My Loved One Has FTD: What Can I Do to Help?
The "Rules of Engagement"

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A diagnosis of dementia is difficult for both the person with dementia – and for their loved ones. One of the most difficult things for loved ones is to figure out what they should be doing to make this journey easier for all involved. This door will help you to learn about what you can do to help. This section is divided into 2 parts:

I. Stopping unwanted behaviours to get your loved one re-engaged in life
II. Understanding abilities

Key Points of this Handout:

- Each person diagnosed with FTD is affected by the disease in his/her own unique way. While there are common behavioural and physical features and symptoms of FTD, there are many other factors that need to be taken into account when deciding how to help.

- Begin by asking the question: Why the behaviour?

- Don't forget about meeting social and emotional needs. We all have them, even if they are not clearly expressed.

- Become a detective, always trying to figure out what is happening because of the FTD – and what is happening because of something else.

- Always consider the needs, interests, skills and abilities of your loved one when making decisions about what to do.
- Focus on finding meaning and purpose in the things you do and the activities you plan.

- Consider the Montessori Methods for Dementia™ principles, and think about these as the "Rules for Engagement" laid out below in section II.

I. **Behaviour management:** Stopping unwanted behaviours to get your loved one re-engaged in life

For the person diagnosed with FTD, medications may be able to treat some of the symptoms, but they do not help with important aspects of daily living, such as finding things to do that hold meaning and purpose – at the individual's level of ability. Engagement in life is important – regardless of age and ability.

Initial Symptoms of FTD:

changes in personality and behaviour.

While changes to the brain are responsible for most of the behavioural observations you will make, **they are not responsible for all that you are observing**. It is important to figure out if there is anything you can do to help – and this begins by asking:

"Why the behaviour?"

Do you ever find yourself asking: Who is this person?

The changes in personality and behaviour are mostly caused by what is happening to the brain. However, it is important to ask if there are other factors that might be influencing changes in behaviour. If your loved one is behaving in a way that is unlike his/her earlier personality, don't always assume that ALL of the behaviours are due to the FTD. It may be something else.

Ask the following questions:

"Why is this happening?"

- Is he/she bored?
- Is she frustrated because he/she can't **do** things he/she used to be able to do or can't **remember** where he/she has put things or is there something else that is contributing to his/her frustration? Keep asking yourself what might be contributing to the frustration until you find the answer.
- Is he/she lonely?
- Is he/she angry or agitated because he/she feels no one comes to visit? (And remember, this is a personal evaluation, you may think there has been lots of support but that is not his/her opinion. If she/he claims no one has been to visit, and you know someone just visited, it is likely the memory that is the problem, so provide a "Visitor's Book" and have people put their name in the book and leave comments about what they did during the visit. Then refer the loved one to the book, to remind him/her of the visit.)

Look at what is going on (or not going on) and ask if there are things you could do to respond to these situations.

"When is this happening?"

- Are some of the behaviours occurring when the person is bored or when he can't remember something?
- Do the behaviours arise when there is too much going on (thus caused by an environment that is overly stimulating for someone struggling with brain changes)? (Note: A person with FTD responds well to a calm environment. For example, some people have found that sitting someone with FTD under a hairdryer provides a calming effect.)
- Do the behaviours occur when they are trying to do things that are beyond (or below) their current level of ability?

"When is this not happening?"

- Do these behaviours occur when the person is busy, involved in activities he/she enjoys (such as taking a walk or completing tasks around the house that are within his/her range of ability)?
- Does the behaviour occur when the person is enjoying meals with family? Why or why not?

Your role is to become a detective.

Find the clues and look for solutions to solve the problem. Some of the behaviours you will observe are due to boredom, frustration and other issues that arise because of the FTD.

In your role of detective, your task is to find ways to help the person who is struggling with a difficult disease. Based on what we know about FTD, there are many variations in the way it presents itself in individuals. **In your role of detective, you need to figure out what is going on and what you can do to help**. Just as a detective takes on a case, studying the details he/she has at his/her finger tips, looking for clues about what happened and why, and relentlessly looking to solve the case, your job is to keep asking questions until you "solve the case".

Note: This "case" may be opened in many different ways each and every day. Once you find solutions to situations, you can use the same strategies on a different day!

Think about what you already know. Don't assume the behaviour you are observing is because of the FTD.

ALWAYS ASK:

What is happening? Is what you are observing occurring because of the changes to the brain?

– or –

Is this happening because of something else?

Once you understand these aspects of the behaviour, you will be more effective in choosing an alternate activity for your loved one. Proceed to the next section for suggestions as to what works.

II. Understanding Abilities

Once someone has been diagnosed with FTD it can be difficult to know what the individual is still able to do safely or with a little assistance. There are a few things that are useful to know as you try to figure out what they will be capable of doing. Patients may be able to complete tasks but require help starting them, because the 'starter' part of the brain is not working well.

- Remember what they were liked to do most in the past and use this information to help you to figure out what to do in the present. Always consider your loved one's past and present interests, skills and abilities when choosing activities.

- Recognize that when we learned to do things, we started out learning the easiest things - then we moved up to a more difficult level of learning and doing. For example, you first learned what a picture of a dog or cat was, but you didn't learn how to read the words dog or cat until you were a little older. When you think about the person with dementia, use this same type of thinking. If he/she can no longer understand the words, we use pictures to help him/her to get through the day (e.g. - when reminders/memory supports are needed or games are played – for example, a game of trivia can be played successfully if you give the person two answers to choose from – thus helping them to provide the answer by having a memory cue – the actual answer - to support the memory loss). ALWAYS:

    - FOCUS ON TASK BREAKDOWN,
    - PROVIDE CUES AS NEEDED AND
    - WORK AT THE INDIVDUAL'S LEVEL OF ABILITY (e.g. – if the person can no longer read, use pictures or actual items to support memory loss).

  The point is – first things you learned – are easiest to communicate!

Procedural Memory is Spared during Much of the Illness

Procedural memory includes regularly practiced activities, such as brushing teeth, combing hair and getting dressed and skills such as playing an instrument.

The most important thing to remember is that the person must continue to "do" these things – because the more they "do" these things, the longer they will retain the ability. People with dementia can be prompted to regain activities they were able to do in the past – AND – they can be taught new things. This is the formula:

1. Consider how easy the task needs to be for this person (as the FTD is advances, the task and instructions need to be very simplified – while people in earlier stages may be able manage a more difficult task – as the disease progresses the tasks need to be broken down into small steps).
2. Demonstrate what you want the person to do – one step at a time (if there is more than one step) - using as few words as possible – especially as the disease progresses. This will help the person focus his mind on the task at hand. Too many words are confusing.
3. Let the person try to do the task. NEVER indicate that it has been done incorrectly. Say things like, "What would you think if we did it like this?" If the task was too difficult, simplify the task - and as the person gets better at the task, over time you can make it more difficult.
4. ALWAYS provide all the information and items needed for the task to be completed successfully. For example, with a puzzle, you would photocopy the completed puzzle for the person to place the pieces directly onto the photocopy.

How To Make Decisions About What To Do

The Rules for Engagement: Montessori Methods for Dementia™

The RULES FOR ENGAGEMENT! (Montessori Principles for Dementia)

☐ **Support Independence**:
  ○ Help your loved one by doing things that provide support – rather than taking over the task and doing it for him/her. Think of meaningful things to do that contribute to his/her independence. Many times people think that ability is lost because of the dementia, when in fact it is because the person hasn't been doing these things

(so they no longer remember how). The more they do things, the longer they will continue to do them. Caution against "over caring" and "over doing"!

- ☐ **ALWAYS consider needs, interests, skills and abilities.**
    - ○ **Always think about what the person would like to do and then think about what skills and abilities the person has to complete the task. In the early stages you may not need to modify tasks to a great extent, but later you may need to think carefully about task breakdown (which means that you will do things one step at a time – making sure each step is understood, completed and accomplished before moving onto the next step).**

- ☐ **Provide Opportunities for Your Loved One to Make Decisions (at his/her level of ability):**
    - ○ **Make decision-making easy by simplifying options. For example, when you go shopping the options are over-whelming. Make things easier by selecting a choice of two options (for example, ask your loved one if she wants to buy tuna in water or tuna in oil). Another example would be to ask if he/she would prefer to eat at 5:00 p.m. or 6:00 p.m., or would she like coffee or tea, or chicken or beef, or if he would like to do a puzzle or read a book (Note: there are books that have been specially designed for dementia – available at www.aging.mcmaster.ca).**

- ☐ **Keep things simple – at the level of difficulty required for their level of ability.**
    - ○ **You may not know how simple or difficult things need to be until you experiment. (Remember – you need to think like a detective!) If something is too difficult (for example the person struggles with using/following a schedule, begin with simple details such as the time he/she will have breakfast, lunch and dinner, then add details such as what time someone will be visiting, then keep adding additional details over time).**

- ☐ Demonstrate what you want the person to do.
    - ○ **Activities are always demonstrated, one component at a time,** to ensure that each step is understood and can be repeated. Try not to talk too much when you are helping your loved one understand what to do – as too many descriptive words can be confusing for someone with dementia, especially as the disease progresses.

- ☐ Activities are created in a manner that allows them to progress from **simple** (but never "babyish") to **more complex AND** from **concrete** to **abstract** and, **vice versa,** as needed, according to needs, interests and level of ability.

  - ○ **If you want the person to fold laundry you might need to begin with something easy, such as a basket of towels. If you want to make this more challenging, eventually you could add socks that need to be sorted (perhaps all the same size and colour at first then different sizes or colours and then both different sized and colours). Remember, the more they do something (as long as it is of interest and at their level of ability) the better they will get at completing the task.**

☐ Memory aids are used to support memory loss.
  - ○ Provide as many details and strategies as you can to support memory loss. Place information on cupboards and drawers about what is inside, provide directional signs to help find their way, if you want them to remember something, provide the information on cards or in any way that provides details. When playing games or creating activities make sure all details are provided (so they never have to pull the memory from their file in their brain). You can create games that involve asking questions (that are of interest and based on what they know) and they select the answer – by providing 2 – 4 answers on cards from which they can choose. The answer is on the table – and therefore they don't have to count on pulling the answer from their brain.

☐ Introduce activities that have meaning and purpose.
  - ○ Find meaning and purpose in the activities and routines you select and aim for successful outcomes by considering interests, skills, abilities and needs. For example, if a man loved golf, find magazines that he could look at, give him golf clubs and golf balls to polish/clean or create a game that includes questions that would be of interest to him (with the answers provided - from which he can choose). Enjoyment in what one is doing contributes to meaning and purpose and overall quality of life.
  - ○ When thinking about what types of things he/she might enjoy doing, consider creating a routine by writing it in a day timer or putting details on a dry erase board or in a book or on a piece of paper. Find the perfect match between what the person enjoys doing and the routines that will provide meaning and purpose each day.

☐ **Activities contain a control of error (to support the feeling that the task was completed successfully)** and free of unimportant detail (as extra details and pattern can create clutter and confusion for a brain that is impaired). Details are clear and easy to see.
  - ○ **Let's take the example of setting a table. If the person attempts to set the table and just places things where he/she thinks they go, does it matter if the fork is on the "wrong" side or the fork and knife are beside each other? As long as they are on the table and one can now sit to eat, the task was successful. It is important to note that it is easier to set the table if there is a plain table cloth, table top or placemat. "Busy" designs create confusion for someone who is challenged with dementia. (See example below.)**

It is important to consider each of these rules each and every time to think about, and create, things for the person with dementia to do. If the individual is struggling with what you have chosen to do, ask why this is happening. If you review the rules you may find that:

- there wasn't enough information provided (you forgot to put information in front of them), or
- the task was too difficult and needs to be broken down into easier steps, or
- the task was too easy and they are offended by the simplicity, or
- they were not interested in what you asked them to do. For example, someone who hated doing laundry might not want to fold a basket of towels or socks. Someone who loves to help in any way possible might enjoy helping with any household task.

Dr. Montessori set up her classroom to explore and learn, at the child's level of ability. In dementia, we take these areas of the classroom and use them to help us see what the person with dementia is able to do and what we can do to support independence and quality of life. These include:

- Activities of daily living (the activities that one engages in to get through the day)
- Social and cultural needs (making connections with other people and continuing to be connected to the world around them)
- Cognitive (in other words, things that provide opportunities to use their brain to "think", make decisions and problem solve)
- Sensory Stimulation (this includes anything that involves smelling, touching, tasting and hearing)

To summarize:

- Think about what your loved one can do, what he/she is interested in and what he/she needs
- Use these four areas to help ensure you are thinking about a wide range on needs, interests, skills and abilities

EXPLORING THE CREATIVE ARTS

There is interesting evidence showing that people with FTD have produced impressive pieces of art and learned/continued to play musical instruments – after the diagnosis of FTD. When you combine boredom with creative talents, you may find remarkable things happen. Some believe that the amazing works are created because the person does not fear being judged (by self or others) – so they just do what comes naturally without the inhibitions commonly experienced when the frontal lobes are in full control.

The next section provides examples of how these principles are put into practice.

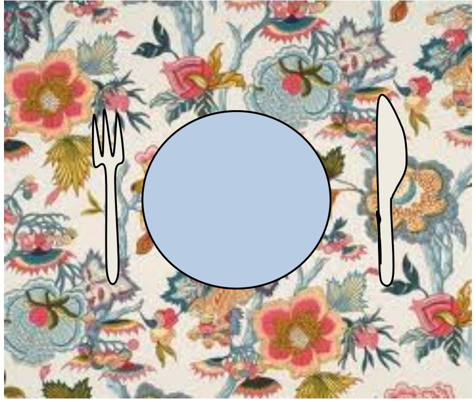
This example involves the task of setting the table.

1. **Avoid unnecessary details and clutter – the first diagram below is a place setting drawn on a very busy place mat. It is difficult to see the items on the place mat. It is important to simplify things as much as possible. If you look at the next picture you will see that the objective of simplifying has been reached – but you can't clearly see the white plate on the white place mat. The next example is best – there is a distinct contrast between the colour of the background (the place mat) and the plate and cutlery.**

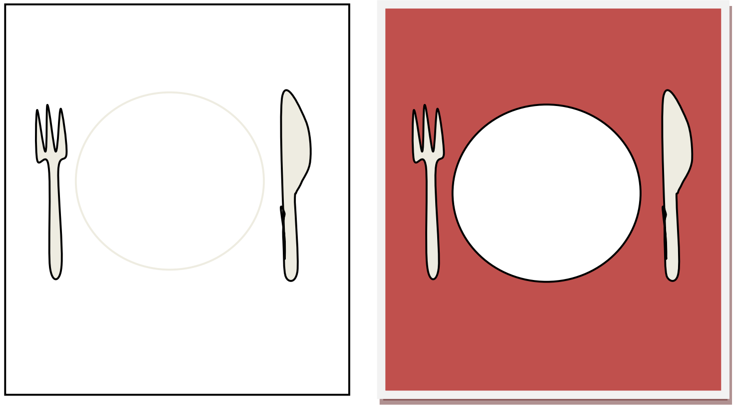
2. **Setting the Table: Some people may still be able to set a table without assistance. Others, however, may have lost the ability – not because of the diagnosis – but because they have not been doing things they easily did before they were diagnosed. When this is the reason for the loss of ability it is important to begin by breaking things down into steps, and supporting memory as needed. Your loved one may only need you to hand her/him the items and he/she will immediately know what to do. Others may appear confused if you simply hand them the items for setting the table. If this is the case, begin by placing a guide (e.g. – draw the plate, the fork, the knife and spoon on a plain plastic place-mat to provide a template that shows where each item will be placed.) Once the individual does this a number of times, the diagram may no longer be needed. The drawing provides clear cueing to show the person where things are to be placed.**

Look at the differences in the examples below.

Can you find the cutlery?



Which one is easiest to see - white dishes on white cloth or white on red?



General suggestions (using the principles provided above):

- When the person with FTD needs important details related to activities of daily living (e.g. – where things are in cupboards, what he/she will be doing today, where he/she will be going or who is coming to visit today) we can help him/her out by providing the details in a variety of ways.
    - For Activities of Daily Living: Supporting memory loss
        - If your loved one is struggling to remember where things are kept, put labels on cupboards with details about what is in the cupboard – using clearly printed words (for those who can read). If the person no longer reads (or never read) use pictures (of what is inside the cupboard) to help support memory loss. Make sure the words/pictures are large enough to be seen. Always ask if the person using the information can see the information **before** you use it – and make sure he/she understands the words and pictures you select before you put them in place. (Note: Another option is to replace cupboard doors with ones that have a glass front. This is an excellent idea, but not always a practical idea when cost is considered.)

Examples for kitchen cupboards:

Cups

Coffee Mugs

Forks
Spoons
Knives

Dinner Plates

Small Plates

Using Pictures (for those who don't know how to read or have lost the ability to read)

Assistance with Daily Life and Living: Helping with daily schedules

- Imagine how difficult it must be for those who cannot remember what they are going to be doing each day. Since details about the day are facts – the person with dementia cannot usually remember these specific details. There are a couple of ways to help with this.
    - The CELL PHONE: A couple of people that I have talked to, with dementia, used a cell phone regularly before they were diagnosed. When they found out what was in store for them they decided they wanted to maintain their ability to use their cell phone. Since they continued to use their phones (and this included putting their schedule into their phone along with important details they want to have accessible as needed) they were still able to use their phone 5 years after they had been diagnosed with dementia. For example, I asked one man how old he was and he looked his age up on his phone. If your loved one was previously able to use his/her phone (or other technology), continue to help him/her use this type of technology as long as possible. It is very empowering to have control over the information one needs throughout the day. (Note: Using a cell phone is actually a skill – and skills fall under the type of memory that is not lost early in dementia. If the person continues to use the cell phone they will maintain their ability longer than those who stop doing things they had previously learned to do.)

    - An Agenda or Daytimer: Another way to help the person who is struggling to remember important facts and details is to put the details into an agenda or a day timer. Even if the person doesn't seem to need these reminders in the beginning, it is important to build the habit of looking for the information in a designated location. This will help when the memory for this type of detail begins to fail.

    - Many adults already use a day timer and/or their kitchen calendar to keep details about what they have to do and where they need to be each day. For those in the early stages of dementia you could use a standard day timer and teach the person to fill in the details (with supervision, especially at first). If the standard day timer is too difficult to use, consider using one that is designed for people with dementia.

*Please find the Sample Daytimer for loved ones with dementia in a separate link in **Learn More About Dementia & Downloadable Resources.**

EXAMPLES OF ACTIVITIES

When creating activities always remember to consider:
- Skills
- Interests
- Abilities
- Needs

Doing Puzzles

Many people enjoy doing puzzles. This activity is well suited to someone with dementia IF you find a puzzle that is designed for the person's level of ability – AND you put a photo copy of the completed puzzle on the table to be used as a guide for putting the pieces together (if they need this memory support). (Your objective is to do all you can to support memory loss – the photo of the puzzle will help with finding where each piece will be placed.) The example below is a sponge puzzle that has been enjoyed by people who loved to fish. In fact, many stories have been told as the puzzle was put together.

The second example is a sorting activity. Sorting ability is usually spared in FTD well into the middle stages (and beyond). In this example, a photo copy was made of the packaging before it was taken apart. All the items are then put into a bowl or onto a tray and then the empty tray is put onto the photocopy (or you can put one of each of the items into the tray – providing the guide/cue that shows the person where the items are to be placed). If you want to begin with a simple task, just pick two of the items to be sorted, then when that is done successfully, sort three, then four, etc. Those in the earlier stages may be able to take on the full job right from the beginning. Once again, remember to work at the individual's level of ability – and don't be surprised if he/she gets better at doing things – because the more they do it – the better they usually get at doing the task at hand. (Note: other things that are similar to this type of sorting include putting medications into a dosette; sorting cutlery drawers; sorting items in tool boxes or sewing baskets; and sorting items of clothing from drawers or baskets.)

This is a photo copy of the puzzle – it will help guide the placement of the puzzle pieces.

This is a photo copy of the package – and it will help guide the placement of the puzzle pieces. Another way to do this is you could also put one of each item into each section to guide where the items will be placed.

Note: Someone in the later stages may not be able to do this at first. But if you begin by just giving the person just two items to place in the sections, then as he/she gets better you could add another item, then as that is

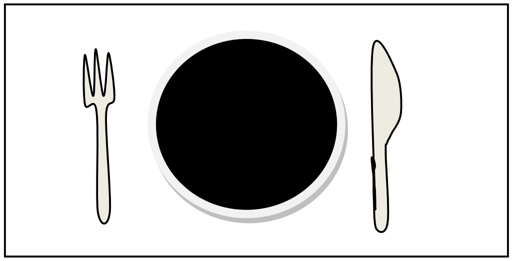
Examples of routines for someone at home:

Setting the table: If your loved one has stopped doing some of the basic household tasks it doesn’t mean that he/she can’t be helped to do these things once again. However, if he/she has forgotten how, the individual may need some instructions. You could label this as: “Today’s To Do List”

1. Get cutlery from top drawer: 2 forks and 2 knives
2. Place cutlery on table: One fork and knife on each place mat
3. Take 2 large plates from the cupboard (note: make sure cupboard is labelled if the person struggles with remembering where to find things)
4. Put large plates on placemats
5. Get two drinking glasses and put on table (by now the person should have enough cues to know where the glasses will go – it not – add the instruction “Put a glass on each place mat”
6. Get dinner napkins from bottom drawer and put on table
7. Get salt and pepper from cupboard and put on table

If the person needs help remembering what has been done, add a check box or have the person cross out each thing that has been done. The more the person does this, the better he/she will get at remembering what has to be done. It can become a role and a routine (at the same time every day if possible). You would do this with the person until he/she can do it with no assistance.

For someone with more advanced memory loss you could create a placemat that has the outline of where the items should be placed. This provides support for the memory loss.



These “Rules” have proven to be the basis for “engagement”.

Is the person:

Overactive, restless, distractible and/or disinhibited

(IN OTHER WORDS ---- TOO MUCH ENERGY OR DOING THINGS THAT YOU FIND CHALLENGING TO DEAL WITH)

In this case you are going to want to find out “why this is happening” and find things that will calm the individual (and that may include finding things to do at the individual’s level of ability)

Or

Apathetic, lifeless, with no initiative and without emotions

(IN OTHER WORDS ----- NOT ENOUGH ENERGY AND LITTLE INTEREST IN LIFE)

In this case it is important to provide encouragement and finds ways to motivate the person to engage in life.

OR

In the later stages of the disease, are they struggling with movement and conversation?

Sensory stimulation is important at this stage. Gentle hand massages, weighted clothing and bright colours to stimulate the senses add to quality of life. Assist with conversation by providing pictures that can be used for cueing memory. Consider gliders (a rocking chair that glides) to help reduce agitation or sitting under a hair dryer to provide a calming effect when needed.