

RESPITE SERVICES

*Enhancing the Quality of Daily Life for
Caregivers and Care Receivers*



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CAREGIVING: RECOGNIZING THE NEED FOR RESPITE



Faculty at the University of Utah Gerontology Interdisciplinary Program have been conducting research related to caregiving since 1984. Over these years, we have learned that many family caregivers are going far beyond their abilities and circumstances trying to be the best possible caregivers.

This is a very commendable goal. Unfortunately, many of these heroic caregivers are risking their own personal well being and sometimes their family life in the process. Many caregivers are not fully aware of the short and longer term consequences of "doing it all alone" because they are so overwhelmed with managing their daily tasks and responsibilities.

We hope that you are not one of these family caregivers, but you may need to pause long enough to read this brochure and find out if you are. The purposes of this brochure are to:

- Help family caregivers better assess their abilities and circumstances
- Allow caregivers to become aware of sacrifices that they are making
- Encourage family caregivers to seek the help of respite services and
- Provide suggestions to make respite most effective.

We are convinced that when caregivers use respite services they are better able to preserve quality in their own daily lives and enhance overall family life. An additional benefit is that the loved ones in need of care usually get better quality care from their caregivers because the caregivers are more likely to have some balance in their lives and better health.

AVOIDING POTENTIAL PROBLEMS



CAREGIVING REQUIRES THOUGHTFUL REFLECTION

Before we describe some of the various forms of respite services, we would like to summarize some of the main findings that research has revealed about caregivers and what often happens when they do not get sufficient help with their caregiving tasks. You need to be aware of these possibilities so that you know what is happening in your own life. We want to help you become better informed so that you can make better decisions about your caregiving situation.

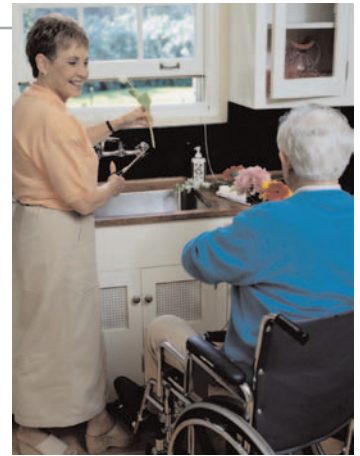
Although not all caregivers experience overwhelming stress, research has documented that caregivers are at a greater risk for experiencing the following problems. Are you experiencing any of them?

- depression
- guilt, anger, resentment & denial
- declines in physical health
- strained social and family relations
- sleep disorders
- anxiety about aging
- neglect of self and others
- less marital closeness
- work absenteeism
- loss of income
- more negative attitude toward care recipient
- loss of free time
- abuse
- sleeplessness
- exhaustion

Research has shown that caregivers can reduce some of these negative results by using respite services along with asking for help from others. Looking out for your own well-being is similar to being a passenger on an airplane and being told that in case of an emergency you should place the oxygen mask on yourself first before caring for someone else. Why? Because you can be a more effective caregiver if you are healthy, happy and alive.

We know from research that family caregivers provide 80% of all the caregiving in the U.S. But we need to be careful in applying the label of "hero" if we end up encouraging caregivers to exceed their capabilities and sacrifice other highly valued and important parts of their lives. Depressed, divorced, and burned-out heroes will not be able to be caregivers for long. The truly heroic caregivers are those who do the very best that they can providing care, but they also recognize and value their own well-being, families and relationships and find a way to balance these competing goals.❖

CAREGIVER BURDEN INVENTORY



PROVIDING CARE TAKES SKILL,
PATIENCE, AND TIME

In order to help you better understand how your caregiving is impacting some important aspects of your life, you can answer the questions on the next page (Caregiver Burden Inventory: Modified). These 24 questions were developed by gerontological researchers Mark Novak and Carol Guest (1989).

This burden scale measures the impact of caregiving on the caregiver's flexibility with time, physical health, social relationships, emotional well-being and life course development issues. We have used this scale in our research studies and believe that it is very helpful in identifying problem areas. We reworded two of the items (#17 & #18) to make the questions more relevant to all caregivers, which is why we call it a "modified" scale (Caserta, Lund & Wright, 1996). After each question, choose a response that describes your feelings or views. If you have a total score above 36 when you add up the points, you are very likely to be at risk for burning out as a caregiver because you indicated a response of "sometimes" on half of the items.

When scores are near or above 36 we strongly suggest that you use respite and other services. (Please remember that earlier we suggested all caregivers use respite, especially long before caregiving becomes stressful.) Before we show you another list of questions to help you evaluate your situation, we recommend that you seriously look at any item on the burden scale where your answer was scored as a 3 or 4 ("quite frequently" or "nearly always"). If you have a 3 or 4 as an answer, you need to give careful thought about why you scored so high on the question and see if you can find a way to reduce the stress you are experiencing.

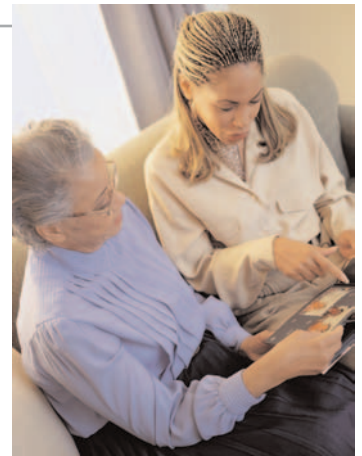
This scale can help you identify specific aspects of your life and situation that might need immediate attention. Also, you might consider contacting your doctor or a mental health professional to get their advice. Near the end of this brochure is a list of national and local resources that you can contact for more information and help. ❖

Burden Scale (Next Page)

For each item circle a number in the columns to the right that represent how often the statement describes your feelings.

Burden Scale (printed with author's permission)		Responses				
		Never	Rarely	Some-times	Quite Frequently	Nearly Always
Items						
Time Dependency Items						
1.	He/she needs my help to perform many daily tasks	0	1	2	3	4
2.	He/she is dependent on me	0	1	2	3	4
3.	I have to watch him/her constantly	0	1	2	3	4
4.	I have to help him/her with many basic functions	0	1	2	3	4
5.	I don't have a minute's break from his/her chores	0	1	2	3	4
Development Items						
6.	I feel that I am missing out on life	0	1	2	3	4
7.	I wish I could escape from this situation	0	1	2	3	4
8.	My social life has suffered	0	1	2	3	4
9.	I feel emotionally drained due to caring for him/her	0	1	2	3	4
10.	I expected that things would be different at this point in my life	0	1	2	3	4
Physical Health Items						
11.	I'm not getting enough sleep	0	1	2	3	4
12.	My health has suffered	0	1	2	3	4
13.	Caregiving has made me physically sick	0	1	2	3	4
14.	I'm physically tired	0	1	2	3	4
Social Relationships Items						
15.	I don't get along with other family members as well as I used to	0	1	2	3	4
16.	My caregiving efforts aren't appreciated by others in my family	0	1	2	3	4
17.	I've had problems with my marriage (or other significant relationship)	0	1	2	3	4
18.	I don't get along as well as I used to with others	0	1	2	3	4
19.	I feel resentful of other relatives who could but do not help	0	1	2	3	4
Emotional Health Items						
20.	I feel embarrassed over his/her behavior	0	1	2	3	4
21.	I feel ashamed of him/her	0	1	2	3	4
22.	I resent him/her	0	1	2	3	4
23.	I feel uncomfortable when I have friends over	0	1	2	3	4
24.	I feel angry about my interactions with him/her	0	1	2	3	4
Total Score = _____ (0-96)						

SATISFACTION WITH CAREGIVING



HELPING OTHERS CAN BE
REWARDING

Caregiving presents many challenges and difficulties but being a caregiver can be rewarding as well. Other researchers have developed a set of questions that can help to identify how much satisfaction family members are experiencing by being caregivers (Lawton et al., 1989).

Please read the following 9 questions or statements and select an answer that best fits your views. Just like on the previous list of questions, you can add up all the points and learn more about your overall satisfaction from being a caregiver. We hope that you will have a score of 27 or higher, because having some satisfaction will help you be a better caregiver. Unlike the other scale, a high score on this scale indicates a positive sit-

uation. A score of 27 or higher means that you "sometimes" have satisfaction related to all 9 items.

Also please look at each statement carefully to learn more about where you get the greatest satisfaction or might want to get more. If you presently do not have much satisfaction, try to identify ways to enhance it. Sometimes professional help is needed, through counseling or simply asking service professionals for their advice.

Again, please review the list of agencies and organizations near the end of this brochure and contact them for more information and help.❖

Respite Can Help Families Continue to Remain as Families



Satisfaction Scale (Next Page)

For each of the following questions circle a number to the right that represents how often the statement describes your feelings.

Satisfaction Scale (printed with author's permission)		Responses			
Items	Never	Rarely	Some- times	Quite Frequently	Nearly Always
How Often Do You Feel. . .					
1. You really enjoy being with him/her	1	2	3	4	5
2. Helping him/her has made you feel closer	1	2	3	4	5
3. You take care of him/her more because you want to than out of a sense of duty	1	2	3	4	5
4. His/her old self is showing through in spite of his/her current condition	1	2	3	4	5
5. That he/she shows real appreciation of what you do for him/her	1	2	3	4	5
6. The knowledge that you are doing your best gets you through the rough times with him/her	1	2	3	4	5
7. That his/her pleasure over some little thing gives you pleasure	1	2	3	4	5
8. That it makes you happy to know that he/she is being cared for by his/her family	1	2	3	4	5
9. I do pretty much what I have to do, not what I want to do, in relation to him/her	5	4	3	2	1
Total Score = _____ (9-45)					



“The primary reason for participating in an activity is to experience the pleasure of doing it.”

– Jitka M. Zgola, O.T.

WHAT HELP DO CAREGIVERS NEED MOST?

In our national study of nearly 900 caregivers, we found that having respite time was their most desired and needed service.

RESPITE BREAKS CAN PROVIDE TIME TO RELAX, READ, AND REVIVE YOURSELF



It is in everyone's best interest to encourage and help most caregivers do a bit less rather than more caregiving, to restore a more appropriate balance in their lives. Sharing the daily tasks of caregiving with family members, neighbors, friends and professionals does not mean that the primary caregiver is weak, unloving, selfish, or failing to meet family obligations. Seeking and obtaining help shows maturity, commitment, concern, self respect and an informed, positive and balanced understanding of the realities of caregiving. We hope that you are among those who are willing to ask for and seek appropriate help from others.

Caregivers often need many different kinds of help, including education, skill training, counseling, emotional, spiritual, social and financial support, legal, home maintenance and transportation services. There is a growing need for care managers, gerontological service specialists and other new types of professionals to help caregivers find their way through a complex system and arrange for an appropriate package of services to fit their specific needs, which also change over time. Many of the organizations listed near the end of this brochure can help you find the services you need.

There is one service, however, that stands out among most caregivers because it has the potential to improve or at least preserve the quality of their daily lives. In our national study of nearly 900 caregivers, we found that having respite time was their most desired and needed service (Caserta, Lund, Wright & Redburn, 1987). Another study in Michigan revealed that service professionals also identified respite as the most needed service for caregivers (Shope et al., 1993). Other studies highlighting the need for greater use of respite are increasing each year (Family Caregiver Alliance, 2006; Koslowski and Montgomery, 1995, Feinberg & Kelly,

1995; Alzheimer's Association Report, 1996; National Alliance for Caregiving & AARP, 2004; Cox, 1998; Zarit, Stephens & Townsend, 1998).

Respite simply means having some time away from the responsibility of providing care. It is an opportunity for caregivers to do just a bit less, have others share the tasks and achieve some well earned balance in their lives. Respite time can be obtained at home or through a variety of adult day centers. It can range from one or two hours at a time to several days each week.

The following quotes from caregivers show some of the diverse needs that respite can help meet.

- "If only I could get a few moments of alone time, it would help me be more patient."
- "I can't take a bath, fix dinner or make a phone call without interruption. I have no privacy."
- "I need to take care of myself personally and to do things not possible when my husband is around."
- "I need time to run errands and spend more time at home alone."
- "I need to be able to work and be with other people."
- "I miss being with my friends."
- "I wish our family could take a short vacation like we did before."
- "I would like to return to work, at least part-time."
- "I wish I could go to a movie with my friends."
- "I want to play golf again or simply to take a walk."
- "I gave up most of my hobbies but would like time to do some of them again."❖

WHAT TYPES OF RESPITE SERVICES ARE THERE?



ADULT DAY SERVICES OFTEN PROVIDE STIMULATING ACTIVITIES FOR CLIENTS

Although not every community has a full range of respite services available, there are several types of services (Hayes, 1999). The most common form is **in-home respite**, usually offered through home health agencies where professionally trained persons make home visits and attend to the needs of the family member who needs care while the caregiver can leave the home.

Another common type of respite is **adult day service**, usually provided at a community-based site such as care centers, nursing homes, churches, assisted living facilities, senior centers and hospitals. Adult day service respite often offers the advantages of establishing regular, sufficient and relatively affordable opportunities for respite. Sometimes community or health service providers offer **overnight** and **multiple days** of respite.

This type of respite can allow families to maintain family vacations and other group activities that far too many caregivers discontinue. Remember, families need respite just as individual caregivers do, in order to preserve quality family life.

Another type of respite that is now available is called **Video Respite**.[®] This refers to a series of 20-50 minute videotapes that we developed to capture and maintain the attention of persons with dementia. Research has shown that these tapes are effective for

many persons with moderate to advanced stage dementia and that they are stimulating, positive and calming (Lund, Hill, Caserta, & Wright, 1995). When the care recipient watches and participates along with the video visitor on the television, the caregivers have opportunities for respite breaks in their homes. You can call us at **801-581-8198** for information on the video tapes.

With these types of respite services becoming more available, most caregivers should have opportunities to use them and make them regular parts of a daily or weekly routine.

Another, often overlooked, form of respite is **informal respite**. Many friends and relatives often say, "Please let me know how I can help." Far too often, caregivers never accept these offers. Yet, having friends or relatives come to your home or take your loved one to their homes is an ideal way to share caregiving responsibilities.

You need and deserve this respite time. Rather than feeling guilty, you should allow others the opportunity to be helpful – to you and your loved one. Using respite services is one of the most effective ways to enhance the quality of life for caregivers and persons with dementia.❖

Don't delay. . .seek assistance today.

“Engaging in meaningful activities is important to all of us as we age; it's no different for those who are cognitively or physically impaired.”

– Dale A. Lund, PhD

GETTING THE MOST OUT OF RESPITE



PLAN AHEAD TO ENSURE THAT YOUR RESPITE TIME IS WELL SPENT

Research has shown that respite needs to be used by caregivers at least two days per week, regularly, and in blocks of time to be effective (Zarit, Stephens, Townsend & Greene, 1998). However, using respite services does not automatically result in wonderful benefits to all caregivers. Early research showed mixed results about the benefits of respite help. In fact, our national research study revealed that the 36% of caregivers who were using respite services did not have lower levels of burden than non-users. More recent studies, however, are concluding that respite helps most caregivers and care-recipients but there are important suggestions that caregivers need to follow in order for respite to be MOST EFFECTIVE.

First, caregivers need to consider using respite services much earlier in their caregiving careers. Far too many caregivers try to do nearly everything on their own, without assistance, for as long as they can. Many studies have shown that respite is most helpful to caregivers when they use it before they become exhausted, isolated and overwhelmed by their responsibilities (LaSasso & Johnson, 2002; Cox 1998; Gottlieb & Johnson, 2000; Whitlatch, Feinberg & Sebesta, 1997). Burden levels can be high among many caregivers who use respite because they waited too long to get help. Time away from caregiving, even short periods, is needed to help maintain friendships, social activities, health and overall balance in one's life. Once these essential features are lost, they are difficult to regain.

Second, caregivers need to have sufficient and regular amounts of respite time. Again, research has revealed that infrequent and irregular use of respite reduces its

effectiveness. Caregivers need to be able to anticipate and look forward to some kind of regular or scheduled times when they know they will have at least short breaks free of the constant responsibilities of providing care. In one of our studies, 25% of the caregivers said that they did not have enough respite time. Temporary and only short-term use of respite does not provide the help that most caregivers need (Grasel, 1997; Zarit, Stephens, Townsend & Greene, 1998; Whitlatch, Feinberg & Sebesta, 1997).

Third, caregivers need to give careful thought to how they want to spend their respite time and make the necessary arrangements in advance to insure that they do these things while they have respite. This sounds like common sense, but it is surprising how many caregivers do not end up using their free time consistent with their needs and intentions. Our research team examined the ways caregivers used their respite time and was surprised to learn that 46% of them reported that they were only "somewhat" or "not very satisfied" with how they had used their respite time. We tried to identify specific activities that might lead to better results and found that the most dissatisfied caregivers spent more time than they wanted doing housework, eating, shopping, and working. Those who were most satisfied with how they had spent their respite time did things that they had wanted and planned to do.

Rather than suggesting one or two specific activities for respite time, it appears to be much more important that caregivers give careful thought to what they most want to do and do it when they have respite. One of the dissatisfied caregivers said, "I need to organize my

time better to do hobbies." Those who fail to plan ahead often end up "wasting time" by watching too much television or doing nothing.

If you want to go to lunch or a movie with friends it requires advance planning to make sure that it happens. When the respite time is over, it is best if you feel like the respite break was meaningful or purposeful. Some caregivers wanted to clean, work in the yard, read, be with friends or even sleep. Respite was most effective for these caregivers when they fulfilled their needs and plans. Good use of respite time does not just happen, it requires a thoughtful review of needs, some planning and self-respect. You must plan ahead to make sure that you spend your respite time doing things that you miss the most. This is your chance to restore some balance in your life. You may even need to be a bit selfish to make sure you spend some time enhancing your own life. One useful way to plan ahead is to take some time to set a concrete attainable goal for how you want to spend your respite time. In our research we discovered that caregivers who spent their respite time doing the things that they desired had more favorable out-

comes. (Please see the goal setting box below to help you accomplish this.)

Fourth, respite is most effective when it is used along with other kinds of assistance. Respite is the most wanted and needed service for caregivers but it should be used along with other services or assistance and not stand alone as a single strategy (Alzheimer's Association Report, 2004; NAC/AARP Report, 2004). Caregivers need education, emotional and social support, and a sense of belonging with others. When respite is part of a more complete package of help, caregivers are better able to meet the many needs that we all have to be well, happy and enjoy daily life.

Caregivers are well advised to seek help and suggestions from professionals and friends and especially from those who are very experienced in caregiving to become more aware of their own needs and what services are available. Please remember, use respite early in your caregiving career, use it regularly, engage in meaningful activities during respite time and use it in conjunction with other services.❖

USE GOAL SETTING TO MAXIMIZE YOUR LIMITED RESPITE TIME



Please find a piece of paper and write down 1 to 3 specific goals of what you would like to accomplish during your respite time next week. Your goals can be anything (e.g., sleeping, cleaning, going to lunch with a friend), but they must be attainable during the respite time that is available to you. We recommend that you choose activities that:

- ◆ you have always enjoyed doing
- ◆ you did before you became a caregiver but may not have been doing lately
- ◆ have religious or spiritual meaning to you
- ◆ may improve satisfaction with caregiving
- ◆ may reduce the stress you might feel from caregiving
- ◆ may increase your respite time

At the end of the week, ask yourself whether you accomplished each of the goals and also whether you are satisfied with your effort at accomplishing each goal. Be honest with yourself, and use this information to revise your goals for the following week's respite time. Caregivers who use their respite time to do what they intended to do feel less burden and more satisfaction with their caregiving role.

INFORMATION & RESOURCES

* Please feel free to add an insert of additional resources and services unique to your area.

N A T I O N A L R E S O U R C E S

Alzheimer's Association

www.alz.org

1-800-272-3900

National Institute on Aging (NIA)

<http://www.nia.nih.gov>

1-800-222-2225

AARP

www.aarp.org

1-888-OUR-AARP

1-888-687-2277

Alzheimer's Disease Education and Referral Center

<http://www.nia.nih.gov/alzheimers>

1-800-438-4380

Children of Aging Parents

<http://www.caps4caregivers.org/>

1-800-227-7294

Eldercare Locator

<http://www.eldercare.gov>

1-800-677-1116

National Alliance for Caregiving

www.caregiving.org

1-310-718-8444

Family Caregiver Alliance

<http://www.caregiver.org>

1-800-445-8106

National Association of Professional Geriatric Care Managers

<http://www.caremanager.org>

1-520-881-8008

National Family Caregivers Association

<http://www.thefamilycaregiver.org>

1-800-896-3650

National Respite Network

<http://www.chtop.org>

1-919-490-5577

National Adult Day Services Association (NADSA)

<http://www.nadsa.org>

1-800-558-5301

Senior Corps (Senior Companions Program)

<http://www.seniorcorps.gov>

1-202-606-5000

Easter Seals

<http://www.easterseals.com>

1-800-221-6827

L O C A L R E S O U R C E S

Nearly every town, community and city has services available to help caregivers. We suggest that you use your local telephone directory, the internet and in most areas you can call **211** for information and referral sources. You can identify and contact some of the following for help.

- State unit on aging
 - Area agencies on aging
 - Alzheimer's Association local chapter
 - City and county social services
 - Respite service provider
 - Home health agencies
 - Gerontology and Geriatric programs at colleges and universities
-

I N T E R N A T I O N A L R E S O U R C E S

Alzheimer's Disease International

www.alz.co.uk/

+44 20 7620 3011

S T A T E O F U T A H R E S O U R C E S

Utah Coalition for Caregiver Support

www.caregivers.utah.gov

(Family Caregiving in Utah - booklet (PDF) available at web site).

College of Social Work

Neighbors Helping Neighbors (NHN) is a relatively small but growing and developing organization committed to helping the elderly remain in their own homes for as long as possible by building communities from the inside out. The program acts as a bridge between an outstanding community philanthropist (Mr. Wilford Goodwill) and the University of Utah. As such, NHN ensures effective linkage of academic theory with applied social work and community practice in the field of aging.

Email: ryan.engar@socwk.utah.edu

<http://www.socwk.utah.edu>

1-801-581-5162

University Health Care - Geriatrics Clinic

To serve the public by improving health and quality of life is the University Health Care mission. We accomplish this with our commitment to excellence in education, research and clinical care. The University Health Care support the mission and vision of the University of Utah by serving the public and improving the health and quality of life through excellence in education, research and clinical care.

<http://uuhsc.utah.edu>

1-801-581-2121

Caring Connections: A Hope and Comfort in Grief Program

The College of Nursing has developed a variety of community and hospital programs to meet the grief and bereavement needs of people experiencing loss and death. All people are welcome to participate as their circumstances suggest.

Email: caringconnections@nurs.utah.edu

<http://www.nurs.utah.edu/caringconnections>

1-801-585-9522

Center for Alzheimer's Care, Imaging & Research

At the University of Utah's Center for Alzheimer's Care, Imaging and Research, patients, caregivers and physicians will find the Intermountain West's most comprehensive treatment, research and education resource for Alzheimer's disease and dementia. The center works to raise standards for dementia care by empowering patients, caregivers and physicians with the most current knowledge available. "The center is designed to take advantage of the significant advances in dementia research and to get those advances into the community," explains Dr. Norman L. Foster, the center's director.

E-mail: neuro.scheduling@hsc.utah.edu

<http://uuhsc.utah.edu/cacir/about.html>

1-801-585-6387

Y O U R F U T U R E

We hope that this brochure will help you better understand your current caregiving situation and that you will do a better job of taking care of your own life. Many professionals, organizations and service providers are available to give you more information and offer help. Remember, it is important for you to enhance the quality of your life, and the lives of your family and loved ones.



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- Articles on Caregiving Written by the
Authors of the Brochure
(These publications are available
upon request – 801-581-8198)
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MISSION AND HISTORY

The Center on Aging (aging.utah.edu) has an established thirty-two year history of providing educational and research programs in gerontology at the University of Utah. It has sponsored undergraduate and graduate gerontology certificate programs as well as a Masters degree program in Gerontology. In addition to its strengths in gerontology education programs, it is recognized for a well-established research program focused on bereavement, coping with loss of a spouse and caregiving. In June 2004 its name was changed from the Gerontology Center to reflect a desire to become more comprehensive and expand the scope of its service and research activities.



The bristlecone pine tree (*Pinus longaeva*) - the earth's oldest inhabitant with a life span of 4,000 years - is found only in Utah and five other western states. Its extraordinary longevity and ability to adapt and survive in extremely harsh environmental conditions above 10,000 feet embodies the investigative spirit and mission of the Utah Center on Aging.

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Every day is another chance to discover more about yourself what are your strengths and limitations as a caregiver; what are you really like as a family member or friend; what are you learning about your own ability to express love, patience, and caring; and what are you discovering about your priorities in life?

– Leonard Felder, Ph.D.



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