

2021 EDITION

DEMENTIA CAREGIVER SURVIVAL GUIDE

TIPS FOR CARING FOR A
VETERAN WITH
DEMENTIA

DEMENTIA CAREGIVER SURVIVAL GUIDE

AUTHOR

Natali N. Edmonds, PsyD ABPP

CONSULTANTS*

Lauren Moo, MD

Sowmya Iyer, MD, MPH

Dat Hoang-Gia, CNS

Stephanie Hartz, LCSW

Jaye McLaren, OTR/L

*Consultants from the Veterans Health Administration Office of Rural Health funded Geriatric Research Education Clinical Center (GRECC) Connect Program. GRECCs are centers of excellence focused on aging.

THIS IS A VETERAN-FOCUSED ADAPTATION OF THE DEMENTIA CAREBLAZER
SURVIVAL GUIDE BY NATALI EDMONDS.

WHAT THIS SURVIVAL GUIDE IS FOR:

This guide is intended to help family members care for a Veteran with dementia. The strategies and information included in this guide can be applied no matter where you live, no matter what stage of dementia the Veteran has, and no matter what resources are available near you.

May these pages help support you along your caregiving journey.

TABLE OF CONTENTS

| | |
|--------------------------------------|-----------|
| 1. PREPARE FOR THE MISSION | 4 |
| 2. UNDERSTAND DEMENTIA | 7 |
| 3. COMMUNICATION TIPS | 11 |
| 4. TRY IT OUT | 19 |
| 5. DIFFICULT BEHAVIORS | 20 |
| 6. CHANGING ROLES | 29 |
| 7. DEMENTIA AND MENTAL HEALTH | 42 |
| 8. UNDERSTAND YOUR MIND | 45 |
| 9. SAMPLE COPING STATEMENTS | 49 |
| 10. SELF-CARE EXCUSES | 50 |
| 11. GROWING THROUGH GRIEF | 54 |
| 12. YOU DID IT! | 58 |
| 13. APPENDIX | 59 |

PREPARE FOR THE MISSION

You've come so far already. If you're reading these words then that tells me you are currently caring for one of our nation's heroes. You've probably sacrificed a lot to support your Veteran. Whether that was moving across the country, supporting your loved one through a deployment, or simply being present through your loved one's challenges of being in the military and adjusting back to civilian life. Even outside of the military, you've probably faced many challenges and obstacles in your own life. And despite all that, you are here. You are surviving. You are making it through this thing we call life. So before we go any further, I want you to take a deep breath and acknowledge how far you've come. You are amazing.

Now you're faced with another one of life's challenges. Your loved one has dementia. No matter what type of dementia your loved one has, there is one thing that is the same - it comes with challenges. I'm guessing I don't need to tell you that. If this guide somehow found you, then you've probably already had a taste of the struggles that come along with caring for someone with dementia.

No one asks for their loved one to be diagnosed with dementia. It just happens. All of a sudden, it seems like your world has turned upside down. You find yourself responsible for things you never had to do before and you are scared about what the future looks like for you and your loved one.

If you are like many other caregivers, you may have found yourself facing struggles such as:

- Wondering how much longer you will be able to provide care
- Wondering where to turn for help and how to ask for help
- Wishing your loved one would stop saying mean things and stop accusing you of things that aren't true

- Trying to convince your loved one to shower or change clothes
- Feeling all alone with no one who understands
- Feeling guilty for losing your temper or wishing it was all over
- Noticing that your personal relationships with others have slipped away and you have stopped doing the things that you enjoy

If you have had any similar concerns, then this guide is for you. In the pages that follow, I am going to share common dementia symptoms and how you can respond to help you feel less stressed, improve your loved one with dementia, and most importantly improve your relationship with your loved one. I promise this is possible and I have full faith in you.

For starters, it's important to know a bit about the disease and the best way to interact with your loved one. As dementia sets in and starts to progress, the brain isn't able to fully understand everything like it did in the past. This means you have to learn a new way of communicating and interacting with your loved one. The ways that you approached things in the past may no longer work, and in many cases will backfire and lead to arguments, mistrust, and more stress. So the first thing I want you to know is that to have the most success caring for your loved one with dementia, you are going to have to change.

Before we go any further, I have to give you my full honest warning. Even though your loved one with dementia is the one with the disease, the biggest way to help improve your loved one is to change yourself.

GASP! Yes, you have to change in order for your loved one to improve.

I know it doesn't make much sense at first, but this is reality when you love someone with dementia. It's what you have to do if you want your loved one to be as calm and happy as possible. It will make your life much easier as a result. It will also help make sure that you and your loved one can continue to have some positive and enjoyable moments together.

In order to improve yourself **AND** your loved one, you must understand some basic things about the disease. The things your loved one with dementia does that seem to make no sense will all of a sudden make more sense. In the pages you are about to read, you are going to learn some of the best ways to handle the challenges that come with caring for someone with dementia.

I promise you are not alone. Many dementia caregivers around the world started out feeling overwhelmed, frustrated, and depressed. They felt like they were at the end of their rope and that there was no hope for their situations. Once they started changing their approach and using the information provided in this guide, their loved ones with dementia started to improve, their relationship started to improve, and their own health started to get better. The same is possible for you.

I encourage you to take the chance on improving your situation. If you wish that things were a bit easier and you're ready to make a change, then continue reading.

In the next chapter, I'm going to explain why your loved one with dementia seems to purposefully give you a hard time.

UNDERSTAND DEMENTIA

No, your loved one isn't purposefully trying to drive you crazy. I promise!

Sometimes, it can feel like your loved one is literally trying to drive you crazy. Why else would they insist on not showering, insist they can continue driving, or constantly accuse you of things that aren't true? In some cases, your loved one may even blame you for their struggles!

- Have you ever tried to convince your loved one to change their mind?
- Have you ever tried to convince your loved one to do something they didn't want to do?
- Have you ever tried to correct your loved one when they said something that wasn't true?

I'm guessing if you have ever tried to do any of the above things, it didn't go smoothly. Why do you think that happened?

Many caregivers think that their loved one is in denial. In a minute, I'll explain why that isn't actually true and why we can't respond to our loved ones with dementia in the same way we would respond to people without dementia.

When you understand what is happening with the disease process, then you understand that the way you've been responding to your loved one has actually been making the situation worse! That's okay, it's never too late to start making changes.

As I mentioned in the last chapter, caring for someone with dementia requires learning an entirely new way to communicate. You can't interact with your loved one with dementia like you interact with others. Once you learn this new way of communicating, your situation will significantly improve.

So, what is happening? Why does your loved one argue with you when you remind them they can no longer drive?

Why does your loved one refuse to do the basic things like change their clothes or take a shower?

Why does your loved one seem to treat you worse than others when YOU are the one that does so much for them?

Let me explain.

It's not denial, it's something called anosognosia.

ANOSOGNOSIA

This is a process in dementia where your loved one's brain does not have the ability to understand the problems they are having. The term anosognosia means "lack of awareness." It literally means your loved one does not have the ability to be aware of their disease and all of the problems their brain is having. It's a common symptom in dementia.

Because your loved one is not capable of being aware of their problems (no matter how much you try to explain), they see YOU, as someone who is just getting in the way and preventing them from doing the things they want to do. Instead of seeing you as someone trying to help and keep them safe, they see you as someone who treats them like a baby.

Here's an example:

Your husband with dementia is no longer able to manage the finances even though he has always been the one in charge of finances. He forgets to pay the bills, pays the wrong amount of money, and is sometimes even scammed out of money from people calling the home.

However, your husband doesn't believe this. Even when you show him the overdraft fees, the late payments, the proof of scams, he STILL does not believe you. Instead, he makes up reasons for the things you are pointing out (i.e., someone hacked his account, you are stealing his money, the banks are corrupt, etc.).

Your husband now starts to resent you. He accuses you of trying to steal his money! The more you try to explain the situation, the more he mistrusts you and argues with you. He has even started to hide money from you and make financial decisions behind your back. After all, in his mind, you are trying to take away control of his money for no reason!

Do you see how this can lead to resentment, anger, and frustration for both you and your loved one?

Anosognosia is the reason that your husband doesn't believe you. This is why no matter what you say, no matter how much evidence you have, and even if you are able to physically prove your point, your loved one does not budge in his belief.

So, what the heck are you supposed to do to avoid the arguments and frustration if your loved one will not believe the truth no matter what you tell them?

This is where that new way of communicating starts to be important. You need to learn a new way to communicate with your loved one that doesn't highlight his weaknesses because he isn't capable of even being aware of those struggles!

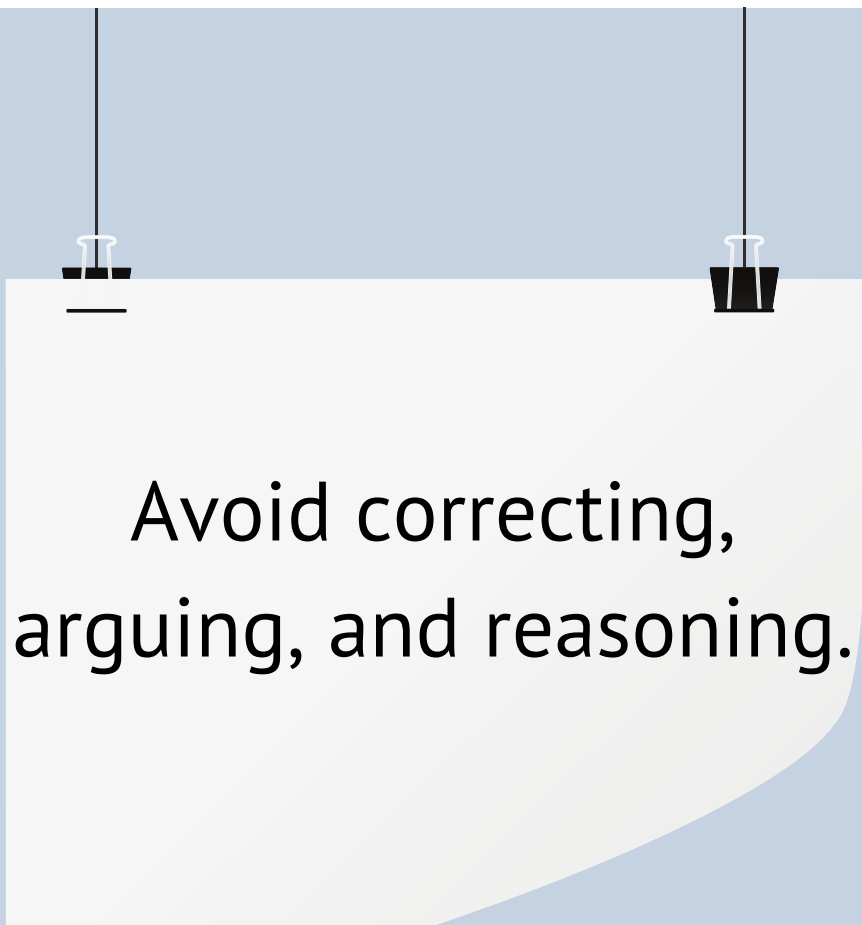
You also need to stop trying to argue, correct, reason, and rationalize with your loved one with dementia. As you can see with the example above, the more you try to explain, the more frustrated you and your loved one becomes.

You can't make a blind person see. And many times, you can't make someone with dementia reason. The brain simply doesn't have that capability. So, stop communicating with your loved one as if their brain is working perfectly.

In the next chapter I share some dementia communication tips that will help you avoid the pitfalls of correcting, arguing, and reasoning with your loved one with dementia. This is especially important because we don't want to argue and highlight their weaknesses, but we also can't allow them to do things that have serious risks (like falling for financial scams).

I'll also share how you can use these approaches in a way that helps your loved one feel valued, respected, and capable of still being in control of their life.

Most people, especially Veterans, don't respond well when someone tells them they can't do something that they believe they can do. Also, it usually doesn't feel good to constantly remind someone of their weaknesses and difficulties. That's a sure fire way to create more strain in the relationship. So let's talk about specific ways you can offer help and respond to your loved one without highlighting the the fact that they ne



**Avoid correcting,
arguing, and reasoning.**

COMMUNICATION TIPS

The 4 tips below are a few approaches to help you interact and communicate with your loved one with dementia. These tips are designed specifically for people with dementia and are often the complete opposite thing you would naturally consider, which is precisely why these tips are really important.

If you use the approaches below, your interactions with your loved one will be more enjoyable and your relationship will improve. Less frustration, more joy. Yay!

Ready to improve your relationship with your loved one? Here we go!

TIP #1: CHOOSE KINDNESS OVER TRUTH

This tip really starts to get into the nitty gritty of how interacting with someone who has dementia is so much different than interacting with someone who does not have dementia. Many people are taught that you should tell the truth at all times. They are taught that lying is wrong and should be avoided at all costs. “Lying” has many negative connotations and it’s easy to understand why when we think of the usual definition of lying. However, in dementia care, a good approach is to choose kindness over truth whenever possible. Sometimes choosing kindness over truth means you aren’t telling the truth.

Sometimes, “lying” is the kindest thing you can possibly do. Stick with me here and at least understand the reasoning behind this before you throw this idea away. You can choose to never use this approach if you don’t want, but I at least want you to understand the reasoning behind this approach.

When people think of lying, they think of the traditional reason to lie is to deceive someone, usually so they can get some type of personal gain. In dementia, a compassionate lie is not meant to deceive, it is meant to relieve.

Let me say that one more time. **Choosing kindness over truth is not meant to deceive, it is meant to relieve.** It's actually the kindest approach you can take in many situations.

If the truth about something is bringing your loved one with dementia significant anxiety, worry, or pain, what can you do to relieve that pain? What can you do to show kindness rather than staying focused on the truth? Below are some examples to help demonstrate how valuable this approach can be.

Example: Your dad with dementia has not worked in over 10 years. He wakes up every morning and starts to get ready for work.

Typical Response: *"Dad, you don't work anymore, remember? You stopped working 10 years ago."*

New Response: *"Dad, the boss called, you have the day off from work today! Let's go for a walk."*

Reminding your dad that he doesn't work anymore is likely going to make him either... #1) Not believe you and continue to get ready, #2) Feel anxious that he no longer works and didn't remember that fact, or #3) Feel sad because the thing that he did for so long no longer happens.

Instead of viewing lying as all bad, I want you to think of your reason for lying. Is it to relieve your loved one's pain or is it for personal gain? If the primary cause is to relieve your loved one's pain, then by all means, do it. This is going to save you and your loved one so much heartache.

Here's another example of when a kindness over truth can help.

Example: Your husband has dementia and is no longer safe to drive. You are getting ready to drive to a doctor's appointment when your husband says, I'll drive.

Typical Response: “You can’t drive anymore, you have dementia and the doctor said you aren’t safe.” This is likely to lead to arguments, resentment, and frustration.

New Response: “I actually feel like driving today. Let me chauffeur you around.” Smile, open the passenger door for him, and motion for him to go inside.

The new approach is much more likely to avoid arguments and does not make your loved one feel bad for reminding him of something he is no longer able to do. Notice how you don’t remind or bring attention to your loved one’s inability to drive.

Whether you have dementia or not, no one likes to be reminded of what they can’t do. Because there are many things that may pose a safety risk for people with dementia, it can feel that much of what you say to your loved one is negative or a reminder of their disease. Get creative, think of things you are able to tell your loved one that reduces the chances for anxiety, sadness, and anger.

**WHATEVER YOU DO, RESIST THE URGE TO ARGUE,
CORRECT, OR REASON WITH YOUR LOVED ONE.**

TIP #2: CHOOSE YOUR BATTLES

There will be **MANY** things that your loved one says and does that do not make sense, that are wrong, or may be completely strange.

Before you correct your loved one, ask yourself, “**Is it necessary for me to correct?**”

There will be many struggles along your caregiving journey and it is up to you to decide which ones you want to focus on and which ones are better left alone. In the past, there may have been times when defending yourself, proving your point, or “winning” a battle was especially important. It may have helped you feel heard and it may have helped you advocate for yourself. However, when it comes to choosing battles in dementia, it’s important to understand that many times your loved one may no longer have the ability to fully understand your point of view, AND, the energy of choosing a battle may no longer come with a reward. Most times, it’s quite the opposite.

If your loved one insists that the chicken they are eating for dinner is pork, let it be. If your loved one insists on saying they used to be a rocket scientist when

Caregiver Rule of Thumb

If what your loved one is saying or doing is not a safety risk, then let it be. This will improve your relationship with your loved one AND reduce your level of stress since you aren’t constantly correcting them.

Ask yourself, would you rather be right or would you rather be happy?

Get familiar and know what could be coming. The more you recognize the challenges as part of the disease, the easier it will be for you to deal with the challenges when they happen.

Please note that I am not saying caring for someone with dementia is easy or will ever be easy. Loving someone while watching them drift away in front of your eyes is one of the hardest and most heartbreaking things. But preparing yourself and getting informed about the disease will help you feel more in control, it will help you think of ways to respond, and it will help you realize that you are not alone.

TIP #3: JOIN THEIR WORLD

You may try to interact with your loved one with dementia, the way you've always interacted with you loved one. You may even try to interact with your loved one the way you would interact with people who don't have dementia. You will find out quickly that this approach does not work most of the time.

One of the biggest barriers to being able to successfully use this tip is believing that your loved one is purposefully not wanting to change or follow your direction. This is especially true if you've had to be assertive throughout your relationship to make sure your voice and opinion was heard. That approach usually backfires when you use it with someone who has dementia.



**IT'S NOT ABOUT MAKING SENSE IN YOUR
WORLD, IT'S ABOUT MAKING SENSE IN THEIR
WORLD.**



As humans, we immediately jump to trying to explain or rationalize with our loved ones with dementia only to find out that it backfires on us. In order to know the best way to respond to your loved one with dementia, you have to take the time to view things from their perspective. Remember, their brains are slowly dying and they are not able to understand much of the information that we are so fortunate to understand. What seems like a completely reasonable explanation to us, may not make any sense at all to someone with dementia.

Example: You are caring for your mom with Lewy Body dementia. She is terrified every time she wakes up and yells that there are people watching her.

Typical Response: “*Mom no one is watching you.*” You don’t understand it and tell her everything is okay and there is no reason to be afraid. Your efforts to talk to her don’t help. She continues to insist every morning that there are people watching her. You are frustrated that your mom isn’t listening to you and your mom continues to be scared every morning.

New Response: “*It’s okay, mom. I’m here. You are safe.*” You now take time to enter her world. You take what you know about dementia and look around the room. You notice that there is a mirror right next to her bed and realize that when she wakes up and sees her reflection, she thinks it is another person. You decide to take the mirror out of the room and now your mom no longer yells that people are watching her when she wakes up. Success!

**IF YOU WANT YOUR LOVED ONE
WITH DEMENTIA TO CHANGE, THEN
YOU ARE THE ONE THAT HAS TO
CHANGE.**

From your perspective, you understand that no one else is in the room. But from your mom's perspective, she cannot understand that. You can either continue to try to convince her and be frustrated every morning, or you can take the approach of joining her world and getting creative with your response.

TIP #4: YOUR BEHAVIOR IS MORE IMPORTANT THAN YOUR WORDS

In dementia, the ability to understand words gets harder and harder. Because of this, your nonverbal behavior becomes more important than ever. You are basically a mirror to your loved one. Whatever emotion you are showing on your face will be the emotion your loved one with dementia shows back to you. If you look stressed, nervous or frustrated, then your loved one with dementia will likely be stressed, nervous, or frustrated.

This is good news! This means that if you look happy, calm, and peaceful, your loved one is likely to be happy, calm, and peaceful. Nonverbal behaviors are often the key to what separates a typical dementia caregiver from an excellent dementia caregiver.

If your nonverbals are giving messages of stress and frustration, you can pretty much forget about getting your loved one to do anything you want. Your loved one will not be able to focus on what you want them to do because they are going to be stressed.

Situation: It's bath day for your wife with dementia.

Typical Response: You are already nervous because this is a stressful experience. You are tense, your face is stressed, and you are talking sternly to your wife to make sure she understands that she needs to get in the bath. You start to help her undress when she hits you and refuses to get in the tub.

New Response: It's bath day but you tell her it's spa day. You know this is a stressful day for your wife so you make sure that you are in a good mood and mentally prepared for the task. You make sure the bathroom is warm,

her favorite music is playing, that the water temperature is good, and you are constantly smiling and telling your loved one they are okay. Before you start taking your wife's clothes off, you tell her what you are about to do. You move slowly and make sure to smile throughout. Your wife is able to get through the "spa" experience.

Here are good communication skills to practice with your loved ones.

- Nod.
- Smile.
- Look at your loved one when talking.
- Be mindful of your tone of voice.
- Avoid looking rushed or tense.
- Keep your posture and body open and inviting. Your body language is important.
- Don't multitask. If you are interacting with your loved one, stop and focus on the communication.
- If it feels good, feel free to touch (i.e., holding their hand, putting your hand gently on the shoulder/back, etc.). This will depend on your loved one's comfort level and receptiveness.

TRY IT OUT

Take a moment to write down your biggest communication struggle and think about ways you can try to respond to them using the information you just learned. Think about joining their world, seeing things through their eyes, and researching or asking others about how they have handled similar situations. Remember: sometimes just changing your own thoughts about the situation and using coping statements can make all the difference. Give it a try.

BIGGEST CURRENT STRUGGLE:

POSSIBLE WAY TO USE KINDNESS OVER TRUTH:

THINGS YOU CAN STOP CORRECTING AND JUST LET BE:

THINGS YOU'RE TRYING TO CHANGE THAT YOU DON'T NEED TO CHANGE:

NONVERBAL BEHAVIORS TO START USING:

SEE IT FROM THEIR POINT OF VIEW. POSSIBLE WAYS YOUR LOVED ONE BE VIEWING THE SITUATION:

**OTHER POSSIBLE REASONS THAT MAY BE CAUSING THEIR BEHAVIOR:
(CONSIDER PAIN, HUNGER, BOREDOM, ANXIETY, NEED FOR BATHROOM, ETC.)**

DIFFICULT BEHAVIORS

The 4 tips above can help you respond and possibly even prevent many difficult behaviors. In this chapter, I want to share with you a very important mindset that can help you if you find that your loved one continues to have “difficult” behaviors no matter what you try. First, I want to make the very important point that **if your loved one is having what you would consider a “difficult” behavior, it means they are having a difficult time.** These behaviors are an attempt to communicate some type of distress and are not done to drive you crazy no matter how much it may seem like that’s what they are doing.

DETECTIVE MINDSET

Let’s talk about what you can do to help stop, reduce, and hopefully prevent these behaviors from happening in the first place. In these situations, it’s important for you to use what I call the “detective mindset.”

When you think like a detective, you don’t think with your emotions. Emotions tend to cloud it all up and make you miss important information. Can you imagine a detective of a crime scene getting so caught up in the unfairness and the cruelty of a murder? The emotions would cause the detective to miss the clues, miss key evidence, and not think clearly.

It doesn’t mean that the crime isn’t awful and that detective doesn’t give herself some time to process, but it means that the detective knows that if she let the emotions take control in this critical moment, then someone could get away with a crime.

As a dementia caregiver, your goal is to prevent or reduce the difficult behavior. In moments when you are trying to focus on this, put on your detective hat. There's a time and place for processing emotion and making sure you get care for yourself, we'll talk about that soon. For now, as you are trying to solve for a difficult behavior, it's important we stay in detective mode.

I'm going to go over some basic steps for you to follow to help you put on your detective hat. But first, I want you to realize that for every approach you take that doesn't work, that is simply feedback and information. It means you are one step closer to figuring out what will work. Just like a detective may realize that her initial hunch was wrong, that means that she can rule out that possibility and be one step closer to solving the mystery.

It's important for you to know that you are never failing when you are trying to figure out how to respond to a difficult behavior. You are simply learning and most of the time, that means things aren't solved on the first try. It's totally okay. You are still on the right track.

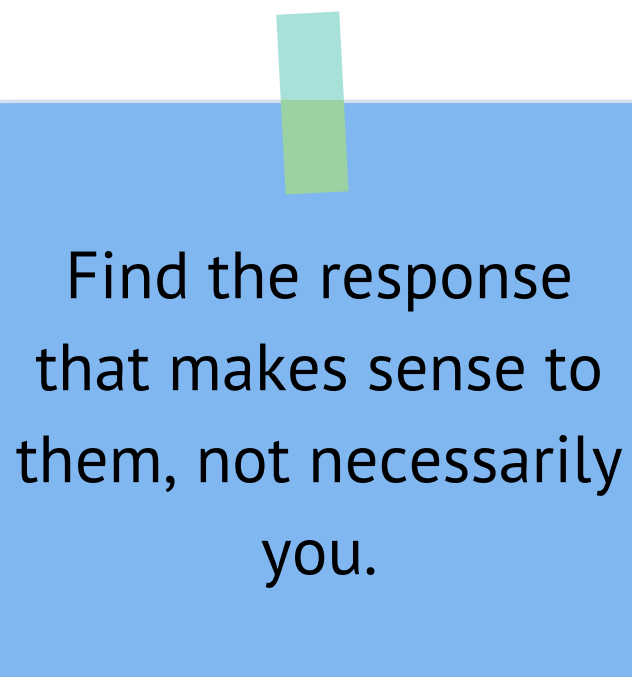
WHAT'S CAUSING THE BEHAVIOR?

Whenever someone with dementia is displaying a behavior that you are finding difficult, that means it's also difficult for your loved one. **A “difficult” behavior is a distressing behavior. It means your loved one is in some type of distress and is responding in a way that is trying to meet a need, even if it doesn't make sense to you.**

It's easy (and totally normal) to feel frustrated with some of the difficult behaviors, but keeping in mind that your loved one is also feeling frustrated and in some type of distress helps maintain a sense of compassion in the moment.

In order to find the cause of difficult dementia behaviors, you have to spend some time gathering information on what exactly is happening. The reason it's so hard to stop difficult behaviors from happening is because we usually try to solve them from our point of view. Instead, we need solve it from the point of view of the person with dementia. This means that the cause of the behavior may not be obvious to us. It might not even make sense to us. That's why tracking the behavior and getting specific with the information helps.

When trying to find ways to respond to a challenging dementia related behavior, it's important to find the response that makes sense to them.



On the next few pages, I break down some important questions you will want to ask yourself as track and try to respond to a difficult behavior. Most people with dementia have more than one difficult behavior, but for purposes of this exercise, I want you to choose just one behavior. Once you've had success with that one behavior, you can apply the same approach to others.

BE A DETECTIVE

As you answer the questions below, be as factual as possible. Remember, you are being a detective so try to leave the emotion out of your answers. Write down as much detail as possible. I'm going to go through the questions using an example and then you can try it on your own.

Let's start with one behavior. In the space below, write down the one behavior you are going to focus on.

The behavior I am focusing on is:



He yelled and threw the remote control at me.

Now, fill in your responses to the questions below. This is the **OBSERVATION** stage. Be sure to be as detailed as possible. Something that doesn't seem important to you can actually be a big piece in solving for the behavior.

A

Antecedent: This is what happened just before the difficult behavior.

Write down anything you can remember. **What was your loved one doing/saying? What were you doing/saying just before the behavior? Who was around? What was happening right before the behavior began?** Write down everything you can remember.



It was just before lunch time. My husband was in the living room watching TV. No one else was around. He was sitting in his favorite recliner. I had walked into the room to open up the curtains a little bit and let some natural light into the room. I walked in, passed in front of him as usual and opened the curtains next to the TV. No one else was around. Everything else about the day was normal. There were no visitors or phone calls.

B **Behavior:** This is where you write down **exactly** what happened. Leave out any of your judgements or interpretations and try to stick to the facts only.

What exactly did your loved one say?



“Get out of the way! Don’t do that!”

What exactly did your loved one do?



He raised his voice. Threw the remote control toward me. He raised his voice as he said, “Get out of the way! Don’t do that!”

Who was around when this behavior happened?



It was just me and my husband. No one else.

Where exactly did it happen? Be specific about location. (Instead of writing at home, for example, write in the bedroom while he was sitting up on his bed).



It happened in the living room. He was sitting on his favorite recliner watching TV.

When exactly did it happen? Again, be specific down to the time of day.



It was about 11:45; just before our usual lunch time.

What else stands out to you about the specific behavior and environment?



He seemed a little scared when he yelled out loud.

C **Consequence:** This is what happened **just after** the difficult behavior. Write down **exactly** how you responded.

What exactly did you say and/or do after the behavior?



I raised my voice and told said “Don’t throw that at me!” I then told him that I was just trying to get some light into the room.

What exactly did your loved one say and/or do after the behavior?



He told me to stop, get out of the way, and not to open the curtains ever again. He then refused to sit and eat lunch with me later.

How was your response to the behavior?



I tried to explain to him why it's good to have light in the room. I asked him to come eat lunch multiple times and shared how he needs to eat for his health.

Use these questions and write down your answers after each time the behavior occurs. You may already have some ideas about what caused the behavior just from filling this out. If not, that's okay. It's important not to skip over this step. The more detailed you take this, the more success you are likely to have when you start to change the behavior.

It's time to take all the information you gathered in the observation stage and put it into action.

Remember to work with one behavior at a time. The behavior you have been gathering information on and the behavior you are focusing on is:



He yelled and threw the remote control at me.

Now, fill in your responses to the questions below. Be sure to be as detailed as possible. Something that doesn't seem important to you can actually be a big piece in solving for the behavior. Remember, it doesn't have to make sense to you, and many times, it won't make sense to you. We are looking at things through your loved one's eyes.

BRAINSTORM

Write down all the possible reasons your loved one did what they did. Write anything that comes to your mind. Don't censor yourself or hold back on ideas. Challenge yourself to come up with at least 15 different reasons your loved one did what they did. **There is no such thing as silly or too strange here. Let your brain run wild.**



- *He hates me and is trying to make my life hard.*
- *He didn't sleep well last night.*
- *He was hungry; it was just before lunch.*
- *The light hurts his eyes.*
- *He thinks people are spying on him.*
- *I interrupted his TV program.*
- *I walked in front of his field of view blocking the TV for a moment.*
- *He thought I was going to turn off the TV.*
- *He thought I was going to want to change the channel.*
- *He was afraid I was trying to leave the house.*
- *He has a urinary tract infection.*
- *He might be having a reaction to a new medication.*
- *This is a way for him to feel masculine and in control.*
- *He is upset that he can't open the blinds on his own.*
- *Maybe his clothes are too tight and uncomfortable.*
- *Maybe he didn't recognize who I was.*
- *He thought I was an intruder.*
- *He was having a PTSD flashback.*
- *Maybe I scared him because he didn't hear me coming into the room.*

EXPLORE

Choose **one** of the reasons you wrote down in the brainstorming session to try out first. **The reason for the behavior that I am going to focus on first:**



I walked in front of his field of view blocking the TV for a moment.

Based on that one reason above: How will you change your approach?



I will minimize how often I walk into the living room while he watches TV.

How will you change your environment?



I will move his recliner 3 feet away from the wall so when I do walk into the living room, I can walk behind him and not have to walk in front of him. This way I won't block the TV.

PREPARE

What will you do if the behavior doesn't stop after you've made the changes in step 2? What will you tell yourself? This is important because it helps mentally prepare you to keep going even if your first guess doesn't work. Much like a detective, the first hunch may not be correct. It's okay. What do you need to tell yourself to keep going in that situation?



I will tell myself that with every possible way that doesn't work, I will be one step closer to figuring this out. I am never failing, I am always learning.

RESET - REVISE - REPEAT

If your initial attempts did not work, you go back to step 1 and choose a new reason for the behavior from your brainstorming session. From there, you go through the rest of the steps.

For example, if you moved the furniture and didn't walk in front of the TV the next time you walk in the living room to open the curtains, but your husband still yells at you and throws the remote at you, you will go back to your brainstorming list of possible reasons and choose the next reason you will focus on. From there, you will go to step 2 and ask yourself how you will change your approach and the environment.

Repeat this as often as necessary until you discover the underlying cause of the behavior.

If you find yourself getting frustrated that you aren't finding the cause as quickly as you like, it's better to take a break from this detective work than to continue trying new approaches. Trying new approaches from a place of frustration will likely make the behavior worse. It's okay to take a break and come back to your notes whenever you feel ready to do so again. This information never goes to waste. You can start again at any time.

Refer to page 60 in the Appendix for practice worksheets for you to use

SPACE FOR NOTES:

CHANGING ROLES

There are many qualities of Veterans that are important to consider when it comes to giving them care. For starters, many Veterans have spent a large portion of their lives doing things independently for themselves. Many have even been in positions of leadership or authority. This means that they may not be as open and receptive to the idea that they now need help. This puts you in a difficult position because you realize they need the help but your loved one may not agree. Even if your loved one does realize in some way they need help, they usually don't like people reminding them that they are no longer able to do things they were once able to do without difficulty.

There are many role changes that come with dementia and it's important to understand how to make a smooth transition into the new role so that you increase your chance of success AND maintain a good relationship. One of the saddest parts of dementia is watching a relationship slip away and deteriorate because the caregiver (you) are trying to give care to someone who is having a hard time accepting that care.

Let's talk specifically about what you can do to maintain the best possible relationship with your loved one while still giving them the care they need. First let's focus on the Veteran.

- THE VETERAN: HELPING THE TRANSITION -

Here are some general guidelines to help the Veteran transition into this new stage of life that requires more care.

TIP #1: AVOID CORRECTING WHEN POSSIBLE

Because dementia impacts the brain to the point that the person will have difficulty making decisions and doing certain activities, there will many times when your loved one is doing things wrong or inefficiently. To help maintain

your relationship with your loved one, you want to avoid correcting your loved one unless it's absolutely necessary or when safety concerns are present. This will also help your loved one maintain a sense of independence.

What is one thing your loved one currently does incorrectly or inefficiently that you can “let go” and not correct?

TIP #2: REMEMBER THE RELATIONSHIP

Sometimes, we get so wrapped up in caregiving that it seems the only interactions we have with our loved ones become caregiver-patient interactions. Before your Veteran was diagnosed with dementia, they were a soldier. They may have also been a leader, an employee, a spouse, a parent. It's easy to forget your individual identities when the caregiver relationship takes over. It's important to maintain some sense of your relationship beyond the caregiver relationship.

Here are some general ideas to do this:

- Do something together every day that doesn't involve caregiving (listen to music, go for a walk, tell a joke, watch birds, share memories of past vacations, look through photographs, etc).
- Give a genuine compliment to your loved one. This is a really good one because it trains your brain to look for something you can honestly compliment AND it helps your loved one feel good about themselves. You can compliment their smile, sweater, appetite, choice of music, etc.

What is one thing you can do together starting today that has nothing to do with caregiving?

TIP #3: DON'T HIGHLIGHT THE NEED FOR HELP

Your loved one will require help with many things along the way. Whenever possible, provide that help without them knowing. The more you bring attention to the fact they need help, the more likely they will start to resist your efforts in the future and the more strain it puts on your relationship.

Here are some ideas about how to help without them knowing:

- If they frequently spill drinks and this requires you to clean up in front of them, perhaps you switch the cups to plastic cups with lids **WITHOUT** mentioning it's because they are spilling their drinks. Perhaps you introduce them as "fun new cups."
- If they need your help cutting up meat at the table, perhaps all your meals are automatically served with the meat already cut up because that's the way you wanted to make the meal.
- If they are confused about using the remote control, get a universal remote with big buttons or tape off buttons that aren't needed.
- If your loved one has trouble buttoning up shirts, perhaps the shirts are gradually swapped out for pullover shirts.
- If your loved one is no longer safe to drive, when you both head out to leave the home, you can say something like, "*I feel like driving today*" and head straight to the drivers seat. There is no need to remind your loved one that he/she can't drive. Be creative in how you can accomplish your goal without making it obvious.
- If your loved one has always been the one to manage the finances and asks about the bills, you can say, "*si set everything up for automatic bill payments, one less thing for you to deal with.*" If they have trouble accepting this, try to redirect to another activity.

Again, it's important to note that you aren't letting your loved one know you are making the changes because it will be easier for them. You are making these changes naturally without calling attention to the fact that your loved one was struggling.

What are ways you can offer help without highlighting that they need help?

TIP #4: ASK FOR THEIR HELP

Because so much of caregiving is YOU providing help, the person with dementia can often feel useless or feel like a burden. Sometimes, the person may also resist care further because they are used to being the ones in control and don't like being the one needing care. This is why it's important to be creative in coming up with ways you can help them feel valued. You might not actually need their help, but you are coming up with ways to involve them and make them feel needed.

When coming up with things your loved one can do to contribute or help around the house there are a few things to keep in mind. **First**, make sure that whatever you offer is safe for them and within their ability level. **Second**, make sure that whatever you ask them to help with is something that won't have negative consequences if done incorrectly. For example, if your electricity bill is due tomorrow and you give that as a task to your loved one who may forget, then that will be something that results in a negative consequence such as late fees, possible power shut off, and more work for you to do in fixing the issue by making phone calls, etc. Getting your loved one to help shouldn't lead to more work for you.

There is no shortage of ideas on getting your loved one involved in helping engaging them in a pleasant activity.

Here are some activities in different categories. Feel free to come up with your own.

PURPOSEFUL ACTIVITIES:

.....

- Fold towels
- Sort or organize buttons, coupons, magazines, nuts/bolts, movies, etc.
- “Polish” silverware with a dry cloth
- Set the table (feel free to switch to plastic plates)
- Dust the coffee table/furniture
- Help with gardening/watering (consider giving them a spray bottle to water plants)
- Look through family photos
- Sweep/mop/vacuum floors
- Spend time with a pet (brush, feed, walk, etc.)
- Visit with grandkids
- “Fix” things around the house using safe tools
- Assemble/disassemble discarded equipment (e.g. bicycles, computer parts, broken fans, VCRs, etc.)

SPIRITUAL ACTIVITIES:

.....

- Read scripture
- Listen to religious music
- Watch a religious gathering/event on TV
- Pray
- Spend time in nature

PHYSICAL ACTIVITIES:

.....

- Walk
- Chair yoga (the internet is a great place for free online videos)
- Stretch
- Ride stationary bike

CREATIVE ACTIVITIES:



- Draw/color/paint
- Sing
- Dance
- Watch clouds
- Look at birds
- Tell jokes

MILITARY SPECIFIC ACTIVITIES:



- Sort/polish/look at military awards
- Go through military pictures and certificates
- Watch military movies on TV
- Listen to military cadence songs (The internet is great for free online songs)
- Organize/sort military hats and t-shirts
- Talk about military experiences (military specialty, basic training, buddies, etc.)

Remember, choose something within their ability level that won't have major consequences if done incorrectly or not at all. Also, feel free to ask for "help" with things you don't actually need help with or with things you don't need done at all. The goal is preserving the relationship and helping them feel valued. This is a powerful tool, especially for Veterans who may be accustomed to being needed and providing help most of their life. Be sure to avoid any attempts to correct as they do the task and know that on some days, these strategies will work and on others they may not work. It's okay and it's all part of the caregiving mission.

BONUS TIPS



- Choose activities that align with their previous interests. For example, if they loved working on construction projects, sorting nuts/bolts could be a good activity.
- If there is a time of day where your loved one usually starts to have anxiety or shows some distressing behaviors, consider engaging in one of these activities before that usual time. This is what I like to call “getting ahead of the behavior.”
- Don’t rule out activities that they’ve never been interested in before. With dementia, the person may develop new interests and be open to things they weren’t open to before the dementia diagnosis. I’ve seen many Veterans with dementia enjoy coloring and puzzles even though they never did these activities in the past.
- Consider doing some of these activities with your loved one. This can help foster the relationship.
- You don’t have to pressure yourself to come up with a ton of different activities. You can repeat a task your loved one seems to enjoy as many times as you wish. For example, you can keep a laundry basket of towels that need folding for your loved one to do. When your loved one goes to bed, you can undo all the towels so he will have more towels to fold tomorrow.
- Consider saving some tasks that your loved one can do alone for times when you need some alone time. That way, your loved one can be engaged in a safe activity while you do whatever you need or want to do.
- Think out of the box and shop in the kids section for activities, supplies, etc. Items made for kids are often cheaper than items made specifically for older adults.

What is one thing you can ask your loved one to “help” you with?

- THE CAREGIVER: YOUR CHANGING ROLE -

Having a loved one who served in the military likely means you had to be on your own for significant periods of time in your life. Perhaps your loved one was deployed and away from the home for long time periods of time, or, perhaps they worked long hours away from the home. No matter what the previous relationship looked like with your loved one, the fact that your loved one now has dementia means your relationship has changed and your role in the relationship has changed. Here are some general guidelines to help you transition into this new stage of life of being a dementia caregiver.

TIP #1: HAVE COMPASSION

As a caregiver, you're great at showing compassion to your loved one with dementia. How good are you at also giving yourself some of that compassion? Be careful not to beat yourself up for not knowing what to do. Don't get down on yourself for struggling with many of the difficult situations that arise. This is new territory for you. You've never been in this position before. Often times, things that worked before may not work when you try them again. Things can constantly change and it's easy for you to use that against yourself by thinking you aren't doing a good job. Whenever you catch yourself feeling bad about how you handled a difficult situation, I want you to consider asking yourself what you would tell a good friend in that same situation.

What would you tell a good friend who was in your same situation?

TIP #2: PRACTICE SELF-CARE

So many caregivers feel that practicing self-care is unrealistic when so much of their time and energy is spent caring for their loved one. In chapter 10, I will go over how to overcome many self-care excuses. In this section I want to help you understand that when you take good care of yourself, you take better care of your loved one with dementia.

Most of us wouldn't want to get surgery from a well-intended surgeon who loves her patients so much that she skips lunches, stays up late worrying about her patients, and doesn't take time off work. We'd prefer the surgeon who is well rested, who took time to eat lunch that day, and who makes sure she does what she can to get some sleep and time away from work. We know that we are in better hands and have more chance of success when the well-rested surgeon is caring for us versus the surgeon who has good intentions but hasn't eaten in 12 hours. The same is true for you and every other human being on this planet.

You have a responsibility to take care of your own health. Self-care is not optional. It is not a luxury. It is not a sign of weakness. You can't give good care to others on a long-term basis unless you also give yourself good care.

There is no level of stress you have to be at to start self-care. You don't have to wait until your gas tank is empty or you are completely burned out. Self-care starts right now and continues every day for the rest of your life. Self-care is a daily practice.

I want you to take a moment and think of all the things you do on a daily basis that you never ever question whether they are worthwhile doing. Things like brushing your teeth, showering, sleeping and eating food are all things you do every day because in order for you to get the benefits you have to keep doing them. When you eat a meal, several hours later you get hungry again. You never ever question whether eating is working. You never say, "I just ate 5 hours ago! Eating doesn't seem to be working so I'm going to stop." No, you don't say that. When you get hungry you eat again. When your body is dirty you shower again. So many caregivers feel that because they practice self-care and get stressed again, they feel it's not worthwhile. That's the opposite of what's happening. Feeling stressed is precisely your cue to keep up your self-care!

What are your current thoughts about self-care? How do you think self-care would help you in your current caregiving situation?

TIP #3: ASK FOR HELP/ACCEPT HELP/HELP YOURSELF

So many caregivers are doing everything on their own. Perhaps you don't have any other family or friends who are available to help out. It's important to overcome any of your beliefs about help that may get in the way of you asking for help, accepting help, or finding ways to help yourself.

First of all, there is no special badge or award you will receive for doing everything on your own. In fact, doing everything on your own will lead you to be at a higher risk of burnout and increased risk for your own health decline. Amazing athletes have coaches. Great military leaders have a team to help them. Wonderful parents have teachers and babysitters to provide education and care for their children. Caring doctors have nurses and check-in staff to help them care for their patients.

In every area of life, people receive help. It doesn't take away any of their greatness. If anything, it adds to their greatness because it allows them to continue to show up and provide care. For some reason, this understanding seems to go away when it comes to caregiving. You might feel embarrassed or shame about your loved one's disease, or perhaps you want to protect your loved one from other's knowing about their disease.

Sharing and asking for help can be uncomfortable. Just because something is uncomfortable, or you've been used to doing things on your own before, doesn't mean it has to stay that way. As you'll soon discover (if you haven't already), in order to thrive in this caregiving journey you will absolutely require some help and that can feel uncomfortable.

HELP YOURSELF

If asking for help seems extremely uncomfortable for you, I want you to consider ways you can start to help yourself. There are likely things you can do right now to make life easier.

You want to give your loved one good care and it's important to do what you can to keep them healthy. It's also okay to choose the easy route every now and then. This is a marathon, not a sprint. It's okay to lower your standards every now and then. Give yourself permission to:

- Order takeout, pre-made foods, or simply have cereal for dinner.
- Buy electronic gift cards for family member gifts instead of shopping in the store.
- Have the same type of meals weekly.
- Wear the same type of clothes regularly (for yourself and/or your loved one).
- Don't worry if your home isn't perfectly clean and tidy.

ACCEPTING HELP

There are likely people in your life who would like to help from time to time but truly don't know how to offer you that help. They often say things like, "Let me know if there is anything I can do to help." During the holidays or special occasions they may even ask you for gift ideas for you or your loved ones. These are wonderful opportunities to work yourself up to the point of being able to ask for help. Here are some examples of what you can say the next time someone offers help or gifts.

- *"I've always loved your cooking. If you ever want to make us a meal, we'd love to have your delicious food. It would save me from making dinner that night."*
- *"I could really use some help with mowing the yard from time to time."*
- *"I'd love it if you were able to sit with Joe for a few hours some time while I ran some errands."*

The key here is to think ahead of time of what you could ask for when the opportunity presents itself. Notice how you don't even need to ask for help with the direct, hands on care. Simply think of something you'd like some help with and be prepared to say that the next time someone offers help.

When it comes to gifts during holidays and special occasions, think of things that can make your life easier such as easy to pull on/off clothing for your loved one, store gift cards, restaurant gift cards so you can get takeout, etc.

ASKING FOR HELP

Asking for help can be one of the hardest things for a caregiver to do. This is especially true if you have any feelings of shame or embarrassment about your loved one's diagnosis. If you feel this way, I encourage you to think about how you would respond to learning that someone you know has a loved one with dementia. Do you think they should feel embarrassment or shame about their loved one having a medical condition? Usually, we have negative thoughts about ourselves and our situations but don't have those same reactions to other people in similar situations. It's possible to ask for help while still honoring and maintaining your loved one's privacy. You are always in charge of what you want to share and how you want to share that information. Other people are not entitled to know everything about your condition. You may want to take some time and think ahead of time of how you want to respond to questions you receive about your loved one.

I'm going to give you some example sentences you can try. You can change them up to match your situation. Remember, everything feels uncomfortable the first time you try it. The worst thing that can happen is they say no. Then you are in the same exact situation you are in right now.

- *"I'd like to run some errands next week. Do you happen to have any time to come sit with Phil for a few hours while I'm gone?"*

- *"I could really use some help mowing the yard. Do you happen to know of someone who is looking for some volunteer or community service work?"*

- **What are your current thoughts about asking for help or receiving help with caregiving?**
- **What would you think about a good friend in a similar situation who asked for help or received help with caregiving?**
- **Are there any differences in the answer you gave about yourself and the answer you gave about your good friend? If so, what do you make of that difference?**
- **What is one thing you can do (or stop doing) now to “help yourself?”**
- **What is something you can say to someone who offers to help?**

TIP #4: WELCOME JOY

WITHHOLDING SOURCES OF JOY FROM YOURSELF DOESN'T HELP YOU OR YOUR LOVED ONE.

Many caregivers feel guilty when they have the opportunity to do something nice for themselves. They may have an opportunity to have lunch with a friend, go for a drive, or take a short trip. Since their loved one may not be able to do the same things, they feel guilty. In some cases, they may even turn down or avoid certain activities that they would enjoy because their loved one isn't able to participate. I don't want you to do that. Your own wellbeing and happiness is just as important as your loved one's and it's easy to lose sight of yourself when caregiving demands increase.

What are some ways you've been withholding joy from yourself because your loved one has dementia? How does that help and/or hurt your caregiving experience?

DEMENTIA AND MENTAL HEALTH

Many Veterans have mental health conditions that exist in addition to the dementia. In these situations, it can be difficult to know if your loved one is struggling with a symptom of their mental illness or a symptom of their dementia. Many times, it's both.

There are many similarities between mental health conditions and dementia. For example, someone with depression may not care much about how they look. They may not want to change their clothes every day. They may need some encouragement to shower. They may not spend much time on combing their hair or shaving their face.

The same symptoms can exist with dementia. The person with dementia may not shower. The person may not change clothes. The person may not comb their hair. The person may no longer know how to go through all the steps. They may have a hard time starting the tasks. They may not even have the awareness or understanding that personal hygiene is something they should focus on.

Don't assume that all behaviors the person had before the diagnosis are a result of the mental health condition. It's easy to think, "She's always been that way", or, "He's just being lazy, he does this all the time."

It's important to understand that even though the behavior may look the same, it may now actually be a result of the dementia.

Not all behavior struggles are a result of a mental health condition (like depression or post-traumatic stress disorder). Likewise, not all of their behavior struggles will be a result of their dementia diagnosis. This is why it's important to keep a behavior journal, notice the patterns/triggers and follow up with healthcare providers to figure out what is causing the behavior and what the the best approach is for responding to the behavior.

I would like to go a bit deeper on dementia and PTSD. There are many symptoms of PTSD that can worsen when someone develops dementia. As dementia progresses, many times more recent memories (like what they did yesterday) start to fade away and memories from long ago (like memories of their trauma) are still clear as day. This means that some of the traumatic experiences that led to their PTSD are more clear than things that happened today or yesterday.

Also, someone with PTSD who is usually on high alert and suspicious, can become even more suspicious as their brain has difficulty putting together all the pieces of the environment. This can be seen when someone with PTSD starts losing their memory and becomes suspicious or paranoid about family members they no longer recognize. Anxiety and fear can also increase as the person's hearing, vision, and physical abilities start to decline. Because dementia and PTSD often increase fear and anxiety, I want to take a moment to talk about gun safety.

When someone has dementia, their brain will eventually decline to the point where they are no longer safe to operate heavy machinery or certain equipment. This is true with power tools, vehicles, guns, and with riding lawnmowers,.

In military culture, many people are familiar with guns and have them in their homes. It's important to know that at some point they won't be able to operate the gun safely. They may forget how to use it. They may forget who a certain family member is and think they are a stranger breaking into the house. They may think someone is trying to hurt them. The combination of PTSD and dementia makes this a real possibility. I bring this up here so that you can monitor and decide when the time has come that your loved one is no longer safe to have access to firearms or other weapons. Some signs that suggest you should start considering firearm safety include:

- **Your loved one is suspicious or paranoid about people.**
- **Your loved one doesn't recognize certain family members who are around.**

- **Your loved one is often angry and upset.**
- **Your loved one talks about hurting themselves or someone else.**
- **Your loved one has a hard time working other equipment such as cars, remotes, toasters, microwaves, etc.**

If you decide that your loved one is no longer safe to have access to weapons, there are many ways to handle the situation to maintain your loved one's dignity and minimize the chances of your loved one becoming upset. Do you remember Tip #1 in Chapter 3? In that chapter, we talked about choosing kindness over the truth. There may be situations where not revealing the entire truth can help in minimizing stress for your loved one. If you suspect your loved one will be resistant to the idea of getting rid of their weapons or disagree with you that they are no longer safe to have access to them, consider the following ideas:

- **Have a relative/friend “borrow” them for a hunting or shooting trip.**
- **Have the weapons “cleaned” by a friend, family member, or business.**
- **Remove them from the house and not saying anything (this is a good option if they don't ask about the weapons or look for them).**
- **Put gun locks on all firearms in the home (you don't have to let them know you are doing this). Talk to your VA provider about how you can get gun locks.**
- **Store guns and ammunition in separate locked locations.**

UNDERSTAND YOUR MIND

Sometimes it can feel like your loved one is purposefully trying to drive you crazy. We've already learned that many of your loved one's behaviors are a result of the dementia, and that anosognosia (i.e. lack of awareness), is one of the biggest reasons why your loved one might be resistant toward your attempts to help.

Even though you may know this, there will still be times when you are frustrated and feel convinced that your loved one knows what they are doing. Usually this is because your loved one may have had some similar behaviors before their dementia diagnosis.

Regardless of the reason for your loved one's difficult behaviors, thinking your loved one is purposefully trying to give you a hard time will ruin your ability to provide good care and will increase the chances that your loved one will continue to have difficult behaviors. Your loved one will pick up on your frustration, irritability, and overall negative attitude.

Let me tell you about a proven principle that psychologists world-wide use to help people improve their mood and ultimately improve their lives.

Our thoughts create our feelings, and we act and respond based on how we feel.

Most people think that situations create our feelings, but that is not true. This is why people in the same situation feel and act different ways. The thing that makes the difference is the thoughts that we think.

You may be asking, *"How on earth could changing my thoughts actually lead to any change with my loved one? I just need my loved one to change. My thoughts have nothing to do with changing them."* Let me explain with a simple example.

Below is an example of how a thought can negatively impact behavior in someone with dementia.

SITUATION: Your husband lost his wallet again and is yelling that you stole his wallet.

THOUGHT: *“He’s such a liar! I can’t believe he has the nerve to accuse me of stealing his wallet after everything I do for him!”*

FEELING: Anger.

BEHAVIOR: You snap back at your husband. The rest of the day is tense with little communication. Your husband chooses not to eat dinner that night and tries to block you from his accounts.

Let’s try this again with a new thought and see how it can improve the behavior.

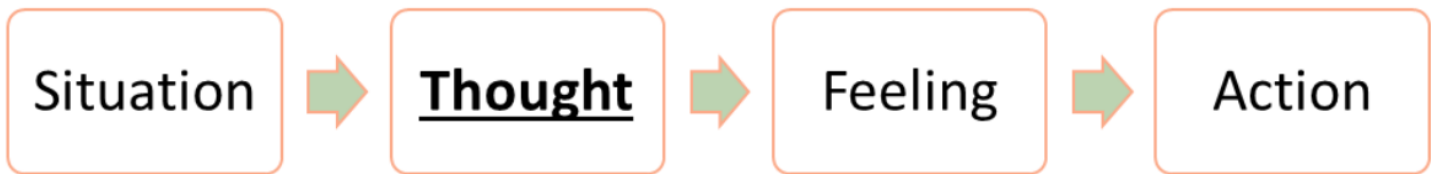
SITUATION: Your husband lost his wallet again and is yelling that you stole his wallet.

THOUGHT: *“His mind is trying to understand how his wallet is missing again. What an awful disease.”*

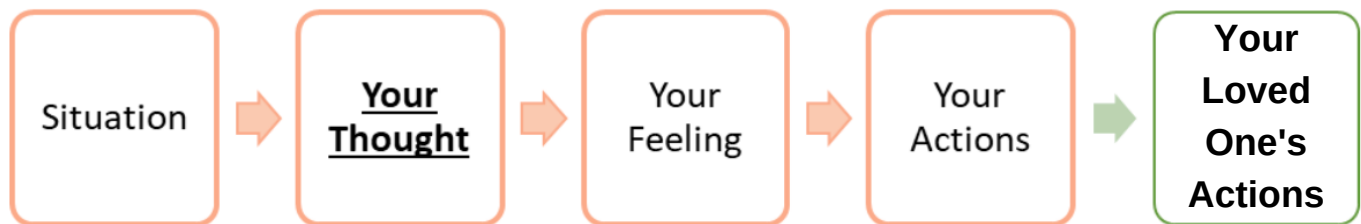
FEELING: Compassion and understanding.

BEHAVIOR: You tell your husband you that you love him, will help him find his wallet and then you two engage in a pleasant activity together.

Do you see how the situation was the same (your husband accused you of stealing his wallet), but your feeling and actions afterwards were different based on what you thought about the situation? This is a really quick example to show how our thoughts are important and to hopefully encourage you to be mindful of your thoughts.



For dementia caregiving, we can take this diagram a step further. Because people with dementia pick up on your emotions and facial expressions more than they do your words, your actions (which are influenced by your thoughts) will start to change your loved one...either for the better or for worse.



Our thoughts become our reality so if you think to yourself, *“My dad is always doing things to drive me crazy!”* Guess what? Your dad will probably always seem to be doing things to drive you crazy because your feelings, facial expressions, and actions will trigger your dad to act in those ways.

Instead, if you think *“This disease is really hard on my dad and I know it’s not his fault. I’m frustrated but I understand.”* Guess what? You will be more calm and understanding of your dad’s difficult behaviors. As a result, your dad’s behaviors will reduce because your feelings, facial expressions, and actions will help your dad feel more comfortable.

I hope that now you understand your thoughts can impact your mood and behavior AS WELL AS your loved one’s actions. Just because you understand the relationship between thoughts and feelings, it doesn’t mean that you aren’t going to find yourself feeling completely frustrated and thinking “negative” thoughts. We are all human and those moments are completely natural.

However, it is not healthy to let those "negative" thoughts hang out in your mind and simmer. When you notice that you are having a "negative" thought toward your loved one, you want to be able to replace those thoughts with something that will be more helpful- for you AND your loved one.

You know hard moments are coming, that is a reality. It's important to know how to get through those tough moments. Knowing the power of your thoughts is actually an amazing thing. It helps you realize that you have much more power and control over your feelings (and potentially your loved one's behavior) than you ever knew possible. This isn't a tool to beat yourself up or criticize yourself on how you've handled things in the past. This is a tool to help you learn and make changes when you decide you'd like to feel better.

On the next page, I've included some examples of coping statements to give you an idea of things you can say to yourself when you feel like you are about to lose all control. These simple statements take no time, and hardly any effort to do when you are feeling at your wits end. Don't mistake simple for not worthwhile. These statements can truly make a difference, but they only work if you use them.

As a caregiver, you need to be aware that your thoughts can actually influence your loved one's behavior – for better or for worse.

.....

**YOUR LOVED ONE ISN'T TRYING TO GIVE YOU A
HARD TIME.**

THEY ARE HAVING A HARD TIME.

.....

SAMPLE COPING STATEMENTS

Take a look below and see what statement matches your style of thinking. Then, try to create your own coping statement.

THINK MATTER OF FACT:

“Yup, here it is. I knew it was coming and I know that it is a part of the disease.”

THINK FUNNY:

“Well, it’s good to know mom’s mouth still works, even if her brain doesn’t.”

THINK CALMLY:

“Just breathe. Nice and easy breaths, I know that I will get through this moment.”

THINK FUTURE:

“I really don’t like this, but I know one day he won’t be around to say anything at all.”

THINK HONESTLY:

*“I am so sick of this sh*t, but I will get through it no matter how hard the days!”*

THINK LIKE YOU:

What can you picture yourself saying in your mind that would be helpful in getting you through the difficult moments? Use words that you can hear yourself saying. Remember, this is just in your mind so you can be as true to yourself as you want without fear of anyone else knowing. Write your statement below.

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

SELF-CARE EXCUSES

Let's take a moment to talk about the many reasons that make it difficult to take time to care for yourself.

I'M TOO BUSY

It's true. You probably are too busy. Loving someone with dementia takes up a lot of time and many of you are also trying to juggle caring for your loved one with dementia AND your own children, job, spouse, parent, pets, etc. **IT IS A LOT.** But taking care of yourself doesn't have to take up all your time. In fact, you can still do everything you are currently doing **AND** find little, simple ways to be kind to yourself during the day. Examples include:

- Take some deep breaths
- Enjoy a moment of peace in the shower and use a new body wash
- Pick up the phone and talk to a supportive friend while you wash the dishes or fold laundry (hands free device of course)
- Move your body. Go for a walk, stretch, dance, etc.
- Give yourself a manicure/pedicure
- Visualize a happy or calming scene
- Watch a funny TV show or movie
- Listen to some of your favorite music when you get ready for the day
- Take time to eat healthy food that will give you energy and make you feel good
- Journal and/or meditate

You do not need a big chunk of time for self-care. You can take advantage of brief moments throughout the day and enjoy the mini-breaks.

Notice how many of these activities could be done while you are physically with your loved one (watching TV, taking deep breaths, going for a walk). Also, notice any activities you are already doing and get creative in finding new, fun, or exciting ways to continue those activities (listening to music when you get ready, using a new body wash in shower, etc.). None of these things take up any more of your time. It's about using the time you already have in a way that supports you. If possible, look into options for having people come to your house and give you a break so you can do even more for self-care.

I FEEL GUILTY

Many dementia caregivers struggle with taking time out for themselves. In their mind they think that taking time for themselves is selfish and makes them a bad caregiver. The complete opposite of that is true. Taking time for yourself is actually one of the best things you can do for your loved one with dementia!

Be honest. Right now, stop and ask yourself what would happen to you if you were all of a sudden too sick to care for your loved one? What would happen to your loved one? If 3 years went by and you hadn't prioritized self care, what would your life look like? Would you somehow be in a better position, the same position, or would you be worse? Sometimes, it takes getting really honest with yourself to realize that not giving yourself the care you deserve will lead to a scary future for you...and your loved one.

Self-care isn't selfish!

WHAT WILL OTHERS THINK OF ME?

When it comes to the stress of loving someone with dementia, it is important to surround yourself with people who support you and want to see you take care of yourself. Loving someone with dementia is hard enough without people around you bringing you down. People who pass judgement on you for taking care of yourself are 1) not the supportive people you need in your life and 2) probably have no idea what it is like to love someone with dementia. If someone continues to pass judgement about your caregiving skills, offer to let them take care of your loved one for a while.

The next page has some questions to help you develop your own self-care plan.

MY SELF CARE PLAN

WHAT ARE SOME SIMPLE THINGS I CAN START DOING TO IMPROVE SELF-CARE?

WHAT WILL I TELL MYSELF WHEN I FEEL GUILTY FOR TAKING TIME FOR SELF CARE?

WHO CAN I ASK FOR HELP IF I WANT A BREAK (FRIENDS, CHURCH, ETC.)?

HOW AND WHEN CAN I ASK FOR THAT HELP?

HOW WILL I RESPOND IF SOMEONE ASKS ME WHAT THEY CAN DO TO HELP?

HOW CAN I ASK MY HEALTHCARE TEAM FOR SUPPORT?

WHAT SUPPORTS CAN THE VETERAN'S HEALTHCARE TEAM OFFER?(ASK ABOUT RESPITE, HOME HEALTH SERVICES, EQUIPMENT, ADULT DAY HEALTH CARE, CAREGIVER SUPPORT, ETC.)

GROWING THROUGH GRIEF

Caring for a loved one with dementia often comes with some emotional pain. It can be hard to watch your loved one lose basic abilities, especially if they've always been someone who has prided themselves on being independent and strong.

Not only is it difficult watching your loved one change, but also, it can be difficult to watch your life change in ways you never imagined. Perhaps your dreams of traveling during retirement are no longer possible. Perhaps you've had to slow down your career path to take time and care for your parent. The way you spend your time, the relationships you have, and the activities/hobbies you have can all change drastically when you take over the care of someone who has dementia.

You might even be feeling some anger or resentment for feeling like you have to put your entire life on hold to care for your loved one. This is ESPECIALLY true if you and your loved one have had some relationship challenges in the past (most people have).

Unlike other illnesses where there is a clear diagnosis and a clear ending within a relatively short time span, dementia can last decades. Throughout that time, there are many losses and changes that can bring ongoing feelings of grief. It's totally normal. There is not one correct way to go through the process.

It's totally normal to have a wide variety of emotions when it comes to caregiving. You may feel compassionate, loving, sad, angry, or resentful. Most likely, you'll feel some combination of all those emotions from time to time.

You are a human being, and because of that, you will feel a variety of emotions. The goal isn't to get rid of any "negative" emotion. It's not possible for anyone to get rid of all "negative" emotions. BUT, I do think it's important to not beat to yourself up for having those emotions.

Many times caregivers struggle because of the mental battles going on in their mind. Those mental battles often make things much worse.

For example, let's say your father asks you the same question for the 100th time in the span of an hour. You handled the situation well for the first 99 questions, but on the 100th time, you snap and yell,

“Dad, how many times are you going to ask me that question? The answer hasn't changed!”

Immediately, you feel guilt for how you responded. It's okay and you can work through the guilt. **HOWEVER**, the trap here is that some caregivers will go on and use this example as a way to beat themselves up even further. They'll say things like, *“I'm an awful daughter.” “I'm doing this caregiving thing all wrong.” “I should've never done that.”* And so on. It's easy to get on the merry-go-round of listing all the things you've done wrong and start beating yourself up.

The only thing that makes those “negative” emotions worse is being upset for having that reaction in the first place and criticizing yourself for not responding differently.

Criticizing yourself is not helpful. It just makes you feel bad. Instead show yourself some compassion. Being frustrated with yourself for getting frustrated causes so much extra pain.

If there is anything you take away from this chapter, it is to show yourself some grace and compassion. Give yourself the same grace and compassion you would give any other person you cared about in a similar situation. There is no human being on this planet that can go through an entire caregiving journey without saying things or doing things they wish they didn't say or do. **IT'S OKAY.** You are human.

So right now, in this moment I want you to promise yourself that you will stop beating yourself up. You may not be able to stop the initial feeling and reaction of guilt, but you absolutely can stop the onslaught of putting yourself down for the simple act of being human. Honestly, if you've gotten this far in reading this survival guide then I can tell you you are doing AMAZING! You are showing that you care and are invested in caring for your loved one. It's okay if you lose your patience every now and then.

If you are struggling with guilt or any other emotion that is bringing you down, ask yourself: "what would I tell a really good friend in this situation?"

Take a moment to think about that. If you were talking to a good friend and they shared that they felt so guilty for snapping at their father and they just can't stop putting themselves down, what would you say to that person? Would you tell your friend that they should feel guilty? Would you tell them that they are doing a horrible job? Would you let your mouth hang open in shock and express your disbelief that they would ever act in such a way?

I'm guessing your answer is **no**.

What would you say instead? I'm guessing you'd say something like "It's okay." "We are all human." "This caregiving stuff is hard." "You're doing the best you can." You would find some compassionate words for your friend.

For some reason it's so much harder to find those compassionate words for ourselves. If you catch yourself beating yourself up for how you handled a situation, I want you to stop and ask how you'd respond to a good friend. Now respond that same way to yourself.

I wish I could tell you that this caregiving journey will be easy, that things will get better, and that brighter days are ahead. The truth is I have no idea what the future has in store for any of us. But I do have 100% faith that you will be able to GROW through whatever it is that comes your way.

There is no “right” way to go through the dementia caregiving journey.

Everyone grieves a bit differently. Showing yourself some compassion and giving yourself permission to allow for whatever comes up along the way can help make the grieving process less of a struggle. Many times, when people think about grief, they tend to think only about death. I want to encourage you to consider all the different changes that you've experienced since becoming a caregiver as you go through the questions below.

HERE ARE SOME QUESTIONS TO HELP YOU PROCESS CHANGES IN YOUR CAREGIVING JOURNEY.

- How has my life changed since becoming a caregiver?

- What are my thoughts and feelings about those changes?

- What am I most worried about?

- How can I show myself some compassion for this chapter of my life?
(If you are struggling, ask yourself what you would tell a friend in this situation.)

- What are some coping statements I can tell myself?

YOU DID IT!

CONGRATULATIONS, caregiver! You are doing an amazing job at supporting your loved one with dementia, even though many times it may not feel that way. I hope you'll review the information in this survival guide as often as you need.

Please be sure to stay in touch with your loved one's VA healthcare team and keep them up to date on how you and your loved one are doing. There are many programs and support services that the VA offers. Often times it's hard to know what to ask for if you don't know all of the different services that are available to you. Below are some questions for you to ask your loved one's healthcare team (VA social workers are a great resource for these types of questions!).

- **What programs does the VA or my community have that can help me care for my loved one? If healthcare agencies can't make it out to your rural area, ask about programs in your community and/or connect with your local area agency on aging to learn about available resources.**
- **What equipment or supplies can the VA issue to my loved one to make life a bit easier or safer?**
- **My loved one is having difficulty with _____. What does the VA have that might be able to help? (fill in the blank with the challenge you are observing, such as: walking, holding onto to utensils, keeping track of his medications, being steady when showering, putting on socks, etc.)**
- **I'd like some more time to myself, are there any programs that can give me a break from caregiving from time to time?**
- **I'm having a hard time keeping up with the household tasks while also caring for my loved one. What programs might be able to help?**

You may not know specifically what kinds of equipment and programs exist or are available in your area, but by asking some of the questions above, your healthcare team can provide you with resources and information to help. This is especially true if you live in a rural area with limited resources.

- APPENDIX -

DETECTIVE WORKSHEET

(See page 23 of the Difficult Behavior chapter for an example.)

As you answer the questions below, be as factual as possible. Remember, you are being a detective so try to leave the emotion out of your answers. Write down as much detail as possible. I'm going to go through the questions using an example and then you can try it on your own.

Let's start with one behavior. In the space below, write down the one behavior you are going to focus on.

The behavior I am focusing on is:



Now, fill in your responses to the questions below. This is the **OBSERVATION** stage. Be sure to be as detailed as possible. Something that doesn't seem important to you can actually be a big piece in changing the behavior.

A

Antecedent: This is what happened just before the difficult behavior.

Write down anything you can remember. **What was your loved one doing/saying? What were you doing/saying just before the behavior? Who was around? What was happening right before the behavior began?** Write down everything you can remember.



B **Behavior:** This is where you write down exactly what happened. Leave out any of your judgements or interpretations and try to stick to the facts only.

What exactly did your loved one say?



What exactly did your loved one do?



Who was around when this behavior happened?



Where exactly did it happen? Be specific about location. Instead of writing at home, for example, write in the bedroom while he was sitting up on his bed).



When exactly did it happen? Again, be specific down to the time of day.



What else stands out to you about the specific behavior and environment?



C **Consequence:** This is what happened just after the difficult behavior. Write down exactly how you responded.

What exactly did you say and/or do after the behavior?



What exactly did your loved one say and/or do after the behavior?



How was your response to the behavior?



Use these questions and write down your answers after each time the behavior occurs. You may already have some ideas about what caused the behavior just from filling this out. If not, that's okay. It's important not to skip over this step. The more detailed you take this, the more success you are likely to have when you start to change the behavior.

**It's time to take all the information you gathered
in the observation phase and put it into action.**

Remember, to work with one behavior at a time. The behavior you have been gathering information on and the behavior you are focusing on is:



Now, fill in your responses to the questions below. Be sure to be as detailed as possible. Something that doesn't seem important to you can actually be a big piece in solving for the behavior. Remember, it doesn't have to make sense to you, and many times, it won't make sense to you. We are looking at things through your loved one's eyes.

BRAINSTORM

Write down all the possible reasons your loved one did what they did. Write anything that comes to your mind. Don't censor yourself or hold back on ideas. Challenge yourself to come up with at least 15 different reasons your loved one did what they did. **There is no such thing as silly or too strange here. Let your brain run wild.**



-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-
-

EXPLORE

Choose **one** of the reasons you wrote down in the brainstorming session to try out first. **The reason for the behavior that I am going to focus on first:**



Based on that one reason above: How will you change your approach?



How will you change your environment?



PREPARE

What will you do if the behavior doesn't stop after you've made the changes in step 2? What will you tell yourself? This is important because it helps mentally prepare you to keep going even if your first guess doesn't work. Much like a detective, the first hunch may not be correct. It's okay. What do you need to tell yourself to keep going in that situation?

(Example: *"I'm committed to figuring this out"* or *"This is taking some time and that's okay."*)



RESET - REVISE - REPEAT

If your initial attempts did not work, you go back to step 1 and choose a new reason for the behavior from your brainstorming session. From there, you go through the rest of the steps.

Repeat this as often as necessary until you discover the underlying cause of the behavior.

If you find yourself getting frustrated that you aren't finding the cause as quickly as you like, it's better to take a break from this detective work than to continue trying new approaches. Trying new approaches from a place of frustration will likely make the behavior worse. It's okay to take a break and come back to your notes whenever you feel ready to do so again. This information never goes to waste. You can start again at any time.

Refer back to the example starting on page 20 if you get stuck or need help filling out this worksheet.

SPACE FOR NOTES: