

Caregiving: A Map of the Territory

Author: Marcia Hutchinson

For: EstateVaults.com

Juggling the responsibilities of caregiving while holding a full-time job, managing a home and family AND still having a life of your own is an enormous challenge. Feelings of stress, exhaustion, sadness, loss of control, guilt, resentment, inadequacy and frustration are all part of the territory. Maintaining your own center and emotional equilibrium while watching a loved one lose their battle for life is one of the hardest things you will ever have to do. But is also an opportunity for profound personal growth as you learn to give of yourself, be of great service, and be present for someone you love during one of life's most mysterious and spiritual passages.

Caregiving has many faces: an adult child nursing aging parents through the end of life; a spouse caring for an ailing or dying spouse; a parent responding to the needs of a chronically disabled child. Responsibilities may range from paying bills and running errands to round-the-clock hands-on nursing. A caregiver can be male or female, young or old. But statistically she is a woman of 57, not surprising since women are socialized to be nurturers and caretakers of others.

It is our cultural "self-image" that we take care of our own, that we do everything we can to keep our loved ones out of institutions if it's humanly possible. There is the unspoken assumption that earlier generations took ailing relatives into their homes and that no one dreamed of sending them to nursing homes or institutions. What we fail to see, is that the world has changed dramatically since those cultural myths developed. We are living through a convergence of social shifts that create a new scenario:

- **Changes in Life Expectancy**

Life expectancies have increased by 30 years over the last century. In the "old days" people who developed an illness either got well or died. Medical advances now allow us to "survive" illness and linger on in a chronically debilitated condition for many years-- requiring the support of caregivers. Advances in home-care technology make it possible and, hence, expected to care for ailing loved ones at home.

- **Changes in Social Demographics**

- People no longer live in the same town in multi-generational families where the tasks of caregiving could be shared by many. In our mobile society, families are scattered far and wide and the responsibilities of caregiving often fall on fewer shoulders.
- Most women work outside the home and are less easily available to care-recipients.

- People are marrying and creating families later in life, finding themselves part of the "sandwich generation" with both children at home and aging parents requiring their care--at the same time.

So when you are faced with the call to help a loved one through a difficult passage, should you drop everything and put your life on hold while assuming the role of caregiver? It is challenging not to fall into this trap. We live with so many oppressive "shoulds." The "loving wife" or the "good dutiful child" "should" sacrifice their own lives to care for a sick spouse or an aging parent. The real challenge of caregiving is to be available to your care recipient while maintaining balance in your life. It often means behaving more like a Project Manager, drawing on personal and community resources, and cobbling together a plan respects the needs of both caregiver and care recipient. It helps to know the terrain.

The Templates of Caregiving

No two caregiving situations are the same. But there are commonalities. Viewing your experience against a template or pattern that others have lived through makes it easier to feel normal in a not-normal-feeling situation. As a caregiver you will be called up to confront "developmental tasks" as you adapt to your new role. Experts have defined stages for viewing the caregiving experience. The stages are not fixed and rigid, and they may overlap and repeat as new challenges arise.

Anticipatory/Expectant Caregiving

When you are first confronted with the need to come to the aid of a loved one, it is a crisis. For some -- what experts call "expectant caregivers"-- you can see a caregiving crisis on the horizon in your future. You then have an opportunity to prepare yourself psychologically and strategically for the inevitable.

- What scenarios seem likely?
- What are your options?
- Who is in a position to help?
- What community resources exist?
- What are the financial realities?

Learning the Ropes

At some point-- either as anticipated or unexpectedly-- you will graduate into the role of "freshman caregiver." You may experience several phases of this stage:

- **Surviving**

You experience your change in role as an emergency to be survived. Shock and numbness are common feelings. To be successful as caregiver you

must survive. To survive, you will need to develop coping skills to do what must be done while maintaining your own center. This is a stage of reacting to an emergency, doing what needs to be done, and getting by staying present-focused and taking one day at a time.

- **Searching**

Still with a sense of urgency, during this stage you will begin to find your stride and feel a greater sense of control over your life in the midst of this great challenge to your emotions and life style. With a greater sense of control comes more energy and resourcefulness. You may find yourself searching internally for answers about your priorities and entitlement and externally for answers about your care recipient' s condition.

- **Settling In**

Here you go on automatic pilot and begin to make peace with the demands of your role and gain a greater sense of control and equilibrium. You find your rhythm, develop a routine and feel a greater sense of competence. This is a practical phase where you become project manager and advocate. During this stage there are great opportunities for deepening your relationship with your care recipient.

- **Separating**

This might include delegating care to another caregiver while you renew yourself or simply stepping back and allowing your care recipient opportunities for independence.

Entrenchment

Approximately two years into the caregiving process, you become entrenched in your role. You are probably exhausted and burned out and feel trapped. It is common to feel resentment and guilt about your resentment. Your major challenge here is to get the support you need to carry on, to realize that you are only human, that you have limits, and that you are entitled to a life apart from caregiving. You need respite if you are to continue while maintaining your physical and mental health.

Transitioning and Confronting Loss

This stage marks a major shift in the caregiving relationship. Here you confront separation and loss when your loved dies or transitions to a nursing home or hospice. Although there usually comes a time when it is better for your loved one and for you to transition them to outside caregivers, it is not unusual to punish yourself for not being able to do more. Be gentle on yourself.

It is time to say good-bye, a time of loss, grief, and relief. Your challenge is to allow yourself to mourn your loss, honor yourself for the sacrifice you have made, while reinventing yourself and re-entering to the world

Throughout the caregiving experience, grief has been a steady companion. You may experience grief over:

- the losses and pain your care recipient has experienced
- the loss of your previous freedom and life style
- the profound changes in your relationship to your care recipient
- the anticipated and actual loss of this important person in your life
- glimpses of your own mortality
- love unexpressed and emotional wounds unhealed

As difficult as this developmental stage of life can be, it also affords you a precious opportunity to learn about yourself-- your generosity and your limits--, to clean the slate and clear away unfinished business --the "if only' s" and "what if"- - to make amends for past injuries, to express the depths of your love, and to come to a place of closure with your parent, spouse, relative, or friend. The more you can live "in the moment" in "the eternal now" and be true to yourself and authentic with your loved one, the easier it will be for you to move forward into the next chapter of your life.