

# TAKE CARE!

Self-Care  
for the Family  
Caregiver™

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## Becoming a Confident Family Caregiver



Sandy Padwo Rogers

How do you define “confidence”? The average dictionary uses the words “self-assurance,” “self-reliance,” and “certainty.” Ask family caregivers what “confidence” means to them and you’re likely to hear a slightly different description, one that includes such words as “perseverance,” “patience,” and “courage.”

What makes someone confident? We all have things at which we excel, things we are comfortable doing. We all have areas in which we feel knowledgeable and capable. Even the most competent and confident individual, though, can be plagued by feelings of self-doubt and fear when faced with an unfamiliar or extremely stressful situation. Not only are these feelings perfectly normal, they are universal.

Carol Levine, director of the Families and Health Care Project for the United Hospital Fund and a former family caregiver for her husband, says that when it comes to dealing with the healthcare system in particular, you might as well be trying to navigate an alien world. “The system is not set up to be friendly to patients or their families,” she says. “It’s a highly stressful experience and can send even the most confident person into a tailspin. Even medical professionals find it difficult when they are on the receiving end of healthcare delivery.”

Just ask Beth Deckert, a registered nurse whose own confidence level was severely tested when she found herself in the role of family caregiver. “Before my husband was diagnosed with MS, I thought that I could get through any challenge or obstacle because I believed in myself

and my abilities,” she says. “But my confidence plummeted when my husband spent eight days in the hospital. Part of me was exhausted and part of me was angry, resentful, and riddled with guilt. Mostly, though, I was frustrated with the hospital system and how ignorant the system was of the families’ needs. I wasn’t given information about the plan of care unless I asked. I wasn’t offered a place to rest until it became evident I was staying. I felt alone despite the enormity of the walls that made up the institution. To make matters even worse, I realized that as a nurse, I had treated family members the same way I was being treated.” Beth’s words make it easy to wonder: If a practicing medical professional doesn’t feel confident when dealing with the healthcare system, how can anyone else expect to?

According to Carol Levine, one of the first steps to becoming a more confident family caregiver is recognizing the fact that it’s not you but,

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rather, the system that's faulty, and that you are not alone in your feelings. "You have to learn to work in a world that isn't designed to be helpful," she says. The key is to acknowledge that in most situations, learning to work in that world and to build that confidence is going to take time. There are some things you can do, however, to ease the process.

### Get to Know Yourself

Learning to be a confident caregiver begins with a bit of self reflection. What are your strengths and weaknesses? What are you good at? In what areas do you need help? Recognizing your own strengths and limitations doesn't diminish your effectiveness as a family caregiver. In fact, this type of self-analysis is an important step in becoming a better caregiver for your loved one.

Are you naturally curious, always wanting to understand things as best

you can? If the answer is "yes," then you'll likely have an easier time gathering the information you need to make caregiving choices.

Are you comfortable dealing with situations on your own or do you feel better when you have someone with you, supporting you in what you do? If you feel intimidated in healthcare settings, it may be helpful to have someone you trust with you during these types of encounters, especially if you are dealing with a healthcare "crisis." This individual will be able to remember the information presented with more objectivity and can help you keep the facts straight. Try to find a family member or friend who is willing to serve as your healthcare buddy, especially in a time of crisis. Just having that extra support can make a caregiver feel more in control and capable of dealing with whatever comes along.

Knowing your strengths and weaknesses allows you to set boundaries and can give you the confidence to know when to say "no" and when to ask for help — things many family caregivers find very hard to do.

Being aware of your strengths and weaknesses and how they may change as you age is a very important step in becoming a confident and capable caregiver.

Knowing yourself and understanding the circumstances that surround you is the first step. But becoming a more confident family caregiver shouldn't end there.

### Do Your Research

You can gain confidence in yourself by being prepared. One way to ensure that you are prepared is through research. Research takes many forms. One of the most important types of research you can do is to find out as much as you can about your loved one's illness or condition. Knowledge is power and being armed with an understanding of what you are dealing with definitely provides you with a powerful tool for conversing with the various medical professionals taking care of your loved one.

Just as it's important to research your loved one's illness or condition, it's equally important to understand the language of healthcare. We can all imagine how uncomfortable it would be to visit a foreign country without the benefit of knowing how to speak the language; the same goes for your dealings with medical professionals. This doesn't mean you need to receive medical training. Rather, learning a little about medical terms that you may be hearing and being able to use those terms appropriately will help you feel more in control and will put you on more equal footing with those with whom you must communicate. If you want to be treated as a true partner in the healthcare team, do the research and learn the language of the other members of the team.

Research isn't only about gathering formal information, however; it's just as much about gaining an understanding of how the environments you will encounter work:

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### Use the Internet Wisely

The World Wide Web is our instantaneous link to a wealth of information and ideas. It is also a source of vast amounts of misinformation. Therefore, it is extremely important when working online to get into the habit of using a few safeguards:

- Stick with reputable organizations. Go to Web sites of government agencies, non-profit organizations, and other entities known for their integrity and their public service orientation. (NFCA has a list on its Web site. Go to [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org).)
- Steer clear of information presented by groups with whom you are unfamiliar. The Internet has made it possible for just about anyone to publicize their ideas regardless of whether or not they are based on scientific evidence. Be vigilant.
- Try to find more than one source for the information being presented. If the information you find is reliable, then confirming it on another Web site should pose no problem.
- Keep in mind the source of the information being presented to you. Be on the lookout for any potential bias that may exist on the part of a site's sponsor.

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doctors' offices, the ER, or an adult day care center, for example. Understanding their rules and practices will make you feel more in command of your caregiving situation and help you get the information you need and the respect you deserve that much more quickly and with less hassle.

### Find an Ally

According to Carol Levine, when dealing with the healthcare system, it's extremely helpful to find an ally within the system itself. It could be a nurse in the physician's office with whom you feel a special connection, a social worker at the hospital, or even your loved one's physician. This individual will be more familiar with the system in general and can help answer your questions and give you the inside story on what's happening and why. "Look for someone who is willing to share their experience and provide guidance," says Levine. "These people are out there and they can keep you from feeling incompetent."

### Learn How to Express Yourself

Family caregivers don't always communicate well. It's easy to understand why. Confusion, stress, and

#### Learn How to Communicate Effectively

NFCA created the Communicating Effectively with Healthcare Professionals (CE) program to give family caregivers the tools they need to be effective members of the healthcare team. To read helpful CE articles, go to [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org) and click on Caregiving Resources.

anger can get in the way of good communication. When communicating on behalf of your loved one, however, it's crucial that you learn to communicate clearly and to avoid putting the individual on the other end of the conversation on the defensive. Stay focused on clear goals and concrete questions when talking with physicians and other healthcare professionals. Control any impulse you have to express

anger. Instead, learn to express yourself in a way that is likely to get the results you want. What do you want to accomplish in the short term? What are your immediate goals? By expressing those goals calmly and clearly, you are more likely to get the results you want. Remember, it's in the best interests of your loved one to handle the situation at hand. You can always seek redress later if necessary.

In terms of communicating your loved one's needs, you have a vital role to play. In the healthcare setting, it's important to show respect for the training and knowledge that the physician brings to the table. Don't forget, however, that you have an expertise that is just as valuable in that you know your loved one better than anyone else.

Because of your expertise, and because of the role you play in your loved one's care, you have the right to be treated as an equal partner in the healthcare team. To ensure a successful healthcare encounter, you need to take charge of the process. If that means politely refusing to leave a doctor's office until all of your questions are answered, that is your right. If it means insisting that you get a second opinion before you and your loved one make a major healthcare decision, that is your right as well. Don't underestimate your role in your loved one's care. After all, if you don't look out for his or her best interests, who will?

### Be Proactive

There are concrete actions you can take to feel more prepared and in control, especially in the event of a healthcare crisis. One proactive step you can take is to ensure that you and your loved one have the legal paperwork necessary for making critical medical decisions. No one likes to deal with these things, but proactive people make it their business to find a way.

Every family caregiver should have a folder of important papers, including the following legal documents:

- A durable power of attorney for healthcare.
- An advance medical directive or living will.
- A do-not-resuscitate order (DNR), if desired.
- Authorization forms for the release of information for office visits, operations, and other medical procedures.

All of the legal documents you will need are easy to complete and may be obtained from your local hospital, your attorney, or your state's attorney general's office. Keep in mind that the legal requirements for, and the effect of, these documents vary from state to state. Once you have the proper documents completed, make sure they are easily accessible in the event your loved one must be hospitalized.

Proactive people always have a better chance of staying on top of a situation, but being proactive doesn't come naturally to all of us. If being proactive isn't in your nature, then you need to find a family member or friend who is. This is especially important if you want to feel at least somewhat in charge of what happens to you and your loved one.

### Give Yourself Time

Gaining confidence takes time and courage. "To be a true advocate, you

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have to be willing to put yourself out there a little bit," says Carol Levine. "Advocates are not always the favorite person in the room, but theirs is a necessary and important job. Over time, you learn to understand the system and to navigate it as best you can."

For Beth Deckert, time spent learning how to navigate the system as a family caregiver rather than a nurse allowed her to gain a new confidence that she has put to good use. "Several months after my husband's hospitalization, I realized that because of the struggles I had endured I had gained a new level of confidence that I wanted to use to help others," she says. "I had struggled greatly not just on a physical level but on an emotional and spiritual level as well. But I realized that I

had survived that tough time. I believed in myself enough to contact the vice president of nursing at the hospital I worked for and I shared with her what family members encounter when they have a loved one in the hospital. Before I knew it, we were discussing possible opportunities to support families. That was a true beginning for me, and it was based on a new level of confidence I had never before experienced."

What many family caregivers have discovered is that "confidence" in caregiving will mean different things to different people. As Beth Deckert explains, "Confidence isn't just one thing. It's something that's built one step at a time. It's having the confidence to say 'no' to the way things are as well as having the confidence to keep focused on the opportunities that exist within the challenges." ■

*Sandy Padwo Rogers is the managing editor of TAKE CARE!*

## Do you receive NFCA's monthly E-letter?

If not, you are missing out on this important membership benefit. Send your name, e-mail address, and membership number (located on the newsletter mailing label) to [communications@thefamilycaregiver.org](mailto:communications@thefamilycaregiver.org). Providing this information will ensure your access to this and other benefits of membership.

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When calling the advertisers whose products and services appear in this newsletter, please tell them you saw their advertisement in TAKE CARE!

## Have You Visited NFCA's New and Improved Web Site?

Take a tour and you will find:

- Twelve easy buttons on the top of the page to help you find information
- Updated statistics, resources and information
- Exciting new ways to connect with other family caregivers
- A special new section on improving caregiving
- Information on your state CCAN volunteers
- Online access to the NFCA newsletter, TAKE CARE!
- An enhanced search engine to help you find your favorite pages quickly
- Access to the NFCA store ... and so much more!



[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

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Education, Support, and a Public Voice