



For
the New
Caregiver



Five Ways to Ease
the Path



Jolyon Hallows

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For the New Caregiver

I've been a caregiver for over twenty years, and I've written a book that deals with caregiving¹. So I'm often asked, "What piece of advice would you give for the new caregiver?" Piece? I have a truckload of advice, most of it gained from my own struggles to give care to my wife, all of it I wish I had known at the start.

In 1996, she was diagnosed with Parkinson's disease and I became her caregiver. I had no idea what that meant, so I had to go through a lot of "on the job" learning. In her last few years, she needed help in all areas of her life: feeding, dressing, hygiene. It was up to me to provide it, so I think I have some qualifications—more like scars—that entitle me to offer advice. I hope it helps you. And if you're not a new caregiver, I hope the advice also proves useful to you.

A couple of words about my terminology. First, I am going to use the term "caree" for the person you're giving care to. Why? Because the usual term, loved one, isn't always apt. I've met those who give care to people they don't love. Perhaps it's out of a sense of responsibility or financial interests. Whatever the reason, "loved one" doesn't fit. If you prefer to use that term, use it. If you find "caree" too clinical, avoid it. It's your choice.

Second, I'm going to refer to your caree as "she" or "her." Why, because I don't like the trend to "them" or "their" and for me, my caree was my wife. And as the person who wrote this, I get to choose. If your caree is a man, please don't be thrown off.

In summary, here are the pieces of advice:

1. Learn
2. Find a confidante
3. Reach an agreement with your caree
4. Practice self-care
5. Get help

Let's look at each one.

1. Learn

You are about to start a new job and unless you're a nurse or care aide, you don't know how to do it. Even if you are a nurse or care aide, being a family caregiver makes demands that are outside your normal duties. So regardless of where you are starting from, you need to learn and there are three areas in which learning is critical: how-to, the disease, and services.

How-to

How do you give a bed bath? Dress someone who can't stand? Make sure medications have been taken? How do you transfer someone without wrecking your back? These and endless other questions constitute the "how-to" part of caregiving. Where do you learn them? From those who do them every day. Bring in a care aide. Hire one if necessary. Then have her teach you. Watch how she feeds your caree. How she transfers her. How she dresses her. Ask questions. Practice while the care aide watches. You may have to pay her, but it's a cheap education.

Consult with an occupational therapist for equipment such as a patient lift or wheelchair. Consult with a physiotherapist for advice on transferring or mobility exercises. How do you find these people? Ask your doctor or your caree's case manager (more about that later).

¹ *A Parkinson's Life: And a Caregiver's Roadmap*. Available at www.AParkinsonsLife.com.

The Disease

Study the disease that has disabled your caree. Whether it's Parkinson's, Alzheimer's, or any of the other afflictions that curse some of us, understanding it improves the level of care you'll be able to give. Learn the specific requirements of treatment. For example, with many diseases, the timing of medications is not important, but with Parkinson's, it's critical to give them exactly on time so you don't disrupt the "on/off cycle."

Research available treatments and technologies. Would any of these benefit your caree? Don't be afraid to ask specialists about other treatments or programs.

Learn about medication side effects. For example, one side effect of some Parkinson's medications is a loss of inhibitions leading to uncontrolled gambling, shopping, or sex. Be alert to these so you can intervene if you see early signs. Intervening does not mean confrontation. It can as simple as calling your caree's doctor.

Where do you learn about the disease? From the medical specialists who treat your caree, from local and national organizations that deal with the disease, and from your local library. Spend a couple of hours there scanning the books they have on the disease, then borrow, or buy the ones that appeal to you.

Services

Learn what social services are available in your area. Do you qualify for home care? How do you access it? Is there a day program for your caree? Respite care? How do you qualify for these, what restrictions do they impose, and what do they cost? Many places offer specialized public transit for the handicapped, free transit for caregivers, or reduced taxi fares. Even some airlines allow caregivers to travel for free—although they still have to pay the taxes and fees.

Where do you find out about these? From your caree's doctor or case manager. One rich resource is local or national organizations that deal with the disease.

2. Find a Confidante

Caregiving is hard, both physically and emotionally. You don't get to do it for just eight hours a day then go home. It is relentless. There will be times you need to vent, to curse, to cry. And you will need someone to listen. Who should that be?

An obvious choice is friends and family. If you have a solid relationship with them, great. But I never used them to vent because that would have altered their roles from that of peer to that of informal counselor. I needed them to be there as friends and family members. I had another reason for not using them as confidantes: there were times I had to say things that would have startled, even shocked them. I didn't want that. Above all, I didn't want someone I cared about to pick up the phone, think, *I can't handle another rant. I'll call later*, then hang up.

Other than family and friends, there are three good choices for confidante: a therapist, a spiritual advisor, and a support group.

Therapists are great confidantes. The good ones don't judge and they will give advice and support. But they're expensive, a hundred dollars an hour and up. Some organizations that deal with the disease offer counseling and there are non-profit services available. Check with your doctor, your caree's case manager, or the organization that deals with the disease.

Your spiritual advisor may be a confidante, but with one caveat. Many spiritual advisors are more concerned with your soul and in that role, they judge you. It's their job. But you need someone who won't judge. Someone who will listen, sympathize, and give support. If you can establish that role with your spiritual advisor, great. If not, be careful. You don't need to have someone pile guilt onto the emotional turmoil you're already experiencing.

Support groups are a wonderful service. They're usually free or charge a minimal amount to pay for the meeting room. The effective ones do just what you need: listen, sympathize, offer relevant advice, and support you. Look for a support group for caregivers, not for people with the disease your caree has. Support groups have another crucial advantage. Because their members are also dealing with the disease, they are a rich source of information about practitioners, programs, and services. I got a lot of hard information from my support group.

But for some people, support groups have an unfortunate association with a touchy-feely-huggy culture which can deter non-touchy-feely-huggy people from seeking them out. For others, disclosing intimate thoughts to strangers is awkward. But don't let your concern prevent you from experiencing the value support groups offer. Seek one out. There's nothing wrong with holding back, disclosing only bland information until you become comfortable.

Where can you find a support group? Organizations that deal with the disease often have lists of them. And at the risk of repeating myself, I caution you to seek out a caregiver's support group, not one for people with the disease. You need to talk to other caregivers exclusively.

The "Early Warning Sentinel"

One of the risks in caregiving is that a caregiver can slide into an emotional state that is consuming. Some succumb to rage, others to clinical depression. Both states are uncontrollable, dangerous, and need professional help. But how do you know when you need that help? Rage and depression both block rational judgment, so you need someone to provide it for you.

Recruit someone you trust to be your "early warning sentinel." Choose a close friend or family member, someone who knows you, cares about you, and whom you see often. Ask this person to be alert to changes in your demeanor, your habits, or your appearance and to report any concerns to your doctor. Make sure you also speak with your doctor in advance. You are not asking your friend to confront you, although he or she may choose to. You are asking someone who is close to you to keep a kind watchful eye on you and to make sure you get the help you may need.

3. Reach an Agreement with Your Caree

I once met a man who had walked out on his wife after she had been diagnosed with breast cancer. My initial reaction was that he was a jerk, but we had a long conversation in which he said the diagnosis had embittered her and had made her abusive toward him, even blaming him for the disease. He finally reached the point where he couldn't take it any more and left.

If you want to object that I only got his side of the story, you're right, but that's not my point. My point is that we caregivers need appreciation and thanks for all we do, otherwise we can start to feel like indentured servants.

So my advice is to make an agreement with your caree at the start of caregiving. This is it: I will look after you and take care of your needs. In return, I need you to acknowledge and appreciate everything I'm doing.

Some writers on caregiving use the term "care partner" in place of "caregiver." In this brochure, I've used the original term, but for this agreement, "care partner" is more appropriate because you are partners, working together.

How do you reach such an agreement? If this is a hard conversation to have, recruit your doctor or your pastor or a close friend to help. It won't make the work of caregiving any easier, but it will make it more meaningful.

4. Practice Self-Care

If there's one message that counselors, social workers, doctors, and therapists emphasize to caregivers, it's "Look after yourself." There are two reasons. The one you'll hear most often is that you need to take care of yourself so that you can take care of your caree. While that's important, there's a second, more crucial reason.

I once had a potential medical problem that led a friend to say, "You can't get sick. Who'll look after your wife?" My response was, "Gee, thanks." This is the second reason to look after yourself. It's something we all should do.

But what does it mean to look after yourself? It means making the time and opportunity to do the things you enjoy, whether that's going to the gym, meeting a friend for lunch, enjoying a round of golf, or just reading and relaxing. It's called "life" and you need to live yours.

If your caree is still independent, finding that time won't be hard as long as you look for it and insist on taking it. But as she worsens, as the demands increase, as she reaches the point where you can't leave her alone, making time for yourself will be a struggle. That's when you need to ensure your caree is looked after when you're out doing what you enjoy. Here are some services.

Home care will send qualified care aides to look after your caree while you're gone. There's usually a charge and a limit to the number of hours you can get, but the care aides are trained and capable. When you first contact the home care agency, they will assign your caree a case manager who will visit you and assess the level of support your caree needs. The good agencies insist on an annual review.

If you can't get home care or if you have exceeded the hours available, call a private nursing agency. Their care aides are also well qualified and are often willing to do more than the basic care, including light housework. But they are more expensive and they usually have a minimum hours requirement.

Day programs are excellent. You drop your caree off in the morning and pick her up in the afternoon. The program staff will provide meals, games and entertainment, and socializing, and they will also give medications. Some of them will even arrange to pick your caree up if you can't get her there. You can find out about day programs and their cost from your caree's case manager or your doctor.

If you need to be away for several days or you just feel the need for an extended break, check out respite care. This is a private room, usually in a care home, where you can place your caree for a few days. Your caree's case manager can give you information including costs and limits on the number of days you qualify for.

In some care homes, respite guests can participate in programs and services that the home offers, such as hairdressers. One caution. If you remain in town when your caree is in respite, don't visit her. She will want to come home and can become upset when you take her back to respite. I made it a point to call my wife every day she was in respite, partly to talk to her and partly to reassure her I wasn't abandoning her.

Finally, you can hire a care aide. This can be expensive, but there may be a program in which insurance or the local health authority subsidizes the cost. Your caree's case manager can tell you more. When you hire a care aide, you are the employer, able to specify what you want her to do. You are also responsible for government employment requirements such as tax deductions. If you're concerned about the paperwork, you can hire an accountant to handle it for you. Some programs will even cover the accountant's costs.

5. Get Help

Asking for help can be a problem for both men and women, but for different reasons. Men are susceptible to the “Real men don’t need no help” attitude. We’ve been taught to handle our own problems. To tough it out and not complain. Asking for help is a sign of weakness.

Women can fall into the attitude that, “As a woman, I’m supposed to be a carer.” They’ve been taught that nurturing is their role. Asking for help is a sign of failure.

And yet there will come a time when caregivers reach the point where they need help. Most diseases are progressive and as the caree worsens, the demands of caregiving become more acute, more time-consuming, and harder, both physically and emotionally.

How do you know when you’ve reached that point? My advice is to find help before you get there. Why? For two reasons. First, the breaking point is not a pleasant place to be. It can result in health problems or even physical violence.

But the second reason is more humbling. For several years, various people advised me to get help. My doctor, the case manager, friends and family, even a patron at the coffee shop we frequented all told me I needed some relief. I always resisted because I told myself I didn’t need help. I was handling it fine.

I still think I was, but the day came when it became obvious to me that I was struggling. So I relented and hired a care aide. By the second day, I was astonished. The care aide was giving my wife personal care I hadn’t even known about. She called it “pampering.” She was leading my wife in range-of-motion exercises and experimenting with different foods to find ones my wife would gobble up. She spotted a couple of potential medical problems that I had seen but not recognized the significance of.

In short, she was giving better care to my wife than I ever had. This shouldn’t be surprising. She’s a trained professional. It’s her job. But I wish someone who had been urging me to get help had said, “Listen, bozo, it’s not about you. It’s about giving the best possible care to your wife. So get help. Any relief you get will be a benefit, but you need to do it for her.” If I had understood that, I’d have hired a care aide years earlier and my wife would have benefitted from superior care.

Summary

Caregiving is hard and you don’t get to choose what care you’ll have to give. That’s a function of the disease and your caree’s condition. But how hard it becomes is partly up to you. If you approach it with the attitude that you need to learn, to be open to help, and to make sure both you and your caree have the best possible life, caregiving will be easier. It will never be fun, nor will it ever become a path you’d choose, but how well you handle it is in your control. I wish you well in your caregiving journey.