

chapter 1

THE CAREGIVER'S ROLE

If you're reading this book, chances are good that you are either a caregiver, or are facing the possibility of becoming a caregiver. Maybe you've been caring for your disabled spouse, or perhaps your aging parent is beginning to show signs of dementia. You're probably struggling with all kinds of difficult questions. Chances are that the person you're caring for never made any real plans for what to do in the event of physical disability or dementia.

Most family members who help their older loved ones don't see themselves as caregivers. Yet a caregiver is anyone who helps an older person with household chores, errands, personal care, or finances. Most caregivers also don't realize that caring for themselves is an important part of providing care for someone else. The simple truth is you can't be a good caregiver if you don't take care of yourself.

If you have been taking care of your spouse, perhaps you are afraid of giving up the caregiver role, even if your own health may be deteriorating as a result of the stress of having to care for your spouse. If you are an adult child, perhaps you are worried about having to provide care for a parent with diminishing health and declining capacity. It is often very difficult for an adult child to step into a relationship reversal by taking over the parental role, but that is often exactly what happens — the child must become the parent, and the parent assumes the role of the child. This transition is fraught with conflict, confusion, and pain. If you're an adult child, most likely you have a career, children, and your own family and personal limitations to deal with. How can you possibly be expected to have to take care of your parents also?

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Many conflicting thoughts and emotions arise when someone is confronted with having to care for an aging parent or a disabled spouse:

- **Love and Responsibility:** a desire to provide the best care for your spouse or for your parents.
- **Fear:** fear of losing your spouse or parent; fear of losing control; fear of the unknown; fear of not being able to conserve financial assets for future needs.
- **Confusion:** not knowing what long-term care options are available, how to get the best care, how much money will need to be spent on nursing care.
- **Guilt:** for not being able to do more for your spouse or parent.
- **Anger and Frustration:** over the fact that your spouse or parent failed to plan ahead and foresee that this day might come.
- **Resentment:** over why you are the one stuck being the primary caregiver.
- **Conflict:** constant arguments with a spouse or parent who has progressive dementia.
- **Self-preservation:** worry about how much of your own limited resources must be used to provide care for your spouse or parent.

All of these feelings are normal and are neither good nor bad. Give yourself a break; being a caregiver is hard, often underappreciated work. Negative feelings do not mean you love the person any less. Allow yourself to feel how you feel and forgive yourself for any negative feelings.

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CAREGIVER STRESS TEST

Which of the following are seldom true, sometimes true, often true or usually true?

- I find I can't get enough rest.
- I don't have enough time for myself.
- I don't have enough time to be with family members other than the one I care for.
- I feel guilty about my situation.
- I don't get out much anymore.
- I have conflict with the person I take care of.
- I have conflicts with other family members.
- I cry a lot.
- I worry about having enough money to make ends meet.
- I don't feel I have enough knowledge or experience to give care as well as I'd like.
- I worry about my own health.

If the response to one or more of these areas is usually true or often true, it may be time to look for help with giving care and help with taking care of yourself.

WHAT YOU CAN DO

Take charge of your life. Don't let your loved one's illness or disability always take center stage. While you might fall into a caregiving role because of an unexpected event, somewhere along the line you need to step back and consciously say "I choose to take on this caregiving role." It goes a long way toward eliminating the feeling of being a victim.

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Set realistic goals. Caregiving creates many conflicting demands on your time; it is vital to set realistic goals. Recognize what you can and cannot do. Define your priorities and stick to them as much as you can. You have the right to set limits and, though it is hard, it is okay to say no.

Seek out help from family and friends. When others offer assistance, accept it and suggest specific things they can do. Some caregivers see asking for help as a sign of weakness, failure or inadequacy, when in fact it is just the opposite. Reaching out for assistance before you are beyond your limits is one characteristic of a strong person. While they might not be comfortable helping with bathing and dressing needs, friends and family can help by running errands, shopping for groceries, preparing meals or just visiting. They can call regularly, taking some pressure off you to be the primary social outlet.

Seek out appropriate geriatric medical professionals. A geriatrician is a medical doctor who is specially trained to prevent and manage the unique health concerns of older adults. Older persons may react to illness and disease differently than younger adults. Geriatricians are able to treat older patients, manage multiple disease symptoms, and develop care plans that address the special health care needs of older adults. Geriatricians are typically primary care physicians who are board-certified in either Family Practice or Internal Medicine and have also acquired the additional training necessary to obtain the Certificate of Added Qualifications in Geriatric Medicine. You can find a listing of Virginia geriatricians in **Appendix E** (page 143) of this book. You can also locate a geriatrician in your area through the Web site of either the American Medical Association (www.ama-assn.org) or the American Board of Family Medicine (www.theabfm.org).

Seek out the assistance of a Geriatric Care Manager (GCM). GCMs are professionals with degrees in one or more fields of human services (e.g., social work, psychology, nursing, or gerontology),

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who specialize in assisting older people and their families with long-term care arrangements. GCMs are typically independent from the resources they recommend, so they can provide an unbiased assessment of each situation. GCMs can work with families and elders prior to the need for services and can also assist in emergency situations. You can find a listing of Virginia GCMs in **Appendix F** (page 147) of this book. You can also locate a GCM in your area through the Web site of Mid-Atlantic Geriatric Care Managers Association (www.gconline.org).

Investigate community and professional resources such as in-home health services or adult daycare. Employ a home health aide to cook, clean and help with bathing, eating, dressing, using the bathroom and getting around the house. Check your local phonebook under “Home Health Care Providers.” These are the types of services that an older parent should expect to have to pay for if they are not available for free in the community.

When you just need a short break, consider respite care. You can hire a companion to stay with your care-receiver for a few hours at a time on a regular basis to give you some time off. In addition, most nursing homes and assisted living facilities offer families the opportunity to place older relatives in their facilities for short stays. Your local area’s agency on aging can help with arrangements. All Virginia Area Agencies on Aging and numerous other helpful resources are listed in **Appendix B** (page 129).