

CHAPTER TWO

Lou crawled out of bed and headed for the bathroom to shower, shave, and complete his routine as he'd done for the past fifty odd years. Rose was awake, and he kissed her before starting the day. Just like he had for as long as they'd been married.

When he came out of the bathroom, she finished pulling up the bedspread on the bed. He frowned. She wore a simple white shirt and blue pants. The outfit looked nice on her, but it was the same one she'd worn yesterday. And the day before that. He knew she hadn't showered, and he noticed there was a stain on the hem beneath her left arm.

Rose had always been particular about her appearance and he debated about saying anything. Maybe she forgot she'd worn it yesterday. He decided she hadn't noticed the stain and would appreciate his help.

"Rose, why don't you wear something else today?" He tried to soften his criticism with a smile.

She stopped in mid-fluff of the pillow and stared at him. "Why?"

"You've worn that outfit three days now. It needs to be washed and you need to take a shower." There he'd said it. He felt the blush rise in his neck, and reached up to pull at his shirt collar.

"I have not."

"Yes, you have."

"No, I haven't. I'd remember something simple like that." He saw the fear in her eyes that she might have forgotten.

"Not necessarily." He carefully took two steps toward her. "Remember the visit with the doctor? We talked about your memory problems." He didn't use the "A" word, Alzheimer's, on purpose. Not only could he not seem to say it, but the thought of it made his throat close up. He knew how much it scared her. It sounded so . . . so . . . awful. In fact, it scared him, too.

Instead, he reached into the closet and pulled out another pair of pants and a blouse. "Here, I like these."

"No," she growled and wrapped her arms around herself as if afraid he'd take the clothes off of her.

"Rose, stop it," he commanded in a voice he hadn't used since the kids had lived at home.

"I hate that outfit." She glared at him. "I hate you."

"No, you don't." Despite his belief that she didn't really hate him, it hurt when

she said it. “Come on.” He stepped closer, extending the new outfit. “You’ll look pretty in this.”

Suddenly, she pulled her arm back, and surprised him when she hit him.

It didn’t hurt—much. He was more startled than injured. He dropped the clothes as she quickly scurried away. He heard the bathroom door slam shut and the lock click. The sounds of loud, gut-wrenching sobs echoed off the still-damp tile.

Lou stood there, not sure what to do, or say, or think. In all the years of their marriage, she had never hit him. He’d never hit her. They’d respected each other.

Had he said something wrong? Said it the wrong way? He hadn’t meant to insult her. He knew how she liked to look nice.

Throughout the day at work, Lou’s guilt grew. He’d hurt her feelings when he insulted her clothing choice, telling her she didn’t look good. Slamming his lunchbox onto the table in the breakroom, he let out a heavy sigh. It felt like when they were first married and were still trying to feel their way around in the relationship. Only this time, he wasn’t sure he’d ever figure it out—or if he did, that it would work the next day.

He pulled out his cell phone. He wasn’t supposed to carry it—company rules—but he’d explained the situation to his supervisor. As long as he kept it in his pocket on vibrate, it was okay.

He dialed the house and sweat broke out on his forehead when Rose didn’t answer until the fourth ring. He knew he worried too much, but he felt a bit—no, a lot—off-kilter these days.

“Hello?” Rose sounded in a good mood.

“Hey, hon. How are you doing?”

She was silent a long minute. “Fine. What’s the matter?” Fear tinged her voice.

“Nothing. I’m at lunch and thought I’d call you.”

“Oh.”

Should he ask her about her clothes? Should he apologize? How much did she remember of this morning? Probably enough that if he mentioned anything, she’d get angry again. But what if she was wearing the same clothes, and what if she wore them again tomorrow? He suddenly felt trapped and wished he hadn’t called her. He chose an easy tack. “What are you doing today?”

“Cleaning house. Nothing any more exciting than any other day.”

“Yeah, sounds like work.”

She laughed. “Guess we’re stuck in a rut.”

“That’s an understatement,” he whispered.

“What?”

“Oh, nothing. I need to get back to work. Just wanted to see how you’re doing.”

“I’m fine, dear. See you tonight. ’Bye.”

“Bye.” Lou disconnected the signal and stared at the phone. He felt like crap. He’d wanted to apologize for hurting her feelings, but didn’t she owe him an apology for hitting him? He slipped the phone back into his pocket and flipped open his lunch box. Nothing looked appetizing. He wasn’t hungry.

Maybe he’d go outside and get some fresh air instead.

CATASTROPHIC REACTIONS AND THE MYTH OF VIOLENCE

You don't need to be afraid of the people in your care. Being afraid of them takes away your control of the situation.

There are techniques and skills which can, and should be learned by all caregivers to maintain that control. In this chapter, we'll address those specific to the time of the catastrophic reaction and to identify the triggers which spark them. In subsequent chapters, you'll find tips specific to each identified behavior which in turn will help you avoid a Catastrophic Reaction.

Today, Lou experienced the first of probably many catastrophic reactions. It was, in comparison, a relatively mild one. But one that left him and Rose further apart, and him with a weight of emotions he could not quite decipher.

In many books on Alzheimer's disease and dementia, Catastrophic Reactions are glossed over, forgotten, or disguised with the terms "aggressive" or "problem" behaviors. In reality, they are the result of caregivers, the public, family, and friends not knowing how to handle the behaviors inherent in dementia, and the confused person's inability to do otherwise.

A Catastrophic Reaction is defined as an intense response to what *seems* to be a trivial event. The dementia patient has a sudden mood change, cries, becomes verbally abusive, or even physically violent. The important piece to notice in that definition is that it's what *seems to us* to be trivial. To them, it isn't trivial at all.

Catastrophic Reactions happen when a person becomes so angry, so frustrated, or so hurt that they can only explode to relieve the overwhelming emotions. It is not a time of rational, normal behavior. And too often, these outbursts result in unnecessary institutionalization, increased home health care, hospitalizations, elder abuse, and mortality.

One of the most enduring myths of Alzheimer's and dementia is that violence is a part of its progression. It's not unusual for family members to say, "We haven't gotten to the violent stage yet." The operative word being *yet*. It's as if they assume their loved one will turn into a violent person at some point in time. This myth is perpetuated by the fact that specialized care units often have locked doors.

Anger, aggression, and frustration are all a part of each one of us. Children throw temper tantrums. Young men get into fist fights over girls. Wives nag and harp at children and husbands who don't complete their chores. We read about road rage in the papers on a daily basis. The list is endless.

All these things have one thing in common. They have a trigger event. We are reacting to something specific that happened. A child is told he can't have a certain toy. A girl flirts with another boy knowing her boyfriend won't like it. We cut each other off in traffic on a regular basis—sometimes purposefully, sometimes not.

Looking back, we can identify the exact thing that set us off, or to use an old cliché—the straw that broke the camel's back. We can identify it in ourselves and even in others we know well.

These are triggers or trigger events.

The frustrating thing about dementia patients is that their ability to analyze and rationalize what's happening to them is impaired. They cannot identify their own triggers and put them into perspective. They cannot tell us what upset them—and may not even

remember getting angry.

To complicate things, we have to realize triggers are both internal and external. The driver who cut us off in traffic, the pain in our thumb when we missed the nail, the long stressful day where nothing went right—those are all external triggers.

Internal triggers are less obvious and not as easy to identify. Old memories buried in our minds are internal. There are television commercials that have managed to find a universal trigger in all of us with the sentimental commercials about home that spark tears in our eyes. We are not crying because the actors are far from an imaginary home, we are crying because a part of us misses our home and family. We identify from our own experiences.

We have all experienced past pain that may or may not come to mind when we hear or see something, but we will probably feel the emotions. These memories can be good or bad. Old anger may be stirred when someone who reminds us of a former, unfair boss walks into the room. We may not like that person because of it, and may not even realize why.

We may not ever know our own, much less each others' internal triggers. Some issues can take years of therapy to identify. The problem with internal triggers is not only in trying to identify what they are, but in controlling the external outbursts that result from them. We need to understand that triggers exist and what they are. That's the first step. The second step is to use that knowledge to try to avoid a similar catastrophic event from happening again.

While we can't always identify triggers, we can diminish their strength. If we don't, the escalation of the anger which is identified with them and their accompanying violence can increase. In a dementia patient, this result is a Catastrophic Reaction.

This doesn't have to happen. Catastrophic Reactions don't *have* to occur. They can be avoided.

When a person is angry—be they cognizant or demented—it's not a wise practice to continue pushing or arguing. We all have buttons, and react when they are pushed. That doesn't go away with the onset of dementia.

A demented person can't be reasoned with, yet people try to do it all the time.

Ask yourself if you really have to win this argument. Why? If you can't answer those questions, it's a clue to back off. If you can—ask yourself again. There is really *nothing* important enough to fight over—and that will be the result if you persist.

All beings, human and animal, have a common basic reaction to being caught in an uncomfortable or perceived dangerous situation—fight or flight.

Alzheimer's and dementia patients are no different from the rest of us. In one sense, their instincts are stronger than their minds' ability to reason the reaction away. They also have a right to the same emotions we have, yet we don't let them have that basic freedom many times.

Too often, they are pushed to the point of anger—and must decide to fight or run. They hit someone and then are called “aggressive.” They run and are labeled as “exit seeking” or “wandering.”

Let's explore how these catastrophic events happen.

The most useful technique during these times is the simple act of backing off. Easier said than done? Sometimes, especially when the other person is determined to get an answer or result. They may not understand why you are backing down. The

element of surprise can work in your favor.

Understanding a Catastrophic Reaction is crucial to understanding all the behavior problems you'll run across in dealing with Alzheimer's and dementia patients. Any behavior, if handled inappropriately, can result in a Catastrophic Reaction. Caregivers who understand they can stay in control of a situation and deal with all behaviors are safer and better off.

Sometimes we're too close to a situation to identify it accurately, or we are too involved to objectively assess a situation. That's why tools like the *Hierarchy of Needs* from Abraham Maslow can be useful.

Maslow listed human needs in a pyramid as shown in Figure 3-1. He proposed that if the basic needs aren't met, then a person cannot progress to a higher function. If our basic needs like food, water, and physical comfort (like using the bathroom) are lacking, we focus on getting them met.

Does the dementia person need to go to the bathroom? Are they unable to find it? Are they hungry? Are they cold? Hot?

Self-Actualization

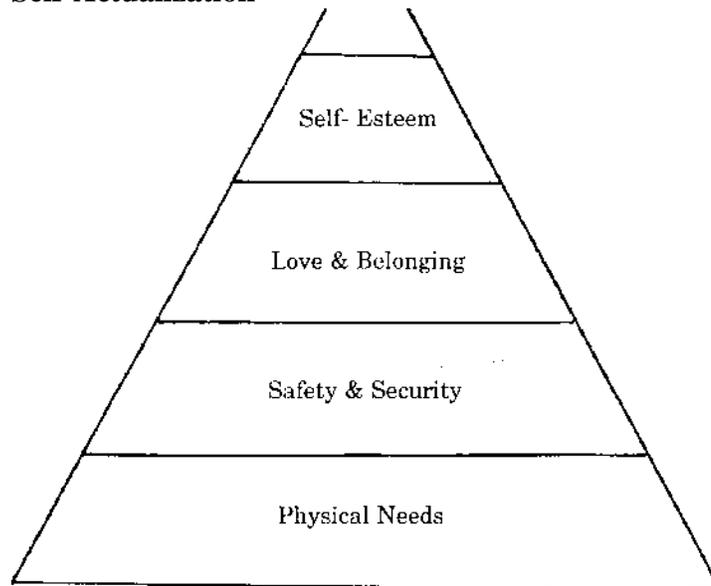


FIGURE 3.1 MASLOW'S HIERARCHY OF NEEDS

Look at all the basic needs. Are they met? If so, then look at the next level. Does the person feel safe?

External triggers are easiest to identify and remedy. There are also good triggers. Track those as well. They are useful in defusing a situation later.

Look around at the environment. It can be one of the most obvious and yet easily missed triggers. Have you ever sat in bumper-to-bumper traffic on a hot summer day, the car next to you blasting its radio, the air conditioner on the fritz, and your kids or the cell phone demanding your attention? It's enough to drive you over the edge.

A dementia patient has less capacity to cope. There's a reason many special care units are simple environments—some too extreme—but they've eliminated or muted a great deal of stimulation, of the possible environmental overstimulation and triggers. You

can do the same by keeping televisions and radios off, or at least only have one on at a time.

You know the person you are taking care of, their likes and dislikes. None of those will change, but what will change will be their ability to voice them. For example, I detest onions. Always have, always will. My husband knows that, and often goes out of his way to inform wait staff to *not* bring me food with them in it. He's being kind to me, yes, but he's also aware he doesn't want to hear me complain, go through the whole issue of sending food back and eating a delayed meal.

If I have a caregiver someday, I hope he or she will be able to inform people of that dislike. Just because a person develops dementia doesn't mean they won't recognize an onion if they eat it.

That's the value of a history. Knowing it and sharing it with caregivers.

This brings up a controversial question. Does a demented person need to know everything about their situation? The answer is, not the overall picture about their illness, especially in the early stages, but definitely the moment-to-moment situation. Do they have to know the specific details? That, of course, will be different every time, so it's another dilemma for caregivers.

There is such a thing as Therapeutic Fibbing. People who are caregivers feel they must be one hundred percent honest with a dementia patient, something they may not have been previously. Are we all totally honest with everyone we know? Probably not. Yet why do we feel the compunction to be so with a person who has a diminished capacity, expecting them to process additional information?

If the information is something we know will upset them, or that they won't be able to do anything about anyway, then there's no reason to tell them or give specific details. This situation comes up most often when important issues arise, such as needing to tell someone about the death or illness of a loved one. But it also arises on a day-to-day basis. For instance, a favorite shirt or blouse has holes yet still, the dementia patient puts it on each morning. What spouse hasn't tossed out holey underwear or worn gardening cloths without asking? Too often, caregivers believe they need to tell the person when they are throwing out that favorite piece of clothing so they won't go looking for it.

There's nothing wrong with getting rid of the clothing, then, if asked about it, saying, "It's in the laundry. I'll wash it tomorrow." Most likely they'll forget the clothing tomorrow. If they do remember, they won't remember your answer.

IDENTIFYING TRIGGERS

The Alzheimer's Association has a business card you can carry with you that says, "Thank you for your patience. The person with me is memory impaired and may require a few extra moments. Your understanding is appreciated." Using something like this will alleviate your need to explain, and eliminate your loved one's embarrassment as you take time to explain their "problem." If you can't find the cards, make up your own on the computer. Using this card may help eliminate unexpected triggers caused by the outside world.

Before you can detect "triggers," you must understand the term. Think of it like the match that lights the fire. If a volatile situation occurs, look back and see if

you can identify the thing that started the whole series of events. Mark those in the journal, and brainstorm ways to avoid them happening again.

The following lists will give you ideas of how to provide an environment that is less stressful, and provide you with examples of both physical and mental triggers common to dementia patients, including a few hints for handling stressful times.

GENERAL GUIDELINES FOR CAREGIVERS

- ❖ Be upfront with friends, acquaintances, neighbors, and the public about the person's condition. It's not contagious, and nothing to be ashamed about. Other people's negative reactions may set someone off by making them feel embarrassed or judged. Dementia makes you confused . . . not stupid.

- ❖ Keep a journal of situations and events that upset the person. Is there a way to avoid those situations? A person who used to be very competent doing the checkbook may lose that ability. Don't just say, "I'll do that from now on." Remove the reminders that they did it. Put the checkbook in another place. If possible, have statements delivered to another address.

- ❖ Try to identify what specifically upsets them. Is it the entire activity, or just a piece of it? Is it the whole bathing process or do they just dislike the cold tile? Look for patterns.

- ❖ Learn from previous experience. If they tire during big family events, limit the time and the number of people. Talk to family members beforehand and explain to them what needs to be done differently.

- ❖ Stick to a regular routine. This will cut down on the number of unexpected and stressful events they have to handle.

- ❖ If an activity or topic can be avoided, do so. If it can't be, don't do it alone. Plan for help.

- ❖ Try to make things fun for everyone, including yourself. If you look like you dread a task, they will pick up on your facial expression and body language, and will anticipate an unpleasant experience.

THE ENVIRONMENT

- ❖ Make changes gradually.

- ❖ Reduce stimulation in the environment. Avoid having more than one source of noise, e.g. music, TV, traffic noise, at a time.

- ❖ Simplify the environment. Simplify and/or decrease clutter.

- ❖ Keep heavy or sharp objects hidden, or totally remove them from the room or house.

PHYSICAL TRIGGERS

- ❖ Take note of recent medication changes. Side effects may cause mood swings. It's also possible they may not be able to tolerate certain medications.

- ❖ Watch for body language showing signs of increased discomfort. Restlessness, fidgeting, blushing, and pacing are only a few typical signs. You'll learn

each person's specific signs quickly. Don't ignore them.

- ❖ Physical discomfort may cause anger. Are they in pain? Ill? Constipated or hungry? Do they need to use the bathroom? Are they too hot or cold? Do their clothes fit properly?

- ❖ Keep a log of sleep patterns. Fatigue may make them more susceptible to frustration and anger.

- ❖ Simplify tasks.

- ❖ Decrease noise.

MENTAL TRIGGERS

- ❖ Don't focus on what they can no longer do. Learn to accept their current abilities. Avoid reminding the person of who they used to be if that upsets them.

- ❖ Give them limited choices, only one or two things to choose from at a time.

- ❖ Provide verbal cues. For instance, when you greet them, say, "Mom, it's Betty." Don't play the guessing game of, "Do you know who I am?" It puts the burden on them. Take burdens, don't give them.

- ❖ Ask if you can help them. Allow them time to respond. Don't automatically do everything for them.

- ❖ Break down tasks into small steps.

- ❖ Give them adequate time to accomplish a task or activity.

- ❖ Plan more difficult tasks for the time of day when they are at their best.

- ❖ Offer positive reinforcement. "After your bath, we'll have a piece of pie."

Follow through!

- ❖ You don't have to announce your intentions ahead of time. For instance, you can go for a walk through the house or building and stop by the bathroom. You don't have to structure everything.

- ❖ Don't talk about them as if they aren't there. Include them so they know they can ask a question or voice an opinion. Misinterpreting a conversation may upset them.

- ❖ Identify other people you bring with you. "I brought Lisa along with me today." If you told them the day before, even the hour before that you and Lisa were going to visit, don't assume they will remember. Don't ask if they remember, it simply reminds them they have a problem.

- ❖ Anger frightens them. If you're angry with someone or something, stay away, and don't try to accomplish difficult tasks until you've calmed.

HINTS FOR HANDLING STRESSFUL TIMES

- ❖ During stressful times, share an activity together that you'll both enjoy and find relaxing. Do you both like to cook? Make cookies and eat your fill. Enjoy a cup of tea? Brew a pot together and sit out on the porch in the sun.

- ❖ Avoid arguing. You won't win because they don't know they can't.

- ❖ Go for walks to burn off energy and steam.

- ❖ Plan personally meaningful activities. Offer them when their agitation

increases.

- ❖ “Come with me,” may work better than an explanation. Extend your hand and smile to get them to join you.

- ❖ Have the doctor write a prescription for specific, difficult tasks. Keep the prescription form handy as a visual and verbal reminder of the doctor’s instructions.