

Dealing with FTLD Behavior

**What Makes Life REALLY
Challenging?**

Laughing VS Surviving

- My goal for you as a care partner...
 - Understanding of what's happening with the person with FTLD type dementias
 - Understand what is happening for YOU
 - Support so you can do more than survive
 - Insight for the moments of joy that DO happen

Beliefs

- People with FTLDs are Doing the BEST they can
- We must learn to DANCE with our partner
- We are a KEY to make life WORTH living
- What we choose to do MATTERS
- We must be willing to CHANGE ourselves
- We must be willing to STOP & BACK OFF

What Are the Most Common Early Issues That Come Up with 'regular' Dementias???

- Not wanting to go to the MD
- Having trouble with new information - forgetting
- Asking the same things over and over – not recalling
- 'Losing' Important Things
- Getting Lost
- Unsafe task performance with unfamiliar tasks
- Repeated calls & contacts
- Refusing to something agreed upon
- 'Bad mouthing' you to others
- Behaving well in public, but badly in private

What Are the DIFFERENT Issues That Come Up with FTLDs???

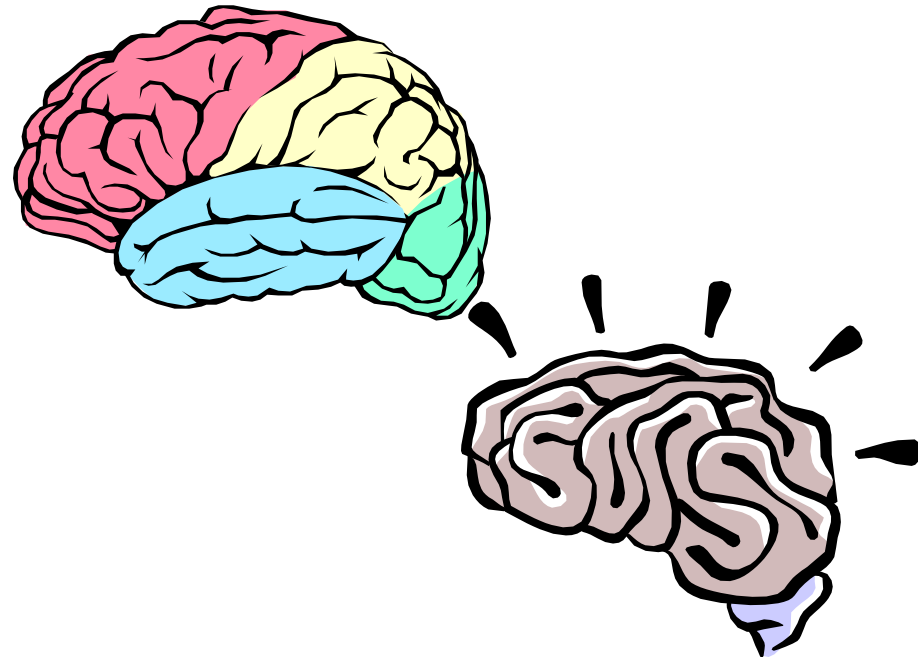
- Just not 'getting it'
- Saying & doing things they shouldn't
- Saying & doing things they NEVER would
- Knowing they shouldn't do something & STILL doing it
- Not being able to see 'it' from another's point of view
- Fixated on some things, unable to focus on others
- Unable to complete even simple tasks consistently
- No insight into what 'it' all means, what's happening
- Being a DIFFERENT person – 'can't be trusted'
- Problems with speech &/or comprehension

What Are the DIFFERENT Issues That Come Up with FTLDs???

- Wanting to eat ‘all the time’
- Taking food or drink from others – grabbing
- Drinking – a lot
- Seeking sex – becoming aggressive sexually
- ‘Over reacting’ to irritations
- Being apathetic – unresponsive – flat
- Knowing exactly what they are doing/saying but NOT being able to *not do or say it*
- Taking excessive RISKS
- Not being able to make a simple decision

Why Do These Things Happen?

- Brain Parts Affected
 - Thoughts
 - Words
 - Actions
 - Feelings
- It is progressive
 - More brain dies over time
 - Different parts get hit
 - Constant changing
- It is variable
 - Moment to moment
 - Morning to night
 - Day to day
 - Person to person
- For each FTLD - 'predictable'
 - Specific brain parts
 - Typical spread
 - Some parts preserved



Why Might These Things ***NOT*** Happen?

- Dementia is individualistic
- The person ‘doesn’t have it in them...’
- The situation doesn’t come up
- Other conditions keep it from happening
- Caregivers have great skills
- The dementia isn’t bad enough yet
- You get LUCKY!

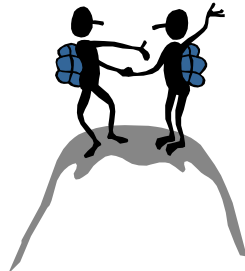
What Makes 'STUFF' Happen?

- SIX pieces...
 - The type & level of dementia ... NOW
 - The person & who they have been
 - Personality, preferences & history
 - The environment – setting, sound, sights
 - Other medical conditions & sensory status
 - The whole day... how things fit together
 - How the helper helps -
 - Approach, behaviors, words, actions, & reactions

What Can YOU Control? OR NOT!

CONTROL...

- The environment – setting, sound, sights
- The whole day... how things fit together
- How the helper helps -
 - Approach, behaviors, words, actions, & reactions



NOT CONTROL

- The person & who they have been
 - Personality, preferences & history
- The type & level of dementia ... NOW
- Other medical conditions & sensory status

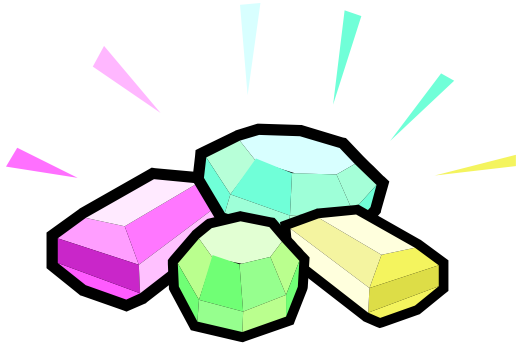
Brain Failure

The person's brain is dying

FIRST –
Become a GREAT Detective
Don't Be a Judge!

***What Level Are You Seeing
NOW?***

Positive Progression GEMS...



Diamonds

Emeralds

Ambers

Rubies

Pearls



Diamonds



Still Clear

Sharp - Can Cut

Hard - Rigid - Inflexible

Many Facets

Can Really Shine



Diamonds



Match CONTROL Needs
Use what has been... if possible

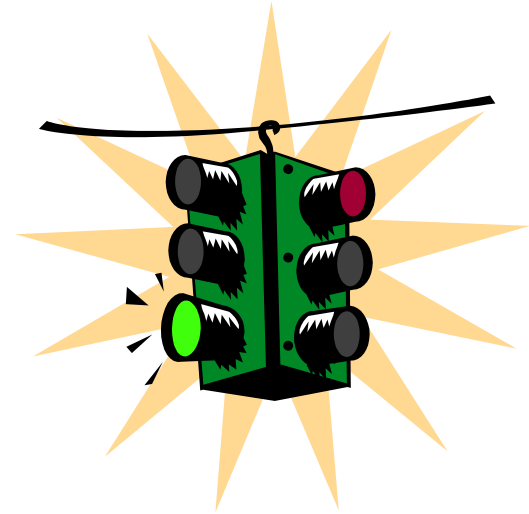
Learn the stories

Protect relationships

Figure Out What YOU Need



Emeralds



Changing color

Not as Clear or Sharp - Vague

Good to Go – Need to ‘DO’

Flaws are Hidden

Time Traveling



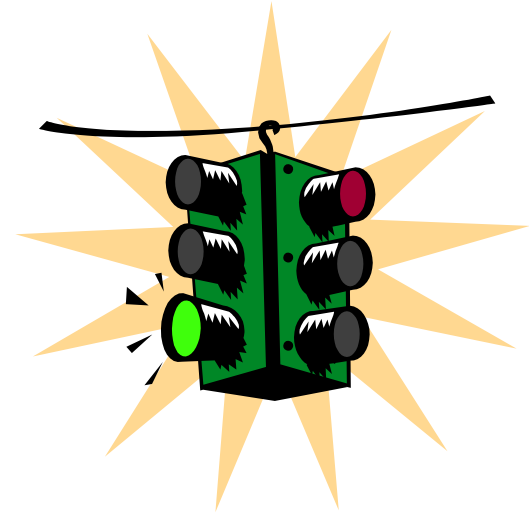
Emeralds

Coming & Going
Doing & Supervising

Hit & Miss

Bits & Pieces

SO WHAT?





Ambers

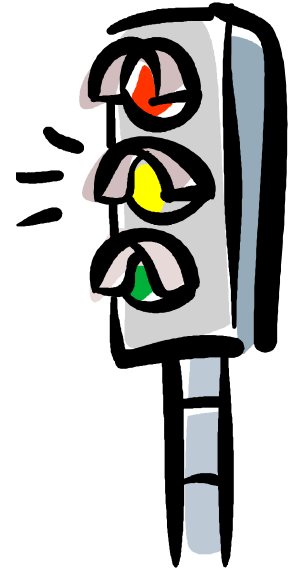
Amber Alert

Caution!

Caught in a moment

All about Sensation

Explorers





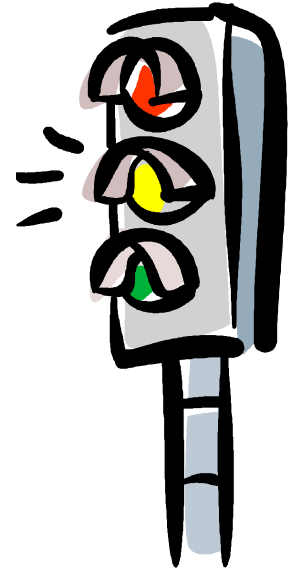
Ambers

“In the Moment”

Seeking - Sensory Need

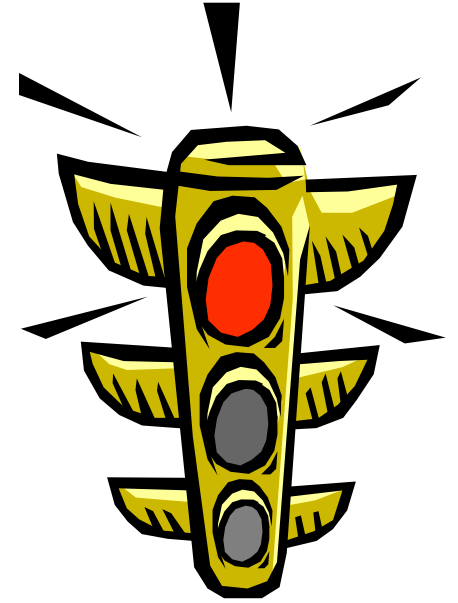
Reacting - Sensory Tolerance

Safe Places – Interesting Places





Rubies



Hidden Depths

Red Light on Fine Motor

Comprehension & Speech Halt

Coordination Falter

Wake-Sleep Patterns are Gone



Rubies

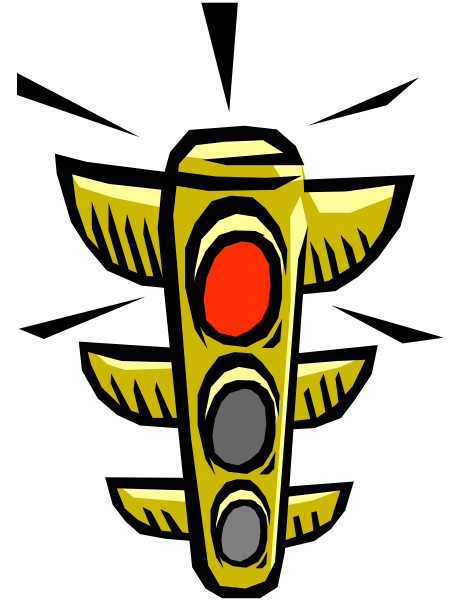
Go, go, go... Stuck in Glue

Moving or Still

Tough transitions

Big muscles – big actions

“What’s the Need?”





Pearls



Hidden in a Shell

Still & Quiet

Easily Lost

Beautiful - Layered

Unable to Move – Hard to Connect

Primitive Reflexes on the Outside



Pearls



More Time WITHIN

Moments of awareness - LAYERS

Comfort – sights, sounds, touch, smells,
tastes, movements

GO SLOW – Be CALM – Stay in Touch

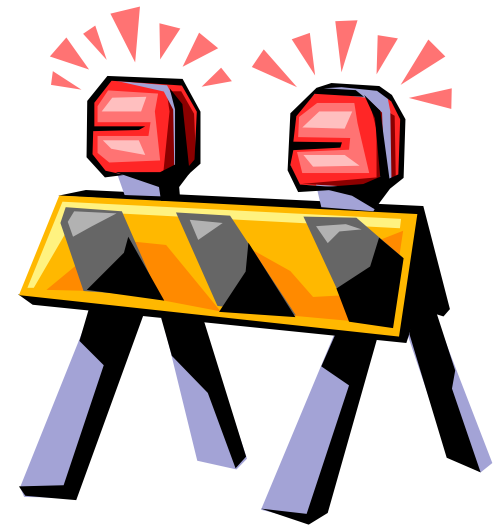
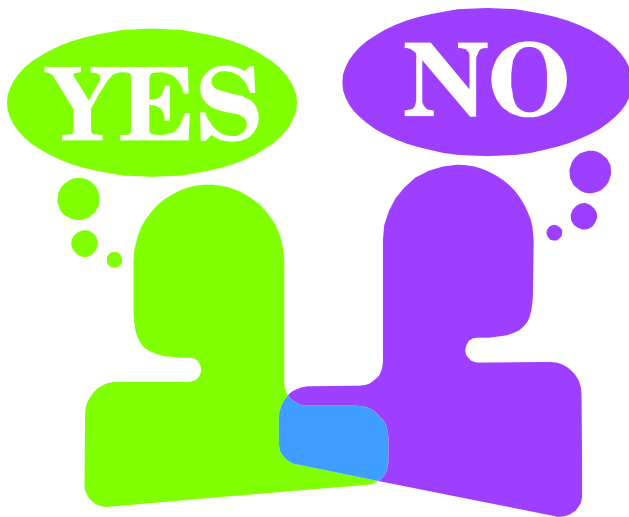
BUILDING Your Skills

KEY SKILLS

- Greet before you treat
- Build a 'team'
- Give cues in a specific sequence
- Respect space and the person
- Wait for a response before going on
- Do one thing at a time
- STOP & Back off if it isn't working
- Try something different as you approach

STOP

Confrontational Communication



Use **SUPPORTIVE Communication**



Positive Physical Approach



Connect

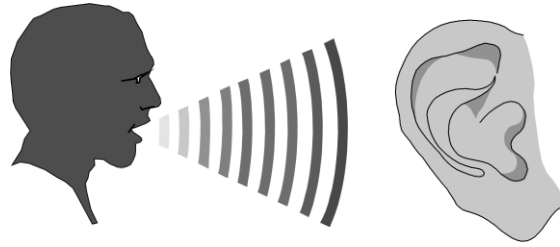
- 1st – Visually
- 2nd – Verbally
- 3rd – Physically

- 4th – Emotionally
- 5th – Spiritually

Your Approach



- Use a consistent positive physical approach
 - pause at edge of public space
 - gesture & greet by name
 - offer your hand & make eye contact
 - approach slowly within visual range
 - shake hands & maintain hand-under-hand
 - move to the side
 - get to eye level & respect intimate space
 - wait for acknowledgement



To Connect

Use a

Positive Physical
Approach

A Positive Approach

(To the Tune of Amazing Grace)

Come from the front

Go slow

Get to the side,

Get low

Offer your hand

Call out the name then WAIT...

If you will try, then you will see

How different life can be.

For those you're caring for!

THEN – Connect Emotionally

- Make a connection
 - Offer your name – “I’m (NAME) and you are...”
 - Offer a shared background – “I’m from (place) and you’re from...”
 - Offer a positive personal comment – “You look great in that” or “I love that color on you...”

THEN – Get it GOING!

- Give SIMPLE & Short Info
- Offer concrete CHOICES
- Ask for HELP
- Ask the person to TRY
- Break the TASK DOWN to single steps at a time

Give SIMPLE INFO

- USE VISUAL combined VERBAL (gesture/point)
 - “It’s about time for... “
 - “Let’s go this way...”
 - “Here are your socks...”
- DON’T ask questions you DON’T want to hear the answer to...
- Acknowledge the response/reaction to your info...
- LIMIT your words – Keep it SIMPLE
- WAIT!!!!

**Use empathy
&
Go with the flow**



How you talk...

- **How** you say it...
- **What** you say...
- How you **respond**...

Hand-Under-Hand Assistance



How can we help... better?

**It all starts with
*your approach!***

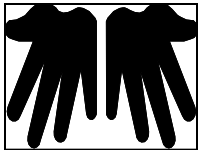
How you help...



- **Sight or Visual cues**



- **Verbal or Auditory cues**



- **Touch or Tactile cues**

Believe -

People with dementia

Are doing

The BEST they can!

What shouldn't we do???

- Argue
- Tell 'WHOPPERS' – that relate to emotions
- Ignore problem behaviors
- Try a possible solution only once
- Give up
- Let them do whatever they want to
- Force them to do it

STOP
resisting
RESISTANCE

When it isn't working:

STOP and BACK-OFF

THINK

Then

Re-approach & Try Something

Different

So WHAT should we do???

Remember

who

has the healthy brain!

I Will Change!

(to the tune of
This Little Light of Mine)

By Teepa Snow

I'm gonna meet and greet
Before I start to treat
I'm gonna meet and greet
Before I check your feet
I'm gonna meet and greet
Before I help you eat

How I start sets us up to succeed!

No more just “Getting’ it Done”
I’m gonna DO with you
No more just “Getting’ it Done”
I’m gonna help you thru
No more just “Getting’ it Done”
We’re gonna work, we two

Cause if I do it ALL, we BOTH LOSE!

I'm gonna laugh and dance with you
Not just watch and frown
I'm gonna laugh and dance with you
Not just stand around
I'm gonna laugh and dance with you
We'll really go to town

For the POWER of JOY I have found!