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# Introduction



“There are only four kinds of people in this world—those who **have been** caregivers,  
those who **currently are** caregivers,  
those who **will be** caregivers,  
those who **will need** caregivers.”— *Rosalind Carter*

According to the Merriam-Webster Dictionary, the definition of caregiver is “a person who provides direct care for children, elderly people, or the chronically ill.” Caregivers can be formal paid care providers providing care in one’s home or in a care setting (daycare, residential, care facility, etc.) or an informal care provider (unpaid individual) such as a spouse, adult children, parent, other family member, friend, clergy, or neighbor who assists others with activities of daily living, spiritual support and/or medical tasks.

More than 65.7 million Americans or 28.5% of the population serve as informal caregivers to a child with special needs or an adult who lives in the community and requires help (National Caregiver Foundation). Most caregivers (86%) are related to the care recipient, 36% care for a parent. Nearly a third of American households report that at least one person has served as an unpaid caregiver in the past year. One in seven caregivers provides care, over and above regular parenting, to a child with special needs (14%). It is estimated that 1.3 to 1.4 million children aged 8-18 care for an adult relative, 72% of whom care for a parent or grandparent.

The majority of informal caregivers (66%) are women who are an average of 48 years old, although men also serve as caregivers. A considerable number of American women find themselves employed

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full-time in addition to caregiving 20 hours a week—the equivalent of a second part-time job.

52 million caregivers provide care to adults (aged 18+) with a disability or illness. 43.5 million of adult family caregivers care for someone 50+ years of age and 14.9 million care for someone who has Alzheimer’s disease or other dementia. Caregiving lasts an average of 4.6 years.

Caregiver services were valued at \$450 billion per year in 2009, up from \$375 billion in 2007. The value of unpaid family caregivers will likely continue to be the largest source of long-term care services in the US, and the aging population (65+) will more than double between the years 2000 and 2030, increasing to 71.5 million from 35.1 million in 2000.

Studies have shown that caregivers are all ages and come from all walks of life. There are many in our church families who are caring for another person—an adult family member, a child with special needs, or a friend. Even the pastor might be serving as a caregiver in addition to their responsibilities to the congregation. Albeit an overwhelming and daunting job, the role of caregiver is often assumed without complaint. Family caregivers are responsible for the physical, emotional and sometimes financial support of another person and the inherent burdens of being an unpaid family caregiver increase the risk for physical, emotional, and mental exhaustion and can lead to depression and burnout.

Burnout can occur when caregivers don’t get the help they need, or if they try to do more than they are able—either physically or financially. Many caregivers also feel guilty if they spend time on themselves rather than on their ill or elderly loved ones

Caregivers need support! It is our responsibility, moreover our duty, as a church family and community members to provide it. We can do so individually or on a greater scale by establishing a caregiver support ministry in our churches.

In the book *Sermons and Talks Vol. 1*, Ellen G. White wrote: “Here is a work for every individual. Christ’s followers are to relieve the necessities of humanity wherever they see suffering or oppression. They are ever to be ready to speak a word in season to him that is weary.” {1SAT 350.2} “We have a work to do for others. We cannot afford to live merely for ourselves. We are to represent the great Medical Missionary, who came to our world to seek and save that which was lost. When we do the work to which God calls us, we are assured of His blessing.” {1SAT 350.3}

Jesus taught the meaning of caregiving by example. He healed the sick, blind, lame, and demon possessed. He showed willingness to be involved in their lives and relieve their hurts and difficulties, even to the most lowly in society. Even when on the cross, he made sure a caregiver was provided for his mother. We are counseled and encouraged throughout the bible to care for others. “If anyone does not provide for his relatives, and especially for his immediate family, he has denied the faith and is worse than an unbeliever.” I Timothy 5:8 (NIV). “Let us not become weary in doing good, for at the proper time we will reap a harvest if we do not give up. Therefore, as we have opportunity let us do good to all people, especially to those who belong to the family of believers.” Galatians 6:9-10



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# Purpose of a Caregivers Ministry



The purpose of the caregivers ministry is to provide a place for caregivers where the love of Christ is demonstrated and felt; where their physical, emotional, and social needs are addressed; a safe and supportive environment for caregivers to meet to share their experiences and feelings, exchange information, and be given resources to assist them, i.e. a caregivers support group in your church.

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# Qualities of a Caregivers Ministry Leader



The Caregivers Ministries leader serves in conjunction with other church ministries such as Health, Community Services, 50+, Faith Community Nurse or Family Life Ministries depending upon how your church is structured. They also function as a liaison between the team and the supporting ministries and community agencies. The Caregivers Ministries leader is responsible for coordinating all programs serving caregivers and reporting to the church leadership and membership about their ministry.

They do need a vision for the caregiver ministry, a practical attitude and basic competencies. The following qualities may enhance one's ability to be an effective local church leader of a Caregiver Ministry.

- **Articulate**—a person who can communicate well with others. Show genuine courtesy to all under all circumstances and maintain confidentiality.
  - **Faithful**—a person who is involved in the life of a local church congregation and is strong in their Christian faith; who understands the role of spirituality wholeness while providing intentional care of the spirit.
  - **Knowledgeable**—a person who is knowledgeable about caregiver issues and is knowledgeable about the organization of the Seventh-day Adventist Church. Take training offered by the North American Division Adventist Community Services for Caregiver Ministry.
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- **Caring**—a person who is concerned about the needs of caregivers and strives to understand their challenges.
- **Resourceful**—a person who is capable of enlisting others to participate in events and programs and is capable of acquiring resources and information available to the faith community.
- **Mature**—a person who possesses a spiritual and emotional maturity; has sound judgment, honesty, enthusiasm, a good sense of humor, and models Christ’s methods of relating.

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# Organizing a Caregivers Ministry



First, think and pray about the mission and purpose of the church and how a caregiver ministry would help to accomplish this mission. In most congregations the aspects of a balanced program will include:

**Spiritual Enrichment**—Keep in mind that the spiritual health of caregivers is as important as their physical health. Helping caregivers turn to God and receive His love and strength can be such a help and comfort to them. Even while the caregiver serves the affected person, meditation and prayer can give tremendous relief. Many caregivers have found reading the Gospels and Jesus' care for others an inspiration. For others the Psalms have brought comfort during the days of depression, teaching the caregiver to praise God even in adversity. Writing about how God has led through trials may relieve some. And time in nature brings refreshment to others. Even when a caregiver is quite confined, a simple feature as watching birds in a birdfeeder outside the window can bring relief from stress.

Caregivers can be given a spiritual assessment to aid in determining their spiritual needs. One popular acronym tool is the FICA model (*Journal of Christian Nursing*, January 2005 - Volume 22 Number 1). These are the areas of assessment and possible questions that could be asked:

F-Faith or beliefs: *What are your spiritual beliefs? Do you consider yourself spiritual? What things do you believe in that give meaning to life?*

I-Importance and influence: *Is faith/spirituality important to you? How has your illness and/or hospitalization affected your personal practices/beliefs?*

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*C-Community: Are you connected with a faith center in the community? Does it provide support/comfort for you during times of stress? Is there a person/group/leader who supports/assists you in your spirituality?*

*A-Address: What can I do for you? What support/guidance can health care provide to support your spiritual beliefs/practices?*

These are open-ended questions that encourage the caregiver to talk about their personal spiritual beliefs.

Following is a spiritual survey to be used by the leader/facilitator of the Caregiver Support Group to help determine what brings order, balance, and direction in the life of the caregiver, in essence what keeps them grounded.

## SPIRITUAL SURVEY

**Please answer the following questions by selecting the one answer that best describes you**

**1. How often do you attend church or other religious or spiritual meetings?**

- 6 More than once a week
- 5 Once a week
- 4 A few times a month
- 3 A few times a year
- 2 Once a year or less
- 1 Never

**2. How often do you spend time in private religious or spiritual activities such as prayer, meditation, or study of religious texts?**

- 6 Daily
- 5 Several times a week
- 4 Two or three times a week
- 3 Once a week
- 2 A few times a month
- 1 Rarely or never

**3. In my life I experience the presence of the Divine (i.e. God).**

- 5 Definitely true
- 4 Tends to be true
- 3 Unsure
- 2 Tends NOT to be true
- 1 Definitely NOT true

**4. My religious beliefs are what really lie behind my whole approach.**

- 5 Definitely true
- 4 Tends to be true
- 3 Unsure
- 2 Tends NOT to be true
- 1 Definitely NOT true

**5. I try to carry my religion over into all other dealings in life.**

- 5 Definitely true
- 4 Tends to be true
- 3 Unsure
- 2 Tends NOT to be true
- 1 Definitely NOT true

**6. I don't know who I am, where I came from, or where I'm going.**

- 1 Strongly Agree
- 2 Moderately Agree
- 3 Agree
- 4 Disagree
- 5 Moderately Disagree
- 6 Strongly Disagree

**7. I feel that life is a positive experience.**

- 6 Strongly Agree
- 5 Moderately Agree
- 4 Agree
- 3 Disagree
- 2 Moderately Disagree
- 1 Strongly Disagree

**8. I feel unsettled about my future.**

- 1 Strongly Agree
- 2 Moderately Agree
- 3 Agree
- 4 Disagree
- 5 Moderately Disagree
- 6 Strongly Disagree

**9. I feel very fulfilled and satisfied with life.**

- 6 Strongly Agree
- 5 Moderately Agree
- 4 Agree
- 3 Disagree
- 2 Moderately Disagree
- 1 Strongly Disagree

**10. I feel a sense of well-being about the direction my life is headed in.**

- 6 Strongly Agree
- 5 Moderately Agree
- 4 Agree
- 3 Disagree
- 2 Moderately Disagree
- 1 Strongly Disagree

**11. I don't enjoy much about my life.**

- 1 Strongly Agree
- 2 Moderately Agree
- 3 Agree
- 4 Disagree
- 5 Moderately Disagree
- 6 Strongly Disagree

**12. I feel good about my future.**

- 6 Strongly Agree
- 5 Moderately Agree
- 4 Agree
- 3 Disagree
- 2 Moderately Disagree
- 1 Strongly Disagree

<p><b>13. I feel that life is full of conflict and unhappiness.</b></p> <ul style="list-style-type: none"> <li>1 Strongly Agree</li> <li>2 Moderately Agree</li> <li>3 Agree</li> <li>4 Disagree</li> <li>5 Moderately Disagree</li> <li>6 Strongly Disagree</li> </ul>	<p><b>14. Life doesn't have much meaning.</b></p> <ul style="list-style-type: none"> <li>1 Strongly Agree</li> <li>2 Moderately Agree</li> <li>3 Agree</li> <li>4 Disagree</li> <li>5 Moderately Disagree</li> <li>6 Strongly Disagree</li> </ul>
<p><b>15. I believe there is some real purpose for life.</b></p> <ul style="list-style-type: none"> <li>6 Strongly Agree</li> <li>5 Moderately Agree</li> <li>4 Agree</li> <li>3 Disagree</li> <li>2 Moderately Disagree</li> <li>1 Strongly Disagree</li> </ul>	<p><b>16. I wonder whether God has abandoned me.</b></p> <ul style="list-style-type: none"> <li>4 Not at All</li> <li>3 Occasionally</li> <li>2 Frequently</li> <li>1 A Great Deal</li> </ul>
<p><b>17. I have felt punished by God for my lack of devotion.</b></p> <ul style="list-style-type: none"> <li>4 Not at All</li> <li>3 Occasionally</li> <li>2 Frequently</li> <li>1 A Great Deal</li> </ul>	<p><b>18. I have wondered what I did for God to punish me.</b></p> <ul style="list-style-type: none"> <li>4 Not at All</li> <li>3 Occasionally</li> <li>2 Frequently</li> <li>1 A Great Deal</li> </ul>
<p><b>19. I have questioned God's love for me.</b></p> <ul style="list-style-type: none"> <li>4 Not at All</li> <li>3 Occasionally</li> <li>2 Frequently</li> <li>1 A Great Deal</li> </ul>	<p><b>20. I have wondered if my church has abandoned me.</b></p> <ul style="list-style-type: none"> <li>4 Not at All</li> <li>3 Occasionally</li> <li>2 Frequently</li> <li>1 A Great Deal</li> </ul>
<p><b>21. I have decided the Devil is responsible for the bad things that happen to me.</b></p> <ul style="list-style-type: none"> <li>4 Not at All</li> <li>3 Occasionally</li> <li>2 Frequently</li> <li>1 A Great Deal</li> </ul>	<p><b>22. I have questioned the power of God.</b></p> <ul style="list-style-type: none"> <li>4 Not at All</li> <li>3 Occasionally</li> <li>2 Frequently</li> <li>1 A Great Deal</li> </ul>
<p><b>23. If I get sick, it is my own behavior that determines how soon I get well again.</b></p> <ul style="list-style-type: none"> <li>1 Strongly Agree</li> <li>2 Moderately Agree</li> <li>3 Agree</li> <li>4 Disagree</li> <li>5 Moderately Disagree</li> <li>6 Strongly Disagree</li> </ul>	<p><b>24. I am in control of my health.</b></p> <ul style="list-style-type: none"> <li>1 Strongly Agree</li> <li>2 Moderately Agree</li> <li>3 Agree</li> <li>4 Disagree</li> <li>5 Moderately Disagree</li> <li>6 Strongly Disagree</li> </ul>
<p><b>25. When I get sick I am to blame.</b></p> <ul style="list-style-type: none"> <li>1 Strongly Agree</li> <li>2 Moderately Agree</li> <li>3 Agree</li> <li>4 Disagree</li> <li>5 Moderately Disagree</li> <li>6 Strongly Disagree</li> </ul>	<p><b>26. The main thing that affects my health is what I myself do.</b></p> <ul style="list-style-type: none"> <li>1 Strongly Agree</li> <li>2 Moderately Agree</li> <li>3 Agree</li> <li>4 Disagree</li> <li>5 Moderately Disagree</li> <li>6 Strongly Disagree</li> </ul>
<p><b>27. If I take care of myself, I can avoid illness.</b></p> <ul style="list-style-type: none"> <li>1 Strongly Agree</li> <li>2 Moderately Agree</li> </ul>	<p><b>28. If I take the right actions I can stay healthy.</b></p> <ul style="list-style-type: none"> <li>1 Strongly Agree</li> <li>2 Moderately Agree</li> </ul>

3 Agree 4 Disagree 5 Moderately Disagree 6 Strongly Disagree	3 Agree 4 Disagree 5 Moderately Disagree 6 Strongly Disagree
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Once the assessment and survey are reviewed, the Caregiver Ministry Leader could partner with the Bible Worker, the Personal Ministry Leader, Elders, or the Pastor to carve out intentional opportunities to minister to the caregiver’s spirituality. Some examples of programs/activities that might be implemented which are the following:

- Mid-day Prayer meeting at the church
- Community home gatherings
- Home Bible studies
- Online or virtual spiritual support
- DVD Library of church services and other spiritual materials

**Socialization (Fellowship)**—Because caregivers are often confined at home to care for the affected person, their social life may come to a standstill. Caregivers should be encouraged to get together with friends outside of their home by making lunch or dinner dates or going to a concert or social event. The family or church family could show compassion by giving time, visiting, calling, or sending e-mails.

**Exercise/Health**—Optimum physical health is so very important for the caregiver. Choosing a caring physician with whom they feel totally confident is so important because of the stresses the caregiver may have to endure. Opportunities for regular physical exercise are essential to the caregiver’s well-being. The caregiver may check with hospitals or community centers to see if they hold exercise programs. And, of course, there are exercise programs on the internet, TV, and DVDs. The idea is to simply, “keep those muscles moving.” The caregiver needs good circulation for good health and as a shield against depression. One of the best exercises is walking. And if a caregiver finds a friend to walk with—all the better. It is best if part of the walk is a brisk pace, and if gradually the caregiver’s walk could include a

hill, great. Almost all towns have a swimming pool and many of them hold water aerobics classes. Another type of exercise that almost all caregivers can endure is found in the stretching exercise books that can be found online, local library, bookstore, or through your church's resources. Many community centers offer different types of exercises if group participation is preferred. Perhaps the church could start an exercise class.

The importance of drinking pure water and eating healthy cannot be overemphasized. Replenishing the body with sixteen to thirty-two ounces of water first thing in the morning with a squeeze of lemon juice would be beneficial. As far as possible, a whole-plant based vegetarian diet is optimal.

**Learning opportunities**—Supply a list of available classes at local community centers, hospitals, senior living facilities, libraries, online, and at the church. Caregivers should be encouraged to pursue their interests or continue their education. Learning should never cease.

**Service opportunities**—Encourage caregivers to pursue opportunities for service based on their interests and abilities. For example: a greeting card ministry, partner with youth ministries and serve as a lecturer or offer advisory support

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# Providing Needed Services to Caregivers



## **Respite Care**

The provision of short-term accommodation in a facility outside the home in which a loved one may be placed. This provides temporary relief to those who are caring for family members, who might otherwise require permanent placement in a facility outside the home. It is important that respite care be provided to enable the caregiver to take time to do whatever they desire.

In an article on developing a respite plan, AARP offers the following tips:

### **Cast a Wide Net**

Think broadly about potential helpers. Aside from family members, you should look to friends from the neighborhood, faith groups, or social clubs who may be able to offer help and companionship. Having a long list of potential helpers will ensure you have a backup in case plans fall through.

### **Start a Respite Co-op**

Consider forming a network with other families who are in caregiving situations. Such co-ops exist in some communities, but you might form one yourself with people you and your parents know or with others you meet in support groups for caregivers.

### **Arrange In-home Services**

In-home services can be provided by volunteers or paid help, either occasionally or on a regular basis. Services may last from a few hours to overnight, and may be arranged directly with an individual or through an agency or organization.

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## **End of Life Caregiving**

The exact role of family caregivers in day-to-day end-of-life care depends on the physical and mental condition of the dying person. The caregiver's most immediate task may be about the most intimate, physical aspects of care: giving baths, helping a loved one eat, get dressed, use of the bathroom, or even breathe. Whatever the specific tasks, hopefully it is a time of love and compassion, a time of resolving outstanding issues and remembering good times.

There are situations and circumstances where the Faith Community Nurse and members of the Caregiving Ministry will be asked to be available to help out during this phase of caregiving. It is important that they be sensitive to the emotional state of the caregiver to determine how much assistance is acceptable. Some caregivers will make their needs clear. Others may be too distraught or emotional to articulate their needs and may require more professional assistance such as a hospice worker.

The term hospice refers to an approach to end-of-life care as well as to a type of facility for supportive care of terminally ill patients. Hospice programs provide palliative (care that relieves discomfort but does not improve the patient's condition or cure the disease) patient-centered care and other services. The goal of hospice care, whether delivered in the patient's home or in a healthcare facility, is the provision of humane and compassionate medical, emotional, and spiritual care to the dying.

### **Stress Management**

Stress management is helpful in keeping the caregiver from burnout, since all the responsibilities may eventually fall to the caregiver. Recognizing the warning signs of stress, what causes your stress and realizing what you can and cannot change is helpful—then one can deal with the stress. Writing out the warning signs of stress, how you react to them, and what would be a positive way to handle the stress, could reveal information necessary in combating stress. Keeping a notebook of “action plans” to create time for the caregiver's pleasure can become an ongoing ritual. “What can I plan for myself