CARING FOR A SIBLING: Living in the Moment

by Michael Gordon, Ph.D.

A dear friend of mine–I'll call Steve–phoned the other day to see if I had anything to offer that might help him deal with his sister's mental decline. She was at that most torturous stage of dementia – aware of her advancing limitations, but wildly unable to accept them. Even though she was no longer able to care for herself without assistance, she vigorously (and, at times, physically) protested any suggestions that involved a change in her living situation.

Steve reached out to me because he's aware that I've had my share of caretaking responsibilities for close family members. He also knows that I have a clinical background which, if nothing else, forces you to think critically about how best to formulate a treatment plan.

It's rare for me to offer detailed advice, even when solicited. The pitfalls are many. I could be dead wrong in what I suggested, making me at least partially responsible for a bad outcome. But more importantly, I know that people are far more apt to accept suggestions if they feel that they largely came up with them on their own.

What has worked for me in these circumstances has been to talk in terms of over-arching principles that guide decision-making. That's the strategy I've followed in many of the books I've written as well as in my past clinical work. If you lay out some solid guideposts, the optimal trail can be easier to discern.

Here's what I offered up to Steve. I'll warn you that nothing you're about to read is groundbreaking or especially astute. It's just the top three priorities I think are important to keep in mind as you're struggling to figure out how to proceed:

Safety first

It's understandable that you might be inclined to hold off advocating for changes because you're concerned about your loved one's reactions to them. You might find yourself backing off from doing what's required because you assume (rightly or not) that any suggestions will be met with furious rejection.

In my opinion, what should steer Steve's decision-making is not how his sister might react to his plan. Instead, everything should follow from the answer to this question: "What does my sister need to be safe?" Are we talking daily visits from an aide? Moving in with me? A day treatment program? A move to an assisted living facility?

Once he's decided on a plan, he'll need to set about doing whatever is necessary to make it happen. Upsetting an already terrified loved one is one thing. Getting a phone call that she was found wandering the street or admitted to a hospital malnourished and dehydrated is quite another. The last thing you want is to find yourself burdened by regrets for not having focused most on ensuring health and safety. It will be much easier for Steve to deal with any caretaking fallout if he keeps reminding himself that his efforts all started from a righteous place. He might also find that, once the dust settles, his sister is calmed by knowing her brother has taken charge of the quest to make her safe.

Don't ask a blind person to see

If you've ever tried to engage in a rational conversation with someone who no longer thinks rationally, you know how supremely frustrating it can become for everyone. I'm embarrassed to think how many times I found myself getting into a debate with my dementing relative and, worse, becoming upset with her for not accepting my superior arguments. Inevitably, I would come to my senses and back off. I'd think to myself, "Idiot, if she were able to be persuaded by fact and logic, she wouldn't be demented. She'd be *compos mentis* and fine."

So much of the decision-making around designing and enacting a treatment plan derives from answers to the question, "Am I asking a blind person to see?" You do not want to force your relative (or child or employee, or anyone else for that matter) into situations where they are overwhelmed by demands they cannot handle. You are simply setting both of you up for failure.

Not long ago I was upset with my diabetic brother when he kept forgetting to bring sugar pills with him. He just needed to put a small pill container in his pocket when he went out the door so he could avoid a hypoglycemic episode and an ambulance ride. But he has intellectual limitations that make reliable compliance with routines a challenge. I could berate him all I wanted to, but ultimately what made a difference was coming up with cuing strategies, such as a big sign on the front door that read, "Take your damned pills!" That has seemed to work just fine.

Maximize dignity and joy

In the early stages, you find yourself constantly assessing the extent of memory loss. You'll ask if they remember going to the movies yesterday or what they had for lunch. That's all reasonable and fine.

But what isn't fair is to keep asking those kinds of questions when you know darn well they won't remember. So if you hear yourself starting sentences with the phrase, "Don't you remember…", discipline yourself to cut it out. You don't want to unintentionally embarrass a loved one who is already sufficiently humiliated by their circumstance.

I once worked hard on a dinner for my relative who has Alzheimer's. She told me how good it was as she cleaned her plate. Not more than five minutes later, though, this is how she responded to my wife asking, "Wasn't that a great meal?" Yes, sadly, the response was, "Oh, we already ate?"

It's terribly easy to say to yourself at that point, "Why should I bother making things special if she doesn't remember it a few minutes later?" or "Why drag her on a snowy day to a concert she'll forget by the time the curtain falls?" It can seem hard to justify the effort and expense.

But then you can come to the following realization (rationalization?): What's most important to someone is their experience in the moment, not their memory of that experience down the road. If Steve prepares a great meal that his sister enjoys, if she's smiling and content, then any costs are well worth it, memories be damned.

Perhaps we could all benefit from more focus on living in the moment, even if memories of those moments come to fade.

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