The Caregiver's Journey®

Finally! Practical Tips and Candid Conversations
for Alzheimer's and Dementia Family Caregivers

4 Tips for Navigating the Elephants

In the Caregiving Room

SUE RYAN

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This guide brings our years of experience in a variety of family caregiving roles. We are sharing our personal experiences, not medical advice, to help prepare you to navigate your caregiving journey.

Introduction

When my first caregiving experience began more than forty years ago, I felt frustrated, overwhelmed, and yes - sometimes frightened. I felt like I was on an emotional roller coaster - often blindfolded. Facing this journey with no roadmap, no mile markers and an unknown destination point is by far one of the scariest journeys imaginable.

I didn't know what to do, how to do it, or where to get help. In the wee hours of the night I found myself in the swirl of emotions, making decisions that must be made and having no understanding of how to keep myself going, let alone feeling positive and balanced. I felt the extreme loneliness and depths of despair that can wash over us in an instant, keeping us in the fog of confusion and wanting to retreat from everything, even life itself.

Our caregiving journey has a wide variety of experiences some of which we're facing for the first time. We can't practice emotions we haven't felt before - and our caregiving journey is filled with them. I worried about things I had no control over, felt disappointed in myself and even felt guilty for taking time for myself. I depleted my confidence, which clouded my decision-making. How could I possibly know if I was making the wisest choice in the fog of it all?

These all took a toll on my state of mind, my health and other relationships in my life.

I began to learn. I found help from so many amazing teachers, good Samaritans, and in the quiet of my inner thoughts and meditations. I began to apply what I was learning and found that I was changing. I was able to see things in a new light, I had more clarity, I had more compassion and that compassion allowed me to not only love myself more, but in doing so, I had so much more love and compassion to share with others.

This became my journey of love… Our Journey of Love, as I shared it with my beloved Jack, and I wrote the book. It is from this journey, my journey, I discovered the way to positively navigate our caregiving journey. There is a way to stay positive and balanced in each emotion, each experience. There is an Emotional Guidance System.

Today I am able to tell my caregiving stories all over the world and do what I love most - is teach and coach others how to positively navigate this journey for themselves.

I developed The Caregiver's Journey® and wrote the book ***Our Journey of Love, 5 Steps to Navigate Your Caregiving Journey*** to guide you and your care receiver to your most positive caregiving journey. You are stronger than you think, and I want to help you find that for yourself. You're worth it, your care receiver is worth it, and your journey together is worth it!

Wisdom is sharing our knowledge to guide others. If I can positively touch even one life as positively as my life has been touched, through sharing the wisdom of my journey, I know the purpose for my journey has been fulfilled.

This guide introduces you to some of my most powerful caregiving lessons through the metaphor of stories with elephants. The elephant is associated with Alzheimer's Disease because they have incredible memories that last throughout their lifetime.

The Parable:

The parable of the elephant and the blind men provides us insights about the importance of what we can learn from others' unique perspectives.

The Training:

Learning how elephants used to be trained awakens us to evaluating our beliefs to make sure they serve us today.

The Bite:

The question "How do you eat an elephant?" teaches us to break things down into manageable pieces to eliminate overwhelm and see where support is helpful for us and for our care receiver.

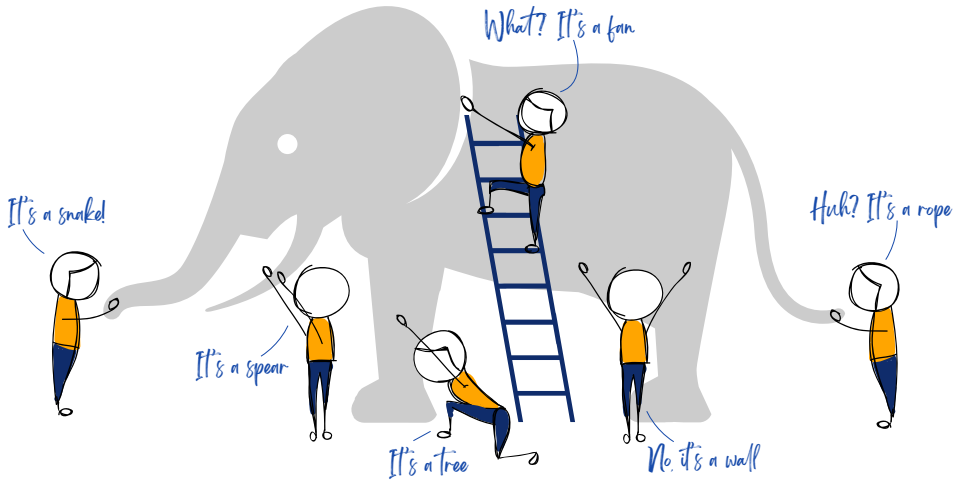
In The Room:

The phrase "the elephant in the room" is a perfect metaphor for one of the most challenging and important components of relationships and of significant changes in our lives - communication. There are a variety of dynamics with the different types of conversations necessary and the people involved. We know some of them are going to be difficult, we would rather not have them, we know we need to - these are like elephants in the room!

TIP 1

Recognize The Unique Perspectives We All Bring

The Parable of the Elephant and the Blind Men



There's an Indian parable about six blind men who come across an elephant. Each man experiences only one part of the elephant and that becomes his reality of the elephant. None of the six has a clear picture of the elephant as a whole. When they each share their perspective, they all disagree, and they argue about who is right and who is wrong about what the elephant is like.

Lessons I use from this parable include:

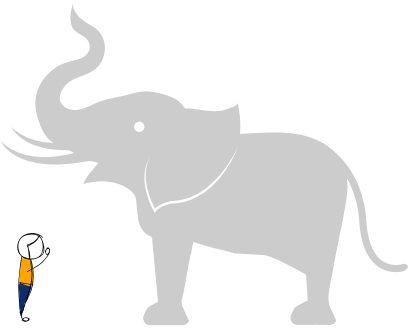
- As an encouragement for me to learn as much as I can and become confident in my perspective.
- Remain ever curious and open-minded to considering, without judgment, other perspectives. I focus on remembering that different perspectives are not right or wrong, they are different.
- I have the choice to maintain my perspective or modify it.
- Develop new collective perspectives if they are more valuable than the individual perspectives of each of us.

The lessons from this parable are important reasons why I don't use the labels others use to describe an experience without understanding their definition and gaining clarity for myself.

Each of the six men experienced an elephant. If I just accept one person's perspective without developing my own perspective with clarity, I may be missing the rest of the elephant—and the best experience possible. If I don't choose the perspective that serves me, I can't have an authentic experience. When I'm trying to see something through a perspective that isn't mine, I miss valuable insights and possibilities - in and from - the experience.

TIP 2

Reevaluate Your Beliefs



Elephant Training

In recent years, elephant training has changed to an approach using positive feedback. Previously, a less humane method was used. I feel the history of elephant training applies directly to my perspective around care support. I realized I had been trained, and trained myself, like the old style of elephant training and, just as it's not right for elephants anymore, it's not right for me anymore either.

Historically, young elephants were tethered to a stake in the ground by a long rope attached to their leg. While they are very young, the rope is strong enough to keep them from escaping. They struggle and can't detach themselves. After a while, they accept their reality and believe they can't escape. Once they have accepted their reality, they don't reexamine it. As they grow, they become much stronger than the rope and because they believe the rope is stronger than they are, they don't test it to reevaluate if it's still accurate.

Throughout my life, I've developed my beliefs from lessons I've learned. The story of how baby elephants were trained sparked an incredible awakening in me. I realized I had not been reevaluating lessons I'd learned at other times in my life to identify if they still served me. I was still tethered to the beliefs of early lessons. For me to consciously choose whether to keep or discard old beliefs, in light of if/how they serve me best now, I have to be willing to discard old beliefs, even if those lessons were taught to me from a place of love and safety.

Here are two examples:

1. Look both ways before you cross the street.

As a young child, everyone told me this! I was told this time and time again for what seemed like years! I was trained to pay attention to my surroundings and make sure I was safe before stepping into the street or parking lot. This was taught to me from a place of love to keep me safe. This training became my unconscious behavior pattern and has saved my life multiple times, even in just the past several years! With so many people distracted by mobile devices, some are not paying close attention. It's a good thing this is my automatic pattern. I choose to keep this old lesson.

2. Don't talk to strangers.

From an early age, I was taught this whenever we went shopping, to events, parks, movies, anywhere there would be strangers. Like the first example, this lesson was taught out of love and safety because I didn't know yet how to discern if someone had my best intentions in mind or not. It became my unconscious behavior pattern. As an adult, my role in sales gives me the opportunity to talk with strangers every day. When I became aware of my unconscious programming, I had sudden clarity and realized the absolute of "not talking to strangers" no longer served me. I choose to engage with people who I have not yet met! While I honor the training of my childhood, I now make conscious choices with my new perspective that serves me very well today.

How does this process of reevaluation help me in my roles of care support every day? I stay present. I focus on how I am supporting my care receiver to make sure they are the most comfortable they can be at the moment and that I am staying in balance.

For example, I meet my care receiver where they are in each moment. I observe how they are experiencing each component of their day. I look at them with "fresh eyes" observing changes. I don't necessarily consider "absolutes" in caregiving, I consider context. I adapt my care when there are changes and take my lead from their needs and abilities.

I observe and ask questions of other care support providers in order to make sure they are getting the support they need and are able to do their job the best way possible. It's important for me to ensure they can adapt and respond appropriately to changes in my care receiver. Because there are periodic changes in my care receiver, I check in with the care support providers on a frequent basis.

Here is one example: Walking. My husband, Jack, has the diagnosis of Alzheimer's Disease. He's always enjoyed walking. When he lived at home, he used to walk 4–5 miles on a daily basis. This has diminished in the past year. I observed other residents in the memory care community where he lives, and noticed some of them experiencing difficulty with their balance, getting out of chairs, and walking. I've learned this also leads to a lack of continence.

Focusing on my goals for Jack to be safe and in an environment that supports his happiness, I focus intentionally on keeping him as healthy as possible. I observe him closely to monitor his balance, ease of walking, and getting up out of chairs. In the beginning of our time in the memory care community, I tried to get Jack to lift light weights—please laugh with me. It wasn't successful at all. Instead, we focused on walking quite a bit.

(A tip here; with diminishing short-term memory, we walk awhile and take a break. We perhaps sit a few minutes or get something to drink. I then ask Jack if he'd like to go for a walk and he says: "Yes." We get more exercise because we break it into shorter segments, and he gets to repeat something he enjoys as if we're doing it for the first time that day.)

One day, I noticed Jack beginning to shuffle his feet rather than picking them up. I saw a correlation between his lack of interest in exercise when I asked him, and the beginning of shuffling. Having learned previously that I'm not the best instructor for him, I reevaluated how to achieve my goals and reached out to community members to find the name of a trainer who worked well with their care receivers (this can also be another family member, friend, loved one).

Through our community, I was introduced to a trainer who Jack was glad to exercise with. The trainer and I worked together with Jack so the trainer would learn how to best communicate with Jack and what would trigger him. We talked about my goals for Jack so the trainer had direction. Yep, they worked great together! Jack would do anything for his trainer and the proof was in the results. Jack was able to get up out of chairs easily, his balance was good, and he picked up his feet when he walked.

When Jack's disease progressed to the point where he couldn't respond to the requests of the trainer, I reevaluated how to achieve my goals. We began focusing on TV videos and adapted movements, increased the amount of time we walked, and I began having Jack "help me" with projects that incorporated movements.

TIP 3

Break Down Your List of Concerns Into Bite Size Chunks

The Bite

I've often heard, and used, variations of the ancient proverb about being deliberate with things that are difficult by taking them one step at a time: "When eating an elephant take one bite at a time." I use the elephant as a reminder every day of how I focus on components of my responsibilities of care support.

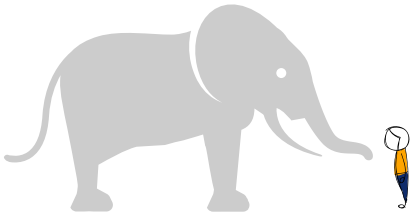
The entirety of care support responsibilities can be overwhelming. If I begin to feel this way, I observe and study it. I work to break it down into smaller and more manageable "bites" until they aren't overwhelming.

When I'm able to view a situation objectively, and not react from ego and/or emotion, I'm able to make conscious choices, act, and move on.

I don't have to be the only one "eating" the elephant. When breaking down my care support responsibilities, I evaluate who the most qualified person is to provide each component of support.

TIP 4

Face The "Elephants In The Room"



In The Room

The phrase "the elephant in the room" is a figure of speech that represents a major issue or concern that's obvious to everyone and not discussed because it is uncomfortable or unpleasant. Through my many years of experience in roles of care support, I've learned there are a lot of elephants in the rooms! Most of the time, a group of elephants is called a herd, a parade, or a memory. In this case, any one of the "elephants", and certainly the whole group of "elephants," is called overwhelm.

Addressing these helps me, my care receiver - and anyone else involved - make informed decisions, create the space for peace of mind, and reduce anxiety. "Elephants" may be many different things including people and things. The people may be us, it may be members of our family, it may be friends, it may be work or community associates, and it may be professionals we rely on.

The things may include the disease itself, impacts of the disease, and conversations we aren't used to having. For example, conversations are sometimes about topics in which we don't have experience. They are sometimes about topics we'd rather avoid. They sometimes involve complex family dynamics, taking on responsibilities in areas in which I don't have experience, and/or don't have interest.

Figuring out how to address the “elephants” can be awkward, messy, and uncomfortable. I’m very fortunate to have learned valuable lessons from others in our support group meetings about addressing the “elephants.” Many of the stories shared were raw and powerful. They helped me see that, no matter how awkward and uncomfortable it is to deal with the “elephants,” it’s much better than the results of not addressing them or delaying addressing them. I’ve heard example after example where avoiding these “elephants” led to serious and negative relationship, safety, financial, medical, and legal impacts. These lessons inspired me to take action so that our impacts are positive.

The list of “elephants” will be different for everyone. As with a group of elephants being called a herd, there are a herd of these issues including:

- Talking about the disease diagnosis, traumatic event, or specific condition.
- Fears about what will happen. This is on the mind of the person who has received their diagnosis, everyone in their family, and those in their circle of support.
- Recognizing symptoms of a disease in a friend or loved one before anyone else may even be aware of it or before it’s been discussed.
- Happiness guilt.
- Taking away “freedoms,” including driving.
- Changes in physical relationships.
- Taking on responsibilities in areas in which I don’t have experience and/or interest.
- Making changes in our environment that support my care receiver being safe.
- Needing additional support.
- What to do in case of emergencies including acts of nature and caregiver health crises.
- Finances, including having enough resources, managing them, and paying bills.
- Insurance.
- Children providing personal care for parents.
- Legal matters including power of attorney, wills, ownership of assets, advance directives to refuse care (ADRT).
- Family disagreements about care responsibilities and options.
- Care support emotions.
- Care giver self-care and/or lack thereof.
- Funerals.
- Organ donation for research or transplant.
- The grieving process.

Bringing the "Elephants" Together

I bring together the elephant parable, training, proverb, and expression to help me navigate my care support journey with my care receiver.

First, focusing on the parable of the six blind men and the elephant, I've learned we bring our own perspective to each item on our list. I've learned there are a variety of human dynamics considerations that impact how we navigate each item.

It's important for me to be aware of these because the items may not have the same importance or emotional charge for each of us.

I don't want to assume anything. I make sure I honor my care receiver's considerations and give him/her the opportunity to honor mine.

Some of the things I consider, in order for us to have our most valuable conversations, include our:

- Natural personality styles.
- Perspectives.
- Previous experiences and the emotions surrounding them.
- Status of current relationships.
- Family dynamics.
- Health considerations—physical, emotional, and psychological.
- Beliefs.
- Religious precepts, doctrines, laws and rules.

Second, reflecting on the training of elephants, I evaluate my beliefs in each area. I want to make sure they serve me where I am today. I consider how I will talk with my care receiver to help them evaluate their beliefs. This is another area where I have had conversations with others before having my conversation with my care receiver, so I can walk through the conversation with someone else first.

One of the most significant disagreements I've heard about from other support group members and their care receivers is in the area of additional care, either in-home or moving to a support facility. Walking through this with someone else first helps me consider my beliefs and theirs as I frame our conversation.

Third, using the proverb about eating the elephant one bite at a time, I decide how I want to separate the "elephants in the room" into separate rooms. This is also known as breaking down my list of concerns into smaller and smaller, manageable components, until I lose my sense of overwhelm and imbalance. One example of this was the issue of having Jack quit driving. I researched everything I could about legal considerations of individuals driving if they have a diagnosis of a type of Dementia. I contacted our Doctor's office and spoke with a member of their staff about how they recommend this issue be addressed, and I spoke with our support group.

- How will Jack feel about losing his independence?
- How should this be addressed?
- Who should address it?
- When is the best time to address it?
- What adjustments do I need to make to ensure Jack doesn't feel uncomfortable asking to be driven somewhere or feel a loss of freedom when he can't just pick up the keys and go?
- What can I do ahead of time to reduce his anxiety before he actually has it?

I look at the list in its entirety, knowing that any one of the items on the list could be overwhelming by itself. I separate the items in groups that are logical to me. I sometimes put the same item in multiple groups to help me create the clarity necessary for optimal success. I created several groupings that I use now in all areas of my life.

Here are examples of how I use these with my care receiver:

- **Urgent:** Items we need to address immediately or in the near future. These include (but are not limited to):
  - Items that are important to address, participate with, and sign while both my care receiver and I have capacity to discuss them. Financial and legal items such as living wills, durable powers of attorney for healthcare, a separate Do Not Resuscitate Order in some cases.
  - Items where a decision needs to be made immediately or within a very short time period in support of providing the best care for our care receiver. Safety issues, changes to their living environment, immediate medical care, healthcare team changes.
- **Complex:** Items we need to process on multiple levels, that include learning about them and/or having a variety of conversations over a period of time. These can be items:
  - We have had little or no experience with.
  - We haven't previously talked about. In the case of second marriages, we may not know our spouse's previous experience with certain issues.
  - Requiring professional assistance to complete: financial, medical, and/or legal.
  - We will share with our family once we make our decisions. Among these are our advance directives, wills, powers of attorney, organ donation and funeral wishes.
- **Emotional:** Learning from others who have dealt with certain issues will give us insight on how to have potentially emotional conversations. This group may include:
  - Fears about what will happen.
  - Taking away "freedoms" like driving.
  - Needs for additional support.

  These are also items where it may be helpful for one of us to have a conversation with someone else before we have the conversation together.
- **Awkward:** Lastly, some of the "elephants in the room" are just awkward. While there isn't an easy way to address them, it is necessary to do so. These include items like:
  - Changes in physical and intimate relationships.
  - Family members providing personal care for other family members.

Using the example of discontinuing Jack's driving, it included some of each of these:

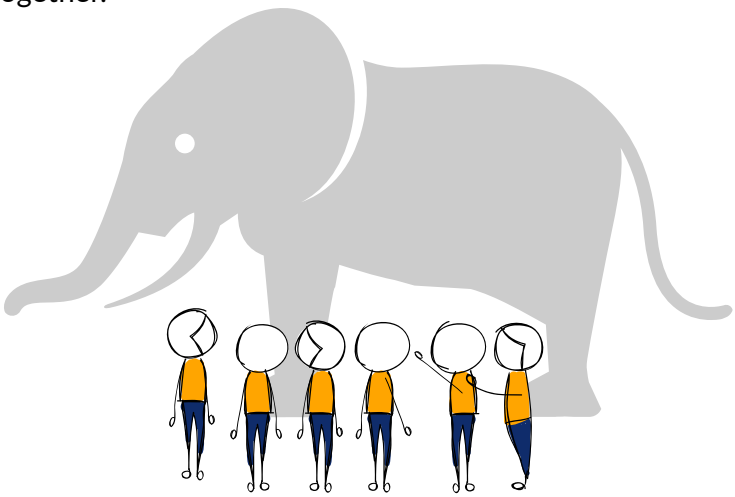
- It was urgent because legally he wasn't supposed to be driving anymore.
- It was complex with many different factors to be considered before determining what I would do and who would be involved.
- It was emotional because Jack had been driving more than fifty years and this was a very tangible recognition of the magnitude of this disease, even while he had very few symptoms. He could consider this a significant loss of freedom.
- It was awkward. I had not dealt with this before personally. My grandmother had been resistant to discontinuing driving. She only drove a few places and they were all close to where she lived. My uncle had put a sign in the back window of her car with his contact information on it. One day, as she drove to church, she lost her way. She pulled to the side of the street, someone contacted my uncle, and she gave him her keys. My Dad, and two other friends I was providing support for, willingly gave up their keys. In support meetings I had heard really rough stories of the struggles in this area.

I created a plan, contacted his doctor, asked him to have the conversation with Jack and leverage the issue of being sued if there was an accident. Our doctor brought up the topic, spoke with Jack in the most compassionate way, and explained the considerations to him. Jack handed me the keys and it was never an issue. I did make sure he always had a ride, I was positive and enthusiastic about driving him, and would sometimes make up errands so we could go out in the car.

Jack and I were fortunate to have visited multiple friends who had made changes in their living arrangements to support their additional needs. We were able to see how these changes helped them thrive in their day-to-day lives. We had also seen the significant and deeply emotional struggles of one couple who was in complete disagreement in this area. In another "elephant" conversation, Jack and I talked about our beliefs based on the positive experiences we'd observed and the couple who was struggling so much. We agreed we would be supportive of each other in this area. This made our hard conversations easier and, when it became obvious it was time for Jack to move into a facility that provided the professional care he needed, I knew it was something he had already agreed would be the right decision.

There will always be elephants in our room. We can face them authentically so they don't overwhelm us, embrace them for their possibilities, and know when we need help with our herd!

We're all on this journey together.



Contact Us

A lot has happened since I created this four short years ago. My dear friend and fellow dementia family caregiver, Nancy Treaster, and I have co-founded the non-profit The Caregiver's Journey®. Our goal is to make your caregiving journey as manageable as possible for you, helping you learn faster and more easily than we did so you're able to navigate your caregiving with strength, patience, and peace of mind.

We began our podcast, The Caregiver' Journey® (thecaregiversjourney.org/podcast), to bring you practical, direct tips and have candid conversations about our experiences, and those of our guests, to support you positively navigating your caregiving journey. We help you tackle common, day to day dementia caregiving challenges more easily, and with more confidence so you feel empowered with knowledge, resources, and fewer surprises.

Here are several ways you can connect directly with us:

Website

thecaregiversjourney.org

Podcast

thecaregiversjourney.org/podcast

www.facebook.com/TheCaregiversJourneys

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"We're all on this journey together."

Sue Ryan and Nancy Treaster

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