Dementia Caregiver's Support Group

Part 2: Strategies for Dementia Caregivers

Introduction

We all want to be the best caregivers we can be. Anyone who has ever been a caregiver knows how difficult the role is. We are going to explore strategies and best practices that can help us be successful in very challenging situations. Sources used to gather this information, include two organizations that I have been privileged to be associated with. Two other organizations will be cited from their publicly published materials.

The following two organizations have been nationally recognized for excellence in creating programs that have greatly improved the quality of life for those diagnosed with dementia and supporting the families and friend that love and care for them.
They come from the dementia programing found at:

- Juliette Fowler Communities, Dallas Texas. I'm Still Here Center for Excellence
- The Mildred and Shirley L. Garrison Geriatric Education and Care Center, Texas Tech University, Lubbock Texas

These approaches are not exclusive to these organizations, but they are the ones I have personally been involved with and have seen these best practices in action. These two organizations have been recognized nationally for innovation, excellence in programing, and extraordinary outcomes.

It is my sincere hope this will help you on your journey as a caregiver.

Ken Carpenter, MS, LNHA

We are Social Beings

People with dementia have the same needs we do. Their disease makes it more difficult to fulfill these needs and requires unique strategies on our part to help them. These needs include human connections, negotiating social situations, and meeting expectations. To fail socially is painful for human beings. Do you remember your most embarrassing moment, the one you never talk about? Even after years have passed you can feel increasingly uncomfortable as you dwell on that moment, perhaps even blushing in shame. Dementia does not remove this sensitivity to social failure. An important goal as a caregiver is to protect our loved one's dignity and sense of social wellbeing. To fail this goal will make all other goals more difficult to achieve.

People with dementia cannot come into our world. We must go with them into their world. The better we understand what it might be like to have dementia, the more effective we will be in connecting with them, protecting their sense of self-worth, and achieve a high quality of life.

Timing and Expectations

A person with dementia perceives time differently and the disease slows their response time. At Juliette Fowler Communities we often use this demonstration during caregiver seminars.
Quick exercise:

"I need two volunteers.

Thank you, Nicole, and Lori,

Nicole, please ask Lori a question.

But!

Lori, please do not answer until I tell you to."
(Wait ten full seconds before telling Lori to respond)

Ten seconds between a question and an answer response is a typical response time for someone with dementia. Many people require much more time to process a question.

Ten seconds is an exceedingly long and uncomfortable amount of time for people without dementia to wait for a response in a conversation. Let us consider the perspective of someone with dementia. Imagine if you were not allowed an opportunity to respond to a question. What if you were asked a question and before you could answer, you were dismissed?

It is important for us to realize the basic challenge of processing time in connecting with a person with dementia. To not allow sufficient time to respond is hurtful and diminishes the person. We are telling them they are inadequate and unimportant. They may become angry and strike out or they may withdraw from us. Patience is a fundamental requirement for successful caregivers.

Choices and Decisions

People with dementia experience a long series of losses. We want to protect their sense of autonomy and sense of worth by letting them make decisions. At the same time, we do not want to overwhelm them with a question they may struggle to answer.

It is best to present limited options and avoid open-ended questions.
Instead of asking "what do you want to wear," ask them "Do you want to wear the blue dress or the red dress.

At mealtime, rather than asking "What do you want to eat?" and "what do you want to drink?"

Try asking, “Do you want a chicken sandwich, or a ham sandwich? “ “Do you want iced tea or lemonade?”

“Telling the Truth” vs “Shared Reality”

One of my favorite definitions of communication is the achievement of a shared reality between people. Achieving a “shared reality” is often difficult for most people. It gets more complicated when dealing with someone with dementia. We have already learned we have to go into their world, that they can no longer fully come into ours.

What do we do when our loved one is unable to share the reality of various facts? What do we do when our mother believes her deceased husband is still alive and she is anxious to see him?

Most of us were raised to tell the truth. What happens when we tell “the truth”?

Mom: “Where is your dad?”

You: “Mom, Dad died 7 years ago”

If you do achieve a “Shared Reality,” and the information that Dad is dead is accepted as truth, Mom goes through the shock of the terrible news. She goes through the pain and grieving again, just like 7 years ago.

Have you ever awakened the day after the death of a loved one and for a moment forgot what happened? That devastating moment of realization is as raw as the first time you received the news.

The person with dementia that is repeatedly “told the truth, “ is destined to relive their most painful moments repeatedly. No one wants that to happen.

What if you do not achieve a “shared reality” and Mom is hurt and angry that you would make up such a terrible lie? The loss of trust can undermine all your efforts to be a good caregiver.

Developing and protecting trust is a fundamental priority for any caregiver.
So, what do you do when Mom wants to see her deceased husband?
Three valuable tools! These concepts are effective in many situations.

- **Validation—**acknowledging the person’s thoughts and feelings. When we are understood, we feel better and tend to be less resistant to new ideas and information. This is especially true for people with dementia. (Please note, this is definition is not the same as the concept of Validation Therapy. Validation Therapy is closely associated with Naiomi Feil and is a clinical approach used by some advanced dementia practitioners)

- **Redirection**—Redirection is a technique that can help calm people with dementia by shifting their attention away from negative feelings and behaviors. Initiating a pleasant topic or an activity can attract the loved one away from what is difficult and disruptive.
- ***"The Greatest Loss from Having Dementia Is the Loss of Memory***
  Sometimes the Best Tool to Deal with Dementia Is the Loss of Memory"
  Kena Philips, Assistant Administrator, Garrison Center.

What does that mean **"**Sometimes the Best Tool to Deal with Dementia Is the Loss of Memory"? When dealing with a person with dementia in a difficult situation, breaking their focus for a few minutes may allow an opportunity to move them past the difficult ideation and to go to a more pleasant and manageable state of mind. Understanding this "loss of memory tool" can improve your success when redirecting your loved one.

Let's go back to Mom waiting for her husband to be there. Consider responses like these.

"Mom, I know you miss Dad; I want to see Dad too, I miss him when he is not here Dad can't come right now, but I know he would if he could" (Validation)."

I'm going to have a cup of coffee and a cookie before we watch Jeopardy, would you like coffee and cookies too?" (Redirection) Hopefully, mom's focus will shift from waiting for her husband to having an enjoyable time watching her favorite game show.

Using redirection and validation in the context of loss of short-term memory can make the task of caregiving much more pleasant and effective, helping our loved ones have a higher quality of life.

The following is from a British organization, *Contented Dementia Trust:*
Three Golden Rules

1. **Don't ask direct questions**
2. **Listen to the expert – the person with dementia – and learn from them**
3. **Don't contradict**

These **Three Golden Rules** run contrary to commonsense communication styles which are taken for granted when dementia is not an issue.
The **Three Golden Rules** are counter-intuitive and those of us without dementia need to develop this entirely new set of communication skills.

Read our simple examples and explore the difference you can make to someone with dementia:

1. Don't ask direct questions
Avoid asking any direct question that requires the person with dementia to search for factual information that may not be stored in their album. They are already aware of their disability.

Asking them to search for facts they may not have will merely increase this awareness, causing them unnecessary distress and potential trauma…

2. Listen to the expert (the person with dementia) and learn from them
Listen to the questions the person with dementia is asking and consider very carefully what the best answer might be from their perspective rather than your own. For people with dementia, feelings are more important than facts. It is crucial that the information they receive generates good feelings for them…
We owe it to the person with dementia to avoid leaving them with anxieties that they cannot, only moments later, explain.

So, we must search for the information and the language that is most acceptable to them. Once we have found the best answer to their most frequent question, this form of words should be used consistently by everyone coming into contact with the person…

Nowadays I try and say something like 'I expect you're right', and straight away the problem that was brewing just seems to vanish. (Validation)

3. Don't contradict:
Do not argue with the person with dementia about which page or which photograph they are choosing to use in their album. They are increasingly likely to use intact memories from their pre-dementia past, in order to understand what is happening around them in the present. The rest of us need to avoid disturbing the sense they are making and start where they are at. We need to take careful note of the language they use, so that we can follow them, rather than expecting them to follow us…

https://contenteddementiatrust.org/specal-method/three-golden-rules/

The following blog was originally posted by Marie Marley on *Huffington Post*:
5 Things to Never Say to a Person with Alzheimer's

Yesterday afternoon, I walked into the spacious room belonging to Mary, a woman with dementia who has few visitors and with whom I've volunteered to spend a little time every week. I greeted her, complimented her on her beautiful turquoise sweater, and shook her hand.

Then I sat down at her little table that was overflowing with books, photographs, the newspaper and other items she wants to keep close at hand. I started off by picking up a small framed photo of Mary with her husband and three children -- two sons and a daughter.

"Tell me about your daughter," I said, using an open-ended question because they have no right or wrong answers. That's a tip I picked up from The Best Friends Approach to Alzheimer's Care by Virginia Bell and David Troxell.

"Oh, her name is Connie," she told me. "She has four children -- two boys and two girls."

She continued, giving me several details about Connie and her family. I then picked up a photograph of Mary and her twin sister, Bernice, and she told me about how they took piano lessons together when they were children. After a few minutes, I asked her if her daughter ever played a musical instrument.

"I don't have a daughter," she said matter-of-factly.

"Oh," I countered, picking up the family photo again and holding it out for her to see. "You just told me you have a daughter. Here she is."

Mary's face fell and she said very quietly, "I guess I do have a daughter."

I immediately felt sorry for her embarrassment and was disgusted with myself for having pointed out her mistake. I realized I'd just broken one of the cardinal rules for interacting with a person who has dementia. I'd just read it in The Best Friend's Approach that very morning: "Let the person save face."

Relating to a person with Alzheimer's

When relating there are many guidelines to follow. I'm going to discuss five of the most basic ones:

Don't Tell Them They're Wrong About Something: To let the person save face, it's best not to contradict or correct them if they say something wrong. There's no good reason to do that. If they're alert enough, they'll realize they made a mistake and feel bad about it. Even if they don't understand their error, correcting them may embarrass or be otherwise unpleasant for them.

Don't Argue With the Person: It's never a good idea to argue with a person who has dementia. First of all, you can't win. And second, it will probably upset them or even make them angry. I learned a long time ago, when caring for my beloved Romanian soul mate, Ed, the best thing to do is simply change the subject -- preferably to something pleasant that will immediately catch their attention. That way, they'll likely forget all about the disagreement.

Don't Ask if They Remember Something: When talking with a person who has Alzheimer's, it's so tempting to ask them if they remember some person or event. "What did you have for lunch?" "What did you do this morning?" "Do you remember that we had candy bars when I visited last week?" "This is David. Do you remember him?" Of course they don't remember. Otherwise, they wouldn't have a diagnosis of dementia. It could embarrass or frustrate them if they don't remember. It's better to say, "I remember that we had candy the last time I was here. It was delicious."

Don't Remind the Person that a Loved One Is Dead: It's not uncommon for people with dementia to believe their deceased spouse, parent or other loved one is still alive. They may be confused or feel hurt that the person doesn't come to visit. If you inform them that the person is dead, they might not believe it and become angry with you. If they do believe you they'll probably be very upset by the news. What's more, they're likely to soon forget what you said and go back to believing their loved one is still alive. An exception to this guideline is if they ask you if the person is gone. Then it's wise to give them an honest answer, even if they will soon forget it, and then go on to some other topic.

Don't Bring up Other Topics That May Upset Them: There's no reason to bring up topics you know may upset your loved one. If you don't see eye-to eye on politics, for example, don't even bring it up. It may just kindle an argument, which goes against the second guideline above. You won't prevail and it's just likely to cause them anger and/or frustration.

So, there you go. A few guidelines for visiting. I hope these will be helpful to you in visiting your loved one and enriching for the time you have together.

www.usagainstalzheimers.org/blog/5-things-never-say-person-alzheimers

Conclusion

I hope this presentation of fundamental strategies and other takes on the subject will help you with the precious task of caring for your loved one with dementia. The role of caregiver is never easy. These basic principles can make a significant difference in the outcomes of your work. You are running a marathon, not a 50-yard dash.

Always remember to take care of yourself. Find friends and people of similar circumstances to share successes and failures with. Find support systems so you can get a break. Perhaps a family member, a part time caregiver, or an adult daycare provider.

Pause long enough to see past how much has been lost. Create new moments. Look and see that the person is still there: their spark of life, and the sparkle in their eye.