

The Three Dimensions of Caregiving

If you are your loved one's caregiver, this means that as she declines you are responsible to look after her and to make sure she eats, wears clean clothes, takes her medications, bathes, has some form of entertainment, and is safe.

This takes twenty-four hours a day, seven days a week, relieved only by the occasional stay in respite or the attention of care aides. It can break anyone and therefore demands that you take some time to look after yourself. After all, in an airliner, when the oxygen masks drop, you're supposed to put yours on first.

There is an anecdote, exploited by motivational speakers, called the "boiling frog." According to the story, if you put a frog in boiling water, it will jump out, but if you put it in cool or tepid water and gradually heat it, the frog will remain in place until it's cooked. Biologists have debunked this—apparently frogs are smarter than motivational speakers—but the story has become a metaphor for how people slide into behaviors over time that they wouldn't take on all at once. And that describes the progress of caregiving.

With Parkinson's, the changes in your loved one will, in most cases, be gradual, as will the demands on your time and effort. At first, you may simply have to help her get up from a chair. When you go for a walk, holding her hand becomes less a gesture of affection and more a means of support. But over time, you will notice that you have become responsible for helping her with all of the activities of her life. And the changes will have

crept up on you in increments, giving you the chance to get accustomed to each one before the next one comes along.

Few of us know how to be caregivers, and aside from training programs for professionals, there are no courses in it. When I reviewed the literature for this book, I was struck by the lack of information for or by caregivers; most of what I found was aimed at patients. Even the websites I found dealt almost exclusively with the emotional side: the anger, grief, despair, and frustration. This was not enough. I agree these are important. But for me, one of the biggest sources of frustration is having to face a problem and not knowing how to deal with it. I wanted something else. I wanted to know how.

So everything I have learned has been from experience, and as writer Steven Wright said, “Experience is something you don’t get until just after you need it.” My journey would have been easier with some kind of road-map. I hope what I’ve learned helps you.

I need to make three points. First, while I am the caregiver for my wife, Sandra, not all caregivers look after their spouses. Some care for elderly or infirm parents, some for disabled adult children, and a few for friends or more distant relatives. Much of what I’m saying assumes your loved one is your spouse. If that’s not the case, please modify the advice to your personal situation.

Second, a note about the terminology I’ll be using. Parkinson’s affects both men and women, but “him or her” or “he or she” gets tiresome, and as a writer, I have too much respect for the language to violate its grammar with “they.” So in this section, I’ll be referring to your loved one as “she.” For me, that’s true, and as the one who wrote this, I get to choose.

Third, Sandra has Parkinson’s, but many caregivers deal with loved ones who have other conditions. If that’s true for you, I hope this information helps. Much of caregiving is specific to the disease: medical interventions vary as do symptoms. But much of it is in common. Giving a sponge bath doesn’t depend upon the condition. Neither does feeding or hygiene. While I can’t comment on the care that depends on the condition, I hope I can help you with its other aspects.

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Caregiving is a mix of physical activities such as giving medications to your loved one or feeding her; installing structural features such as grab bars in the shower or a medical alert system; and dealing with the emotional turmoil that caregiving brings. In the following chapters, I deal with each of these dimensions: physical, structural, and emotional.

Now, I'm sure that some of the pickier readers will say of some activity, "That's not physical, that's structural," or "That activity is both physical and emotional." Disagreement is a risk whenever we try to put anything into categories.* But it doesn't matter where an activity goes, so if it satisfies you to shuffle them around, be my guest. Just don't lose any of them.

A Word about Professions

You are about to enter a world teeming with people who bring various skills to the care of patients: doctors, of course, but also different types of therapists, nurses, care aides, and others. Let me introduce you to the menagerie of specialists, what each one does, and what you can expect from them.

In the following list, I have included some specialties that overlap or may be confusing. I have not included practitioners of alternative medicine.

- Neurologists are medical doctors who specialize in conditions of the central nervous system, including the brain. Many neurologists don't focus on Parkinson's (although most of them have had to deal with it). Their primary interest may be disorders resulting from brain tumors or head injuries.
- Movement disorder specialists are neurologists who deal with diseases such as Parkinson's that impair movement.
- Psychiatrists (note: not psychiatrists) are medical doctors who deal with disorders of the musculoskeletal system, in particular the management of pain.
- Geriatricians *vs.* gerontologists. Geriatricians are medical doctors who specialize in diseases of the elderly. Gerontologists are non-medical specialists who study aspects of aging.

* For example, astronomers quarreled for years over whether Pluto should be categorized as a planet. Pluto lost.

- Psychiatrists *vs.* neuropsychiatrists *vs.* psychologists. Psychiatrists are medical doctors who specialize in disorders of the mind such as dementia or psychoses. Neuropsychiatrists are medical doctors who combine neurology and psychiatry. Psychologists are non-medical professionals who study, among other things, the mind and behavior.
- Physiotherapists *vs.* occupational therapists. There is some overlap here, but broadly, a physiotherapist treats conditions such as injuries or physical disabilities, while an occupational therapist reviews and makes recommendations on the patient's environment, including devices to assist in what they call the "activities of daily living" or ADL.
- Nurses—registered, licensed, practical, and practitioners. The differences between the levels of nursing are those of education and the services the nurse is qualified to provide. Registered nurses (RNs) have the highest level of training and the most responsibilities. In some jurisdictions, nurse practitioners are RNs who have taken advanced courses and are authorized to provide some functions usually restricted to doctors, particularly in remote or small communities. Licensed and practical nurses (LPNs or RPNs) have fewer responsibilities and usually work under more senior nurses.
- Care aides are professionals who provide hands-on care, either in an institution or as part of home services.