing in place of vocalising and evoke positive feelings/ memories
- headphones with talking books or recordings of your voice reading books or reminiscing/ reassuring her. This can be used to simulate your familiar presence when you can't be there in person
- headphones with visual mediation recordings
- regularly moving her chair outside to get fresh air, sunshine and hear the wind in the trees/ birds
- regularly moving her chair around the facility throughout the day to visual points of interest (near windows without too much heat/ glare or in front of a fish tank/ bird aviary. This provides changing visual stimuli and also reduces the noise burden on any one group of residents/ staff
- some time in high staff traffic areas to promote chances of nursing intervention and to also reassure her with their visual accessibility

6 POSITION CHANGE AND MOTION

Specialist: I suspect because of her poor mobility, spine and contractures that she couldn't tolerate a Broda Glider chair, however these are also often good to provide a rocking soothing motion for people who have more mobility but repetitively mobilise/ vocalise.

Simply moving and wheeling Carole’s present tub chair is soothing, much like a baby soothes with motion of their pram. We need motion to ease our boredom/ tension.

Glen: *Carole spends most days asleep. When I feed her, she eats all of every meal. Sometimes staff tell me she ate "most" when they fed her. But maybe three days per fortnight, she will wail. The staff theory is that this is from pain from her L5, crushed when another resident pushed her over, ending her walking. She is on 20mg of a morphine patch (Norspan). I don't think the wailing is caused by pain, because 90% of the time I can fix things in a minute with enthusiastic talking and a quick trip outside in her tub chair. When that does not work, we have a long, bad day until she sleeps from exhaustion.*

Specialist: Evidence does suggest that pain is often a significant contributing factor to vocalising and that vocalising can be reduced with effective comfort measures. We also know that most people at end stage dementia are generally grossly under treated for pain and receive inadequate palliative support. This is because people rely too heavily on verbal requests for pain relief and don't look enough for the behavioural clues for discomfort.

Glen: *I visit with Carole every day and feed her at least one meal. I do her stretches because she sits in her tub chair with her limbs tightly bunched and hands clenched, and I try to ease muscles and joints.*

7 PAIN AND RELIEF

Specialist: I don't know her full medical history so there may be other pain causing conditions. However just from how you describe her limbs, she has contractures caused by ligament shortening and muscle wasting from lack of use. If she has crush fractures (L5 disk) then presumably she also has osteoarthritis/osteoporosis and this is exquisitely painful, especially if the spinal cord is also compressed by the vertebrae. Spinal cord compression often contributes to muscle wasting and nerve pain. So there is just no way that we can say she doesn't have pain. She must have pain and discomfort from her mobility restriction alone. After all, how do you feel once you have been sitting or staying in the one spot too long?

Glen: *Her wailing has not worsened over time. It has not become more frequent nor louder nor more difficult to stop. It is less loud and I can stop it, usually within a minute or two, 90% of the time. Bad weather (cold or wet) limits my responses, as do weekends when the cafe is closed and covered corridors are locked off.*

Specialist: She just doesn't have the cognitive capacity to effectively interpret and verbalise it. Not only that, in my experience/ observation, Morphine alone is not generally sufficiently effective for this type of bone/ nerve pain.

Heat packs and the right chair that provides maximum support/ comfort are critical. The curve of the chair needs to be appropriate to the location of the crush fracture so physio opinion may be useful. She may require assessment by the physio to inform the best balance between lying down and sitting depending on where the fracture is.

It may be that her agitation/ vocalising increases the longer she is sitting up, which could indicate pain as a factor. Careful behaviour charting of the time and factors around her vocalising would also help identify the contribution of pain.

Regarding Carole's present assessment being undertaken by the geriatrician. Without behaviour charting and consideration of all these factors, there will be limited benefit from the Geriatrician review as he won't have all the assessment information he requires to appropriately advise staff or prescribe treatment. I'd say a referral to the Dementia Behaviour Management Advisory service would provide a more holistic and non-pharmacologically focused approach. They would also be in a better position to advise suitable strategies after observing her.

They may also be able to advise whether a weighted blanket could be used in your wife's treatment to reduce vocalising. Much like swaddling a baby to make them feel more secure.

You may well be skeptical (based on your past experiences) that there will be uptake of these strategies and in the context of staffing resources, the facility may not be able to use all of them. But if even some are taken up, that is an improvement. There are also some strategies you can use yourself, to help reinvigorate and give you roles/ purpose within your own visits. Having something to try is better than feeling powerless.

8 PALLIATIVE CARE (=US HOSPICE)

Specialist: Now comes the hard part of this email conversation and this may require more follow up phone/face to face discussion/ explanation.

This may sound daunting, but at this stage of dementia and with your wife's likely bone/ nerve pain, I would generally recommend seeking a palliative care opinion. I'm not saying the end is near. It may/ may not be so. However palliative care is not just terminal care. Palliative care clinicians are the experts in pain/ comfort management.

I understand your fear and reservations around overuse of medication. However, in advanced/end stage dementia we do need to consider and weigh up decisions based on quality of life and comfort. Sometimes this means making difficult decisions without the benefit of Carole being able to communicate her pain/ needs/ wishes to you.

Glen: *See* https://patient.info/doctor/pain-and-pain-relief
And https://patient.info/doctor/pain-control-in-palliative-care

Specialist: These decisions about pain relief may cause some extra drowsiness and alter your ability to interact with Carole. However sometimes this is necessary in order to assure yourself that everything has been done to alleviate her potential suffering. I call this prophylactic pain relief. Showing empathy, (putting yourself in her position to imagine what it might be like or what you might feel) and anticipating and alleviating potential pain.

Sedating and making people groggy with misuse/over- use of psychotropics is vastly different to making people with end stage dementia potentially a bit groggy with the use of medication to alleviate pain/ suffering.

People may try to tell you that she's not ready yet for palliative care, but that will be because they may misunderstand palliative care as end of life care.

I know how deeply you care for your wife. You are now at the stage in her illnesses where there are very few lighter/ easy decisions and days. You have been an amazing advocate and I'm sure you will continue to be until the end.

I support your stance on psychotropics. However, I appeal to you to not close your mind to medication review all together and particularly not in relation to pain relief.

9 LATE STAGE DEMENTIA

We're doing dying all wrong:
https://www.youtube.com/watch?time_continue=837&v=gQVC-8WEB7s

Specialist: I understand the common desire to resist the progression of your partner's illness and to want to hold on to the comfort of interaction with them for as long as possible, even when that interaction is limited. We all hate the idea of losing our partner to a drug haze. But there is comfort in knowing that to make the decision is serving her best interests.

There is as much suffering and pain in dementia as cancer in my view, yet the person with dementia is often forced to go without relief. This is because there is a lack of recognition of dementia as a terminal condition and a lack of focus on the person as a whole, including other pain causing conditions that often exacerbate behavioural symptoms. There is also a lack of knowledge of the signs of transition in to end stage dementia and the need to change care focus when this occurs. Most importantly, there is a lack of palliative care knowledge/ support in the dementia and residential care context. This is not a criticism of you but of a conventional care systems that continues to shy away from preparing carers for this stage of FTD/ dementia.

In the context of aged care accreditation it is often the consumer complaint and advocacy that becomes the force for system change.

I appreciate that I have probably overloaded you with information and have touched in some pretty heavy topics. These considerations are never easy when they are about someone you love and don't want to lose.

When should a dementia carer request a hospice evaluation?

"We talk about death as a failure. In medicine we say, “He failed treatment.” That they “lost the battle,” and so forth. So we find all these exotic ways to keep the subject at a distance, and in daily life it has become easier and easier to become distracted from this. And it means that so ***many people wait way too long to elect hospice***. And if they do enter hospice at all, it’s often in the final days where there is not much time to do all that we can to bring life to a close and provide some comfort."
https://hospicenews.com/2019/07/17/hospice-physician-b-j-miller-life-is-not-a-fight-against-death/

First, we need to consider what is different about death by dementia. It is often accompanied by other ailments. A dementia patient may have diabetes, cancer, heart, respiratory or other vital organ disease, any of which are co-morbidity factors which may be hospice triggers independently. In the absence of such other factors, death by dementia occurs when the brain loses so much control over swallowing or breathing that aspiration pneumonia or organ failure cause death, or mobility failure causes injury resulting in death. The great difficulty for both carer and practitioner in requesting and determining hospice eligibility is that this brain failure is very difficult to gauge and to predict.

Second, we need to consider hospice and the change it makes to care. Again, terminology and practice vary wherever you go. In Australia, the term "hospice" is not widely used, deemed equivalent to "palliative care". In the USA, the terms have different meanings, though very few can describe the differences and agree, but I will try. Palliative medicine and palliative care have as their objective the relief of suffering and the provision of comfort. Hospice has as its objective the quality of life of the whole patient and that includes their relationships with family members when the end of life is inevitable and life must be brought to its close. So palliative care may start earlier than hospice, but hospice is a broader concept encompassing all things and people surrounding the patient.

Hospice is particularly important in dementia cases because it cares for the whole patient and their family. It is a huge departure from the medical practitioner ethos of curing disease in the patient. Hospice is immediately relevant and appropriate for the dementia journey because the needs of the carer have been subordinated always, for years, to the needs of the patient. Hospice is a bigger benefit to a dementia carer because they have been deprived of support by conventional medical practice.

Hospice is part of the health system, costs money, and is under resource stress, so gets surrounded with bureaucracy and rules. Depending where you go and what rules apply, "eligibility" may require a life expectancy not greater than six months or twelve months, may require significant decline over a specific observed period, may require treatment for a comorbidity factor within the last year, and a dozen more measures. They are poor measures, but they are present in a bid to meter out scarce resources.

When should a dementia carer request a hospice evaluation? I have tried to describe my terminology because the language and practice for hospice are so variable. I suggest that **a carer for a person with dementia should request a hospice evaluation when *any one* of the following conditions is met:**

- a GP or RN suggests a hospice evaluation; or
- the patient meets most of the Stage 5 factors or any of the Stage 6 factors listed here below; or
- the carer has observed such a trend in the symptoms of the patient as to be concerned for imminent end of life; or
- the carer is so isolated as a means of life support for the patient that the carer feels it is irresponsible to continue further without hospice support.

STAGE 5

Double incontinence or urine incontinence and difficulty in general
Inability to walk or even stand up by themselves
Inability to feed themselves
General loss of control of movements
Difficulty sitting up straight in wheelchair
Inability to speak in complete, intelligible sentences but perhaps still speaking gibberish
Lengthy intent staring at individuals, zoning out
Slipping into and out of sleep
Difficulty swallowing, liquids 'pool' in mouth etc.
Trying to eat non-food items
Agitation
Weakness
Declining comprehension
Not recognising family members
Needs to be washed and dressed
Doesn't react anymore to loud noises or quarrels
Mute
Still smiles
Fully dependent
Mostly responsive to visual cues rather than sound cues
No initiative
Rigid
Cannot express feelings
Paranoia
Hallucinations

STAGE 6
Great fluctuations in vital signs such as temperature, blood pressure, pulse.
Urine will turn darker and darker
Will stop ingesting food and or fluids.
Dehydration
Cold extremities
Shortness of breath, rattling with breathing
Weight loss
Restless

Barbara Karnes RN, who has a generous overarching philosophy of coming to terms with the reality of death, told me in 2016:

"...how do you tell when a person with dementia is entering the dying process, or needs hospice services? What is different about dying with dementia? It is really only the acceptance, chewing and swallowing of food that can be used as a signal, because all of the other signals present with other diseases, confusion, incontinence etc may have long been present in a dementia patient."

Glen: *I think that comes from the perspective of a hospice nurse without the benefit of prior experience of a particular patient, no experience of their past trends. In those circumstances, chewing and swallowing food may be the best single measure of hospice eligibility for a dementia patient.*

With experience of the ways of the patient with dementia, other changes may be noticed (items in the Stage 6 list).

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https://books.google.co.uk/books/about/With_the_End_in_Mind_Dying_Death_and_Wis.html?id=XcEuDwAAQBAJ&printsec=frontcover&source=kp_read_button&redir_esc=y#v=onepage&q&f=false
“It’s time to talk about dying.”
Slowly.

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10 THINGS YOU NEED TO KNOW ABOUT APPROACHING DEATH

by Barbara Karnes RN

End of Life Resources for Professionals and Families www.bkbooks.com
360-828-7132

1. Dying is not a medical event. It is a personal, social, communal experience. It is not about endless treatments but about living the best we can within the limits of our body and disease.

2. Dying is not painful. Disease causes pain. There are a lot of diseases we can die from that cause no pain. If there is pain we have unlimited ability to manage pain. With our pharmaceutical advances there is no reason for anyone to die in pain.

3. There is a process to dying from disease. We are not alive one minute and dead the next. Gradually the body adjusts to the disease and shuts down. This occurs over a period of months. The process involves gradually not eating, gradually increasing sleep and gradually withdrawing and going inward. http://www.bkbooks.com/shop/gone-mysight-dying-experience

4. We must have an Advance Directive (Even if we aren't sick we need to have an Advance Directive.) An Advance Directive tells medical professionals how we want to live our life until we are not living it anymore. Without an Advance Directive the medical professionals will decide how we live and die. https://www.legalnature.com/lp/ahcd/Free-Advanced-healthcare-directive-form?utm_source

5. A terminal illness is a gift of time. Most people don't know when or how their death is coming. When the doctors tell us they are having a hard time fixing us, as difficult as it is, they are giving us a gift, a gift of time. This is the time to do and say what we want said and done.

6. Get a second opinion, third if necessary. We need to learn about our disease and its treatment options: ask questions about cure, tumor, goals, remission possibilities, best case scenario, worst case scenario. Asking questions and doing research gives us knowledge to make wise decisions. Sometimes the best choice is to do to nothing.

7. Not all Hospices are alike. Research hospices before one is needed. One of the biggest mistakes is calling hospice later rather than sooner. Hospice service is appropriate in most situations as soon as we stop treatment (if treatment was chosen).

8. Be open, talk about feelings, concerns and fears with those close. This is not a time for secrets. We can use this gift of time to mend relationships, smell the roses, express love and appreciation. Not telling someone they have a life threatening illness is depriving that person of their gift of time. We live inside of our body and know what is happening whether anyone tells us or not. Not talking and sharing the "secret" isolates each of us with our thoughts and fears.

9. Everyone is afraid to some degree when we approach the end of our life. Know that as we get closer to death we will care less and less about the exterior aspects of living, a gentle introspection takes fear's place.

10. Everybody dies. Death is a part of living. It is our final act of living. And we still have choices.

We can choose to turn our limited future over to medical professionals and go with whatever they decide to do with us if that is what we want. Or, and many people don't know this, we can choose to take the reins, do some research, ask questions and make decisions on how we want our final act of living to unfold. It doesn't have to be all or nothing either. What do we want our last experience to be? We have the power to make it so.

There are worse ways to die than when having no cognition, therefore no fear.
I was on notice from mid 2016 that Carole's death was imminent. It turned out to be partly false alarm, but we lived nearly three years with plans ready and feeling "on notice". I sometimes wondered why we continued like that, whether I was being selfish when there was no longer any evidence of happiness. But it never occurred to me to do anything different, such as withhold food or drink. Carole ate everything the last two days of her life. She seemed content and I felt rewarded. In her case (and every journey is different), I never had cause to ponder what was in the Advance Care Directive (ACD). I kept on taking Power of Attorney decisions as her advocate for her wellbeing, including to move residence for her safety three months before she died.

I no longer think ACDs are very helpful towards the end of life. The circumstances are not predictable years in advance and we cannot honestly envisage dying without cognition, reliant on the good will and good judgement of those entrusted with our care. With the best will in the world, I could not now write anything helpful about when food and drink should be withheld from me.

Actively dying includes declining control of multiple organs until something critical fails. Your LO may be unaware and unconcerned.

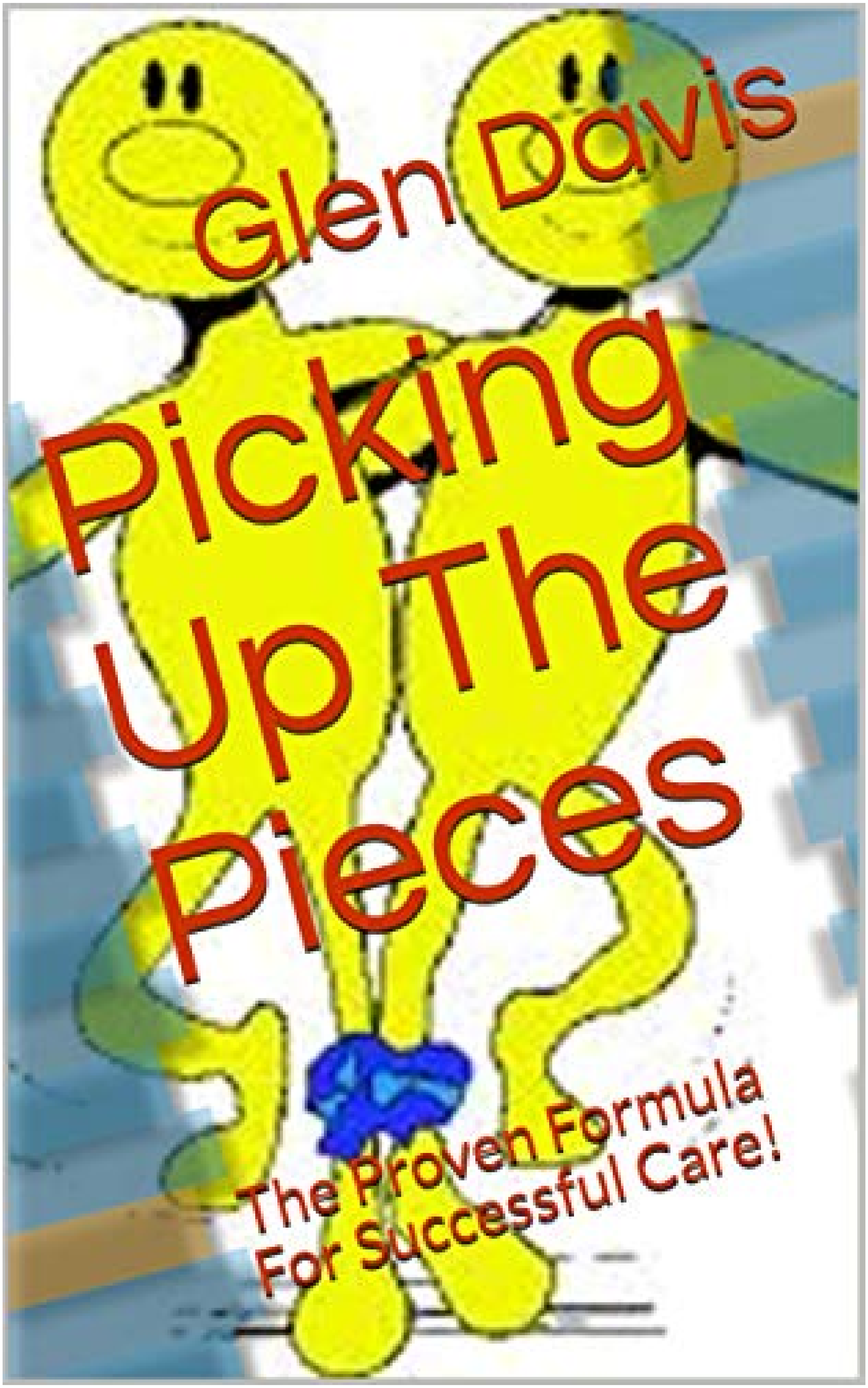
Dementia does not play by the dying process rules. There is no time frame we can put on dementia's progression.
But dementia can break all the rules, even this one.

Dementia is like a road map with many, many roads that eventually lead into a city. Each road is different, each road is of varying lengths and offers various views but all enter into the city at the same place. That place for my dementia analogy is when a person stops eating.
It is true that a person with dementia in end stage will commonly stop eating and from that time, death from dementia follows a predicable path in common with death from other fatal diseases. Carole ate everything for me always, (except when she was erroneously prescribed benzodiazepines, diazepam once and clonazepam another time with disastrous temporary consequences) including during the days before she died. For her, her brain could no longer direct her organs and she died peacefully from multiple organ failure. The only sign that her end was approaching was the 'death rattle' breathing at times during the last two weeks.

Death by dementia comes when the brain loses so much in executive function that it can no longer control essential bodily functions. In Carole's case, multiple organ failure brought about her death. My own personal amateurish observation was that she lost the ability and the will to keep breathing.

Other deaths by dementia that I have observed have varied considerably. One followed a fall in which the head was badly concussed and the patient lost all will and ability to eat or absorb nutrition and death took nearly three weeks. Several died of various infections including UTIs (it is common for families and nurses to generally limit the courses on antibiotics in such cases and my own ACD for Carole instructed that only one course was to be administered if necessary in end stage. Fortunately, Carole needed no infection intervention.) Several lost the will to eat and simply refused food. Their signs of refusal might start off strong, even forceful but unmistakable, then weaken in energy but clearly unwilling. I have heard another carer say that their LO "…grew tired of being tired."

The strength of a person dying of dementia, already seriously sapped in end stage, dissipates rapidly so they can barely move a hand or even open and move their eyes. Because they have no cognition left, there is no fear or desperation.


Glen Davis
Picking Up The Pieces
The Proven Formula For Successful Care!

Picking Up The Pieces.

The Proven Formula For Successful Care! (Carer Fast Track® Series Book11) 2nd Kindle Edition

It is likely that you have found this booklet soon before or soon after the death by dementia of a loved one.

Another carer asked by email how my grieving of my wife Carole is affected by my years of active caring for her. I was not then ready to fully answer, but it occurred to me that it was the start of a new process. So here are excerpts from my reply.

QUOTE

Your questions about grieving Carole. I have endured now the two long slow deaths of my mother in 2015 and my wife. It is certainly different from grieving a sudden death.
With a long time to prepare and to contemplate, I became 'ready'. So there are not things left undone, things I wish I had said. No regretted omissions, which are the cause of much anguish following the sudden deaths of loved ones.
The course of the FTD disease is a very difficult one. At a fairly early stage, in mid 2013, I used Barbara Karnes' video "Gone From My Sight", to look and think ahead.
I formed some early views about "The Judgement" that patients go through in the last months. I formed my theories about other family members' participation in caring. And I converted from Why Me? to Why Not Me?
These events happened nearly six years before Carole died from dementia, so they created foundations for my journey as a carer. And they were complemented by my lifelong habits as a researcher (my 'terminal disease'). And I had lots of wise counsel from other dementia carers.

So my journey as a carer was directed all the way through by these strong foundations; to give Carole every care she needs, to be her one sole related support so that she knew she was loved and not alone, and to tell the story as widely as I can to help other carers. This direction was formed not by the Mother Teresa gene (I was born without my fair share), but by my own self-interest in The Judgement.

The fire'n'brimstone version I created for the Oprah show might never be broadcast, but I am still alert for media opportunities which might arise from my public advocacy. Meantime, I have told the story on the FTD Forum, on Palliverse, to Barbara Karnes, to Prof June Andrews, to a couple of FTD nurses and now, in a way that creates a permanent archive, in my submissions to the Royal Commission, so the ripples continue to spread. Most of all, I have influenced the other carers I have met and whenever my ideas change their actions, those ideas continue to grow. That is my version of immortality of those ideas.

So the process of recalling the good memories of whole Carole has been going on for many years. And yes, the process of grieving and healing will continue to forget the bad episodes and retain increasingly the cherished memories. I have had cause, writing my Royal Commission material, to look back at old diary entries and documents and recall gory details that had already disappeared from my conscious recollections. I know from my earlier experience of my mother's death, this will continue. So I have my teary moments, but plenty of joyful memories too. And I know the process will continue to be long and get easier as it goes.

UNQUOTE

The First Weeks and Months

I do feel alone and redundant and pretty flat without Carole. I have a couple of activities going, but they will be over soon. And then I will not know what to do with myself. "We are never really ready". The caring and advocacy tasks consume all our focus and we defer planning our readiness.

I think I was better prepared for the loss of Carole. I miss her hugely, but I had been missing much of her for a very long time.

It was somebody else, years ahead of me on this road, who found words...

I spent years being the most important person to Carole. I was her Grand Poobah. I could make

things better just by being there. I was Carole's husband. And now I am not. It is a dose of reality that hits like a brick and I am still reeling.
I was somewhat ready and prepared for losing Carole. That had been progressive in the way that FTD is and I had grieved that loss bit by bit with her long journey. What I was not prepared for was losing a chunk of me. That was something I did not anticipate and have to learn about.

I am not sure I will be able to find words to make this easier for anybody else. My feelings for this shock are likely to be no more than one person's perspective on a loss. But I am trying to write it while the feelings are raw.

Another carer was advised by a counsellor to look at the future like a blank canvas. To keep the habits and activities that were enjoyed, where possible. The rest of the canvas should be thought of as what to paint/fill in there. Just start by thinking about it, feel free to erase what you find doesn't work. Teepa Snow does that too and I like it. The progression from looking backward to looking forward is an important part of the healing process. I guess that will happen once I identify new goals and priorities and direct energy to them.

Today, I spent a fortune on plants and materials for a bit of a garden makeover. Gardening is inherently a look-ahead activity and it was good for me. It is exercise, Vit D, nature, and creativity all rolled into one. Even perusing gardening ideas on TV/net/magazine is a stress reliever for many.

Today, I got into earnest discussion with some citrus trees and even started a debate with the herbs! Just as well there was nobody around... they would have put me away.

Another small step. I went back to Carole's former nursing home for the first time since the day she died. I just went to say Hi to other residents, carers and staff who had befriended us. I had a cuppa and a chat and lots of hugs. There were several suggestions about things I should be doing... volunteering, sailing, horse training... I am non-committal. (It is often advised that big decisions should be deferred until you know your own mind.)

One carer had to leave to make an appearance in court. That prompted a story from me that I was forbidden previously from telling.

When Carole was early 20s and single and living near Toronto, Ontario she took her dad's car without permission and drove to see a sailing event. In Rhode Island, USA ! (I suspect there may be a sailor involved in this story...)
It was a long way, so she drove fast.
And was pulled over by a highway patrol. Carole sweet-talked the trooper and was about to drive off with a warning when the trooper's partner said "You can't let her go, look at the speed

she was doing. We have to take her to the Judge."
So Carole is ushered into the back of the patrol car and driven to the Judge's residence where he was having lunch and she was asked to wait.
Eventually, the Judge addressed her to advise he had heard the troopers' account, was advised of the recorded speed and that she was fined $20.
That happened to be exactly the amount in her wallet (which the troopers must have checked).
She paid the 'fine', was returned to her car, earnestly warned, and she drove home. Very fast to make up for lost time.
The legend goes that her father never found out.
But the family saying was born. Whenever we wanted to cast doubt on something Carole said or to suggest she was exaggerating:
"Tell it to the Judge!"

Recounting stories that reveal the character of the deceased loved one is a therapeutic part of grieving. It is Good Medicine.

Another step along this trail...
I have just got back from the journey to sprinkle Carole's ashes on the upper slopes of Mt Warning. It is the first place on the Australian mainland to see the rays of the rising sun, and it overlooks the territory that Carole first rode her great horse, Whiskey. It is a symbolic event. But it helps me to have this done. There is a little peace and closure from this accomplishment.

Three Months

One weekend, three months after Carole died, I drove 15km south along George Bass Drive to a little coastal headland. There is a little bushwalk there through a forest of old banksia trees (named for the botanist Joseph Banks on Cook's ship). It is a very beautiful, quiet, peaceful environment. I surprised a wallaby, snoozing on a patch of winter sun alongside the trail. He hopped only a few metres into the bush and looked interested as I stopped to greet him. The trail quickly reached a small lighthouse and trig point, then followed the clifftop around the headland.

I loved my little walk and its reminders that the great explorers of these seas and this coast were aged only in their 20s. Bass Strait, dividing the mainland from Tasmania, was named for George Bass when he and his young friend Matthew Flinders became the first to circumnavigate the Tasmanian island in 1798. What spirit and resilience they had!

Looking for something else, I bumped into this blog post.
(Buddy's Fourth Law says: Give serendipity a chance! The more you are open to good luck happening, the more likely it is to happen.)
"Google can't tell you how to grieve"

https://www.dawnvance.com/single-post/2015/11/12/Google-cant-tell-you-how-to-grieve
And I find that true. There is a lot of "muddling along" that happens, in the hope that "time heals".

Early in my journey as a carer, I would spend the minute after I put down my head to think about what I might do after FTD. Eventually, those dreams firmed into some plans of catching up with other family members, old hobbies to be renewed, new friends to be enjoyed, travel to be had, projects to be pursued.

And those plans are progressing, fairly slowly. But I'm not sure how much they have to do with grieving. I am finding that the process of looking forward gets interrupted. Quite a bit. And books and articles about somebody else's grief are just that, not yours. It seems to me that the important bit is your own stories, your own values, and the shaking down of the painful memories into a new perspective. So I muddle along in an individual way and that seems to be my grieving process. There's not much science or advice applicable, I think. Future plans are necessary, but not enough by themselves and the grieving process takes its own muddling course.

My culture is to expect much of myself. I get frustrated when goals and plans and progress are hampered. I am having to learn more patience and maybe generosity, maybe humility though it hurts to admit those.

It is supportive to know that others have been on similar journeys. Some of them thrived. So there are precedents for traveling the grieving journey successfully.

The timing, the course must be of your own individual making. You have survived an FTD journey, despite the heightened morbidity risks of a carer. Draw comfort and strength from that success.

There will be interruptions. 'Life is what happens when you were planning something else.' There will be delays caused by others in your life. Yes, but they intrude ! They come gate-crashing in, uninvited, and disrupt. In the middle of a sociable conversation or a thinking process. And the mind goes spinning off and I get too choked up to speak. Grief does not respect your plans. Grief is all emotion and does not respond well to logic. It is messy. It launches surprise attacks, catching you unaware and rendering you all but undone. I have heard it referred to as being ambushed by the grief monster (as if by a different entity). You will not have control. There are lessons to be learned. It is all necessary, unavoidable, uncontrollable, unable to be accelerated.

There will be times you need to simply reflect rather than make change. Think of those times as part of that process. Not a failure but a needed break or diversion, a resting period, or even a reflecting time. "Time heals."

'Be gentle with yourself' about the time it takes and about any delays. There will be moments that catch you out and you choke up, or the tears flow. There may be waves of grief that threaten to depress you. These are times to accept that grieving is a process, it takes time, and it has its highs and lows. Avoid becoming impatient with yourself about the time or about your blues. Step back, reflect on what has been achieved and remind yourself you are doing well.

Six Months

I am making slow progress on myself. I am drifting, treading water. Partly it is deliberate, avoiding making any big decisions for a year, avoiding filling my life with trivia and deliberately leaving a hole to be filled later ("Don't make do, make space!"). Partly it is discomfort with not having plans and targets. Partly it is just loss, loss of Carole and loss of that part of me that made me most important person in the world, grand pooh-bah who could fix things.

The Grief Monster ambushes me less frequently, but it still happens and effectively chokes me up. My mind runs to other carers ahead of me and what they said about the grieving process. But I don't come across thoughts that I can apply to myself. I am reminded that the grieving journey is an individual one.

I did find the anticipatory grief made it easier to accept the loss of Carole. I had anticipated it would, and it did. I was shocked and numbed and hurt but I could mostly talk and think and function. I could notify people (with omissions and mistakes) and make arrangements. When Carole's doctor attended to record the certification of her death, she asked if I had any questions and I could not think of any. I had to take a lot of care about driving. I was definitely not operating at peak. The distinction I make is that I was somewhat prepared for the loss of Carole. I had been on official notice since 2016 and I had made all the preparations, brain donation documents etc. And the doctor had warned me of the significance of changes she was observing and which I had not appreciated were signs that death was imminent.

What I was not well prepared for was the loss of my role, my Grand Pooh-Bah status in Carole's eyes. Why was that a surprise? Only because I was in denial, avoiding thinking about it. I simply deferred it, would not go there in advance.

Having the Grand Pooh-bah job of caring for Carole come to an abrupt end lost a chunk of me. I came to identify that chunk as being my sense of purpose. I needed to review that and wait for a new clear answer to emerge.

“Review and wait”. These do not come easily to me. I felt lost without clarity of purpose and plans.

Many people have heard of a magical one year mark that must be passed before a grieving journey could change. At this stage, that struck me as arbitrary, illogical, unworthy of further thought.

But I set myself a target. The things I would write to help other carers learn from our journey would be written before 23 April 2020, the first anniversary of Carole’s death. I rationalised this as being necessary before I forgot details. I surrounded the target with logic and plans. I identified a critical path of choosing publisher, medium etc and the authorship tasks. But in truth, the target timing had ceremonial significance and I was deceiving myself.

I kept a diary discussing "picking up the pieces", the grieving journey and the carer’s tasks and life after losing their LO.

I listed the subjects that I wanted to write about because I considered they were not yet well covered or I had a perspective to add. I thought about putting them in a book. But I read: Dementia: The One-Stop Guide by the extraordinary Prof June Andrews and I recorded:
“Reading such books was impossible for me in the heat of the caring journey. Those carers in greatest need have not a moment to spend researching, comparing, ordering, waiting, digesting and applying a book. A two-day read was a luxury far beyond reach. There is a place for such books, but they are not ideal for carers in the front line of a FTD journey.”
A Bulletin Board works if it responds to carer's issues right then. Just that subject and immediately. So I resolved that my writings must learn from that model. Nothing should exceed a ten-minute read because that is all the time carers can find.

There was another piece of self-deception. The decision to publish this material was an extension of my role of caring for Carole. Was I avoiding/deferring the identification of my new purpose by extending my old purpose? I could barely conceive the question and dared not attempt an answer. Had I really grown some Mother Teresa genes? Was being a carer going to be part of my identity indefinitely? Scary questions. I pushed them away. I had targets to hit.

Seven Months

Purpose and hope. Future objectives. There have been past times in my life that plans became derailed and I had to rethink things. I reinvented myself many times in my career and became very efficient at doing that. Is this occasion fundamentally different? I have been thinking out loud about that. A friend by email gently observed :

"You are in stage 8, ego integrity vs. Despair, and your existential question is, is it okay to have been me?"

I recognised the source as Erikson and replied

"But I have resolved the stage 8 question. No regrets. So I am in "ego integrity" which is the end of Erikson's road, and here I am wondering what things I do next. My only pull of despair is that I have not chosen my next objectives. I know of others ahead of me on the road who faced the same issues but just seemed to work it out and dropped into volunteer roles, being grandpa, whatever. Here am I wondering out loud and trying to be decisive. I am not ready for Erikson's message that this is the end of the road and there is no more development. Why can I not become an Obi-wan, or a sage? Why is the University of the Third Age not for me? (Rhetorical Qs.)"

The more I think about Erikson (a founding father of modern psychology) the more I rebel. This is the man who gave the world the "identity crisis". He lectured people about what was normal when his own experience and perspective was very far from normal. He wrote about "stage 8" before he experienced it.

So here I am, reinventing myself again.

But I had the advantage of advice. “Remember about the blanks in the canvas yet to be filled.” I had to hasten slowly this time and let emotions catch up. I had to let my heart catch up with my head.

Eight Months

To achieve something of the original objective of my diary, to record the stages of one journey of "picking up the pieces", I must write my thoughts about 'milestones'.

It seems (and my own observations have been reinforced by others I have read) that the first year contains a sequence of these milestones that are characterised in my mind as being the first such event "without Carole". Some of these seem significant as focuses of grieving.

There was her first birthday "without Carole" in November. Her eldest son and his wife called me to mark the day and I was upset and could not contribute much beyond "I miss her."

There was my first birthday but it is now known as the "unmentionable event" in my attempt to suppress any kind of celebration. So it was not particularly a focus for grieving Carole.

But Christmas "without Carole" was very sad. I was deliberately alone, very unworthy company and self-indulgently focused on what was lost. Not at all pretty. I had sent some ecards and some flowers and started a forum thread but those were all things done on previous days. Christmas day, I was a basket case and not proud of it.

A quote flashed through my mind. Great songwriter Leonard Cohen was asked in an interview how he felt when he returned from a five year study of Zen Buddhism to discover his former manager had absconded with all his money. Cohen retorted that he did not recommend it as a spiritual exercise. But much wonderful information was delivered to his heart as a result.

Grief is like that. This grieving process does not have much to commend it. Except that it is better than the alternative. Not all carers survive their LO, so grieving can be seen as an essential part of survival.

But I am about to turn a corner. New Year's Eve is all about novelty. Chinese New Year (25 Jan 2020) is more emphatically about new starts and 2020 is the Year of the Rat, the first in the 12-year Chinese Zodiac. My resolutions are all forward-looking. As usual, I have my carer friends to thank for their many comments which helped bring me to the realisation that every end is a new beginning. There is so much that is still good.

Nine Months

New Year was a turning point in my grieving journey. I recognised the strength of the Asian traditions which had previously meant little to me. I realised the importance of New Year spirit, of resolutions, of turning over a new leaf, of being constructive, of forgiving the past. How could this have been right there all my life and gone unappreciated? I did not spend long beating myself up for my failings because I so strongly welcomed the new beginnings.

I realised that I had to hit rock bottom, alone at Christmas, before my grieving could turn the corner and become more constructive, more forward-looking. It is possible that I experienced a full measure of this "losing a chunk of me" because Carole's journey made me into a very "busy" carer. But I still judge the main reason to be that I simply refused to go there. I did not properly anticipate losing a chunk of myself only because I avoided thinking about it.

I wrote in my diary about the New Zealand volcano on White Island. There were 47 people on the island during the eruption and 17 of them died immediately. Two bodies were not recovered and it is the families of those two whose grief is most unresolved. There are carers who may face a similar issue if they are, for any reason, not at the death or the funeral of their LO or if they lose their LO in a way that lacks the same evidence as a focus. The key to your grieving is to acknowledge your loss, which is every bit as great. Keep close to other carers, your friends and family. Grieving without them would be very grim.

Eleven Months

I hope that reading this little booklet has given you ideas for your own grieving journey better than mine when I started grieving the loss of my Carole.

During the dark, anxious days of our FTD journey, I would dream of “life after FTD”. It was my habit, in the minute after I laid down my head, to start dreaming about the things I might do when time and circumstances allowed. Without that, there would have been only emptiness to look forward to. So I would dream of visiting the kids, renewing old hobbies, starting new friendships, taking trips. Just ideas back then. No plans, dates or anything specific because my commitments were to Carole’s care.

My diary recorded in 2014, five years before Carole died:

“There is only so much that can be said about ambiguous loss. We grieve for what we lost and what we hoped would come. We grieve for our relationship with our LO which can never be what it was.
But there is something left which keeps us going. It can be a love or a love lost, a caring, a calling or a duty felt. It is different for us all, but there is a common element. We put one foot in front of the other, we survive minute by minute, meal by meal and day by day.
We do keep going and we do survive and when the FTD journey ends for our LO we will struggle to refocus and reinvent ourselves. Once FTD touches us this closely it changes us forever.
I was born without my fair share of the Mother Teresa gene. But I have learned from others a bit about being a carer and I do not expect that will ever leave me.”

I hope this booklet might help others prepare for their grieving journey.

I have to say that I made little progress at first. Little progress on my grieving, I mean. I got all the necessary arrangements done quickly as they were all prepared in advance. We had been on notice for nearly three years that Carole’s life would end soon.

This first year after Carole's death is a procession of reminders. I understood better when other carers ahead of me on the road explained their relief at getting past the parade of "first anniversary of X without Carole". Suddenly, I realised the sun would come up again when that “year of firsts” came to an end.

I am still in that "First Year Without", but a remarkable change occurred.

Christmas was terrible, deliberately alone, self-centred, pitying, grieving the loss of Carole and miserable. And a few days later, I had to think about New Year. Suddenly, the real meaning of New Year impressed itself on me, I remembered all the international interpretations and festivities, the traditions of Chinese New Year etc. And I started looking forward more positively, thinking about new beginnings and moving on some plans for "life after FTD".

I have turned the corner on grieving Carole and it gets easier now (three weeks after my solo Christmas Blues) I am applying myself to looking forward with New Year spirit and getting this "year of firsts without" attitude behind me. It is really 'only' an attitude change. But I had to earn my stripes before I could move on. The "year of firsts" comes to an end. Once I understood that, New Year spirit was allowed to fulfill its rightful place and I could turn that corner in the grieving journey.

So now, picking up the pieces is accelerating into “new beginnings”. There are still mopping up activities, like acquitting probate and dealing with the administration of Carole’s will. But some of those old dreams of “life after FTD” are becoming real. I picked up my guitar and started to make eyes and brain and arthritic, rusty fingers remember how to read and play. I am really treasuring my friendships with other carers met in NHs and online and we have had some meetings. I have done some trips and adventures and took pics to record them. I teamed up with others to write some tips for carers on subjects on which we could contribute, and I got some professional commendations for those works so that some future “titles” (as I think of these little lessons) get some cred.

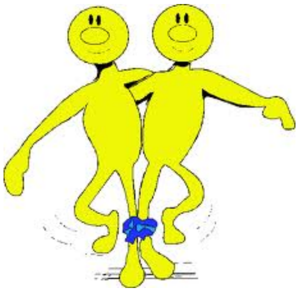
So I turned a corner with the New Year and I am becoming more proactive about “Life After FTD”. I want to try to grab and record the development that let me "turn the corner" in my grieving.

The first was my miserable, wretched, lonely Christmas Day. That was not unexpected but it was certainly not planned. What it did was let me experience the full force of grief. I think I had to do that. I had to hit bottom before I could start improving.

The second was my thinking about New Year. I have been fortunate to experience something of other cultures and developed some awareness of the huge significance of New Year in the process of renewal. I was just lucky that New Year and this understanding came together immediately after I hit rock bottom.

Third was the light-bulb moment when it hit me that the "Year of Firsts" was going to end. All by itself and I did not have to do anything. On 23 April 2020 there will be no more anniversaries that are the "First without Carole". And the sun was going to rise.

These are the events that let me "turn the corner" in my grieving journey. For me, it was not a case of "time heals", it was a case of events and changed conditions doing the healing but certainly those things take time and cannot be hastened.



The Money

One part of my "Picking Up The Pieces" has been **finances**. It is all progressing, but I have learned a couple of lessons. So I thought I would record the story and the conclusions I reached.

Carole had some retirement savings in a superannuation fund. As PoA, I could have drawn them down and expended them on her care. But I did not.

Australia has a financial arrangement for financing residential care partly through the deposit with the provider of a Refundable Accommodation Deposit. (The provider gets the benefit of interest on the investment.) And the other part of the residential care is funded through a daily fee. Within limits, a carer (exercising Power of Attorney for the LO) can trade off between these two costs, reducing the up-front lump in exchange for higher daily fees.

In our part of rural Victoria, the RAD (set by market forces) was $350k in Jan 2015. In the larger cities, the RAD is typically around $1m for a high care Nursing Home.
There are several major factors influencing the RAD/daily fee tradeoff decision:

- interest rates. When rates are low, as now, it hurts less to pay the RAD and forego the interest on investment.
- prognosis. When time is short, it hurts less to pay a higher daily rate.
- affordability. Carole did not have $350k in retirement savings but I did.

So my decision in Jan 2015 was to pay the max RAD to reduce the daily fee. Good decision.
But I paid it from my funds, and later realised that complicated things because the eventual refund goes to the estate of the resident. I took legal advice. 'No worries, there are no death duties, you get it all back from the estate.' True. But I now learn that is not quick or easy. Carole's new NH (2019) has a policy to only refund the RAD upon grant of probate. But for that policy, her estate would not have been sufficient to require probate. And probate costs over $1,000 and takes 9-ish months. (I did it myself because I am a JP and understand the language and process, but I incurred minor delays because of remoteness from the court and difficulties getting certified copies. Throwing $3,000 extra at a probate attorney might have saved say two months.)

The new NH got to care for Carole for three months, but got my money for 12 months. Bad decision. I should have paid minimum RAD in 2019.

But there is one part of the story that survives export to other countries.
My decisions were partly emotional. Carole was losing so much with dementia, I did not want to see her lose her money too. So I preserved it by paying for her care. Not clever. I should have preserved just enough to pay her bequests to her kids.
It would have been very easy to pay for her care using the PoA I held. I could have done that as long as her money lasted, down to a balance to pay the bequests.
So the message is to use LO's money first to pay for care costs. That's what Power of Attorney is for.

Glen Davis

Manejando la etapa de la ira

Manejando la etapa de la ira. ¡La fórmula probada para un cuidado exitoso! (Libro 7 de la serie Carer Fast Track®) Edición Kindle

Cuando la demencia ataca el lóbulo frontal, las inhibiciones que se desvanecen y las obsesiones que aumentan son resultados frecuentes. Con estos filtros emocionales que no funcionan normalmente, la rabia es un resultado frecuente. La ira que da paso a la violencia es un síntoma en más del 20% de las personas con la demencia frontotemporal. Estos síntomas suelen ser una característica de la etapa intermedia de la enfermedad, a veces son los síntomas que causan que una persona sea diagnosticada con la demencia frontotemporal. Cuando el síntoma es una característica temporal, esto domina la relación entre el/la paciente y su cuidador y afecta el cuidado. Entonces se llama "La etapa de la ira".
Estos comportamientos están entre los más difíciles de entender y manejar para los cuidadores. Este libro está dedicado exclusivamente al manejo de la ira o en inglés, the rage stage.

RESEÑAS:

"Genial"... "Debo decir que me conmovió profundamente su descripción de lo que la gente tiene que aguantar, y el estilo y contenido de sus consejos prácticos. Muy pocas personas son conscientes de la medida en que un cuidador familiar debe a veces subyugar toda su personalidad a la persona que ha sido creada por el la demencia frontotemporal, con el fin de mantener la paz y mantenerse a salvo. La mayoría de la gente se rendiría en una etapa muy temprana y saludo a aquéllos que perseveran por el amor y el deber. Ha hecho una muy buena descripción de ello, que estoy seguro será de gran ayuda para muchas personas".
Profesora June Andrews RMN, RGN, FRCN, OBE

"Es tan valioso. Cuando lo publique, ¿me diría dónde se halla el vínculo de la página web para sugerirles a otros que lo lean?"
Barbara Karnes, RN, galardonada como educadora del final de la vida, 2015 Mujer Humanitaria Internacional del Año

Manejo de la etapa de la ira

Lo peor de un viaje de demencia frontotemporal no es lo que nadie quiera ver. Es la rabia. Los cónyuges o los principales cuidadores de una persona con la demencia frontotemporal ven cada episodio y ejemplo de ira. Otros miembros de la familia ven pocos. Los médicos no suelen ver ningún episodio de ira, o sólo uno. Los cuidadores a menudo ni siquiera pueden convencer a los miembros de la familia de que a veces es realmente tan malo.

Los principales sitios web de recursos para la demencia tienen dos omisiones importantes.
- Sorprendentemente, no aparecen las palabras "terminal" ni "fatal". Las principales asociaciones evitan ser las fuentes de estas importantes malas noticias. Si necesita demostrar a

su compañía de seguros o a su proveedor de cuidados paliativos que la demencia frontotemporal es fatal, puede que tenga que recurrir a su médico.
- Hay pocos consejos para ayudar a los miembros de la familia a manejar los síntomas más difíciles del la demencia frontotemporal. Las principales asociaciones tratan de no ser la causa de que los nuevos cuidadores se asusten. No ofrecen consejos para comunicarse con los pacientes con demencia, aunque las comunicaciones defectuosas pueden ser la principal causa del desvanecimiento de las relaciones familiares. Y omiten los consejos para manejar las rabias, que son síntomas comunes de la demencia.

La insuficiencia cerebral con la demencia frontotemporal no es como la enfermedad de Alzheimer (que es unas diez veces más común y más conocida). La primera señal de Alzheimer es la pérdida de memoria. La demencia frontotemporal se nota primero debido a comportamientos extraños y a decisiones inusuales y malas o a la pérdida de palabras.

Es muy difícil conseguir recursos que ayuden a controlar la demencia frontotemporal. Hay resúmenes en la red. Hay artículos para médicos e investigadores médicos. En lo profundo de las publicaciones médicas, hay estadísticas de agresión y violencia de los pacientes con demencia. Pero hasta ahora hay pocas "noticias de primera categoría" o consejos prácticos para los familiares de una persona con esta demencia.

La violencia en personas con demencia es más común de lo que se publica ampliamente. Las estadísticas de violencia en la enfermedad de Alzheimer de inicio temprano reportan que el 17% exhibe severa agresión en el primer año después del diagnóstico y el 20% exhibe violencia durante su viaje. Las observaciones de los cuidadores de cientos de pacientes residentes en asilos de ancianos sugieren que los números son probablemente similares para la demencia frontotemporal.

Los miembros de la familia que se enfrentan a una "etapa de furia de la demencia frontotemporal" necesitan saber más. Necesitan información, estrategias, consejos y sugerencias. Esta enfermedad amenaza la salud, el bienestar y la cordura de todos los miembros de la familia que participan en el cuidado de su persona que sufre de rabia. La rabia a menudo hace que los miembros de la familia ya no puedan cuidar de la persona con demencia.

Los miembros de la familia necesitan saber que no son los únicos. Los cuidadores necesitan saber que hay sobrevivientes que van por delante de ellos en el camino de la demencia frontotemporal, que hay lecciones aprendidas que pueden ser transmitidas. Hay una forma de atravesar esto. Hay recursos que proporcionan un verdadero apoyo a los cuidadores.

¿Qué causa la etapa de la ira?

La demencia es una falla cerebral progresiva que resulta en la muerte. En la demencia frontotemporal, los lóbulos frontales y temporales del cerebro acumulan excesos de proteínas. Estas son proteínas presentes en una persona sana, pero que se acumulan en mayor cantidad en los cerebros de las personas con la demencia frontotemporal. (para leer más, ver Biología del la demencia frontotemporal más abajo.) Las proteínas obstruyen el cerebro y las células mueren progresivamente.

La conducta de la etapa de la ira es causadoa por las inhibiciones que se desvanecen o fallan. Los filtros sociales ya no funcionan para mantener las palabras y acciones aceptables. La planificación, la organización, las decisiones y las secuencias se hacen en partes similares del cerebro pero cada una falla en diversos momentos.

Las inhibiciones que se desvanecen y que inician la etapa de la ira probablemente causen conducta relacionada en algunos pacientes. Esa conducta puede incluir comentarios socialmente inapropiados, tocar a otro sin que éste lo desee, obsesiones pornográficas, abuso sexual, gastos irracionales y excesivos, abuso físico, palabrotas compulsivas y abuso emocional. El cuidador suele quedar profundamente conmocionado y avergonzado por las reacciones de otras personas que no lo entienden y se ofenden.

¿Cuándo se produce la etapa de la ira?

La ira y la agresión tienen más probabilidades de desarrollarse en las etapas intermedias del viaje de demencia de una persona. Esto ocurre también típicamente alrededor del momento en que la mayoría de las personas con la enfermedad alcanza el diagnóstico. Antes de diagnosticar la demencia, los médicos requieren pobre cognición junto con capacidades y conducta en declive. Lleva tiempo observar estos cambios como tendencias.

EJEMPLO 1

El apoyo es necesario cuando se necesita ayuda y tutoría y cuando la causa está en duda, no cuando un extraño/ un médico llega a un diagnóstico. "Desearía haber tenido acceso a esto hace 10 años cuando, como muchos aquí, la demencia no había sido mencionada y me preguntaba yo por qué nuestro matrimonio se hundía. Ojalá cuando me preguntaba "¿y ahora qué?” supiera qué recursos buscar y en cuáles confiar y cuáles eran una insultante pérdida de tiempo y dinero. Podría haberlo hecho todo mucho mejor ahora."

La mayoría de las veces, la etapa de rabia ocurre a la mitad del camino. Pero cada viaje es individual y hay familias que sufren la rabia a lo largo de su viaje y familias que no ven nada de rabia. Algunos pacientes que son violentos o que realizan actos sexuales inapropiados pueden llegar a este punto de la conducta inapropriada más tarde y puede que sean menos extremos. Pueden ser solo un empujón ocasional de otro residente del asilo o resistencia física y verbal al cuidado personal. Una predicción para la furia de la demencia frontotemporal es: Tu kilometraje puede variar." Sólo confía en tu juicio de tu propia experiencia, porque el pasado de cada paciente es su mejor pronosticador. Cada familia construye su propia historia de desarrollo de conducta de la demencia frontotemporal.

EJEMPLO 2

“Mi marido está ahora obsesionado con su acto sexual favorito. Ha llenado la memoria de su teléfono con fotos pornográficas de ello. Habla de ello en voz alta en las tiendas. Lo quiere todos los días, a veces más a menudo. Yo cumplo porque si no lo hago, su estado de ánimo se ve afectado negativamente, y eso lleva a episodios de rabia. No he recibido el apoyo que otras víctimas de la etapa de rabia podrían recibir, en parte porque no he sido abierto sobre lo que está pasando.”

¿Qué formas puede adoptar la etapa de la ira?

Algunas personas que viven con la demencia frontotemporal se mantienen agradables y tranquilas a lo largo de su viaje de la falla cerebral progresivo. Otras experimentan ansiedad y pueden desarrollar comportamientos intensos de ira y agresión, violencia y paranoia.
Un cuidador experimenta rabia por primera vez cuando una persona con demencia le ataca sin razón alguna o se vuelve obsesiva. La rabia puede ser verbal o física o ambas cosas. El cuidador es el primero en sufrir un severo choque emocional. Es normal sentirse sorprendido, desanimado, triste, herido, irritado o enojado. Aprender qué es lo que causa la ira en la demencia, y cómo responder de la mejor manera, puede ayudarle a sobrellevar la situación.

EJEMPLO 3

“Hice una pregunta sobre la lista del mandado mientras mi marido se ataba los zapatos. Se enfureció instantáneamente. Ésta fue la primera vez que tuve que ser rápida para esquivar un puñetazo. Su rabia era tan intensa que mis instintos de supervivencia se activaron. Estaba completamente fuera de carácter del hombre con quien me casé. Fue impactante.”
Cuando las personas con demencia se enojan, pueden levantar la voz, tirar cosas, volverse combativas. Los comportamientos incluyen golpear, patear, empujar, gritar y chillar e incluso intentar atacarle físicamente. Pueden decir palabrotas con vehemencia, aunque nunca antes hayan pronunciado una palabra grosera.

EJEMPLO 4

“Si le doy mi mano, intentará aplastarla. Utiliza toda su fuerza.”
A veces, hay advertencias físicas como un ceño fruncido, una voz fuerte, un rostro enojado o un movimiento agresivo del brazo. Pero otras veces, puede ser difícil de ver la ira que viene. Puede parecer que se eleva de la nada. Esta ira "sin advertencia", "de repente", puede ser la más difícil de manejar debido a su imprevisibilidad. Atrapa a los cuidadores inesperadamente. Es extraordinariamente agotador para el cuidador estar constantemente caminando sobre cáscaras de huevo.

EJEMPLO 5

“Mis niveles de energía (físicos, emocionales, psicológicos, espirituales) mientras vivía en casa eran, bueno, digamos que me quedé sin nada durante años, y consciente de ello.

La demencia frontotemporal me enseñó a no intentar predecir el futuro en absoluto. Tenía que vivir el momento. Un día a la vez.

Ahora me doy cuenta de que mucha de su violencia y hostilidad hacia mí fue a causa del miedo que sentía, el miedo que no yo pudiera proporcionarle lo que necesitara. Él tenía razón, ¡no podía! Se necesita un pueblo, un equipo de tres turnos de profesionales con una residencia segura o un asilo seguro para cuidar a alguien que es físicamente capaz pero que ha perdido la cabeza.

Me golpeó en cinco o seis ocasiones, un par de veces resultando en costillas rotas.

Me tomó un año más o menos después de su colocación en el asilo para que yo empezara a salir de la tierra del la demencia frontotemporal. Mucha de mi energía ahora se destina a tratar de reparar el daño que la enfermedad ha causado a nuestra familia."

Cuando las señales que advierten que un episodio de rabia aparecerá dentro de poco, a menudo no son reconocidas por los cuidadores. Los cuidadores pueden esperar que la conducta pase, o simplemente carecen de la experiencia necesaria para responder. En los meses anteriores al primer episodio de rabia, una persona con demencia puede mostrar "cara de juego" o un cierto tono de voz al maltratar a los animales domésticos o a los niños. Puede levantar el brazo, agitar el puño, dar patadas, acercarse físicamente a otra persona y ponerse "en su cara". Su cara puede torcerse y ponerse progresivamente más fea a medida que las neuronas que controlan los impulsos mueren y las inhibiciones se desvanecen. Estos son indicios observables del daño que quiere hacer. Pero los cuidadores inexpertos tienden a descartar esos signos de aproximación a la confrontación física.

EJEMPLO 6

"Hubo momentos en los que temía por los nietos, ya que le encantaba golpearlos y empujarlos como lo hacía con los perros. Les digo a mis hijos que él no debe imitar un columpio con el niño de 5 años, levantando al nieto por los tobillos y moviéndole hacia enfrente y hacia atrás, columpiándole. Que no se le debe permitir golpear a los perros ni a los nietos en sus cráneos o debajo de sus barbillas, que no se le debe permitir ser brusco con ellos, que no debe estar a solas con ellos a causa de algunas conductas inapropiadas del pasado.

En una ocasión le dije en un tono contundente, "¡¡¡No patees al perro!!!" Me dijo, "Yo SÍ lo haré". Le dije que no volviera a hacerlo y esta vez se acercó a mí con una mano hecho un puño. Me retrocedí. Lenguaje pesado y una orden para "ir allí!" (el sofá) trajo más agresión. Me mantuve firme y él me golpeó el antebrazo 3 veces.

Tengo un plan para huir. He notificado al número 800 de Home Health y a su enfermera de esa institución. He dejado un mensaje urgente para su neurólogo. He avisado a todos los miembros de la familia. He hecho una maleta y mi bolso. El celular y el laptop son fácilmente accesibles. La casa tiene 4 salidas..."

La etapa de la rabia puede o no estar acompañada de una obsesión por la pornografía. El deterioro del lenguaje puede ser una señal de rabia inminente. Una persona que entra en la etapa de ira se vuelve crítica, acusadora, culpa a otros. Todo se describe como "inútil", "asqueroso", "fútil", "horrible". El lenguaje desinhibido incluye maldiciones desenfrenadas incluso por personas que nunca lo habrían hecho cuando estaban enteras.

La demencia afecta a las emociones. Los cuidadores de personas con demencia observarán progresivamente que las emociones de los pacientes se ven afectadas por la enfermedad. La demencia afecta al cerebro, y el cerebro es responsable de almacenar y recuperar recuerdos, palabras y nombres, de tomar decisiones y de reconocer y recordar nuestros valores. El cerebro también controla nuestras emociones y comportamientos. Por lo tanto, dependiendo del lugar del cerebro en el que se produzca el daño, las emociones también pueden verse afectadas. Normalmente, sólo los cuidadores con experiencia 24*7 reconocerán inicialmente los acontecimientos, los patrones y las tendencias de estos primeros cambios en las emociones y los comportamientos. Las tendencias inicialmente no son aparentes en una consulta médica de veinte minutos en una clínica y esto retrasa el diagnóstico. Otros miembros de la familia en esta etapa con menos de contacto 24*7 encuentran que la persona parece muy normal y creíble ya que todavía "me parece BIEN".
Las reacciones de ira pueden ocurrir como respuesta a las acciones de un cuidador. Una persona en la etapa de ira es muy fácil de provocar y se agita fácilmente. Sus obsesiones y delirios pueden tropezar con la irritación y la ira. Esta ira catastrófica puede surgir de un malentendido de la expresión o acción de un cuidador, de los celos o "de la nada", de una obsesión o de acusaciones de este tipo de demencia. Esta "reacción exagerada" en las emociones puede causar ira y agresión.

EJEMPLO 7

Marjorie Grayson, de 84 años, apuñaló mortalmente a su marido Alan Grayson, de 85 años, tres veces en su casa de Orgreave Lane, Sheffield, el 13 de septiembre de 2018, antes de llamar al 999 y declarar: "Acabo de apuñalar a mi marido, creo que lo he matado"...
El juez dijo que sólo después de que se iniciara una investigación la familia se dio cuenta de que había habido "cambios de comportamiento notables recientemente"... Dijo que los expertos en neuropsiquiatría decidieron que Grayson tenía demencia frontotemporal de variante de conducta. (bvFTD)
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

Es muy importante que el cuidador les comunique a los demás (médicos, familiares, etc.) sus temores justificados. Una forma efectiva de hacerlo es grabar (audio o video) las rabias de los enfermos como prueba de lo que están tratando de hacer. Esto necesita hacerse sin que el enfermo lo sepa, lo que en principio parece una invasión de la privacidad, pero puede resultar ser un salvavidas.
En la Etapa de la Furia, la calma puede convertirse en angustia en segundos y sin previo aviso. La demencia puede causar paranoia, delirios y alucinaciones. Las distorsiones de la realidad pueden ser otro resultado del proceso de la enfermedad en la demencia. Estos síntomas pueden presentarse como confabulaciones (en las que la persona no puede recordar algo, e inventa una historia falsa sin intención de mentir, creyéndolo realmente), ansiedad o depresión. No todas las personas con demencia desarrollan estos síntomas, pero pueden hacer que la demencia sea mucho más difícil de manejar.

La etapa de la rabia a veces se presenta como celos y/o acusaciones. Es "la enfermedad que habla, que reina sobre sus acciones o palabras". Pero el lenguaje es muy personal e hiriente para el cuidador y se necesita una gran comprensión de la enfermedad para que el cuidador se abstenga de reaccionar. Es muy difícil para el cuidador entender que usted es sólo el objetivo porque usted es el que siempre está al alcance, el que hace todo.

EJEMPLO 8

Estaba paranoica con el "engaño". Ambos estaban en la cocina discutiendo sobre ello y ella dio la vuelta y le roció la cara/ojos con cloro. Mientras él estaba aturdido e incapacitado ella lo golpeó severamente con una olla de cocina. Fue el momento en que se dio cuenta de que ella no era la misma de antes. La violencia llevó a su diagnóstico (variante de conducta de la demencia frontotemporal o bvFTD). No pudo reconocer que algo andaba mal (anosognosia). Se divorció de él.
Las acusaciones son un síntoma reconocido de la demencia frontotemporal, y son estrechamente relacionadas con la "etapa de la rabia" y las obsesiones. Es la enfermedad la que habla, a través de las inhibiciones que se desvanecen. Saber eso es de muy poca ayuda, excepto que puedes culpar a la enfermedad y perdonar a la persona.
Sus defensas, por imperfectas que sean, son las Cuatro D, Sí No Tenemos Plátanos y ser agradable. Se describen aquí abajo.

¿Se puede tratar la etapa de la rabia con medicamentos?

Es posible que su médico le sugiera medicamentos ISRS o IRSN (SSRI-selective serotonin reuptake inhibitors) que pueden ser útiles para moderar los síntomas. Los antipsicóticos atípicos suelen utilizarse en casos más extremos. (Es posible que haya leído que los antipsicóticos son peligrosos. Esto es cierto, pero los atípicos son menos riesgosos que otros). El objetivo es disminuir los problemas de conducta más graves y de estado de ánimo; el objetivo es hacer que las cosas sean más estables, no "sedar" ni "zombificar" al paciente. La elección del medicamento apropriado para una persona es verdaderamente difícil y puede tomar tiempo y puede que uno haga errores de juicio al principio. Si se puede encontrar un medicamento adecuado, puede hacer una gran diferencia en la calidad de vida del paciente, además de permitir que otros lo cuiden mejor. Si bien la medicación puede ayudar a algunas personas con demencia, por lo general sólo alivia la ansiedad. No siempre evita que el paciente se derrita emocionalmente cuando la rabia estalla y la persona entra en erupción como un volcán. La medicación de la demencia en el hogar no siempre impide que se produzcan los peores comportamientos. Los medicamentos no ayudan mucho con la rabia, excepto en la residencia y bajo constante supervisión profesional para ajustarlos.

Una persona con demencia suele tener anosognosia. Honesta y enfáticamente insiste en que está "bien" y no puede reconocer sus propios síntomas y cambios. A menudo rechaza el medicamento y se niega a asistir a las citas con el médico. Uno puede intentar métodos alternativos para que la persona tome la medicación, lo que puede parecer engañoso para el cuidador. El médico puede ayudar, cambiando la forma del medicamento (por ejemplo, de píldoras a medicación líquida o parches transdérmicos). A veces, se rechazan todos los intentos de medicación.

Consejos para ayudar a prevenir la agitación y controlar la ira

1. Crear un ambiente de calma.
2. Eliminar las fuentes de estrés.
3. Evitar los desencadenantes ambientales. El ruido, la luz brillante y la distracción de fondo (como tener la televisión encendida) pueden actuar como desencadenantes.
4. Controlar la comodidad personal (temperatura, ingesta de líquidos, ropa)
5. Simplificar las tareas y rutinas caseras.
6. Proporcionar una oportunidad para el ejercicio.
7. Evitar decir la palabra "No", especialmente como la primera palabra de una respuesta.
8. Rehusar a discutir. La lógica ya no es tu amiga.
9. Prepararte para dejar las herramientas o lo que sea y actuar por capricho.
10. Dar un paseo juntos. Hacer un picnic.

Hay estrategias de cuidado que son relevantes en las comunicaciones. Frases cortas y para simplificar. Sujeto. Luego la declaración. O pregunta.
Algunas personas con este tipo de demencia tienden a perder los pasos lógicos en una discusión. Sucede porque sus circuitos lógicos en el lóbulo frontal sufren fallas intermitentes. Notamos su tendencia a escuchar el primer punto de una respuesta y, si no es agradable, dejan de seguirlo. La estrategia que hemos desarrollado lentamente como respuesta es una que busca mantenerlos escuchando.
Intentamos que las primeras palabras sean un reconocimiento de su petición o punto de vista. Sobre todo, evitar contradecirlas. Por ejemplo, resistirse a pedirles que "paren". Evite empezar cualquier respuesta con un "No" porque eso les impedirá entender lo que sigue. En su lugar, comience cada respuesta con un "Sí". Eso los mantiene escuchando.
El "Nuevo Sí" significa algo diferente al acuerdo. Es una validación, diciendo "entiendo tu pregunta o petición". Es una estrategia que hemos venido a etiquetar: "Sí, no tenemos bananas".
Implementar esto no es fácil y requiere un poco de práctica. El mejor consejo es empezar cada respuesta con un "sí", especialmente si se sospecha que hay tensión o ansiedad en el tema. Evita las discusiones. Evita las confrontaciones. Mira con calma directamente a una persona con demencia. Incluso tu atención es una señal de respeto y confianza. Si tienes una oportunidad temprana de asentir con la cabeza para entender el mensaje del paciente, hazlo. La discusión, el debate y la argumentación lógicos ya no son herramientas de comunicación efectivas cuando la lógica se ha convertido en una discapacidad en una persona con demencia. La lógica ya no es tu amiga. No "ganarás" una discusión lógica y es probable que desencadene la rabia por la frustración en la persona con demencia.
Cambie sus actitudes o acciones. La persona con demencia ya no puede cambiar las suyas. Cuando finalmente nos damos cuenta de que, debido al proceso de la enfermedad, nuestro ser querido es incapaz de ser diferente, entonces encontramos una manera de adaptar nuestro

pensamiento. Él no puede, así que nosotros debemos hacerlo. Todo depende de nosotros ahora. Deja de pensar en él como una ayuda, un compañero, uno que proporciona consejos. Se molestará con tu insistencia en involucrarlo en tus asuntos. Son **tus**
cosas. ¿Por qué debería preocuparse por **tus** asuntos, tus citas, tus sentimientos, tus cosas? Tu ser querido se está acercando o ya está atrincherado en la siguiente mentalidad de querer/no querer y gustar/no gustar.

QUERER/NO QUERER....GUSTAR/NO GUSTAR.

Entiende que esto es lo único importante para él de ahora en adelante. Usar esta mentalidad para tu ventaja es todo en lo que puede confiar. Haz que todo sea sobre él, atiende a cada uno de sus deseos o necesidades. Pierde tu personalidad cuando estés a su alrededor. Está de acuerdo con todo lo que no sea totalmente peligroso.
Cuanto más profundo sea el proceso de la enfermedad, más fácil será para ti subyugar tus deseos a los de él. Al principio él "me parece BIEN". Esa etapa es muy difícil para nosotros. Tendemos a pensar que puede controlar lo que hace, que está haciendo estas cosas, sean lo que sean, a propósito. Esta "fase" dura mucho tiempo. La persona amada "se verá bien" para todos los demás, menos para nosotros, por un tiempo. Después de un cierto punto la enfermedad dicta, no la personalidad anterior del ser querido, ni la moral, la ética o la razón.

A PESAR DE TODO, DISCUTIR O DEBATIR NO TERMINARÁ BIEN.

No lo hagas nunca. Aunque parezca que es capaz de una discusión razonada, no lo es. Mantén esto siempre presente en tu mente. Escucharle y no discutir es muy beneficioso. En respuesta, usa frecuentemente tácticas de conversación positivas y alentadoras, pero no menciona nada de importancia.

BAJA TUS ESPECTATIVAS. NO ESPERES NADA DE ÉL Y NO TE DECEPCIONARÁS.

No esperes que tu ser querido se preocupe. No esperes que participe cuando "no lo sienta". No esperes que sepa nada. No esperes empatía, humor, participación, conversación ni positividad.

SÍ. SIENTO QUE TE SIENTAS ASÍ.

Rechaza ser el enfoque de su combatividad. La persona que sufre una etapa de rabia puede percibir que no puede hacer nada bien, incluso cuando lo intenta. Quítate física o verbalmente de la situación, así la persona en etapa de ira no tiene nada por lo que pelear y nadie con quien pelear. Esto lo deja indefenso para continuar con sus alegaciones. Si no puedes irte, como cuando viajas, sigue repitiendo periódicamente: "Siento que te sientas así". Si tienes que vivir en silencio, puede ser preferible a vivir con reacciones negativas y enojadas.

CUALQUIER SUGERENCIA QUE INTENTE DESVIARLO DEL CAMINO PROPUESTO SERÁ PERCIBIDA COMO UNA CRÍTICA.

No es razonable. No es lógico. Pero para él SON todas estas cosas. Si continúas sugiriendo algo que no concuerde con sus decisiones, tú serás el enemigo. Tienes que evitar eso a toda costa. Tienes una relación única que proteger, así que debes desviar la culpa a otro. Alguna autoridad es responsable de la cancelación de la licencia de conducir o de las armas confiscadas. Algún médico es responsable del diagnóstico y el medicamento. Ponte de su lado en las discusiones entre ustedes sobre estos asuntos. Elogia sus logros. Puede llegar un momento en que te pases de la raya en los elogios y que una persona normal sospecharía de eso. Una persona en la etapa de furia de la demencia frontotemporal a menudo se lo "traga entero". A menos que se les avise antes, la mayoría de los cuidadores pierden la oportunidad de calmar los comportamientos de la demencia frontotemporal con elogios y palabras admiradores. Para cuando los elogios funcionan, hasta puede ser mejor usar más elogios y más amplios elogios.

APRENDE A CONTROLAR TUS FACCIONES PARA NO DEMOSTRAR TUS EMOCIONES NEGATIVAS.

Permite sólo expresiones positivas o neutrales en tu cara, sin importar las provocaciones. Entiende que las cosas pueden escalar rápidamente cuando el ser querido percibe que desapruebas una acción o que estás molesto/a de alguna manera.

URGENCIA.

Una persona en una etapa de rabia a menudo exhibirá urgencia e impaciencia. Cuando puedas, está listo para actuar según el capricho de tu ser querido. Si está realmente enojado, intenta sugerir un evento tranquilo. "¿Qué tal si vamos al cine?" O "¿Te gustaría hacer un picnic y pasear al perro?" Donde no puedas, usa "Sí, no tenemos bananas": "Quiero ir a casa de mi hermana AHORA".
“Sí, buena idea. Hemos acordado con ella que iremos a cenar el sábado. Es una gran cocinera. ¿Llevamos una botella de vino?”

SEGURIDAD DEL CUIDADOR.

Hacer que el ambiente sea seguro es una
necesidad. Hay que remover las armas, guardar los cuchillos bajo llave, deshabilitar o guardar b ajo llave las
herramientas eléctricas. La primera vez que un cuidador espera o experimenta un evento de ira debe crear un plan de escape. Un "maletín de viaje" debe estar listo con algo de dinero en caso de emergencia y colocado donde lo pueda recuperar, tal vez con un amigo o vecino. El teléfono del cuidador debe ser respaldado y se debe considerar un teléfono desechable.
Todas las sociedades occidentales tienen una legislación para el tratamiento de emergencia de una persona con conducta peligrosa. Esto puede indicar la colocación involuntaria para su evaluación, al tiempo que se garantiza la seguridad del paciente y de los demás. El código para esto en el UK es "seccionado" (después de la sección de las Leyes de Salud Mental en cada parte del UK), en Canadá es "formado" (después de la forma prescrita), en California es "5150"

etc. Los períodos y procesos varían según la jurisdicción, pero con objetivos similares. El departamento de urgencias, la policía, los trabajadores sociales y los Jueces de Paz pueden dirigirte y sabrás cuando necesitas aprender más.

Biología de la demencia frontotemporal

La producción de proteínas del cuerpo es una función normal de los genes. La mayoría de los investigadores piensa que la acumulación de proteínas en los cerebros de las personas con la demencia frontotemporal es causada por la sobreproducción. Pero existe la posibilidad de que se deba a una falla del sistema linfático del cerebro para expulsar el exceso de proteínas.
La presencia de exceso de proteínas inicialmente causa una falla intermitente en la transmisión de una señal eléctrica de una neurona a una sinapsis. Como la falla de una bujía. Debido a que el síntoma es intermitente en las primeras etapas de la enfermedad, la señal puede a veces tener éxito después de que más tiempo y esfuerzo permitan un intento exitoso. Como resultado, un síntoma de la enfermedad (como las dificultades para encontrar palabras, no poder reconocer secuencias o los comportamientos de ira) puede estar a veces presente y a veces ausente en la misma persona durante las etapas tempranas e intermedias de la enfermedad.
Hay otro factor que complica aún más las cosas. El cerebro busca un camino alternativo para el mensaje. Como viajar de Nueva York a Boston vía Canadá. Esto se llama plasticidad y también necesita más tiempo y reducida ansiedad. Y al principio eso a veces hace que se entregue la señal y resulta en encontrar la palabra, el hecho, el nombre u otro recuerdo buscado. Para el cuidador, este rendimiento variable causa dudas de que la tendencia a empeorar esté realmente sucediendo. Otros miembros de la familia con menos contacto tienen mayores dudas. Con la progresión y la acumulación del exceso de proteína, la neurona se ahoga, las señales nunca tienen éxito, la neurona falla, muere y se atrofia. La plasticidad del cerebro continúa buscando y a menudo encuentra rutas alternativas. A través de Georgia. A través de Tijuana. O no exactamente a Boston, pero sí a algún lugar cercano. "No, no John. El otro hombre que nos ayudó, ¡tú sabes!"
El pensamiento, el habla o la conducta se deterioran, y ésto se ve en peores resultados de las pruebas de neuropsicología. Los parientes observan fallas más frecuentes en la función ejecutiva. Algunas tareas, planificación, secuencias, recuperación de la memoria, inhibiciones, destreza, equilibrio, etc. pueden deteriorarse.
Pero sólo cuando las masas de neuronas fallan, mueren, decaen y se disuelven, son visibles los resultados como atrofia en una resonancia magnética. El camino del paciente para alcanzar una etapa de atrofia visible puede tomar años o incluso décadas desde la exhibición de los primeros síntomas.
La mayor disponibilidad de máquinas para escanear el cerebro ha dado lugar a una mayor confianza en su uso para confirmar un diagnóstico de la demencia frontotemporal. Es un enfoque muy conservador que a menudo retrasa el diagnóstico. Puede reducir los errores diagnósticos, pero a costa de un largo retraso y dudas para los pacientes y familiares que se quedan buscando diagnósticos y tratamientos alternativos. Hay muchas consecuencias devastadoras para el paciente-dejar de conducir un auto, dejar el empleo, que le quiten el

seguro de vida o de auto, ser elegible para la asistencia social y la planificación y el bienestar de la familia.
Alrededor del 40% de los casos ocurre en personas que tienen uno o más defectos genéticos (mutaciones) que se sabe que están asociados con la demencia frontotemporal. Hay un número de tales defectos identificados y se espera que se encuentren más. Sin embargo, la presencia del defecto genético por sí solo no es suficiente para desencadenar esta demencia (o la prevalencia de la enfermedad sería mucho mayor de lo que es). Es posible que algunas personas con uno de los defectos genéticos conocidos nunca contraigan la enfermedad. Puede haber un mecanismo desencadenante, como una conmoción cerebral o un delirio. Puede haber un mecanismo genético antídoto que no se ha identificado (aunque los investigadores confirman que las personas con una mutación protectora de la PLCG2, el alelo rs72824905-G, no sólo disfrutan de una mayor protección contra la enfermedad de Alzheimer, sino también contra la demencia y la demencia con cuerpos de Lewy).

Glen Davis

Bien gérer les accès de colère

Bien gérer les accès de colère. Une formule qui a fait ses preuves

(Série ‘Carer Fast Track®’ Volet 7)

Les formes de démence qui touchent le lobe frontal du cerveau entraînent souvent une perte d’inhibitions et des comportements obsessionnels. L’absence de filtres affectifs se traduit fréquemment par des accès de colère qui peuvent, dans plus de 20% des cas de dégénérescence front-temporale (DFT), déborder en violence physique. De tels symptômes se manifestent normalement au stade intermédiaire de la maladie. Le comportement agressif du malade finit par dominer la relation entre le patient et ses aidants familiaux.
Pour les aidants, ce stade colérique (‘Rage Stage’ an anglais) est l’un des plus difficiles à comprendre et à gérer. Ainsi, ce livret est consacré à la gestion des accès de colère dans la DFT.

CRITIQUES/REACTIONS:

« Super » … « Je dois dire que j’ai été profondément émue par vos descriptions des défis auxquels les familles sont confrontées, et séduite par le style et le contenu de vos conseils pratiques. Nous ne nous rendons pas compte de l’ampleur du problème. Pour éviter des problèmes et se sentir en sécurité, le proche aidant doit souvent se plier en quatre pour satisfaire aux exigences du patient, dont la maladie change la personnalité. La plupart d’entre nous auraient déjà jeté l’éponge depuis longtemps et je tiens à saluer tous ceux qui persévèrent par amour et par devoir. Vous avez très bien décrit ce stade colérique et je suis sûre que votre livret sera d’une grande utilité pour l’ensemble des proches aidants. »

Professeur June Andrews, RMN, RGN, FRCN, OBE

« Ce livret est très riche d’enseignements. Quand il sera publié, merci de me tenir au courant pour que je puisse le recommander aux autres »

Barbara Karnes, RN, infirmière et éducatrice spécialisée en soins palliatifs, lauréate du prix *International Humanitarian Woman of the Year* (2015)

Gérer le stade colérique

Dans la dégénérescence fronto-temporale (DFT), le comportement le plus difficile à affronter est souvent la colère. C’est l’époux/épouse ou proche aidant qui constate tous les comportements coléreux du malade, contrairement aux autres membres de la famille et aux médecins, qui y sont rarement confrontés. Le proche aidant peut avoir du mal à convaincre son entourage de l’ampleur du problème.

Les principaux sites web qui fournissent des renseignements sur la démence présentent deux omissions importantes :

- Fait étonnant, les mots ‘mortel’ ou ‘incurable’ y sont rarement employés. Les principales associations œuvrant dans le domaine de la démence semblent ne pas vouloir donner de mauvaises nouvelles, même si celles-ci sont importantes.

- Il existe peu de conseils pratiques qui aideraient les familles à gérer les symptômes les plus difficiles de la DFT. Les associations s’efforcent à ne pas effrayer les nouveaux aidants. Ils n’expliquent pas comment communiquer avec une personne atteinte de démence, même si les échecs de communication peuvent être la cause principale de la dégradation des relations familiales. De plus, ils ne donnent aucun conseil sur la gestion des accès de colère, si fréquents chez les personnes atteintes de démence.

Dans la DFT, le cerveau n’est pas atteint de la même façon que dans la maladie d’Alzheimer (cette dernière est à peu près 10 fois plus fréquente et mieux connue). L’un des premiers signes de la maladie d’Alzheimer est la perte de mémoire. Par contre, dans la DFT, on retrouve plutôt des comportements étranges, des décisions imprudentes et inhabituelles ou la perte du langage.

Il est difficile d’accéder aux informations concernant la gestion efficace des symptômes de la DFT. Sur le web, on trouve d’un côté des descriptions sommaires de la maladie et, d’autre part, des articles destinés aux médecins et aux chercheurs. Au fin fond des publications médicales, on peut tomber sur des statistiques sur l’agressivité et la violence chez les patients atteints de démence. Mais jusqu’à présent, rares sont les informations provenant de celles et de ceux qui se trouvent ‘en première ligne’. Et il manque des conseils pratiques destinés à l’entourage d’une personne atteinte de la DFT.

Il s’avère que la violence chez la personne atteinte de démence est plus courante que ne laissent croire les études à grande échelle. Selon les statistiques sur la forme précoce de la maladie d’Alzheimer, 17% des patients présentent une forte agressivité dans l’année qui suit le diagnostic, et 20% des malades affichent un comportement violent pendant la maladie. Quant à la DFT, si on se base sur des observations de quelques centaines de patients dans des EHPAD, les statistiques sont vraisemblablement similaires.

Pour faire face au stade colérique de la DFT, il faudrait que l’entourage ait accès à de plus amples renseignements. Les familles ont besoin d’information, de stratégies, de conseils et d’astuces. Cette maladie peut nuire à la santé physique et mentale ainsi qu’au bien-être de tous les proches aidants. En raison des comportements agressifs, les proches aidants peuvent décider que le maintien à domicile de la personne atteinte de la DFT n’est plus possible.

Les familles ne doivent pas se sentir seules. Elles ont besoin de savoir que des ‘survivants’ ont déjà passé ce cap et en ont tiré des enseignements pouvant être transmis. Les proches aidants peuvent surmonter cette épreuve grâce à des ressources qui leur fournissent un vrai soutien.

Qu’est-ce qui provoque les accès de colère ?

Le terme *démence* désigne une détérioration progressive du cerveau, dont l'issue est fatale. Dans la DFT, on trouve une accumulation de protéines dans les neurones des lobes frontaux et temporaux du cerveau. Ces protéines existent aussi chez les personnes en bonne santé mais elles s'accumulent en quantité plus importante dans le cerveau de la personne atteinte de la DFT (pour en savoir plus, voir la section *Biologie de la DFT* ci-dessous). L'accumulation de protéines endommage le cerveau, en détruisant progressivement les cellules.

Les accès de colère sont provoqués par la diminution ou perte de l'inhibition. Les règles de comportement social et de langage acceptable ne peuvent plus être suivies. La planification, l'organisation, la prise de décision et le déroulement d'une séquence d'actions se réalisent dans les mêmes parties du cerveau, mais ces différentes capacités sont perdues à une vitesse et à des stades différents.

La désinhibition qui sous-tend le stade colérique peut induire, chez certains patients, des comportements connexes, tels que des remarques socialement inappropriées, des attouchements sexuels sans consentement, une obsession pour la pornographie, de la violence sexuelle, des dépenses excessives et irrationnelles, de la violence physique, un langage grossier ou de la violence psychologique. Le proche aidant est souvent profondément choqué par ces comportements et gêné par les réactions des autres, qui ne comprennent pas et s'en offusquent.

A quel moment surviennent les accès de colère?

La colère et l'agressivité surviennent le plus fréquemment au stade intermédiaire de la DFT, période pendant laquelle on reçoit souvent l'annonce du diagnostic. Pour pouvoir poser un diagnostic de démence, le médecin s'appuie sur la présence de symptômes tels qu'une baisse des facultés cognitives et un déclin des compétences et des comportements. Il faut du temps pour établir que ces altérations traduisent une évolution plus générale.

EXEMPLE DE CAS 1

Le proche aidant d'une personne atteinte de la FTD a besoin de conseils et de soutien dès l'apparition des symptômes, c'est-à-dire plusieurs années avant le diagnostic officiel. « J'aurais bien aimé avoir accès aux renseignements fournis ici il y à 10 ans quand, comme dans bien des cas, on ne soupçonnait pas une démence et je me demandais pourquoi mon couple était en train de s'effondrer. Quand je me demandais ce que j'allais faire, j'aurais bien aimé savoir à quelles sources d'information je pouvais me fier et lesquelles étaient une insulte à mon intelligence et une perte de temps et d'argent. Si je devais m'y remettre aujourd'hui, je pourrais faire beaucoup mieux. »

Le stade colérique survient le plus souvent au stade intermédiaire da la maladie. Néanmoins, chaque cas est différent : certains patients souffrent d'accès de colère tout au long de la maladie tandis que chez d'autres ils ne se manifestent pas du tout. La violence ou les comportements sexuels inappropriés manifestés par certains malades peuvent au fil du temps devenir moins marqués. En EHPAD il s'agirait plutôt de pousser ou bousculer un autre résident de temps à autre ou de refuser (physiquement ou verbalement) des soins personnels. Dans la DFT, il est difficile de déterminer à l'avance la durée et les caractéristiques des colères. Il faut faire confiance à votre jugement et à votre expérience : le comportement antérieur de chaque patient serait le meilleur moyen de prédire son comportement ultérieur. Chaque famille va construire sa propre histoire de l'évolution des comportements.

EXEMPLE DE CAS 2

Mon mari est devenu obsédé par l'un de ses actes sexuels préférés. Son téléphone est rempli d'images pornographiques de cette pratique. Il en parle à haute voix dans les magasins. Il en veut tous les jours, parfois plus souvent. J'obtempère, car un refus le mettrait de mauvaise humeur et pourrait déclenche un accès de colère. Je n'ai pas pu compter sur le soutien dont d'autres 'victimes' pourraient bénéficier, en partie parce que je n'ose pas parler ouvertement de la situation.

Quelles formes peuvent prendre les comportements colériques ?

Certaines personnes atteintes de la DFT restent agréables et accommodantes pendant toute la dégénérescence de leur cerveau. D'autres, en revanche, ressentent de l'anxiété et peuvent présenter des comportements coléreux, agressifs, violents et paranoïdes

Dans un premier temps, il arrive que le malade devienne obsessionnel ou s'en prenne violemment aux proches aidants sans raison apparente. La colère peut s'exprimer physiquement et/ou verbalement. La première fois que ça arrive, le proche aidant est profondément choqué. Il est tout à fait normal de se sentir dépassé, découragé, blessé, irrité ou énervé. Pour faire face à ces crises, il faut comprendre la raison de la colère chez la personne atteinte de démence et apprendre la meilleure façon de réagir.

EXEMPLE DE CAS 3

« Pendant que mon mari laçait ses chaussures, je lui ai posé une question sur la liste de courses que nous allions faire. Il a tout de suite eu un accès de colère. C'était la première fois que j'ai dû esquiver un coup de poing. Sa colère était si intense que mon instinct de survie s'est réveillé. Ça ne lui ressemblait pas du tout. C'était épouvantable. »

Lors d'un accès de colère, la personne atteinte de démence peut crier, lancer des objets, devenir agressif. Le malade peut vous frapper, vous donner des coups de pied, vous pousser, hurler ou même essayer de vous agresser physiquement. Il est possible qu'il sorte des injures, même si jusque-là il n'avait pas utilisé des gros mots.

EXEMPLE DE CAS 4

« Si je lui donne la main, il va essayer de l'écraser, en y mettant toute sa force. »

Il y a parfois des signes avant-coureurs : froncement de sourcils, voix haute, mine renfrognée, bras qui se balance dans le vide. Mais il n'est pas toujours possible de prévoir quand la colère va éclater. Elle semble surgir de nulle part. Ce type de colère, qui explose sans crier gare, est souvent la plus dure à gérer en raison de son imprévisibilité, qui prend les proches au dépourvu. Ces derniers ont l'impression de marcher constamment sur des œufs pour éviter des crises, ce qui les met à rude épreuve.

EXEMPLE DE CAS 5

« Pendant que mon mari était encore à la maison, mon niveau d'énergie (physique, émotionnelle, psychologique, spirituelle) était à zéro. Ça faisait des années que je me sentais au bout du rouleau, et j'en étais bien consciente. La DFT m'avait appris à ne pas essayer de prédire l'avenir ; je devais vivre dans le moment présent, au jour le jour.

Je réalise maintenant que sa violence et son hostilité envers moi provenaient en grande partie de la peur - la peur que je ne puisse pas satisfaire ses besoins. Il avait raison. Il faut 'tout un village', une équipe de professionnels qui travaillent jour et nuit dans une structure sécurisée pour s'occuper correctement de quelqu'un qui est en bonne forme physique mais qui a perdu la tête !

Il m'a frappée cinq ou six fois, entraînant des fractures des côtes à deux reprises. Il m'a fallu plus d'un an après son placement en institution pour commencer à m'en sortir. Aujourd'hui, je consacre beaucoup d'énergie à tenter de guérir les blessures émotionnelles provoquées par la DFT au sein de notre famille. »

Des signes avant-coureurs d'un accès de colère ne sont pas toujours reconnus comme tels par les proches aidants. Ils espèrent qu'il s'agit d'un phénomène passager ou n'ont pas assez d'expérience pour y faire face. Dans les mois qui précèdent le premier accès de colère, on peut remarquer une expression de visage assez particulière chez la personne atteinte de démence, ou un certain ton de voix quand elle maltraite des animaux de compagnie ou des enfants. Le malade peut, par exemple, lever le bras, menacer du poing, donner un coup de pied, s'approcher de trop près. Il peut avoir un regard tordu et de plus en plus menaçant à mesure que les inhibitions s'estompent. Mais des aidants inexpérimentés ont tendance à ne pas tenir compte de ces signes visibles d'un acte de malveillance ou d'une confrontation imminents.

EXEMPLE DE CAS 6

« Il y avait des moments où je craignais pour mes petits-enfants. Il avait l'habitude de les pousser, de leur taper dessus, tout comme il faisait avec nos chiens. Je dis à mes enfants de ne pas le laisser balancer le petit de 5 ans par les chevilles ; qu'il n'a pas le droit de frapper les chiens ou les petits-enfants sur le crâne ou sous le menton ; qu'il ne doit pas les malmener ; et qu'il ne faut pas le laisser seul avec les enfants au vu de ses comportements déplacés antérieurs.

J'ai insisté fermement 'Ne donne pas de coups de pied au chien !!!!' Il m'a répondu 'Je fais ce que je veux !' Quand je lui ai dit de ne pas recommencer, cette fois-ci il s'est approché de moi et m'a menacée du poing. J'ai reculé. Il m'a insulté et m'a ordonné d'aller 'là-bas' (vers le canapé). Face à son agressivité, j'ai tenu bon, mais il m'a frappé l'avant-bras trois fois.

J'ai préparé un plan de fuite. J'ai prévenu les services sociaux et son infirmière de soins à domicile. J'ai laissé un message urgent pour son neurologue et j'ai informé chaque membre de la famille. J'ai préparé un sac de départ. Je peux accéder facilement à mon téléphone et mon ordinateur portable. La maison a quatre entrées/sorties… »

Le stade colérique peut ou non être accompagné par une obsession pour la pornographie. Une détérioration du langage est parfois signe avant-coureur d'un accès de colère. En arrivant à ce stade, le malade devient critique, accusateur, réprobateur. Pour lui, tout est 'nul', 'dégoûtant', 'inutile', 'horrible'. A cause de sa désinhibition, le langage du malade devient grossier, contrairement à ses habitudes antérieures.

La démence peut notamment affecter les émotions, et les proches aidants vont progressivement en ressentir les conséquences. La démence altère le cerveau, qui gère notre capacité à stocker et à récupérer les informations, les mots et les noms ainsi que notre capacité décisionnelle et nos jugements de valeur. De même, c'est le cerveau qui contrôle nos émotions et nos comportements. En fonction de la partie du cerveau qui est endommagée, les émotions peuvent ainsi être altérées. En règle générale, seuls les proches aidants expérimentés sont capables de reconnaître les éléments déclencheurs de ces nouveaux comportements. Une consultation médicale d'une vingtaine de minutes ne suffit pas pour identifier cette évolution des comportements, ce qui retarde le diagnostic. Les membres de la famille qui ont beaucoup moins de contact avec la personne atteinte de la DFT le trouve cohérent et convaincant : « On voit qu'il est en pleine forme ! »

Certaines actions des proches aidants peuvent aussi déclencher un accès de colère. Pendant le stade colérique, il suffit de peu pour énerver le malade. Ses obsessions et ses illusions se transforment rapidement en irritation et colère. Des colères dévastatrices peuvent être provoquées par une mauvaise compréhension de l'expression faciale ou de l'action du proche aidant, par la jalousie, ou par une obsession ou accusation typique de la DFT. Une 'surréaction' émotionnelle entraîne souvent de la colère et de l'agressivité.

EXEMPLE DE CAS 7

Le 13 septembre 2018, Marjorie Granson, 84 ans, a mortellement poignardé son mari, Alan Grayson, 85 ans, à trois reprises à leur domicile d'Orgreave Lane, Sheffield. Elle a ensuite appelé les urgences: « Je viens de poignarder mon mari. Je pense l'avoir tué... »
Selon le juge dans cette affaire, ce n'est que lors d'une enquête que la famille s'est rendue

compte des ‘changements comportementaux importants survenus dans un passé récent”...Le juge a indiqué que, d’après des experts neuropsychiatres, Mme Grayson était atteinte de la dégénérescence fronto-temporale (DFT), variante comportementale.

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

Il est primordial que les proches aidants communiquent aux autres (médecin, entourage familial…) leurs craintes, souvent justifiées. Dans ce but, il peut être pertinent d’enregistrer l’accès de colère (audio ou vidéo), comme preuve du type de comportement auquel l’aidant est confronté. Faire un tel enregistrement, vraisemblablement à l’insu du malade, paraît a priori une atteinte à la vie privée. Ceci dit, c’est une initiative qui pourrait sauver des vies.

Pendant le stade colérique, le calme peut se transformer en détresse en l’espace de quelques secondes, sans aucun avertissement.

La démence peut s’accompagner de la paranoïa, de crises de délire et d’hallucinations, ainsi que de déformations de la réalité. Dans ce contexte, il peut s’agir de fabulations (pour combler une lacune mémorielle, la personne fait un récit imaginaire sans intention de tromper; il y croit), de l’anxiété ou de la dépression. Toutes les personnes atteintes de la DFT ne présentent pas forcément ces symptômes, mais quand ils se présentent, ils rendent la maladie beaucoup plus difficile à gérer.

Le stade colérique se présente parfois sous forme de jalousie et/ou d'accusations. Il faut reconnaître que 'c'est la maladie qui parle'. Néanmoins, le malade peut s'en prendre directement au proche d'une manière très blessante. Il faut une connaissance profonde de la maladie pour éviter de mal réagir. L'aidant aura du mal à comprendre qu'il devient la cible de la colère tout simplement parce qu'il est toujours présent, celui qui fait tout.

EXEMPLE DE CAS 8

« Elle pensait qu'il la trompait et en était devenue paranoïaque. Ils étaient ensemble dans la cuisine en train de se chamailler à ce sujet. Brusquement, elle s'est retournée et lui a aspergé les yeux et le visage d'un produit de nettoyage à base d'eau de Javel. Alors qu'il était assommé, incapable de bouger, elle l'a violemment battu avec une casserole. C'était à ce moment-là qu'il a réalisé qu'elle ne se ressemblait plus. Cette violence a abouti au diagnostic de dégénérescence fronto-temporale, variante comportementale. Elle n'avait aucune conscience de sa condition (anasognosie) et elle a divorcé. »

Les accusations sont un symptôme reconnu de la DFT, étroitement lié au stade colérique et aux obsessions. Même en sachant que 'c'est la maladie qui parle' du fait de la désinhibition, les accusations sont difficiles à accepter. On peut essayer de blâmer la maladie et pardonner la personne qui la subit.

EXEMPLE DE CAS 9

Des agents de police de l'état de Michigan ont trouvé le suspect, blessé par balle à la main gauche. Sa femme avait reçu des tirs de balle à la main et à la hanche, tandis que leur fille, qui avait souffert de blessures au torse, a été trouvée morte au sous-sol

La femme a expliqué aux policiers que son mari, au premier stade de la démence, était vexé car on lui avait retiré les clefs de la voiture.https://www.9and10news.com/2020/03/16/charlevoix-county-man-arrested-for-murder/

Vos 'mesures de défense' – aussi imparfaites soient-elles – consistent à adopter un comportement agréable ainsi qu'á suivre les *Quatre D* et *Oui, nous n'avons pas de bananes* (Ces techniques sont détaillées ci-dessous).

Peut-on calmer les accès de colère à l'aide de médicaments ?

Il se peut que votre médecin prescrive un médicament ISRS ou IRSN pour aider à gérer les symptômes (ces médicaments sont généralement utilisés pour traiter la dépression). Pour les cas plus sévères, on a souvent recours à des antipsychotiques atypiques. (Vous aurez peut-être lu que les antipsychotiques présentent certains risques, ce qui est vrai. Par contre, les risques présentés par des antipsychotiques atypiques sont plus faibles.) Le but d'un tel traitement est d’atténuer les comportements les plus graves et gérer les sautes d’humeur. Il s’agit de stabiliser le patient et non pas de le ‘droguer’ ou de le ‘zombifier’. Il peut s’avérer difficile de trouver le médicament qui convienne le mieux à chaque malade ; c’est parfois en tâtonnant que l’on y parvient. Ceci dit, trouver le médicament le plus adapté peut améliorer de façon significative la qualité de vie du malade mais aussi permettre une meilleure prise en charge par les proches aidants.

Si les médicaments peuvent s’avérer utiles pour certaines personnes atteintes de démence, il faut toutefois reconnaître que généralement ils ne font que réduire quelque peu l’anxiété. Quand le malade devient agité et sa colère explose, on ne peut pas toujours éviter une crise. Le traitement médicamenteux à domicile ne mettra pas forcément fin aux comportements les plus dérangeants. Les médicaments utilisés n’agissent pas trop sur les accès de colère, sauf en institution/EHPAD sous la surveillance permanente d’une équipe médicale capable d’ajuster le schéma thérapeutique.

La personne atteinte de démence souffre souvent d’anasognosie. Le malade, qui n’a aucune conscience de ses symptômes ni de ses problèmes de comportement, va insister sincèrement et catégoriquement sur le fait qu’il va très bien. Il va refuser de prendre des médicaments ou de se présenter à un rendez-vous médical. On peut avoir recours à d’autres méthodes pour encourager le malade à prendre ses médicaments, mais pour le proche, agir ainsi peut paraître malhonnête. Le médecin pourra modifier la forme du médicament (par exemple, sirop ou patch transdermique plutôt que comprimé) mais dans certains cas toutes les tentatives dans ce sens sont vouées à l’échec.

Quelques conseils pour prévenir l’agitation et gérer les accès de colère

Créez une ambiance calme. Tentez d’éliminer les facteurs de stress.

Réduisez les déclencheurs environnementaux, tels que le bruit, les éblouissements, les distractions de fond (comme le bruit du téléviseur).

Assurez le confort du malade (température ambiante, apport liquide, vêtements).

Simplifiez les tâches et les routines.

Créez des occasions pour faire de l’exercice.

Evitez de dire ‘Non’, surtout en début de réponse.

Ne le raisonnez pas. Vous ne pouvez plus compter sur la logique.

Soyez souple, en laissant libre cours à votre spontanéité. Faites une balade en voiture. Préparez un pique-nique.

En matière de communication, il existe des stratégies pour aider les proches aidants. Faites des phrases simples et courtes: tout d'abord, précisez le sujet, suivi par la déclaration ou question.

Il arrive que les personnes atteintes de la DFT soient incapables de suivre les étapes logiques d'une discussion suite à un dysfonctionnement intermittent des 'circuits logiques' du cerveau. Ils ont tendance à se focaliser sur le premier élément d'une réponse et, si cette réponse ne leur plaît pas, à cesser d'écouter. Nous avons donc progressivement élaboré une stratégie pour tenter d'améliorer leurs capacités d'attention.

Tout au début de votre réponse, essayez de prendre en compte le point de vue ou demande exprimés par le malade. Surtout, évitez de le contredire : par exemple, ne lui dites jamais 'Arrête !' Evitez aussi de dire 'non' en début de réponse ; le malade cessera d'écouter. Si, en revanche, on commence chaque réponse par 'oui', la personne restera à l'écoute. Dans ce contexte, plutôt que d'exprimer son accord, le mot 'oui' représente une validation : « Oui, j'ai compris ta question ou ta demande. » On a baptisé cette stratégie 'Oui, nous n'avons pas de bananes' (d'après une chanson américaine bien connue). La mise en œuvre de cette technique n'est pas évidente et nécessite pas mal d'entraînement. Le meilleur moyen de réussir est de commencer chaque phrase par le mot 'oui', surtout si le malade semble tendu ou anxieux.

Evitez les disputes. Evitez les confrontations. Regardez le malade calmement et droit dans les yeux pour faire preuve de votre respect et de votre disponibilité. Hochez la tête, si l'occasion se présente, en signe de compréhension.

Toute discussion ou argumentation logique s'avèrent inutiles dans la communication avec une personne atteinte de démence. Vous ne pouvez plus compter sur la logique. Vous ne pourrez pas remporter une discussion logique et vous risquez de déclencher un accès de colère provoqué par la frustration ressentie par le malade.

Il faut que nos attitudes, nos comportements changent car la personne atteinte de démence est incapable de modifier les siens. Lorsque nous nous rendons enfin compte que la maladie empêche la personne d'agir autrement, nous pouvons modifier notre façon de penser : **Lui/elle** ne pouvant pas se transformer, c'est à **nous** qu'il appartient de le faire. Dorénavant, tout dépend de nous. Le malade n'est plus notre soutien, notre partenaire, notre 'baromètre'. A quoi bon lui demander de participer à nos activités ? Ce sont NOS activités. A quoi bon attendre de lui qu'il s'intéresse à nos problèmes, nos rendez-vous, nos sentiments ou quoi que ce soit. Notre bien-aimé(e) pourrait déjà se trouver dans un état d'esprit du type 'je veux/je ne veux pas' et 'j'aime/je n'aime pas'.

JE VEUX / JE NE VEUX PAS…J'AIME /JE N'AIME PAS. Il faut comprendre que, pour le malade, ne comptent plus que ses goûts et ses aversions. Il faut tirer partir de cette attitude et faire en sorte que tout tourne autour de lui, en essayant de satisfaire tous ses désirs ou besoins. Il faut perdre sa propre personnalité quand vous êtes près de lui. Il faut accepter toute proposition qui ne soit pas carrément dangereuse.

A mesure que la maladie évolue, il sera plus facile de se plier aux exigences du patient. Au début, il a l'air d'être 'en pleine forme'. Cette étape est très difficile pour le proche aidant, qui a l'impression que le comportement du malade est volontaire et qu'il pourrait faire un effort pour se maîtriser. Pendant cette étape, qui dure un bon moment, tout le monde, sauf l'entourage proche, trouvera le malade 'en pleine forme'. A un stade ultérieur, la maladie prend clairement l'ascendant sur ce qu'étaient la personnalité, la moralité, l'éthique et la logique de notre bien-aimé(e).

DISCUTER OU CONTESTER FINIRA TOUJOURS MAL.
A tout prix, évitez de discuter. Contrairement aux apparences, le malade n'est plus capable de mener une discussion rationnelle. Il faut garder cela toujours présent à l'esprit. Il peut être salutaire de l'écouter sans pour autant entamer une vraie discussion. On peut répondre de façon positive et encourageante mais sans jamais aborder des questions de fond.

IL FAUT REDUIRE VOS ATTENTES. SI VOUS N'ATTENDEZ RIEN DE LUI, VOUS NE SEREZ PAS DEÇU.
Ne vous attendez pas à ce que votre bien-aimé(e) se soucie de vous ; qu'il s'implique dans un projet quand il n'a pas envie ; qu'il soit au courant de quoi que ce soit. N'attendez pas de lui de l'empathie, de l'humour, de l'implication, de la conversation ou de la positivité.

« OUI. JE SUIS DESOLÉ QUE TU LE PRENNES COMME ÇA. » Refusez d'être l'objet de son agressivité. Aux yeux du malade sujet à des accès de colères, vous aurez forcément tort, en dépit de vos efforts. Il faut mettre fin à la discussion et/ou vous éloigner physiquement pour qu'il n'y ait plus de sujet de discorde et plus personne contre qui se battre. Ainsi, le malade ne pourra plus vous dénigrer. Si vous ne pouvez pas vous éloigner, par exemple quand vous partez ensemble en voyage, répétez périodiquement « Je suis désolé que tu le ressentes de cette manière. » Vivre dans le silence peut s'avérer préférable à supporter un climat de colère et de négativité.

TOUTE PROPOSITION VISANT A LE DETOURNER DE SON BUT SERA PERCUE COMME UNE CRITIQUE. Pour vous, son point de vue est irraisonnable, illogique. Mais pour lui, c'est tout le contraire. Si vous vous obstinez à lui faire des propositions qui vont à l'encontre de ses convictions, vous deviendrez son ennemi, chose qu'il faut à tout prix éviter. Pour que vous arriviez à protéger votre relation unique avec le malade, il faut rejeter la responsabilité sur quelqu'un d'autre. C'est une administration publique qui lui a retiré son permis de conduire ou confisqué ses armes. C'est le médecin qui a posé le diagnostic et prescrit ces médicaments. Dans vos discussions sur ces mêmes sujets, vous vous rangez de son côté. Vous le félicitez pour ses réussites. Vous faites l'éloge de toutes ses qualités. Dans des circonstances normales, un tel discours paraîtrait excessif. Mais la personne atteinte de la DFT sujette à des accès de colères sera aux anges. Sans avis préalable, les proches aidants pourront rater l'occasion de calmer les comportements difficiles de la DFT grâce aux louanges et à l'approbation. Arrivé au stade où vanter les mérites du malade porte ses fruits, l'entourer d'un vrai concert d'éloges peut être encore plus efficace.

APPRENEZ A CONTRÔLER L'EXPRESSION DE VOS EMOTIONS NEGATIVES. Efforcez-vous de garder une expression positive ou neutre, quelle que soit la provocation. Sachez que la situation peut rapidement dégénérer quand votre bien-aimé(e) s'aperçoit que vous désapprouvez son comportement ou quand vous êtes vexé en quelque sorte.

URGENCE. Au stade colérique de la maladie, le malade se montre souvent impatient : il a besoin d'agir immédiatement. Si possible, soyez prêts à vous soumettre à ses caprices. S'il a la bougeotte, proposez-lui une activité tranquille : « Allons au cinéma » ou bien « Faisons un pique-nique et promenons le chien. » Dans le cas contraire, utilisez la technique 'Oui, nous n'avons pas de bananes' : par exemple, s'il dit « Je veux aller voir ma sœur tout de suite, » répondez 'Oui, c'est une bonne idée. On a déjà convenu de dîner chez elle samedi. Qu'est ce qu'elle cuisine bien ! On lui apporte une bouteille de vin ? »

SECURITE DU PROCHE AIDANT. Il est impératif d'assurer la sécurité de l'environnement familial. Il faut que les armes soient confisquées, les couteaux mis sous clef, les outils électriques désactivés ou gardés sous clef. Dès que le proche aidant craint ou a déjà connu un accès de colère, il faut prévoir un plan de fuite, en préparant un sac de départ et de l'argent liquide. Le sac doit être facile à récupérer – vous pouvez le déposer chez un ami ou voisin. Quant à votre téléphone portable, pensez à faire une sauvegarde de vos données. Vous pourriez aussi envisager l'achat d'un portable prépayé.

Toutes les sociétés occidentales disposent de lois autorisant la prise en charge d'urgence de patients qui présentent des comportements dangereux. Il peut s'agir d'un placement non volontaire qui a pour but d'évaluer l'état du patient et d'assurer sa propre sécurité ainsi que celle d'autrui. La durée d'un placement non volontaire peut varier d'un pays à l'autre, mais les objectifs sont semblables. Les urgences hospitalières, la police, les assistants sociaux et les services d'aide juridique peuvent vous orienter. Vous saurez quand le moment est venu pour en savoir plus.

Biologie de la DFT

Les gènes inscrits dans notre ADN sont en quelque sorte des recettes pour fabriquer des protéines. La plupart des chercheurs estiment que l'accumulation de protéines dans le cerveau de la personne atteinte de la DFT est due à une 'surfabrication'. Mais il est possible que cette accumulation soit provoquée par un mauvais fonctionnement des réseaux lymphatiques du cerveau qui empêcherait l'évacuation de l'excès de protéines.

Dans un premier temps, la présence d'un excès de protéines se traduit par une transmission défaillante du signal électrique entre neurones au niveau des synapses, un peu comme le raté d'allumage des bougies d'une voiture. Les symptômes étant intermittents au premier stade de la maladie, parfois le signal passe. Par conséquent, on peut constater une fluctuation de certains symptômes de la DFT (difficultés à trouver ses mots ou à mener à bien une série de taches ; accès de colères) pendant les stades initial et intermédiaire de la maladie.

Il existe un autre facteur de complication : le cerveau cherche un autre itinéraire pour transmettre le message – un peu comme si on allait de Paris à Lyon en passant par Marseille. On parle de la plasticité cérébrale. Par contre, pour profiter de cette plasticité, il faut non seulement davantage de temps mais aussi la réduction de stimuli extérieurs. Dans un premier temps, le malade arrivera parfois à trouver le mot, l'information ou le souvenir qu'il cherchait. Pour le proche aidant, ces capacités variables ont tendance à remettre en cause la réalité de la dégradation des capacités. Et pour d'autres membres de la famille ayant moins de contact avec le malade, cette variabilité peut susciter encore plus d'incertitudes. L'évolution de la maladie, accompagnée de l'accumulation de protéines, conduit à l'atrophie et à la mort neuronales. Néanmoins, grâce à la plasticité cérébrale, on cherche – et parfois on trouve – des voies alternatives. En passant par Lille. Ou Barcelone. On n'arrive pas jusqu'à Lyon, mais on n'est pas trop loin. « Non, je ne parle pas de Roger mais de l'autre homme qui nous a aidés – tu vois qui je veux dire ? »

On observe un déclin des fonctions cognitives, comme en témoigne une baisse des résultats dans les tests neuropsychologiques. L'entourage remarque une altération des fonctions exécutives ainsi que des difficultés liées à la planification, l'accomplissement ou l'enchaînement de certaines tâches, la mémoire, les inhibitions, la dextérité manuelle ou l'équilibre.

Mais ce n'est qu'en cas de perte massive de neurones que l'atrophie qui en résulte est visible en IRM. A partir de l'apparition des premiers symptômes, le processus peut prendre des années, voir des décennies, pour arriver au stade d'une atrophie visible à l'imagerie.

Grace à la forte croissance du recours au scanner, il est devenu l'outil le plus répandu pour confirmer le diagnostic de DFT. Néanmoins, il s'agit d'une approche qui traduit parfois une trop grande prudence. Certes, l'utilisation du scanner réduit les erreurs de diagnostic mais peut aussi entraîner d'importants retards et de périodes de doutes pour les familles, qui seraient amenés à se tourner vers d'autres diagnostics ou traitements. Les conséquences d'un diagnostic tardif peuvent être désastreuses sur le plan de l'emploi, de la conduite automobile, des contrats d'assurance, de l'éligibilité aux aides sociales, des projets familiaux et du bien-être des proches.

Environ 40% des cas de la DFT surviennent chez les personnes qui présentent une ou plusieurs anomalies (mutations) génétiques associées à la maladie. Si jusqu'à présent on n'a identifié qu'une poignée de ces mutations, on s'attend à ce que d'autres soient découvertes. Il faut toutefois souligner que la présence de la mutation génétique seule ne suffit pas pour déclencher la DFT (sinon, la prévalence de la maladie serait plus élevée). On peut présenter la mutation génétique sans jamais contracter la maladie. Dans certains cas, il peut exister un mécanisme déclencheur, tel qu'une commotion cérébrale ou un épisode de délire. Il est possible qu'il existe un mécanisme 'd'antidote' génétique encore inconnu (les chercheurs ont déjà confirmé que les personnes présentant une mutation 'protectrice' PLCG2, la rs72824905-G allele, bénéficient d'une protection accrue non seulement contre la maladie d'Alzheimer mais aussi contre la DFT et la Démence à Corps de Lewy.