



Obtaining respite, defined as having time away from performing caregiving tasks and meeting various responsibilities, has been found to be the single most desired and needed service by family caregivers to older adults. Although respite has the potential to enhance the quality of life for most caregivers, far too many caregivers wait too long to use the services, do not use them often or regularly enough, or spend their respite time unwisely (thus not deriving the maximum benefit). Also, many caregivers feel guilty and reluctant to use the services even when they are available. This article helps document the value of using respite services, describes the various forms in which they are available, and offers suggestions on how to make the most out of these promising services.

**Key words:** respite, caregiving, older adults, quality of life

## Respite Services: Enhancing the Quality of Daily Life for Caregivers and Persons with Dementia

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### Recognizing the Need for Respite

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 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 overwhelmed with managing their daily tasks and responsibilities. This article sets out to

- educate health professionals about the value of respite services;
- 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.

There is growing evidence 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 enjoy better health.

### Avoiding Potential Problems

Caregivers need to be aware of the adverse affects of insufficient help with caregiving tasks so that they can understand what is happening in their own lives and make better decisions about their caregiving situation. Although not all caregivers experience overwhelming stress, research has documented that caregivers are at a greater risk for experiencing many problems (Table 1).

Research has also shown that caregivers can reduce some of these negative effects by using respite services along with asking for help from others.<sup>1</sup>

Family caregivers provide 80% of all the caregiving. But we need to be careful in applying the label of “hero,” as such expectations can encourage 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 provide care to the very best of their ability, but also recognize and value their own well-being, families, and relationships and find a way to balance these competing goals.

### Assessing Caregiver Burden

In order to help caregivers understand how caregiving is impacting some

**Table 1: Problems Caregivers Can Experience**

<input type="checkbox"/> guilt, anger, resentment, and denial	<input type="checkbox"/> less marital closeness
<input type="checkbox"/> declines in physical health	<input type="checkbox"/> work absenteeism
<input type="checkbox"/> strained social and family relations	<input type="checkbox"/> loss of income
<input type="checkbox"/> sleep disorders	<input type="checkbox"/> negative attitude toward care recipient
<input type="checkbox"/> anxiety about aging	<input type="checkbox"/> loss of free time
<input type="checkbox"/> neglect of self and others	<input type="checkbox"/> abuse
<input type="checkbox"/> sleeplessness	<input type="checkbox"/> exhaustion
<input type="checkbox"/> depression	

important aspects of their lives, they can answer the questions on the caregiver burden scale (Table 2). This burden scale measures the impact of caregiving on the caregiver's time, physical health, social relationships, emotional well-being, and life course development issues. After each question, caregivers select a response that describes their feelings or views. If the total score is above 36, the caregiver is very likely to be at risk for burning out as a caregiver. When scores are near or above 36 we strongly suggest that they use respite and other services (though it is suggested that all caregivers use respite long before caregiving becomes stressful). We recommend that caregivers seriously look at any item on the burden scale where their answer was scored as a three or four ("quite frequently" or "nearly always"), give careful thought about why they scored so high on the question, and try to identify ways to reduce the specific type or source of stress. This scale can help caregivers to identify specific aspects of their life and situation that might need immediate attention. Caregivers should consider contacting their physicians or mental health professionals for advice.

### Assessing Satisfaction Derived from Caregiving

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 satisfac-

tion family members are experiencing through caregiving (Table 3).<sup>4</sup> Caregivers are asked to read nine questions or statements and select an answer that best fits their views. Similar to the previous list of questions, all of the points are totalled to convey an overall assessment of the satisfaction derived from caregiving. Unlike the other scale, a high score on this scale indicates a positive situation. Ideally, most caregivers have scores of 27 or higher, indicating that the caregiver "sometimes" has satisfaction related to all nine items.

The scale can help determine where caregivers get the greatest satisfaction and where improvement is needed the most. Again, caregivers who have low levels of satisfaction should consider seeking professional help through counselling or simply asking service professionals for advice.

### Respite Services

It is in everyone's best interest to encourage and help most caregivers to do a bit less rather than more caregiving in order to restore a more appropriate balance in their lives. Sharing the daily tasks of caregiving with family members, neighbours, 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.

Caregivers often need many different kinds of help, including education; skill training; counselling; emotional, spiritual, social, and financial support; legal advice; 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 organizations listed near the end of this article can help caregivers find services they need (Table 4).

There is one service, however, that stands out to most caregivers because it has the potential to improve or at least preserve the quality of their daily lives. In our Gerontology Center's study of nearly 900 caregivers, we found that having respite time was their most desired and needed service.<sup>3</sup> Another study in Michigan revealed that service professionals also identified respite as the most needed service for caregivers. The number of studies highlighting the need for greater use of respite services is increasing each year.<sup>1,6-13</sup>

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 care centers. It can range from one or two hours at a time to several days each week.

Although not every community has a full range of respite services available, there are several types of services (Table 5).<sup>14</sup> 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 daycare service, usually provided at a community-based site such as daycare centres, long-term care facilities, churches,

**Table 2: Modified Caregiver Burden Scale**

Items	Response Choices				
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
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
<b>Development Items</b>					
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
<b>Physical Health Items</b>					
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
<b>Social Relationship Items</b>					
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 are 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
<b>Emotional Health Items</b>					
20. I feel embarrassed over his/her behaviour.	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
<b>Total Score (0–96)</b>					

For each item, the caregiver must circle the number that represents how often the statement describes his/her feelings. A score of 36 or more suggests a need for respite services.

Source: Novak M and Guest C, 1989.<sup>2</sup>

**Table 3: Caregiver Satisfaction Scale**

Items	Response Choices				
	Never	Rarely	Sometimes	Quite Frequently	Almost Always
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. 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
<b>Total Score (9–45)</b>					

For each item, the caregiver must circle the number that represents how often the statement describes his/her feelings. A score of less than 27 suggests a need for professional guidance.

Source: Lawton M.P. et al., 1989.<sup>4</sup>

assisted living facilities, senior centres, and hospitals. Daycare 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 our gerontology centre 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.<sup>15</sup> While the care recipient watches and participates along with the video visitor on the television, the caregivers have opportunities for respite breaks in their homes. Information about these videotapes is available by calling our centre at (801) 581-8198.

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 into their homes or take the loved one to their homes is an ideal way to share caregiving responsibilities. Caregivers need and

deserve this respite time. Rather than feeling guilty, they should allow others the opportunity to be helpful to them and the older care recipient. Using respite services is one of the most effective ways to enhance the quality of life for caregivers and persons with dementia.

### Getting the Most Out of Respite

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

**Table 4:** Sources for Further Information

<b>Canadian Sources</b>
Seniors Canada On-line: <a href="http://www.seniors.gc.ca">www.seniors.gc.ca</a>
Canadian Red Cross (respite care in your community): <a href="http://www.redcross.ca">www.redcross.ca</a>
Veterans Affairs Canada: <a href="http://www.vac-acc.gc.ca">www.vac-acc.gc.ca</a>
Canadian Association for Community Care: <a href="http://www.cacc-acssc.com">www.cacc-acssc.com</a>
Canadian Home Care Association: <a href="http://www.cdnhomecare.on.ca">www.cdnhomecare.on.ca</a>
How to Care: Eldercare Survival Guide: <a href="http://www.howtocare.com/home-care6.htm">www.howtocare.com/home-care6.htm</a>
National Respite Locator Service: <a href="http://www.respitelocator.org/canada.htm">www.respitelocator.org/canada.htm</a>
<b>U.S. Sources</b>
Alzheimer's Association: <a href="http://www.alz.org">www.alz.org</a> ; <a href="http://www.alzheimers.org">www.alzheimers.org</a>
National Institute on Aging (NIA): <a href="http://www.nia.nih.gov">www.nia.nih.gov</a>
American Association of Retired Persons (AARP): <a href="http://www.aarp.org">www.aarp.org</a>
Alzheimer's Disease Education and Referral Center (ADEAR): <a href="http://www.alzheimers.org">www.alzheimers.org</a>
Eldercare Locator: <a href="http://www.eldercare.gov">www.eldercare.gov</a>
National Alliance for Caregiving: <a href="http://www.caregiving.org">www.caregiving.org</a>
National Association of Professional Geriatric Care Managers: <a href="http://www.caremanager.org">www.caremanager.org</a>
Caregiver Zone: <a href="http://www.caregiverzone.com">www.caregiverzone.com</a>
National Family Caregivers Association: <a href="http://www.nfcacares.org">www.nfcacares.org</a>
Administration on Aging: <a href="http://www.aoa.dhhs.gov">www.aoa.dhhs.gov</a>
National Council on Aging: <a href="http://www.ncoa.org">www.ncoa.org</a>
Caregiver Network: <a href="http://www.caregiver.on.ca">www.caregiver.on.ca</a>
National Respite Network: <a href="http://www.archrespice.org">www.archrespice.org</a>
National Adult Day Services Association: <a href="http://www.ncoa.org/nadsa">www.ncoa.org/nadsa</a>
<b>International</b>
Alzheimer's Disease International: <a href="http://www.alz.co.uk">www.alz.co.uk</a>

of our studies, 25% of the caregivers said that they did not have enough respite time. Research has shown that daycare respite needs to be used by caregivers at least two days per week, regularly, and in blocks of time to be effective. Temporary and only short-term use of respite does not provide the help that most caregivers need.<sup>1,18,20</sup>

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. 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. Those who fail to plan ahead often end up wasting time by watching too much television or doing nothing. If a caregiver wants 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 the caregiver feels that 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. Caregivers must plan ahead to

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.<sup>13,16-19</sup> Burden levels can be high among many caregivers who use respite because they've

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

**Table 5:** Types of Respite Services

In-home respite	Professionally trained persons make home visits and attend to the needs of the family member so that the caregiver can leave the home.
Daycare services	Community or health service providers offer overnight or multiple days of respite, which can allow vacations and other regular group activities.
Video Respite™	This series of videotapes that captures/maintains the attention of dementia patients allows the caregiver respite breaks in the home.
Informal respite	Accepting offers from friends/family to care for the loved one can offer respite.

make sure that they spend their respite time doing things that they miss the most. This is their chance to restore some balance in their lives. Caregivers even need to be a bit selfish to make sure they spend some time enhancing their own lives.

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.<sup>11,12,16,21</sup> 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 should be advised to seek help and suggestions from professionals and friends, especially those who are experienced in caregiving, to become more aware of their own needs and what services are available. Respite needs to be used early in the caregiving career, used regularly, and caregivers need to engage in meaningful activities during their respite time and use it in conjunction with other services.

## Conclusion

We hope that this article will help physicians in educating caregivers to better understand their current caregiving situations and do a better job of taking care of their own lives. Many professionals, organizations, and service providers are available to give appropriate information and offer help. The sources listed in Table

4 are excellent organizations to contact for further referrals. ♦

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