



48 Quick Tips for Dementia Care Partners

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Introduction

I'm really happy you grabbed your copy of *48 Quick Tips for Dementia Care Partners*. The original idea came together from repeated requests from family care partners, who told me they needed to know what to do in a variety of situations--quickly! It evolved from there.

Here are the main 3 things that motivate me, inspire me, and create the passion I have on this topic:

1. **One “Oh, \$%#@!” moment after another.** That describes my first day (and to a marginally smaller extent, my first 6 months) in long-term care. There's nothing quite like being in the middle of a tough situation, but not knowing what to do to make it better.
2. **My family's been ravaged by dementia.** I've lost 5 grandparents in 8 years to Alzheimer's disease, complications from Alzheimer's disease, vascular dementia, and Parkinson's-related dementia. I know how hard it is to care for a person living with dementia, from both the family and professional side.
3. **BEST. JOB. EVER.** Then came that magical day when I realized I could actually jump into a moment with a terrified, upset, anxious person and change their emotional state from freaked out and melting down to positive, reassured, and calm. Is that not the most awesome super power *ever*?!?!

I hope you get lots of good ideas, different ways to look at situations, and feel supported by the time you're done with this. This symbol  (cooking with fire) indicates a way to kick it up a notch with a particular tip.



I value your feedback and would love to hear from you. You can reach me at christy@dementiasherpa.com.

Sending you hugs and endless amounts of patience!

Christy

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Behavior Quick Tips

Rummaging

If you notice your parent rummaging through a drawer, she is likely looking for something.



Rather than trying to redirect to a different activity, offer to help in the search. Helping will keep the frustration level relatively low, and the “behavior” from escalating.

Redirection

Use “addition before subtraction” when you need to redirect from an undesirable situation. Years ago, I had a resident take my keys out of my pocket. Instead of trying to get them back immediately, I offered her coffee and a cookie because those were more appealing. *Success!*, no argument required.

Resisting Care & Pain

When people living with dementia are resisting care (such as hitting, kicking, or pulling away), it can be a sign of untreated pain. Remember that just because they can't verbally say “I'm in pain” doesn't mean they don't feel it.

Pain

People living with dementia often say “no” to most questions, and are notoriously unreliable reporters of pain (& location of pain).

Resisting Care & Approach

Problems can also be caused by our approach.



For best results:

- Approach from the front
- Drop down to knee level or below
- Be respectful of personal space (about arm length, for each of you)
- Establish rapport before launching into a task
- Use a simple, concrete sentence to state your purpose (“I’m going to help you get dressed,” instead of a question)
- Leave and reapproach later rather than getting into an argument if the person is resistive
- Most important: always approach with kindness

Wandering

About 70% of people with dementia eventually wander. Wandering can be a sign of diminished safety awareness, impaired judgment, or looking for someone or something.



Plan for this by enrolling in the Alzheimer’s Association’s [Safe Return](#) program, which also allows you to register as a care partner. If something happens to you, first responders will know your parent is depending on you and take steps to ensure his safety and care.

Repetitive Questions

These can be a sign someone doesn't remember information, as well as a sign of anxiety. Check for the emotion behind the words and then offer reassurance. For example, “Your doctor appointment is Monday and I’m going to be right there with you,” while also giving a hand squeeze or hug.



Distract & redirect immediately after offering reassurance.

Anxiety

Finding out about things like a doctor appointment in advance can cause anxiety, which often leads to repetitive questions. A good rule of thumb is to think about how often you’d like to

answer the question and offer reassurance, *then* decide when it's appropriate to share information.

Offering Reassurance

This is one of the most important things you'll ever do for a person with living with dementia! Maintain eye contact, listen, smile, hug, hold hands.



Saying things like “You're fine!” or “Why don't you calm down,” or “You just need to relax” are phrases that significantly increase anxiety...often with a big side helping of anger!

Overstimulation

Busy public places (ie, Costco) can be over-stimulating, which often leads to “behaviors.” If you notice hand-wringing, restlessness, fidgeting with zippers, or the like, it's time to GO! In fact, it's probably past time.



- Schedule your outings during off-peak times
- Cut 25%-50% from your to-do list
- Limit the amount of time away from home

“Why is this happening?”

If your parent is engaging in the same “behavior” frequently, note what was going on just prior to the “behavior” starting, because that was most likely the cause. Next, eliminate the cause.

Sundowning & Light

As the days get shorter, sundowning can become a problem. Make sure multiple lights are on. In the summer, make sure the blinds are open, too.

Sundowning & Structure

Know what time the sundowning starts, then engage your parent in a structured activity about 30-60 minutes prior to the start of sundowning, continuing all the way through to bedtime. Watching tv doesn't count as a structured activity.



To successfully pull off a structured activity, have your supplies ready to go beforehand. Get your parent situated so he can hear and see you and then give him both verbal and visual cues about what to do and how to do it. Give one concrete instruction at a time.

Structured Activities

Great structured activities to do together are taking a walk, making bread, hand massage with lavender-scented lotion....Use your imagination, or download [101 Things To Do](#).

Morning Struggles

Mornings are easier when you work with a person's natural body rhythms. Dementia won't turn someone who's never been a morning person into one.



Dementia *will* cause disinhibition, though, making it much more likely your parent will show you exactly how much she hates mornings.

HALT!

If you notice your parent getting irritable, remember to HALT! Mentally review if she could be Hungry (or thirsty), Angry (or overwhelmed by the environment), Lonely (or unengaged) because she doesn't know what to do next, or Tired and then eliminate those unmet needs.



It could be a combination of these, so keep working through the list if meeting just one need doesn't completely change your parent's state/demeanor.

Is it really a behavior?

Ask yourself who it's a problem for--you, or your parent. If it's only a problem for you, it's probably *not* a behavior.

Underlying Message

Behaviors are attempts to communicate. Figure out the underlying message of the behavior and you'll know why it's happening.

WSB Syndrome

People living with dementia aren't immune from WSB syndrome (waking up on the wrong side of the bed). It happens to all of us sometimes.

Denial

Did you know that about 80% of people living with dementia don't think they have dementia? This is often called denial, but it's actually a condition called anosognosia. The person with dementia can't help it. Instead of arguing, try moving on to a different topic. Even if people living with dementia did know they have it, they would forget.



The most important thing for people living with dementia to know is that you are there for them.

Arguing Quick Tips

Arguing

Do not argue. Ever. You will not win, ever. But you will feel worse. Arguing is likely to set a tone for the day that you don't want to promote. It's not worth it; just don't do it.

What's in it for you?

When it comes to arguing with a person living with dementia, ask yourself what's in it for you. Remember, you can be right, or you can be happy.

Distraction & Redirection

If an argument seems to be looming, try distraction and redirection. Distract with something unrelated, then redirect to a different area/topic.

Jedi Mind Trick

Rather than arguing, agree, empathize, and validate. "Yep, I see why you're so angry. I think I'd be angry too. I'm so sorry you're going through this right now."

Set The Tone

Start the day by giving your parent a hug "just because." Believe it or not, this works particularly well with "grumpy" folks.

Perception Quick Tips

Shifting Our Perception

Sometimes caring for a person living with dementia can be frustrating, but if we can shift our perception even just 5 degrees, then we can change the outcome of the situation.

Perception Shift #1

Instead of seeing it like, "I know she's doing that on purpose!" try seeing it like, "She's trying to communicate something to me. What is it?"

Perception Shift #2

Instead of seeing it like, "He's probably faking it," try seeing it like, "He's in brain failure. He can't help it."

Perception Shift #3

Instead of seeing it like, "She's in denial," try seeing it like, "She has a condition called anosognosia; she truly doesn't know she has dementia."

Perception Shift #4

Instead of seeing it like, "He's driving me crazy asking the same question every 2 minutes!" try seeing it like, "He can't remember the answer I gave him because he has dementia."

Perception Shift #5

Instead of seeing it like, "She's just being manipulative," try seeing it like, "She's lost control of so much in her life. That must be really scary for her."

In General

Offer Positive Reinforcement

Encourage, reassure, and come to the rescue. "Looking good! You did a great job combing your hair. Let me just fix that one little spot in the back right quick." If he starts swatting at you to get away, just go away. It's not that big a deal, really.

Give Ample Time To Complete Tasks

Putting on shoes and a jacket is no longer a 2 minute job when dementia is involved. A good rule of thumb is to allow for double the time you think it should take, then add an extra 15 minutes or so for good measure.

Use Concrete Language

Say “I need you to put your shoes on now” instead of “it’s time to get ready.”

Task Segment

Give 1-2 steps at a time. Try “Sit down, then put your leg in your pants,” rather than “It’s time to get dressed.”

Use Visual & Nonverbal Cues

Place your hand on the lower back to encourage walking while pointing to where you want to go, rather than using nothing but words.

Treat Pain Seriously

People living with dementia are notoriously bad at accurately reporting pain but they are in high mileage bodies. Dementia isn't a cure for arthritis or any other condition that causes pain. Dementia just makes it harder for the person to tell you about the pain verbally.



I’ve seen two Tylenol three times daily work miracles on “behavior” problems.

Aromatherapy

This can work like a charm for people living with dementia! Use essential oils in a diffuser or spritz.



- Waking: Eucalyptus (try body wash and a spritz in the air for the morning routine)
- Appetite Stimulation: Citrus (also the scent of baking bread and/or cookies, obviously!)
- Calming: Lavender or Geranium (try lotion and hand massage)
- Sleep: Lavender (try spritzing the pillow case just prior to bedtime)

Increasing Fluid Intake

Getting people living with dementia to drink enough fluids can be challenging, because they'll often say 'no' when offered. Try adding lemon, lime, orange, or cucumber slices to water to make it tastier.

Want To Have A GREAT Day?

Encourage and praise abilities rather than focusing and commenting on deficits. Just like all of us, people living with dementia prefer it when people recognize their strengths instead of focusing on weaknesses.

Skip Reality Orientation!

It doesn't work. No matter how many times I tell you the sky is green and the grass is blue, you won't believe me because your experience is telling you I'm wrong. It's the same for people living with dementia.



Instead of reality orientation try validation therapy.

It goes like this: your parent says something like she's waiting for her mom to pick her up from school. Instead of arguing or correcting, you say something like, "Oh? Tell me about your mom," or "What's the very best thing about your mom?" You've just turned a potentially negative situation into one where your parent feels heard, understood, and accepted :)

For Best Results

Use gentle and soothing words, touch, and approaches in every interaction. You'll be amazed at the difference when you make a conscious effort to do this instead of allowing yourself to be sucked into a task-oriented mindset.

Dementia's About More Than Memory Loss

Receptive Communication

People have difficulty with understanding what you're saying. Try showing them rather than telling.

Expressive Communication

People have difficulty with accessing the words they want to use. Allow extra time for a response. People also can struggle with matching a thought with the right word. Suggest a word or encourage her to show you.

Fine Motor Skills

Don't take over doing tasks such as buttoning shirts and tying shoes because it's quicker/easier. Encourage independence by cheerleading and allowing extra time.

"Apathy"

Holding on to a thought long enough to turn it into a meaningful action becomes impossible. People aren't just sitting there, apathetic. They literally don't know what to do next.

Appetite

Some people always feel full, and others may always feel hungry--because of the signals their brains are sending. Telling them they just ate--or didn't--doesn't help.

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