

Caregiver vs. Care Partner: Why You Need to Know the Difference

*3 Strategies for Protecting Your Relationship and Finding Meaningful Moments
in Dementia Care*



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Have you ever wondered why Teepa Snow and her team use the term *Care Partner* over the commonly used term *Caregiver*?

In the U.S., the general public uses the term *caregiver*, and it is what most of us are accustomed to hearing. However, there is a fine delineation between being a caregiver versus a care partner; one that can make a big difference in the way you

offer care for your person living with Alzheimers disease or another form of dementia.

When you go from being a caregiver to being a care partner, your entire approach and the way you see the person in your care is likely to shift. Why?



Simply said, because a caregiver **gives** care, while a care partner **partners** in care. While this difference may seem trivial at first, it can create a powerful shift in mindset of your role, resulting in a much-improved relationship between you and the person you partner with in care.

Instead of doing things **to** the person, you may find yourself starting to do things **with** the person. Instead of you doing things *to* them, you will begin to see them as a partner in this journey. This is likely to result in an improved relationship between you two, and enhance the quality of care for the person.

As an example, a caregiver may use the spoon to **feed** the person living with dementia. A care partner on the other hand, uses *Hand-under-Hand*® to **assist** the person with eating. This not only provides a motor cue to eat, but also improves your connection and provides an increased sense of independence for the person.

In research, *Hand-under-Hand*® has been shown to increase the amount of food eaten (important for many older adults), and elicited the least amount of *resistive behaviors* (e.g., motions showing distress and lack of desire for getting fed, such as turning away, clamping lips), as compared with other techniques that involve feeding people, rather than helping them eat (Batchelor-Murphy, Amella, Zapka, Mueller & Beck, 2015; Batchelor-Murphy, Amella, Rose & Bales, 2015).

If this approach and philosophy appeal to you, and you'd like to try to improve

your relationship and quality of care, here are three things to keep in mind as you work towards being a care partner instead of a caregiver:

1. Look for ways for the person to be *your* care partner at times



Dementia care is not a one-way street. It is a relationship between you and the person living with dementia. A healthy relationship involves a *give and take* on both sides, and this remains true when dementia is in the picture.

See if you can spot some opportunities where they can **help you**.

As an example, if your mom was a very good cook, next time you're preparing dinner you could say something like *Hey, mom! I sure wish I had your cooking skills. Your homemade spaghetti sauce is amazing! Truth is, I could really use your help. Do you think you could peel the garlic for me? That would really help a lot.* Or perhaps just, *Hey mom, do you think I'm doing this right?* She might not be able to do, but she might be able to give her opinion.

A joint activity like that not only offers engagement and a sense of being needed to the person, but you both may enjoy moments where she gets to be your mom again, creating joy and memories.

In another example, you could ask your dad if he could help you sort through some old photos, as there a lot of people you don't recognize: *Oh, dad! You've always been really good with faces. This woman right here (pointing at her in the photo), is that Patty, or somebody else?*

You may be surprised how a person that may not have a lot of language left can turn into a real source of information, while offering the person a sense of purpose and value by letting them help you.

Truth is, if you think you always **have** to be the care partner, you're less likely to get your own needs met. See if you can find ways to foster a true *give and take relationship* between you two. Try to see the person in your care as having value and purpose, and help them feel it, too.

2. Take care of yourself



Wait, wait - don't stop reading here! We know what you're thinking. It's likely along the lines of *Gee, thanks. If I had the time to take care of myself I would or Great, something else I'm not doing right.* We get it. We really do.

Caring for a person living with dementia can be entirely exhausting. You may have no idea how you can possibly fit in time for yourself, and here we're asking you to do just that.

Yet, time for yourself doesn't have to be a multi-day vacation or other time-consuming task. Instead, a small shift can reap big rewards if repeated over time. ***So, can you identify just one small thing, one habit shift, that you can start making today?***

Could you maybe go to bed a little earlier? Or maybe skip that second glass of wine in the evening to help you sleep a little better? Or maybe, next time you're in a multi-story building, could you take the stairs and not the elevator, even just for a single level?

Make the bar so low that you're starting on your path to self-care because that is all you *can* do. Make the change so small that it becomes really hard to fail at it.

The point is not to add more stress to your life, but to see if there are tiny, 1% improvements, that you can make in one area or another, that compound over

time into something bigger. And if you feel ready, you can tack on the next low-bar behavior change to benefit your well-being over time.

So now, being a care partner in this very moment, take a quick pause and pick one thing to improve upon. Just one. Don't make it more than that. Start small with just one thing, such as a deep breath right now, and do it repeatedly until it turns into a habit.

And if you don't achieve it this week, you can self-assess, say *maybe that was too ambitious*, and pick something simpler to achieve. And if you met your goal, see if you can add on one other, tiny change next week.

The truth is, you have to take care of yourself, at least a little bit, to be and remain a care partner. And if you can't take care of yourself right now and the best you can do is be a caregiver, then that is okay too. Any improvement starts with awareness, and just by being here and reading this, you have reached that state.

3. Continuously challenge your beliefs, stay curious, and accept that things will change



A good caregiver recognizes and remembers who this person is, who they were, knows what their profession was, and more. A care partner, in addition, will also ***respect and value*** the person for who they are, then, and now.

This can be hard to do as you see the person change before your eyes, and you may notice abilities that they once had slowly dwindle. To counteract this, ***regularly challenge your own understanding or beliefs about who this person is and what their preferences are.***

As an example, maybe your mom was always meticulous about her appearance, in

particular her lipstick. As she progresses through this journey, however, you notice that she no longer cares about how she looks. Instead of seeing this as a negative, maybe you can embrace this change as a newfound freedom from vanity.

Or maybe your dad used to be a really good bookkeeper, but now you find overdue bills in his apartment.

Try to remember that only because a person may not have the same abilities now as they once had, that doesn't make them less. As Teepa once stated, ***dementia does not rob someone of their dignity; it's our reaction to them that does.*** Try to challenge the truths *you think you know* about the person, and stop making assumptions.

Things will change throughout the dementia journey you both share; that one is certain. Yet, if you are able to try and stay curious, accepting, flexible, and open-minded, you'll be that much closer to being a true *care partner*.

Conclusion



Caring for a person living with dementia can be truly challenging. You will likely go through times of struggle and exhaustion. Be gentle with yourself.

Transitioning from caregiver to care partner is a journey in itself. Just like the person living with dementia is doing the best they can, so are you with where you

are at this point in time.

See if you can find moments of joy by finding ways they can be *your* care partner at times, and try to implement that tiny little habit change to help yourself stay healthy. By staying curious, challenging your beliefs, you may see that you can accept that things will change.

Don't beat yourself up if you temporarily fall back into old habits; that is entirely normal. Instead, appreciate your newfound awareness, and that you can tell the difference between old habits and the new ones you're developing. Rome wasn't built in a day, and neither are dementia care skills. Give yourself time, and remember that ***you are important***, too.