

Caregiving - An Important Role

Respite Care - A Necessity

Regardless of how we become a caregiver it is often a shock and always an emotionally draining experience. In the "hubbub" that follows, amidst the reorientation of our schedules, the search for resources, the fears about the future, and the challenges of the day—to—day, we never stop to think about what has happened and devise a plan that takes into account the health and well being of all concerned — including ourselves. We just go on automatic pilot and do, and do, and do.

Somewhere along the line however, it is vitally important that we do stop, take a breath, and try to gain some control over the situation, rather than letting the situation control us. It is vitally important that we choose to take charge of our lives, and believe in ourselves.

What does that mean — choose to take charge of our lives? Obviously we cannot control everything that happens to us, or to our loved ones. But we can make active choices about how we are going to deal with the circumstances of our lives.

- Caregiving is complicated. It is forever changing, and it usually involves a variety of people, not just the caregiver and the care receiver. Recognizing this is critical if we are going to give ourselves permission to actively make choices and not always be on the receiving side of consequences.
- The choices that we can make, or have to make, during the course of our caregiving experience will change as circumstances change. It is impossible to really know what it would be like to have your mother living with you and your family when she is frail and needs lots of help if she is only 61 years old now and the picture of health.
- Knowing that circumstances change, including our own health and innate capabilities is vital to learning to believe in yourself.

Believing in yourself means recognizing your strengths and your limitations and knowing that it is okay to set boundaries, and to say: "yes I can and will do this, but I'm sorry, I just can't do that".

- Being a caregiver, a willing and loving caregiver, doesn't mean you discard the word "no" from your vocabulary.

We need to know our own limits and the consequences of our actions.

- The lifting we could easily do five years ago, may be having dire consequences for our back today.
- When we started spending more time helping grandma it didn't seem to impact the kids, but now they are feeling the loss of our attention and getting into trouble at school to prove it.

Caregiving is a relationship — between many people. Believing in yourself recognizes that you are one of those people. Making choices in your own interests isn't selfish — it is often the most important thing you can do for all concerned.

What does it mean to be a happy person when you are a family caregiver?

How can you gain a feeling of confidence in your abilities and have a sense of pride in your achievements?

How do you stand up for yourself, take care of yourself and find a balance between your own needs and those of your loved ones?

These are important and heady questions!

Four Messages to Live By

1. Believe in Yourself — and Take Charge of Your Life

Often we become caregivers very suddenly, without warning — a husband is diagnosed with cancer, a child is in a car accident, a parent has a stroke. At other times, caregiving creeps up on us — we know mom is forgetting things and we slowly start taking on some administrative tasks and calling more often, until one day we realize she no longer has the capacity to live safely on her own.

2. Protect Your Health

It is easy to lose your true self while being a family caregiver. It is easy to lose your identity as an individual and that is why it is so important to cling to the core of your personality.

- Do the things that make you happy, that let you say: "I feel like 'me' when I am doing this or that, or I like 'me' when I am being this way."

Caregiving so often keeps us off balance. It is easy to get lost in its physical and psychological maelstrom—the sadness, the frustration, the stress and strain on your body and your mind, the financial worries, the emotional pain—you know them well. All the more reason to step out of the frame on a regular basis, and rekindle your special light by cultivating the other parts of yourself, to learn to give to yourself in addition to giving to others.

- The morning jog you take that provides a surge of energy and a sense of well being.
- The career that not only "brings home the bacon", but also provides you with personal satisfaction.
- It might be as simple as a 15 minute bubble bath you allow yourself every Friday evening as a way to calm yourself down and welcome the weekend.

How do you create some balance between caring for others and caring for yourself?

- Believe in your value as a human being and your right to a few minutes of personal space, at least several times a week. If you can take more than that, it is a bonus from which you will prosper, but all of us, even the busiest of caregivers can find 10 or 15 minutes several times a week to care for themselves. The trick is to start and to focus those few minutes on you, your interests, and your dreams.

The idea is to love, honor, and value the essential part of yourself that you've slowly been losing to caregiving.

- Whether its taking long walks, practicing yoga, painting, praying, baking, or reading, the specific act doesn't matter. What matters is staying in tune with the question: "if you are not for yourself, who will be for you—and if not now—when."

3. Reach Out for Help

In caregiving circles we hear a lot about the word support. Family caregivers regularly seek supportive relationships with other caregivers, knowing they can provide the emotional sustenance needed during difficult times. What support doesn't do however, is change the circumstances under which you are living. It doesn't relieve you of some of your responsibilities. That's the work of a different word—and that word is HELP.

Providing help is something that family caregivers know a great deal about. It is what we do every day. The question is how often does someone lend you a helping hand? If you are like most family caregivers, the answer is not often enough.

We have learned that the first step in getting help is the recognition that caregiving is far too big a task to undertake alone. This is true for all caregivers, but particularly for those who are assisting loved ones with multiple needs or providing round—the—clock care.

- Some people have a hard time admitting they need help.
- They feel guilty even thinking they can't juggle everything themselves, or they believe no one else can do their job as well as they can.
- They forget that the totality of caregiving, like all jobs, is made up of lots of individual tasks, not all of which are of the same importance, or require the same skills.

Many people think asking for help is a sign of weakness, but that isn't so.

- Asking for help is a sign of strength because it is an acknowledgement of the difficulty of the situation at hand.
- It is a sign of strength because it requires putting pride aside and acting in the best interest of your loved one and yourself, and that isn't an easy thing to do.

Respite Care

Respite is the service most often requested by family caregivers, yet it is in critically short supply, inaccessible, or unaffordable regardless of the age or disability of the individual needing assistance.

- **What is respite?** Respite provides temporary relief (respite) from the tasks associated with caregiving. It is intended to provide time off for family caregivers who ordinarily care for someone on a regular basis.
- **Where do you find it?** Respite care may include in-home assistance, a short-term nursing home, assisted living stay or adult day care. Respite can vary from a few hours to several weeks.

While the focus has been on making sure families have the option of providing care at home, little attention has been paid to the needs of the family caregivers who make this possible.

- Research has shown that providing respite can have a positive effect on the health of the caregiver.
- Without respite, not only can families suffer economically and emotionally, caregivers themselves may face serious health and social risks as a result of stress associated with continuous caregiving. Three fifths of family caregivers age 19-64 surveyed recently reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non caregivers.
- Respite has been shown to help sustain family caregiver health and wellbeing, avoid or delay out-of-home placements, and reduce the likelihood of abuse and neglect.
- An outcome based evaluation pilot study show that respite may also reduce the likelihood of divorce and help sustain marriages. http://en.wikipedia.org/wiki/Respite_care

4. Speak Up for Yourself

The first step in standing up and being counted as an advocate for your loved one and yourself and as an activist for all caregiving families is to recognize that you are a family caregiver, in addition to being a wife, a mother or dad, a daughter or son, a sister, brother, friend, niece, etc. It is important to acknowledge your role as a family caregiver because that bonds you with the millions of other family caregivers in America who share many of the same worries and concerns that you have. Acknowledging that you are part of a group, a very large group, helps provide the strength and the conviction that you often need to Speak up for your loved one and yourself.

In conclusion:

Ten Tips for Family Caregivers

1. Choose to **take charge** of your life, and don't let your loved one's illness or disability always take center stage.
2. Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
3. **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
4. When people offer to help, **accept the offer** and suggest specific things that they can do.
5. **Educate yourself** about your loved one's condition. Information is empowering.
6. There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
7. **Trust your instincts**. Most of the time they'll lead you in the right direction.
8. Grieve for your losses, and then allow yourself to **dream new dreams**.
9. **Stand up for your rights** as a caregiver and a citizen.
10. **Seek support** from other caregivers. There is great strength in knowing you are not alone.

Learn about **Family Caregiving: It's not all up to you** at www.familycaregiving101.org or www.nfcacares.org These sites are designed to provide family caregivers with the basic tools, skills and information they need to protect their own physical and mental health while they provide high quality care for their loved ones.

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Information provided by Highlands Ranch Senior Outreach Services.
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