

Caregiver Support Network



Volunteer Training Manual

Caring for the Needs of Veterans and
Their Caregivers



Table of Contents

Introduction	3
<input type="checkbox"/> Office of Care Coordination	4
<input type="checkbox"/> Voluntary Service Office	4
<input type="checkbox"/> Basic Terminology of Caregiving	5
<input type="checkbox"/> Benefits of Training	6
<input type="checkbox"/> Legal Notice	6
The Decision to Become a Volunteer Support Caregiver	7
<input type="checkbox"/> The Case for More Volunteer Support Caregivers	7
<input type="checkbox"/> What Motivates a Person to Become a Volunteer Support Caregiver?	8
<input type="checkbox"/> Trends in Volunteerism	8
<input type="checkbox"/> To Become a Volunteer Support Caregiver: The Importance of the Decision	9
<input type="checkbox"/> Most Commonly Asked Questions by Volunteers	9
<input type="checkbox"/> Attributes of a Good Volunteer	11
<input type="checkbox"/> Psychological and Social Issues	12
<input type="checkbox"/> <i>EXERCISE 1: Being a Volunteer</i>	15
Understanding Caregiver and Care Recipient Needs	17
<input type="checkbox"/> Basic Needs for Primary Caregivers and Care Recipients	17
<input type="checkbox"/> Common Stress Reactions	18
<input type="checkbox"/> Practical Interventions for Primary Caregivers	18
<input type="checkbox"/> Symptoms of Caregiver Burnout	20
<input type="checkbox"/> How Volunteers Can Help	22
<input type="checkbox"/> Listening Skills	22
The Role of the Volunteer Support Caregiver	24
<input type="checkbox"/> Volunteer Assignments	24
<input type="checkbox"/> Volunteer Position Descriptions	25
<input type="checkbox"/> Evaluation/Competencies	26
<input type="checkbox"/> The Care Plan	28
<input type="checkbox"/> Organizing Tasks and Activities	28
<input type="checkbox"/> Activities to Keep the Care Recipient Vital and Independent	31
Volunteer Rights and Responsibilities	32
<input type="checkbox"/> Nonperformance by a volunteer	32
<input type="checkbox"/> Do's and Don'ts for Reducing Risks	33
<input type="checkbox"/> Confidentiality and Patient Privacy	34
<input type="checkbox"/> Guidelines for Emergencies	36
<input type="checkbox"/> Expectations, Challenges and Dealing with Disappointments	37
The Importance of Clear Communication	37
<input type="checkbox"/> Assertiveness Tips for Volunteer Caregivers	38
<input type="checkbox"/> Understanding Other Cultures	39
<input type="checkbox"/> <i>EXERCISE 2: Appreciating Our Differences</i>	41
<input type="checkbox"/> Dealing with Problems	42
<i>Continued on next page...</i>	

Relating to the Primary Caregiver Family	42
<input type="checkbox"/> Basic Concepts and Principles of Family Systems	42
Safety Issues	43
<input type="checkbox"/> Advocacy	44
<input type="checkbox"/> Household Safety	46
<input type="checkbox"/> Guidelines for Preventing Falls	46
<input type="checkbox"/> The Importance of Cleaning a Home for Germ Control	47
<input type="checkbox"/> Four Sets of Tasks for Household Cleaning Chores	48
<input type="checkbox"/> Handwashing	49
<input type="checkbox"/> Additional Precautions Against Infection	49
<input type="checkbox"/> How to Dispose of Body Waste	49
<input type="checkbox"/> Hygiene in the Kitchen	50
<input type="checkbox"/> Nutrition and Meals	50
Medication Issues	52
<input type="checkbox"/> Medications: Questions to Ask	53
<input type="checkbox"/> Reasons Why Some People Refuse Medications	53
<input type="checkbox"/> Volunteer Assistance with Medication	54
<input type="checkbox"/> Reading the Label	55
<input type="checkbox"/> Medication Record	56
<input type="checkbox"/> Storing Medication	56
Dealing with Relationships and Loss	57
<input type="checkbox"/> Preparing for Endings	57
<input type="checkbox"/> When a Care Recipient Recovers	58
<input type="checkbox"/> The Benefits of Introspection and Self-Knowledge	58
<input type="checkbox"/> Recommended Steps for Preparing for the End of Caregiver Support Assignments	60
<input type="checkbox"/> Preparing for the End of the Volunteer Relationship When the Care Recipient is Dying	61
<input type="checkbox"/> Five Reactions to Terminal Illness	62
<input type="checkbox"/> Seven Fears Faced by the Dying	62
<input type="checkbox"/> Grief and the Aftermath	64
<input type="checkbox"/> The Stages of Grief	67
<input type="checkbox"/> <i>EXERCISE 3: Self-Assessment of Your Beliefs about Death and Dying</i>	68
Getting the Most Out of Your Volunteer Assignment	70
<input type="checkbox"/> <i>EXERCISE 4: The Case of Mr. Ruiz</i>	71
<input type="checkbox"/> Recognition and Rewards	73
<input type="checkbox"/> Getting a Veteran Involved	73
<input type="checkbox"/> Beginning Your New Assignment	74
<input type="checkbox"/> Addendum: FORMS	

A Training Manual for the
Caregiver Support Network

■ **Introduction**

VA Voluntary Service (VAVS) and the Office of Care Coordination (OCC) have joined together to form the *Caregiver Support Network* to prepare volunteers to more effectively assist primary caregivers of veterans. This training manual is designed to help community organizations and volunteers to provide compassionate support to those offering care to America's veterans in their homes.

■ **Office of Care Coordination**

The VA is implementing care coordination in response to the changing care needs of veteran patients in the 21st Century. As an increasing proportion of veteran patients live longer and healthier lives they are seeking alternative options, when feasible, to hospital and institutional-based long-term in managing the chronic diseases they suffer from such as diabetes and heart failure.

Care coordination in VHA is defined as: *"Care coordination is the wider application of care and case management principles to the delivery of health services using health informatics, disease management and telehealth technologies to facilitate access to care and to improve the health of designated individuals and populations with the specific intent of providing the right care in the right place at the right time."*

In support of its mission, one of OCC's responsibilities includes offering support to caregivers. Making the home into the preferred place of care places the caregiver in a pivotal position in the care delivery process. OCC works with other VA offices/departments, clinicians, educators and caregiver groups to understand the needs of caregivers and how they can be supported.

■ **Voluntary Service Office**

The Department of Veterans Affairs Voluntary Service (VAVS) has provided over 58 years of service to America's veterans seeking care in VA health care facilities. Since 1946, VAVS volunteers have donated 663.5 million hours of service.

With more than 133,000 volunteers, VAVS is the largest volunteer program in the Federal government. More than 350 national and community organizations support VAVS. The program is supported by a VAVS National Advisory Committee, composed of 63 major veteran, civic and service organizations, which reports to the Under Secretary for Health. VAVS volunteers and their organizations annually contribute an estimated \$42 million in gifts and donations.

As VA has expanded its care of veteran patients into the community, volunteers have become involved. They assist veteran patients by augmenting staff in such settings as hospital wards, nursing homes, community-based volunteer programs, end-of-life care programs, foster care and veterans outreach centers.

The *Caregiver Support Network* is another way that VAVS is supporting the needs of veterans and their families in this changing health care environment. VAVS seeks to involve additional volunteers, community and faith based organizations, in addition to educational and corporate entities to support this initiative.

■ **Basic Terminology of Caregiving**

Throughout this training manual, you will see terms such as “volunteer,” “volunteer support caregiver,” “caregiver,” “family caregiver,” “primary caregiver,” “care recipient,” and “care receiver.” Because these terms can be confusing, following are definitions and notations that will help clarify what is meant when these terms are used in the text of this manual.

Volunteer: A person who offers to provide a service to another individual or organization of his/her own free will and without pay.

Volunteer Support Caregiver: An individual who has chosen to provide assistance, as a volunteer, to a primary caregiver or to an older adult who has a chronic disease or condition or who needs some level of assistance because he or she can no longer function independently. In the context of this manual, the terms “volunteer” and “volunteer support caregiver” sometimes are used interchangeably because the only kind of volunteer mentioned in these sections is an individual who serves as a volunteer support caregiver.

Caregiver/Family Caregiver: A person who provides care (emotional, custodial, paramedical, legal, etc.) for another person who is chronically ill or disabled. Family caregivers may be a spouse, parent, adult child, sibling or other blood or appointed relative, of the care recipient. Family caregivers differ from professional caregivers in that they are providing care because of their sense of obligation and their emotional relationship with the care recipient, not because caregiving is their chosen profession.

Primary Caregiver: A person who provides the majority of hands-on care to another individual who is chronically ill, disabled or emotionally or mentally unable to function independently. This person usually is the one who makes most of the decisions and organizes care and services for the care recipient. This person may not necessarily be a blood relative, but rather a close friend or partner. In the context of this manual, the terms “caregiver” and “primary caregiver” sometimes are used interchangeably because the only kind of caregiver mentioned in these sections is a person who provides the majority of hands-on care (emotional, custodial, paramedical, legal, etc.) to an adult who is chronically ill, disabled or emotionally or mentally unable to function independently.

Care Recipient/Care Receiver: The person who receives hands-on care from another individual or individuals. In the context of this manual, the terms “care recipients” and “care receiver” are used interchangeably to refer to the veteran patient.

■ ***Benefits of Training***

This training manual has been created with the following benefits in mind:

- To provide effective volunteer assistance to the veteran care recipient and primary caregiver.
- To assure that the primary caregiver knows that he or she is not alone and has the help of an agency with skilled volunteers and supportive resources in the community.
- To help provide volunteers with comfort and confidence from strengthening old skills and acquiring new skills after completing a volunteer support caregiver training program.
- To maximize the quality of services provided by volunteers, while minimizing potential risks of harm.
- To help community-based organizations more effectively support and encourage volunteer involvement in the *Caregiver Support Network*.

■ ***Legal Notice***

This training manual is not intended to, nor does it replace, the professional care, advice and services of physicians, nurses and other members of the VA health care providers, or legal or social service agencies. Neither does this training manual purport to train employees of these services. Individuals participating in the Caregiver Support Network agree to do so in a volunteer capacity only.

Certificates of completion will be issued, although there is no accreditation or licensure given or implied for using the materials and information included in the manual, nor is the content considered to be all inclusive.

■ *The Decision to Become a Volunteer Support Caregiver*

There is a growing need for well-trained volunteers to support primary caregivers and veteran care recipients coping with the daily challenges of living with a chronic disease, illness, disability, or condition of aging. Serving as a Volunteer Support Caregiver can be extremely fulfilling and allow individuals and groups an opportunity to meet a tremendous need in their communities, while maintaining the flexible scheduling so important to many.

How will you know whether this is the assignment for you?

■ *The Case for More Volunteer Support Caregivers*

It is estimated that, by the year 2050, more than one out of every five people will be age 65 or older. That means that over 20 percent of the population in the United States will be comprised of older adults. In fact, those over age 85 are the fastest growing segment of our population.

This can be a blessing for most of those who reach this stage in their lives with fairly good health, but can be a tremendous hardship for those with serious illnesses. It also can be a burden to their healthier spouses and their adult children who are likely to become their primary caregivers.

Adult children who are the “baby boomers,” born between 1945 and 1965, will probably spend more time caring for their parents than they have caring for their own children. The children of these “boomers” will have to face even more years as caregivers.

The rapidly changing demographics in the United States will create health care needs for the growing older adult population unlike anything we have ever seen. Because of this, our health care system, our government programs, our community-based services and ---most of all--- our families will be greatly challenged.

According to Dr. Gregory Spencer, a demographer with the U.S. census Bureau, the “baby boom” is predicted to become the “centenarian boom” over the next 50 years or so. By 2025, there will be nearly 500,000 centenarians—and about 1.3 million by 2050.

Since fiscal year 2000, the number of veterans being treated in VA facilities has been increasing. Not only have the “baby boomers” found themselves caring for their elderly parents, but they are also growing older themselves and representing a growing portion of the veteran population seeking health care services from VA. Because the criteria for receiving VA nursing home care can be stringent, there is increasing likelihood that the aging veteran will need to be cared for in his or her home or that of a family member.

In addition, VA has taken an active role in transitioning the health care of injured/ill returning combat veterans from Military Treatment Facilities to VA. The Seamless Transition Program has added a new demographic and a new dimension to VA health care. Many of the returning soldiers from this country’s most recent military conflict are young, perhaps even as young as 19-21 years of age. Prior to this, VA primarily saw aging veterans accompanied by an adult child or spouse as the primary caregiver. Now, in facilities where returning combat soldiers/veterans are being treated it is not uncommon to see a very young patient with their parents, a young spouse and/or possibly young children. Although unfortunate, these young veterans may eventually be care

recipients, and their parents or spouse caregivers for those suffering long-term or permanent illness or disability. This has prompted VA and VAVS to look closely at how we can support the families of this next generation of American veterans.

As more adults who maintain a reasonable level of health and quality of life, they become good candidates for training as volunteer support caregivers. In addition, VAVS will look toward young people who are willing to make a commitment to VAVS, to veterans and their families, as well as community organizations with people of all ages to meet this critical need in our veteran community.

■ *What Motivates a Person to Become a Volunteer Support Caregiver?*

Most volunteers are motivated by their commitment to a particular cause and organization, and by a sincere desire to help others. For the most part, volunteers are highly motivated people whose energy and positive attitudes are an invaluable resource.

- Volunteer support caregivers work mainly from their faith and their life experiences. They may see it as a concrete way of expressing their faith.
- People become volunteer support caregivers because they see a need in the community, in a friend or relative or in themselves and they connect with a community organization that meets that need.
- Volunteers often want to help people stay independent in their own homes longer. They may see it as preserving and protecting the dignity and respect of individuals.
- Volunteering as a support caregiver can provide opportunities to develop new skills, meet new people and take one's mind off one's own problems or losses.
- Sometimes, after having been a primary caregiver for a loved one who has recovered or died, a person will volunteer to support other caregivers to share the benefit of previous experience and to continue to have meaningful connections with others.

TRENDS IN VOLUNTEERISM

- Volunteers have increasing demands on their time because most volunteers are employed.
- More volunteers are looking for short term (episodic) volunteer opportunities.
- Nearly all volunteers need flexibility and find it difficult to commit to regular hours.
- Volunteers want freedom to act quickly, so they prefer smaller, locally controlled organizations.
- Volunteers (especially "baby boomers") expect challenging and interesting assignments.
- Volunteers are coming from a broader cross-section of our society (i.e., growing number of professionals, youth, unemployed and ethnically diverse.)
- Today's volunteers expect to be treated professionally with respect, dignity and appreciation.
- The growing number of older adults over age 70 are volunteering more than they used to. This group can identify with changing and increasing needs of older adults.
- Family and group volunteering are gaining popularity.
- People are interested in working for causes, not just organizations.
- There are many more people with professional skills available to community nonprofit organizations than in the past.
- There are many motivations for volunteering.

■ *To Become a Volunteer Support Caregiver: The Importance of the Decision*

As a volunteer support caregiver, an individual becomes a part of the support system for an older care recipient, the primary caregiver and the family:

- By deciding to help a veteran care recipient and primary caregiver, the volunteer will support the family's ability to care for the veteran in a familiar home setting.
- By deciding to befriend a veteran care recipient and primary caregiver, the volunteer support caregiver will share the joys and sorrows that are part of another's life.

■ *Most Commonly Asked Questions by Volunteers*

The idea of becoming a volunteer support caregiver initially may seem intimidating for many people. The following is a list of some of the most commonly asked questions asked by potential volunteers.

WILL I BE INTERVIEWED?

As a participant in this training program, most likely you have already undergone an interview. The interview process allows the Voluntary Service staff member an opportunity to evaluate the appropriateness of individuals interested in serving in the *Caregiver Support Network*. The interview will also assess previous experience, strengths, weaknesses, interests, availability, special considerations and preferences for volunteer assignments.

Once accepted into the program, please be sure to keep Voluntary Service informed about:

- Your desire to change volunteer assignments
- Health or physical conditions limiting activity or ability to perform assigned tasks.
- Your access to transportation to get to caregiving site.
- Any convictions for violation of any laws, including traffic violations or any other legal offenses. You will be subject to a background check in accordance with VHA policy.
- Who should be notified in case of an emergency and how to reach that person.
- Personal references who are not family members.

Liability: As "Without Compensation" (WOC) Employees, VA volunteers are covered under the Federal Tort Claims Act as long as they are acting within the scope of their assignment. This means that any volunteer working in an established assignment has the same protection and rights to medical treatment as a VA employee. In the following sections, we will review the roles and responsibilities of being a Volunteer Support

Caregiver. You will receive a volunteer position description outlining this information. Be sure that you are not performing tasks that are not a part of your volunteer position. This is the best way to protect yourself, the organization, the veteran, and the caregiver.

WHAT KIND OF WORK IS INVOLVED?

The type of work can vary from a couple of hours each week to 2-3 days per week spent helping a veteran care recipient the primary caregiver. As a volunteer, you should feel comfortable in expressing any concerns with your assignment or issues that may arise with the VAVS staff member. You will have access to VAVS personnel and the Social Worker/Case Manager/Care Coordinator responsible for referring the veteran to the Caregiver Support Network to discuss issues related to your volunteer assignment.

This is one of my dreams that has been fulfilled. I get such energy when I receive calls from care receivers about how much they appreciate the friendly visits, phoning and help they get from volunteers.

*Jeannette Graves
Interfaith Volunteer
Caregivers Program of
Co-op City
Bronx, New York*

WHAT SKILLS DO I NEED?

Volunteers do not need any specialized skills to volunteer in Caregiver Support Network. You have most likely gone through an orientation with Voluntary Service to review the VA and VAVS mission and our expectations from you as a volunteer, an introduction to the personnel responsible for Care Coordination, resources available to volunteers and instructions regarding how to ask for advice or emergency assistance.

In addition, the information that you will obtain from this course will prepare you with the skills and tools needed to perform your assignment effectively.

The training course will include how to communicate with professional care providers, understanding the aging process, Traumatic Brain Injury (TBI) and other areas related to specific health conditions of the veteran care recipient to whom you will be assigned., practical “do’s and don’ts,” legal issues, safety issues, respite care, listening skills, the importance of sensitivity to and awareness of the veteran’s emotional needs, the possible attitudes and feelings of the primary caregiver, how to set one’s own limits, guidelines for friendly visitors, telephone reassurance and so on.

The skills that you will develop during this training course will assist you in your assignment regardless of your level of formal education or economic background. Working within the Caregiver Support Network may prepare you for new career opportunities or, if you are already employed, may bring greater respect and recognition from your employer and your community.

Volunteer experiences also provide valuable opportunities for everyone to give back to their communities and to the veterans who have given of their lives in service to our Nation.

HOW MANY HOURS WILL I HAVE TO WORK?

The number of hours volunteer support caregivers agree to work is dependent upon the individual volunteer. Our organization offers assignment that fit the number of hours and days volunteers are willing to work and their lifestyles and other personal and professional commitments. Reliability is the key element for consideration here.

Once a veteran has been assigned, you will receive a volunteer schedule (*see Forms section*), a copy which will be provided to the primary caregiver, in addition to a copy being maintained in Voluntary Service. You should try to meet your commitment to an assignment for a certain or number of days per week and hours per day during a set number of months. If you cannot meet a particular commitment on a given day or week, please try to give plenty of notice, so that alternative arrangements can be made. Be sure to let a staff member know when:

- you will not be able to visit.
- your volunteer caregiver schedule or availability changes; or
- you are sick. Don't push yourself to keep your caregiving appointment when you are ill. You may inadvertently compromise the health of the veteran care recipient.

Canceling at the last minute or failing to show up for the assignment may disappoint the veteran care recipient and/or the primary caregiver; it may also compromise the integrity of the *Caregiver Support Network*, VAVS and the VA overall.

■ *Attributes of a Good Volunteer*

- Good volunteers engage in proper and positive efforts.
- A good volunteer is someone with vision, motivation and a willingness to act.
- There are few limits to someone's ability to volunteer. A volunteer does not need to have physical strength or dexterity. A volunteer does not need special education or training; these can be taught.
- A volunteer needs common sense and a willingness to work in cooperation with others. Social skills may be taught or improved upon.
- "Service with a smile" is a slogan that sums up the value of volunteers. A volunteer gives service cheerfully, willingly and with joy.
- A volunteer must have a sense of priority. He or she cannot be all things to all people. A volunteer needs to learn that problems can be solved by taking many small bites rather than on big swallow.
- A volunteer must have a positive attitude balanced with a realistic view of the world.
- A good volunteer faces up to adversity and say, "Let's roll up our sleeves and get to work---we can do something about this."
- Enthusiasm is an important quality in a volunteer, one that will grow as the volunteer experiences the satisfaction of pursuing and realizing a worthy goal.

- To be effective, a volunteer must feel that an organization's purpose is worthwhile and consistent with one's personal beliefs.

Americans have benefited from our tradition of self-help and grassroots community action. We regard volunteerism as an extension of individual liberty, freedom of action and responsible citizenship. The privilege of this liberty and freedom has been paid for through the sacrifice and service of the men and women in the armed forces of our Nation's military. We owe them a debt of gratitude, and for this reason we recruit highly dedicated volunteers to serve them and their families.

■ *Psychological and Social Issues*

The role of the Volunteer Support Caregiver is vital to the care and treatment of our veterans. We take very seriously the mental, physical and emotional health of volunteers enlisted to serve them. Ask yourself these questions as you prepare for an assignment within the Caregiver Support Network. There is no shame in admitting that this may not be the most suitable assignment for you. Issues arise when you are not willing to accept your own limitations--- issues that affect you, the organization, the caregiver, and the veteran. Be honest and thoughtful in your consideration.

DOES THE VOLUNTEER HAVE THE RIGHT ATTITUDE?

If a volunteer's personality is optimistic, viewing others and most situations as basically good, then the volunteer's attitude about caregiving, the veteran care recipient and the primary caregiver will be positive. Volunteers can also help bring out the best in the care recipient.

Key Point: See your role as one responsible for fostering a positive and nurturing environment for both the veteran and the primary caregiver.

CAN THE VOLUNTEER RESIST THE URGE TO CONTROL?

It takes a wise person to understand that the only real control possible is that of oneself. The volunteer cannot control others' attitudes, desires or feelings. The best the volunteer can do is influence the care recipient or the primary caregiver by the volunteer's reaction to their behavior.

The veteran care recipient is an adult and, assuming competency, has the right to determine the course that his or her life will take, including accepting or rejecting a doctor's (or anyone else's) advice. This is probably the hardest fact for a primary caregiver or a volunteer support caregiver to accept.

Key Point: Stay in touch with the boundaries of your volunteer caregiver role.

DOES THE VOLUNTEER KNOW WHEN TO HELP AND WHEN NOT TO?

When the need for care of an ill or disabled veteran arises, often the volunteer support caregiver's first instinct is to rush in and take over. If it is an emergency situation, the volunteer's instinct probably is correct. However, in most instances, "Let me do it for you" is not the kindest or even the most appropriate thing the volunteer can offer. This is where judgment plays a key role.

Volunteer support caregivers sometimes walk a fine line between helping and hindering the veteran care recipient. The volunteer has to avoid doing too much, helping too much, being too protective—and ending up hurting the very person the volunteer is trying to assist. This is especially true of the veteran care recipient is recovering from an illness and needs to relearn skills in order to maintain a level of independence.

While attending to their volunteer assignments, volunteers sometime inadvertently "walk into" complex family dynamics and situations with which they should not interfere. Although it is tempting to try to be helpful, the volunteer should avoid offering opinions or taking sides in these situations.

Key Point: Take the lead on when and how much assistance to offer from the veteran care recipient. Be sensitive to their feelings.

CAN THE VOLUNTEER SUPPORT CAREGIVER ACCEPT CHANGE?

Accepting change is necessary, especially in a caregiving situation where things can change suddenly. Accepting change is especially difficult if the volunteer support caregiver has a hard time accepting that he or she cannot control anything or anyone else.

The veteran care recipient may undergo many changes the volunteer will have to deal with in support caregiving. Changes may be physical and/or mental can be the result of disease or an attitude shift by the veteran care recipient. The cause is incidental to the fact that the volunteer must accept these changes and deal with their consequences.

Key Point: Being receptive to change is essential in your ability to support the veteran care recipient and the primary caregiver.

CAN THE VOLUNTEER ACCEPT THE INEVITABLE?

Caregiving support responsibilities have a tendency to engulf a volunteer's life, but they don't have to. Keeping the situation in perspective will help the volunteer

remain relatively peaceful and guilt-free when the need for caregiving has ended.

Regardless of what the primary caregiver, volunteer, veteran care recipient or doctor does, the veteran care recipient may eventually die, particularly if the veteran is elderly. The volunteer never likes facing this fact, but he or she will need to come to terms with it, not only for his or her own sake, but also for the sake of the veteran care recipient.

The care recipient must adjust to the idea of death on a personal level. This means going from the abstract idea that death will come someday to the realization that death is likely to come sooner rather than later in some instances.

The elderly veteran may have an easier time accepting death than the volunteer support caregiver. In the later stages of life, time is perceived in a much more finite way than when someone is 35 or 40 years old. If the veteran has a terminal condition, regardless of age, acceptance of death is especially necessary.

Discussing death as part of life promotes greater acceptance for everyone, including the care recipient, the primary caregiver, the volunteer and the family.

Other than death of the veteran care recipient, the caregiving relationship may have other transitions along the way. If the volunteer caregiver was enlisted to assist the primary caregiver during a long term rehabilitation process of the care recipient, the relationship may be terminated following successful rehabilitation. A suspension or termination of the relationship may occur if the veteran is hospitalized, if the veteran or the primary caregiver relocates, or simply if there is a need to make a change. We will address the issue of loss in Section ___ of this manual.

A woman cared for members of her family until their deaths. After the third one, she thought that she never wanted to do this again. However, after a period of recovery, she decided that she had become an expert in caregiving. There were others who needed her help.

*Ms. Mardythe Di Pirro
Interfaith Volunteers for
Charity in Action
Hampton Bays, NY*

Key Point: Be willing to accept the limitations of the caregiving relationship.

IS THE VOLUNTEER EMOTIONALLY WELL BALANCED?

Volunteer support caregivers have many responsibilities, not only to the care recipient and to family commitments, but to themselves—a responsibility to take care of their own needs.

On the surface, this may sound selfish when the volunteer is supposed to be concerned about the older care recipient, primary caregiver and family. But it really isn't. Remember: the only way to have something to give to another is to first gather it yourself.

Key Point: Monitor your own physical, mental and emotional health throughout the volunteer caregiving process.

CAN THE VOLUNTEER PRIORITIZE?

It's easy to get caught up in the endless round of chores that need to be done, especially if the veteran care recipient is very ill. Sometimes we personally overburden ourselves to avoid having to think about the seriousness of the situation. In doing so, the more important things can get lost. Volunteers should try instead to concentrate on the things that are necessary to sustain the quality of life and learn to cherish time.

Key Point: Keeping the expectations of the veteran care recipient and the primary caregiver in check is beneficial to the caregiving relationship.

EXERCISE 1: Being a Volunteer

Overview: The responsibilities and challenges of volunteers and the contributions they offer are significant. It is important that volunteer support caregivers understand their role and the value they offer to the organization. This exercise is designed to explore individual perceptions and motivations for volunteering and clarify expectations.

EXERCISE 1: Being A Volunteer

Answer the questions individually and then discuss them with a partner.

1. What do you think of when you hear the word “volunteer?” Give one-word description of a person who is a volunteer.

2. What are barriers to becoming a volunteer?

3. What factors motivated you to become a volunteer?

4. What specific attributes and abilities do you have to offer as a volunteer?

5. What do you perceive to be the benefits of volunteering and what do you expect to gain from the experience?

6. What do you expect your role and responsibilities to be as a volunteer?

■ *Understanding Caregiver and Care Recipient Needs*

Caring for an ill, injured or disabled person full-time is a challenging responsibility for the primary caregiver under any circumstances. However, it is particularly difficult with the care recipient is a parent or spouse who is suffering from a chronic, progressive or life-threatening illness.

Primary caregivers often ignore or sacrifice their own needs to devote their time and attention to care for a loved one. It takes a special kind of person spend his or her time in this way- focusing on the needs of the care recipient. Primary caregivers also have their own lives, health challenges, outside interests and other responsibilities. Often, those who take on the role of primary caregiver are the children or spouses of the older adults for whom they are caring. In more recent cases affecting veterans returning from Operation Iraqi Freedom and Operation Enduring Freedom, the caregiver may be the parents of a young service member or new veteran. These primary caregivers frequently have families and problems of their own.

Primary caregivers need help, encouragement and emotional support. However, they are not always comfortable asking for it. It doesn't always occur to a primary caregiver that it is "okay" to ask for help from friends, family and community social service organizations, or even the VA.

A very important aspect of a volunteer support caregiver's job is to be sensitive to and address some of these needs for help, encouragement and emotional support.

This support may take the form of verbal encouragement, such as telling the primary caregiver that he or she is doing a great job.

Support may also take the form of understanding when the primary caregiver needs time alone or to be with other family members or pursuing other interests. It means standing in to relieve the daily stress of a draining job, perhaps so that the primary caregiver can just get some rest. It also will mean knowing the household, anticipating the needs of the care recipient and being ready to step in as necessary in a way that is as seamless as possible.

■ *Basic Needs for Caregivers and Care Recipients*

In the course of their assignments, volunteers will have the opportunity to meet and assist many different kinds of individuals and families. These can be both exciting and challenging experiences. It is important for volunteers to know that, no matter how unique the circumstances and the personalities are, all of us have basic needs. These include:

Physical Needs

Food
Clothing
Shelter
Rest
Activity
Avoidance of pain
Safety, escape from danger

Psychological Needs

Love
Affection
Recognition
Acceptance
Security
Trust
Socializing

Common Stress Reactions

Common stress reactions caused by day-to-day frustration and unmet needs of primary caregivers and care recipients may include:

- Fear
- Depression
- Anger
- Aggression
- Regression
- Illness
- Anxiety
- Fatigue
- Discouragement
- Tension headaches
- Backaches
- Muscle tension
- Insomnia

When these basic needs are **not** met, a person at any stage of life will experience stress and other physical and emotional reactions. This often is the case with primary caregivers, who frequently focus on meeting the needs of the care recipient and family, leaving their own needs unmet. Care recipients also feel stress when they are unable to express their needs or they are misunderstood or ignored.

■ *Practical Interventions for Primary Caregivers*

- **Strengthen problem-solving abilities.** When each problem arises, it should be dealt with quickly. When problems pile up, they add to stress and can become overwhelming. It is important for the primary caregiver to be proactive when problems occur by calling doctors and other health care professionals, seeking help from other family members and friends and requesting additional support from community organizations, as needed.
- **Improve coping skills.** When the circumstances of caregiving can not be changed, the primary caregiver can reduce stress and regain control of emotional responses by using some of the following:

- ❖ Humor – the ability to laugh at oneself, to see the lighter side of daily foibles and mishaps and not to take things so seriously.

- ❖ Relaxation techniques – deep breathing, progressive muscle relaxation, meditation and yoga.

- ❖ Faith – if one has religious and spiritual beliefs, praying to a “higher power” or seeking support from one’s religious affiliation.

- ❖ Positive thinking – staying hopeful and using a realistic approach to changes and improvements that are possible. Stopping the downward spiral of self-defeating thought patterns.

- **Manage the needs of the care recipient.** Focusing on the physical and psychological needs of the care recipient and addressing legal, financial and other practical matters with help from others.
- **Manage the relationship with the care recipient.** An ongoing good relationship between spouses or between a parent and a child may become strained when roles are reversed, as the child becomes the caregiver and the parent becomes the care recipient. As the care recipient’s social contacts become more limited, he or she can become even more dependent on the primary caregiver and family as the only connections to the outside world. It is a challenge to keep the relationship balanced and not to take conflicts too personally.

- **Obtain useful and relevant information.** While attempting to meet the needs of the care recipient, a primary caregiver should seek information on a variety of topics, which may include:
 - ❖ The diagnosis, prognosis and treatment options for the care recipient's disease or condition.
 - ❖ The symptoms of the disease or condition at various stages.
 - ❖ The health care needs of the care recipient at various stages of the disease or condition.
 - ❖ The expected emotional responses to the disease or condition from the care recipient and other family members.
 - ❖ The kinds of professional, para-professional and volunteer support services available to assist the care recipient and primary caregiver and how to gain access to them.
 - ❖ The short-term and long-term financial and legal implications of the care recipient's disease or condition.
 - ❖ The end-of-life decisions and considerations of the care recipient.

- **Stay healthy.** While focusing on the needs of the care recipient, a primary caregiver should set a priority to maintain good health. The primary caregiver should be encouraged to maintain a lifestyle of:
 - ❖ Proper nutrition. Getting the right balance of nutrients and foods.
 - ❖ Activity and rest. Achieving the right balance of busy time and down time.
 - ❖ Regular exercise. Twenty minutes to one half-hour at least three times a week.
 - ❖ Prompt medical attention. Recognizing the warning signs and symptoms of stress, anxiety and illness, and seeing a doctor promptly.

- **Manage family issues.** Primary caregivers and care recipients can come from functional or dysfunctional families. Unresolved family conflicts may resurface and new ones may arise when a key family member takes on the role of primary caregiver of an older family member. This kind of situation can disrupt the family's routine. Primary caregivers often fall into this role without help from other family members.

- **Handle feelings.** Primary caregivers need opportunities to express the range of feelings they may be experiencing – from frustration, anger, guilt and fear to anxiety, loneliness and depression. These feelings should be accepted as valid and reasonable, given the circumstances. Primary caregivers sometimes need help in learning how to handle these feelings constructively. They should be encouraged by volunteers to get help if they can't sleep, feel hopeless, have frequent crying spells or are using more drugs or alcohol to numb their feelings.

- **Strengthen communication skills.** The ability to communicate one’s feelings can be a safety valve in emotional situations. It is especially important for primary caregivers to

SYMPTOMS OF CAREGIVER BURNOUT

A volunteer should report the situation to the Home Health Coordinator when the primary caregiver shows any of these signs:

- Disruptive sleep patterns, including insomnia or habitually oversleeping; never feeling rested, even when the primary caregiver has managed to have a full night’s sleep; sleep troubled by disturbing dreams or nightmares.
- Altered eating patterns, including not being able to eat or overeating; significant weight gain or loss.
- Increased sugar consumption or use of alcohol or drugs.
- Increased smoking or a strong desire to start again after having quit.
- Frequent headaches or sudden onset of back pain; increased reliance on over-the-counter pain remedies or prescribed drugs.
- Irritability.
- High levels of fear or anxiety.
- Impatience.
- The inability to handle one or more problems or crisis.
- Overreacting to commonplace accidents such as dropping a glass or misplacing something.
- Overreacting to criticism.
- Overreacting with anger toward a spouse, child or care recipient.
- Alienation, even from those who offer relief and help.
- Feeling emotional withdrawal.
- Feeling trapped.
- Thinking of disappearing or running away.
- Not being able to laugh or feel joy.
- Withdrawing from activities and the lives of others around the primary caregiver.
- Feeling hopeless most of the time.
- Loss of compassion.
- Resenting the care recipient and/or the situation.
- Neglecting or mistreating the care recipient.
- Frequently feeling totally alone, even though friends and family are present.
- Wishing simply “to have the whole thing over with.”
- Playing the “if only” game: Saying over and over “If only this would happen” or “If only this hadn’t happened.”
- Loss of hope, purpose and meaning.

be able to handle negative feelings about their caregiving responsibilities and the care recipient. It is helpful to learn how to use assertive, rather than aggressive or passive, communication with family members, the care recipient and health care providers.

- **Ask for help.** Primary caregivers need to know that it is okay to ask for help from other family members and/or from outside organizations. They should not have to carry the entire load by themselves. Providing information about additional resources is helpful, but not enough. Sometimes primary caregivers need to be convinced that accepting additional help in no way diminishes their value or ability to provide the best care for the care recipient. It is important for primary caregivers to find a way to communicate a need for help. This can be one-on-one, at family meetings or during individual and/or family counseling sessions.
- **Plan for the future.** Deciding to keep the care recipient at home or in the primary caregiver’s home, or to move the person into a long-term care facility is difficult, even when the primary caregiver can no longer handle the responsibility.

Volunteers give validation, hope and heart to people who may need a reason to live as much or more than they need help.

*Inez Russell
Friends for Life
Waco, TX*

It is important for volunteers to pay attention to stress reactions and other behaviors that suggest that some of the primary caregiver’s or veteran care recipient’s needs are not being met.

By being prepared for some stress reactions, volunteers will know not to take these reactions personally. To be helpful in these situations, volunteers should encourage primary caregivers to be assertive about expressing their needs, maintaining a health lifestyle, seeing a doctor about their own symptoms and health concerns

and seeking additional outside help when needed.

When a volunteer observes stress reactions on a regular basis and is not sure how to handle a particular situation, he or she should ask the Home Health Coordinator for guidance. When a primary caregiver shows extreme stress reactions regularly, he or she may be experiencing “caregiver burnout.”

■ *Caregiver Burnout*

“Burnout” is a very serious problem for primary caregivers, care recipients and their families. It occurs when the caregiving burden becomes too great for the primary caregiver to bear. The caregiving burden is the total physical, emotional, financial and psychological needs of the care recipient with which the primary caregiver must contend day in and day out. Burnout can be devastating.

The spouse and children of the primary caregiver may lose their own family caregiver to the anger, depression and despair that stems from burnout. The care recipient also may lose the quality of care and comfort provided by the primary caregiver.

The volunteer can be objective while observing, recognizing and calling attention to symptoms of caregiver burnout. The volunteer also can intervene by alerting the Home Health Coordinator to the primary caregiver’s situation, so that more assistance, counseling help and medical attention may be arranged.

It is normal for a primary caregiver to have some of these thoughts or feelings some of the time. It is a cause for concern when the primary caregiver shows even a few of these symptoms on a daily basis. The situation has reached a crisis when the primary caregiver begins to strike back by mistreating the care recipient or family members, neglecting personal health or having thoughts of suicide.

The volunteer in this situation should bring these observations of symptoms immediately to the attention of the Home Health Coordinator or to a relative of the primary caregiver.

THE THREE STAGES OF CAREGIVER BURNOUT

STAGE ONE – FRUSTRATION

The primary caregiver expresses continuing frustration and disappointment over the care recipient’s deteriorating condition or lack of progress. The primary caregiver has difficulty accepting that the quality of care and effort has nothing to do with the actual health-related decline or mood of the care recipient.

STAGE TWO – ISOLATION

The primary caregiver struggles to maintain a sense of purpose in working so hard to provide care. He or she may express feelings of loneliness, being unappreciated, second-guessed or criticized by other family members and the care recipient. Reality of the care recipient’s condition and the limitations of caregiving are not accepted. The primary caregiver is reluctant, unable or unwilling to reach out for help from others.

STAGE THREE – DESPAIR

The primary caregiver feels helpless and adrift. The primary caregiver is unable to concentrate and loses effectiveness as a caregiver. He or she is no longer excited about the progress or response of the care recipient to quality care. As a consequence, the primary caregiver neglects personal care and well-being, loses interest in the community, social contact and activities, such as reading books, watching movies or other stimulating activities.

Adapted with permission from *Preventing Caregiver Burnout*, James R. Sherman, Ph.D., Pathway Books, 1994, pp.8-10

■ *How Volunteers Can Help*

Volunteers can help by understanding the basic needs of both the care recipient and primary caregiver and observing behaviors and emotional reactions that may suggest certain needs are not being met, a volunteer can try to improve the situation.

Often, both the care recipient and their primary caregiver feel isolated and unappreciated. They also may believe that no one really cares about or understands their feelings or needs. The care recipient may not be consuming enough food for proper nutrition. The primary caregiver may not be getting enough rest because of chronic sleeplessness and worry.

By expressing concern, by listening to the care recipient and primary caregiver describe how they feel, what they need and worry about; by providing companionship; by helping with food preparation or by providing socialization, a volunteer can help bridge the gap of unmet needs. A volunteer's understanding of basic needs is only the beginning.

By recognizing stress reactions and their possible causes and understanding why primary caregivers and care recipients react as they do, volunteers can respond to them with more empathy and support.

Volunteers can also help to empower primary caregivers by encouraging them to take better care of themselves, see medical attention and take time for rest, relaxation and recreation – away from their ongoing caregiving responsibilities.

Beyond helping to meet the basic needs, volunteers also can help primary caregivers reduce stress reactions by assisting them in addressing some practical concerns and needs.

■ *Listening Skills*

Volunteers can provide valuable support by simply listening to what primary caregivers and care recipients have to say about their situation, how they feel and what things are bothering them. This may not change the situation. However, it gives them a needed release for their feelings and helps them to know that someone cares enough to listen. And, sometimes, just expressing a need or concern to someone else begins the process of finding a solution or improving the situation.

In order to maximize their ability to help others, volunteers should learn how to be good listeners.

■ *Good Listening*

Complete communication is the giving and receiving of information with speaking and listening. Listening is more than just hearing words. Listening should involve hearing what is being said *and understanding*. Good listening takes practice, an open mind and discipline.

A person should never presume to know exactly what another person wants, thinks or feels, without asking or being told. Good listening requires one to be careful about interpreting what was said before there is understanding.⁴

Volunteers should use good listening skills to help build positive relationships, clarify directions and create opportunities for primary caregivers, care recipients and other family members to express themselves openly and honestly without judgment.

TEN PRINCIPLES OF GOOD LISTENING

1. Stop talking. You cannot listen while you are talking.
2. Put people at ease. Help others feel free to talk by creating a “permissive environment.”
3. Show that you are ready to listen. Look and act interested. Pay attention while others talk. Listen to understand rather than to reply.
4. Remove distractions. Don’t doodle, tap, or shuffle papers while others are talking. Turn down the radio or TV and shut the door, if necessary.
5. Empathize. Try to put yourself in their place, so that you can see their point of view.
6. Be patient. Allow plenty of time. Do not interrupt. Don’t move toward the door or walk away until they have finished talking.
7. Keep your temper under control.
8. Avoid argument and criticism. This puts others on the defensive.
9. Ask questions. Encourage others to talk and show you are listening.
10. Stop talking. This is the most important principle, because all of the other principles depend upon it. You just can’t be a good listener while you are talking.

■ *Active Listening*

Active listening is the process by which a volunteer can gain a clearer understanding of what the primary caregiver or care recipient is saying and why it is being said. Active listening requires the listener to reflect back on what was just said and ask questions to clarify its meaning. By using active listening techniques, volunteers can establish more trusted and caring relationships and avoid confusion or a lack of understanding.

*Our volunteers are
the bright spot in
older people’s days.
The telephone call
in the morning or
the warm hello at
lunch delivery may
be the only contact
they have during the
day.*

*Lana Campbell
Hackney County Senior Citizen
Association, Inc.
Levelland, TX*

ACTIVE LISTENING TECHNIQUES

- Accept what another person is saying, especially about his or her feelings.
- Clarify understanding of what another person has just said by:
 - Restating or paraphrasing to the other person what you think was said.
 - Checking your perceptions of the meaning of what was said with the other person.
- Probe further by asking the other person to clarify what was said.
- When clarifying understanding or responding to what another person has just said:
 - Use the other person's preferred name. A person is more responsive and comfortable when called by a name that he or she likes.
 - Use a low and respectful tone of voice.
 - Use direct eye contact
 - Use short words and simple sentences, but do not talk down to the other person.
 - Discuss only one idea at a time. Be sure that the other person understands the one idea before introducing another idea.
 - Give the other person plenty of time to respond. Do not rush him or her. Sometimes it takes a while for another person to understand an idea or question and then to respond.
 - Try to continue the conversation even when it does not completely make sense to you. This is important for maintaining the other person's self-esteem. This shows acceptance of the other person even when you fail to understand what is said.
 - Offer help, if needed, by suggesting a word if the other person is struggling to find one. It is frustrating for a person who knows what he or she wants to say, but cannot find the right words.

■ *The Role of the Volunteer Support Caregiver*

The purpose of this section is to describe and clarify the important role that volunteer support caregivers can play in assisting veteran care recipients, their primary caregivers and their families. This section also provides tools for preparing volunteers for their assignments and guidelines for meeting challenges and expectations.

■ *Volunteer Assignments*

VAVS has a long and distinguished history of serving the needs of veterans in various capacities. The Caregiver Support Network exists to serve a growing need to support those outside of the medical environment who have the day-to-day responsibility of caring for sick and injured veterans in their homes. Participants in the *Caregiver Support Network* have the opportunity to choose from a number of volunteer assignments designed to meet this need. The following are some brief descriptions of the kinds of assignments volunteers are typically given to support the veteran care recipient, their primary caregivers and families.

- ***Chore Services/Housekeeping Volunteer:*** Assist with household cleaning, meal planning and preparation and minor maintenance chores unable to be performed by a veteran care recipient and/or primary caregiver.
- ***Errands/Shopping Volunteer:*** Runs errands and shops for groceries, medicines or other supplies needed by a homebound veteran care recipient and/or primary caregiver.
- ***Friendly Visitor:*** Provides support through human socialization, conversation, friendship and companionship.

- ***Handyperson/ Yard work Volunteer:*** Performs minor repairs, installations and basic yard work that are too difficult or demanding for a veteran care recipient and/or primary caregiver.
- ***Pet and Plan Care Volunteer:*** Helps care for and maintain pets and plants for a veteran care recipient and/or primary caregiver.
- ***Reading Volunteer:*** Reads correspondence and printed publications to an older care recipient with poor vision, blindness or other related health condition.
- ***Respite Assistance Volunteer:*** Provides needed respite breaks for a primary caregiver, while providing companionship, support and a needed presence for a veteran care recipient.
- ***Special Needs Volunteer:*** Completes a one-time special task for a veteran care recipient and/or primary caregiver.
- ***Spiritual Support Volunteer:*** Assists a veteran care recipient and/or primary caregiver in maintaining spiritual or religious practices with no references or persuasion towards one's own faith or religion.
- ***Telephone Reassurance Volunteer:*** Provides regular telephone contact to convey support and concern about the well-being and the quality of life of a veteran care recipient and/or primary caregiver.
- ***Transportation Volunteer:*** Provide round-trip transportation and accompanies a veteran care recipient and/or primary caregiver to locations for needed health care services, such as a doctor's office or hospital.

■ ***Volunteer Position Descriptions***

Volunteer position descriptions are used to:

- Help volunteers determine the kinds of services they might provide.
- Describe the range of volunteer assignments available and the qualifications and training required.
- Help volunteers understand what is expected of them when they accept an assignment.
- Assist VA staff in developing and implementing volunteer training sessions.
- Provide a frame of reference for conducting performance evaluations.

The volunteer position descriptions include:

- A title and brief description of the volunteer job.
- The objective of the volunteer job.
- The duties to be performed
- The qualifications required to perform the duties of the assignment, including attitude, willingness, skills and experience.
- The time commitment required to accept and complete the volunteer assignment, including the hours per week and the anticipated length of time required to complete the assignment.
- The training needed, including specialized training and continuing education.
- The contact person, to whom the volunteer should report issues/concerns related to his/her assignment.

■ *Evaluation/Ongoing Training*

Volunteers serving in the *Caregiver Support Network* will be periodically evaluated to offer an opportunity to give the volunteer concrete positive feedback and to seek the volunteer's feelings and opinions about how things are going and how they might be improved.

Evaluations will generally be conducted in an informal setting. However, there are instances when a more formal and/or written evaluation is required:

- If the volunteer wants to use his or her volunteering as a way of gaining new skills or honing old ones to enter or re-enter the paid work force.
- If the volunteer is seeking to work at a higher level within their assignment area or the VAVS program
- When there have been significant achievements or significant problems.

Outside of these reasons, a written formal evaluation may not be used, although review of the competency checklist that follows will be done, at least, on an annual basis. The competency checklist is used to ensure that the volunteer's skill is at a satisfactory level of service and continues to meet the minimum requirements for serving in the *Caregiver Support Network*.

In addition to the general annual volunteer education, there may also be a need for periodic training for *Caregiver Support Network* volunteers, either as a group or specific volunteers. These may include:

- When there is a policy or procedural change in the operations for the Caregiver Support Network.
- When there has been a common area of concern or ongoing issues amongst the volunteers, staff, primary caregivers, or veteran care recipients.
- When the medical or psychological condition of the care recipient changes, requiring adaptations for the volunteer support caregiver.

Volunteer Support Caregivers should make every effort to attend these and other training sessions when presented. Failure to attend mandatory training may result in the reassignment, suspension or termination of a *Caregiver Support Network* volunteer.



**CARING FOR THE CAREGIVERS
VOLUNTEER COMPETENCY
ASSESSMENT FORM**

Assessment Period Covered: _____

Initial Assessment:

On-going Assessment:

Volunteer's Name _____

Volunteer Supervisor's Name: _____

Duties and Responsibilities:

Competency Level: E= Exceeds the Standards

S= Competent – Self-directed/training may be desired

C= Competent through education/training experiences

Basic Competencies	E	S	C
• The volunteer participates in training where they are assigned.			
• Demonstrates a good attitude and is willing to learn			
• Listens attentively to others without interruptions.			
• Treats patients and staff with respect without regard to culture, personality, or background.			
• Courteous in all interactions with patients, staff, and visitors.			
• Suggests ways to improve work assignment.			
• Is positive and upbeat in their work assignment.			
• Is receptive to change and accepts new ideas.			
• Knows how to direct patients/families for special needs			
Age Specific Competencies			
• Interacts with everyone in a respectful manner and is considerate of physical abilities and age restrictions.			
• Provides assistance to individuals in a manner that takes into account the special needs of the elderly or infirmed.			
Assignment Specific Competencies			
• Knows how to report an emergency.			
• Is able to establish good communication with the patient and Caregiver.			
• Is always looking out for the patients safety needs and reports problems to the respite coordinator.			

Volunteer's Signature: _____ Date _____

Reviewer: _____ Date: _____

■ *The Care Plan*

A care plan is created by:

- Assessing the care recipient's situation, the strengths and caregiving abilities of the primary caregiver and other family members.
- Defining the needs for care.
- Setting objectives for care.
- Determining what services will be provided by health care professionals and what services will be provided by community organizations staff and volunteers.

A care plan may be created by a home care agency, care manager or hospital staff, before an individual is discharged from a hospital. One or more care plans may be required, depending on the complexity of the situation. The older care recipient may need skilled care from several professionals, including a registered nurse, physical therapist, social worker or home health aide.

The care recipient and primary caregiver may need assistance with meals, transportation, respite, shopping/other errands, housecleaning, minor repair jobs, correspondence and paperwork and other support services from community organization staff and volunteers.

Of course, the primary caregiver also must complete daily tasks and activities that relate to the care plan and provide ongoing care and support to the older care recipient. The care plan should provide an organized structure and flexibility to handle changes in the care recipient's condition and unexpected occurrences.

When a volunteer support caregiver takes on a new assignment, it is important for him or her to understand enough about the care plan to know what the objectives are, what health care professionals will be providing care on-site and how his or her services support the care plan.

If a care plan has not been created, a volunteer should request specific guidance from the VA contact person about the type of care the older care recipient is receiving and the kinds of volunteer assistance the care recipient and primary caregiver may need.

In addition, the volunteer should gain a clear understanding of how his or her assigned services fit into a daily plan of tasks and activities mapped out by the primary caregiver.

■ *Organizing Tasks and Activities*

A primary caregiver often is under pressure to maintain the living environment, manage the household and provide care and support to children still living at home, as well as to the older care recipient. These responsibilities can only be met if the primary caregiver is organized. Otherwise, important daily tasks will not get done.

A volunteer support caregiver can help both the primary caregiver and the older care recipient by assisting the primary caregiver in organizing a schedule of daily, weekly and monthly tasks and activities to be done in order of priority and determining who should be responsible for completing them.

Getting organized can take time. However, having an organized plan of tasks and activities can save time in the long run. If an organized activity plan has not already been developed and in use when a volunteer begins an assignment, the volunteer may assist the primary caregiver in creating this plan. To do this, the following four basic steps can help:

- **List**
- **Prioritize**
- **Act**
- **Network**

LIST

Listing all daily, weekly and monthly tasks and special activities is critical to the planning process. Examples of tasks include: awakening the care recipient at a set time; helping the care recipient with personal hygiene, dressing and toileting; preparing and feeding the care recipient breakfast, lunch and dinner; changing bed linens and towels as appropriate; helping the care recipient with daily exercise and organizing and administering medications on schedule as prescribed by the doctor. The habit of checking the list off as tasks and activities are completed helps one keep track of how much is being accomplished and of what still needs to be done.

A list should be created that progresses through the day from early morning to late evening.

As a list is created for the tasks and activities of each day, a pattern begins to emerge. After a while, much of what is being done each day is repetitive, so these tasks and activities can remain on a basic daily list. Activities that are not as repetitive on a daily basis also should be added to the basic list. These might include doctor's appointments, visits from family or other family members, or shopping trips.

PRIORITIZE

Tasks and activities to be accomplished should be listed and assigned a rating according to their level of urgency or importance.

A simple rating system can be used - Level 1, Level 2, and Level 3 - with Level 1 assigned to the most urgent or important activities and with Level 3 to the least urgent or unimportant activities. Any activity or task assigned a rating of Level 3 should be completed only after all Level 1 and 2 activities are completed. Here's an example:

- Pay bills - Level 1
- Buy and prepare food for meals – Level 1
- Order refills of medications - Level 1
- Make flight reservation for business trip - Level 1
- Fold and put away clean laundry - Level 2

- Take clothes to the dry cleaners - Level 3
 - Pick up books ordered by the bookstore – Level 3
-

ACT

To get organized, it's important to set priorities and make detailed lists of daily tasks and activities. It's even more important to follow through with action. Acting by completing tasks and activities and crossing them off the list helps the primary caregiver stay focused, measure daily accomplishments and alleviate the pressure and anxiety of feeling overwhelmed.

It is recommended that volunteers keep thorough records of their volunteer hours, the general services they provide and some observations about the care recipients to whom they are assigned. A Volunteer Journal form will be provided for this purpose.

NETWORK

One person alone cannot complete all of the tasks and activities on the list. A volunteer can help the primary caregiver identify friends, family members and others in his or her network who might be willing and able to take on some tasks. A volunteer may also be able to suggest additional resources available through other community organizations. This information might be gathered by the VA, veterans' service organization or the volunteer's own knowledge of the community.

■ *Activities to Keep the Older Person Vital and Independent*

Recovery from illness or injury may take an extensive period of time, particularly with an older adult. The care they require may also last for an extended time. It can be something that the care recipient becomes used to and thinks they need in order to survive. They can become dependent on their primary caregivers and give up activities that they are capable of doing for fear of becoming sick or further injuring themselves. They convince themselves that it is safer to stay at home, to avoid physical exertion, to rest. However, without exercise, persons who are capable of performing certain tasks will soon lose the ability to perform them.

By encouraging care recipients to continue to use their bodies and minds, primary caregivers are helping them to regain some of their independence.

The benefit to the care recipient is a greater sense of well-being, self-esteem and a feeling of taking control of some aspects of his or her life. The benefit to the primary caregiver is a relief from some of the burdens of caregiving.

Each day is made up of several types of tasks and activities. The veteran care recipient should be encouraged to do as many of these as possible to help maintain feelings of self-sufficiency, vitality and independence.

They include:

- Things we have to do: Eating, drinking, sleeping and going to the bathroom.
- Things we should do: Brushing teeth, combing hair, bathing, dressing and doing chores around the house.

- Things we like and want to do: Reading a book, playing games, taking trips, eating at a restaurant, going to church, dancing, hiking, singing, watching TV and movies.

■ ***Activities to Keep the Care Recipient Vital and Independent***

- **Arts and Crafts**

Simple art projects can be stimulating, even if they have never worked on these before. Projects may include painting with water colors; creating collages with magazine clippings, fabrics and other materials; nail art which involves pounding nails into a block of wood and then wrapping them with colored yarn; caly design, such as molding clay with the hands oor imprinting Various objects into the clay to create designs; and flower pressing; etc. Occupational and/or Recreational Therapists are good resources for helping to identifying appropriate art activities.

- **Moving to Music**

Older people with sight problems or who are dealing with the effects of a stroke, Parkinson's disease, heart disease or other medical problems can benefit from slow movement to music. For others dealing with any sort of mobility problem, loss of a limb or any changes in their physical condition, this type of activity provides a way to get reacquainted with their body. Even just swaying from side to side, or simply moving the arms or the feet, is considered exercise. The VA facility may have a dance or music therapists to help identify appropriate music activities.

- **Large-Type Newspapers**

Having an awareness of world events helps keep individuals who are homebound connected. Many city newspapers come in large-type editions designed for people who have trouble reading small type.

- **Books on Tape**

Having to give up reading when they become visually impaired is one of the most difficult adjustments for some older adults. Others suffering from a sudden loss of decline in their sight may have a similar reaction. There is a wide variety of books on tape available through the local library.

- **Pet Therapy**

Many older adults appreciate the attention and feeling they get from spending time with companion animals, such as dogs and cats. Of course, not everyone is an animal lover; but if the care recipient enjoys spending time with the family's cat or dog and is not allergic to the animal, it beneficial to make time for this activity.

Voluntary Service may have a pet visitation program already in place that could be extended to the home of care recipients with prior approval from the Home Health Coordinator, the Primary Caregiver and the Care Recipient.

- **Collecting Memories**

For the care recipient who is fairly active, but homebound due to illness/injury and for those with dementia, reminiscing is important. Questions that might spark memory-filled conversations include: What was your previous occupation? What branch of the military were you in? What is your favorite type of food? When did you first eat it? What hobbies do you enjoy? What is your happiest family memory? How did your family celebrate holidays? What season of the year do you like best and why?

If interested, the Veterans History Project provides a template for chronicling the lives of veterans and preserving it in the Folklife Center at the Library of Congress. Voluntary Service can provide more information on this project.

■ ***Volunteer Rights and Responsibilities***

Volunteer support caregiving is a two-way street. Veteran care recipients and their primary caregivers receive invaluable support and assistance. Volunteer support caregivers receive the opportunity to help others and gain new skills, a sense of accomplishment, new friendships and recognition for their contributions.

Volunteers commit time, talent and energy to fulfilling their volunteer assignments. Their work can be challenging and demanding. To stay motivated and avoid "burn-out," volunteers need to be aware of their "rights" and comfortable with basic assertiveness skills to help protect those rights. Keeping expectations clear avoids miscommunication and frustration - and helps keep volunteers positive and satisfied with their experience.

- ***Nonperformance by a Volunteer***

This is a special area of law in which social policy justifies an imposition of "duty to act or perform properly" even though a volunteer is not paid. According to the law, a volunteer has entered into a special relationship with a promise to perform, and the VA is relying upon the volunteer's promise.

There is liability when a volunteer does not perform a task which he or she has agreed to perform. This liability can be: (1) to the person or persons whom the volunteer has agreed to perform a service; (2) to the VA facility for which the volunteer promised to perform the service; or (3) to third persons who became involved due to the nonperformance of the volunteer.

VOLUNTEER SUPPORT CAREGIVERS HAVE THE RIGHT TO:

- Information about the veteran, primary caregiver and family with whom they will be working.
- An orientation and ongoing training to prepare them adequately for their volunteer support caregiving assignments.
- Know what is required of them prior to starting their volunteer assignments.
- Respect from the older care recipient, primary caregiver and family and the assigning organization.
- Situations that are not hazardous to their well-being.
- Feedback on the effectiveness of their work to enable them to improve their abilities to help others.
- Privacy if they choose not to disclose their home address or phone number to the care recipient, the primary caregiver or family

Nonfeasance, or "failure to act," can have serious consequences. A volunteer who agrees to drive a vehicle to deliver meals for Meals-On-Wheels can cause those dependent on the service to go hungry if the volunteer does not perform this service. A primary caregiver or care recipient can be deprived of necessary medical care if a volunteer who has agreed to provide transportation to a doctor's office does not show up at the arranged time.

The VA can lose its credibility and reputation as a service provider and important community resource when volunteers fail to perform. In addition, relationships with other agencies and organizations can be disrupted or damaged. Our ability to attract new volunteer and donors can be greatly hindered or reduced.

In order for volunteers to experience greater success and satisfaction in their assignments and reduce risk, it is imperative to follow all policies related to the **Caregiver Support Network**, as well as the guidelines on how to conduct yourself as an agent of the VA.

DO'S AND DON'TS FOR REDUCING RISK ON VOLUNTEER ASSIGNMENTS

In order to reduce risk, volunteer caregivers should follow these ethical and legal guidelines:

- DO attend orientation, ongoing training and workshops offered through the VA.
- DO act responsibly and committed to your volunteer assignment by following all recommended practices, guidelines and suggestions provided during your orientation and in ongoing training sessions.
- DO limit your assignment to the services you agreed to perform.
- DO exercise caution and use common sense and good judgment when performing your services.
- DO understand the insurance coverage provided by the VA. Check with your insurance company regarding coverage of your automobile while on assignment. If you are providing transportation services, you must have appropriate insurance coverage.
- DO inform your Home Health Coordinator if you are unable to service care recipients and/or primary caregivers who have infectious diseases.
- DO develop a positive working relationship with the care recipient, primary caregiver, other family members and other on-site health care and social service providers, as appropriate, and maintain open communication with them.
- DO submit accurate records and reports of your completed tasks, ongoing services, hours completed and mileage used on assignment, as requested by the Home Health Coordinator.
- DO know ahead of time what steps should be taken in case of emergencies. Ask the primary caregiver, other family members, appropriate health care providers and the Home Health Coordinator what you should do to be prepared to handle emergencies.
- DO maintain trust and confidentiality. Keep the primary caregiver's and care recipient's personal issues and information in confidence except in case of emergency or danger. In these cases, the Home Health Coordinator must be notified.
- DO accept a confidence carefully and honestly. Tell the care recipient and primary caregiver before hearing confidential information that you may have to tell the Home Health Coordinator if it involves potential danger or risk.

Continued on the following page.....

- DO respect the spiritual and religious practices of the primary caregiver, care recipient and family. Avoid discussions on religion or your religious preferences. Instead, practice compassion and tolerance.
- DO maintain an open mind. Be accepting of others.
- DO be aware of your actions of body, speech and mind. Think first.
- DO report any problem immediately to your contact person at the VA.
- DO report any suspicions of abuse. If you suspect any abuse - physical, emotional, sexual or financial - YOU MUST report it immediately to your contact person at the VA.
- DO complete the **Reporting Form** after each visit.
- DON'T perform "hands-on" or personal care services, such as bathing, toileting, massage, etc., for your care recipient unless you have had special training and are authorized to perform these services.
- DON'T try to perform a service if you are not sure how to do it, or if that service may endanger the care recipient, primary caregiver or yourself.
- DON'T give prescription or over-the-counter medications or offer medical advice while on assignment.
- DON'T expose the care recipient, primary caregiver or other family members living in the household to contagious diseases. If you develop a cold, flu, fever, etc. - or become exposed to a contagious disease (such as chickenpox or tuberculosis), notify your contact person at the VA immediately, so that alternative arrangements for covering your assignment can be made until you are well.
- DON'T offer to take a person to the hospital, unless it has been prearranged. In cases of a medical emergency, call 911 and close family members or friends of the care recipient and/or primary caregiver.
- DON'T offer your opinions in family matters. All decisions about the care recipients' welfare should be made by the primary caregiver, care recipient, other family members, the health care provider and/or social services professional.
- DON'T cash checks or sign any legal papers with or for the care recipient or primary caregiver.
- DON'T accept money or any gift of value. This can be misinterpreted by others in the family and community. Suggest a donation to the VA if the person or family wishes to show support and appreciation.

■ **Confidentiality and Patient Privacy**

Each patient or resident has certain rights and privileges. It is important that each staff member and volunteer honor these patient rights. These specific patient rights are posted in various locations around the facility. Please familiarize yourself with them.

Volunteers may learn a great deal about the personal problems of patients while working with them and must understand that all personal data is confidential. Each volunteer is responsible and liable under the Privacy Act of 1975, Health Insurance Portability and Accountability Act (HIPAA) and Veterans Health Administration (VHA) Privacy Policy. HIPAA includes mandated regulations that govern privacy standards of health care information and specify the purposes for which information may and may not be released without authority from the patient.

■ **VHA Privacy Policy**

VHA has established policies and procedures that grant the veteran certain rights regarding his/her health information and provide guidance on the use and disclosure of Protected Health Information (PHI). PHI consists of the following:

- Receive a copy of the VA Notice Individually Identifiable Information (i.e. Social Security number, health information, etc.)
- Demographic Information (i.e. address, phone, age, gender, etc.)
- This information can be in any form (verbal, written, electronic)

The Privacy Act, HIPAA Privacy Rule and VHA Privacy Policy provide the veteran with the right to:

- of Privacy Practices
- Receive a copy of his/her own protected health information
- Request an amendment to his/her personal records
- Request a listing of disclosures of health information from his/her personal records
- Request and receive communications confidentially
- Request a restriction on the use or disclosure of his/her health information

VHA also has established policies and procedures providing guidance on how PHI may be used within VHA and disclosed to organizations outside of VHA.

VHA workforce members including volunteers may use PHI only when the information is needed to perform their official volunteer duties for the purpose of treatment, payment and health care operations. Use of PHI for any other purpose requires the written permission of the patient. PHI may be disclosed **ONLY** if prior written permission from the patient has been obtained or other legal authority permits the disclosure.

As a volunteer, you are required to keep all PHI that you may discover in the course of your assigned volunteer duties strictly confidential. Here are some requirements:

- No talking in public areas about Protected Health Information as listed above
- Keep PHI out of public areas (i.e. elevators, stairways, open areas, etc.)
- Secure any records you may be working with before walking away
- No discussing with anyone, inside or outside VA Black Hills, any PHI you may learn while carrying out your assigned duties as a volunteer.

Pictures and voice rights of patients are to be fully protected. Only an authorized designee of the VA may take photographs or make audio/video recordings of patients.

■ *Possible Outcomes for Not Complying with VHA Privacy Policy*

Unlawful release of Protected Health Information could result in:

- Organization-specific sanctions (i.e. lawsuits, not receiving accreditation)
- Filing of a complaint by a victim of a Privacy Policy violation
- Civil and criminal penalties for VHA Privacy Policy violators
- Fines up to \$50,000 and/or imprisonment

All volunteers must be responsible for safeguarding Protected Health Information (PHI). As a VAVS volunteer, you have a responsibility to keep all patient information, learned in the course of your duties, confidential and secure. Do not discuss any PHI discovered in the course of your assignment with anyone. Remember that you would want your personal information and health records treated in the same confidential, professional manner.

As a volunteer, take pride and ownership in the fact that your organization is concerned about privacy and recognizes its importance in providing quality healthcare.

■ *Guidelines for Emergencies*

An emergency situation may occur whenever volunteers are on assignment. It is important for the volunteer to remain calm, focus on helping the person who is in the emergency situation and notify the proper authorities immediately for needed assistance.

WHEN THE PRIMARY CAREGIVER OR CARE RECIPIENT DOES NOT ANSWER THE DOOR:

- Check the premises, look through the windows, ring the doorbell or try to call on the phone to get a response.
- Contact a neighbor or, if appropriate, a building manager or superintendent who has keys. If entry is possible, ask the neighbor, building manager or superintendent to assist in entering the premises.
- Call the nearest relative or friend to inform them of the situation.
- Call your contact person at the VA medical center and report the situation.
- Call the health care provider, caseworker or social worker, as appropriate.
- Call the local police or 911 and report the situation if you are unable to reach the persons described above or are unsure of what else to do.

WHEN A CARE RECIPIENT OR PRIMARY CAREGIVER HAS AN ACCIDENT:

- *If the person is unconscious:*

- Do not move the person, except in a hazardous situation, such as a fire. - Immediately call 911 for an ambulance or other emergency assistance. - Notify the nearest relative or friend after 911 has been called. If there is no relative or friend to contact, notify your contact person at VA Black Hills Health Care System.

- *If the person is conscious:*

- Do not move the person, except in a hazardous situation, such as a fire. - Ask the person to describe what happened, where it hurts, etc., if he or she is able to speak.

- Immediately call 911 for an ambulance or other emergency assistance. Notify the person's doctor, nearest relative or friend, caseworker (if applicable) and the VA medical facility

Remember to report all emergency situations to your contact person at the VA medical facility either at the time the situation is occurring or as soon as possible. Do not try to handle emergency situations on your own. Always contact close friends and family members of the person in the emergency situation and appropriate emergency medical personnel for assistance.

■ *Expectations, Challenges and Dealing With Disappointments*

Volunteer caregiving is a two-way street. Veterans with needs and their primary caregivers receive invaluable support and assistance. Volunteer support caregivers receive the opportunity to help others and gain new skills, a sense of accomplishment, new friendships and recognition of their contributions.

Volunteers commit time, talent and energy to fulfilling their volunteer assignments. Their work can be challenging and demanding. To stay motivated and avoid “burn-out,” volunteers should be aware of their “rights” and comfortable with basic assertiveness skills to help protect those rights. Keeping expectations clear avoids miscommunication and frustration—and helps keep volunteers positive and satisfied with their experiences.

■ *The Importance of Clear Communication*

Volunteers must be communicate clearly and directly with the veteran care recipient and primary caregiver, so that everyone agrees on what services are to be performed and what tasks are to be accomplished, as well as the date and time by which these should be done.

Sometimes care recipients ask for services beyond what the volunteer has agreed to provide. What should happen if a care recipient or his or her family member requests services that the volunteer doesn't want to, or cannot, provide?

The following scenario offers some appropriate volunteer responses.

Volunteer support caregiver Ann has been assisting her care receiver, Edna, for several months by reading the newspaper and cutting out coupons during her visit. One afternoon, Edna asks Ann if she will take her to the store in order to use and coupon due to expire that day. How might Ann respond?

Ann could:

- 1. Check her watch and say, "I'm sorry, Edna, but I still have to be home in one hour for a family dinner. Perhaps I could pick the item up on my way home and bring it to you on my next visit."*
- 2. Say, "I'm sorry, Edna, but I am not permitted to transport you in my car. Perhaps I could cut the coupon out and leave it for your son and remind him before I go that you asked for it."*
- 3. Say, "Well Edna, I would love to be able to help you get this, but I am not really comfortable assisting you in and out of my car. There may be another community organization that can assist you with shopping. If this is a service you would like, I'd be happy to pass it along to your Social Worker."*

These responses are honest and gentle, but clear and definite. Remember, the objective is a satisfying experience for the care recipient, the primary caregiver and the volunteer. Fulfilling a request that will inconvenience or harm a volunteer will not meet this objective—clear expectations will.

Volunteers may have difficulty setting boundaries at first. (Many people do!) Contact the VAVS Program Manager or staff member, or the social worker for support and guidance. The following are some basic assertiveness tips before beginning your assignment that may be helpful.

ASSERTIVENESS TIPS FOR VOLUNTEER CAREGIVERS

- It's okay to be straightforward (assertive) with a care recipient and primary caregiver.
- Assertive people are direct and honest. Assertive people show a genuine concern for other people's rights and feelings as well as their own.
- It's okay to ask questions or to say more time is needed to think about a request.
- It's okay to say what you are willing to do and not do.
- It's okay to turn down a request. Offer to report additional needs you can't meet to the VA and VAVS staff.
- It's okay to say "no" to others and repeat it if it isn't heard the first time. It isn't necessary to offer excuses or justifications for saying "no."
- Don't say "Yes, I'll do it." when you want or should say "No, I am unable to do it." If you are not careful and truthful about your feelings, you will become frustrated with your assignment. Your assignment will become a chore, instead of a joy.

■ *Let's Practice*

Below are selections of "what if?" scenarios. They cover a number of issues that may arise during the course of a volunteer support caregiver's interaction with a veteran care recipient. Break into small groups and choose one of the following to discuss within your group. At the completion, choose two people to role play the scenario; or choose a spokesperson to give some appropriate language for dealing with the problem and the group's justification for addressing it in that manner.

What if?

1. ...the veteran criticizes students today as inconsiderate hoodlum. What is your response?
2. ...the veteran asks your help in administering medication (i.e. eye drops.) What do you do?
3. ...the veteran complains about his or her family?
4. ...the veteran criticizes you (e.g. you are too fat, too thin, wear the wrong clothes, etc?)
5. ...the veteran has recently learned he/she has cancer or other serious medical problem? How would you respond? What would you talk about?
6. ...it is time for you to leave and the veteran does not want you to go. How would you prepare him/her for your departure?
7. ...after 30 minutes of visiting with the veterans there seems to be nothing more to talk about? He/she does not seem to respond to any suggestions.
8. ...the veteran offers you a gift?
9. ...the veteran says that you do not need to come any more?
10. ...you know that the veteran is on a special diet and he/she asks you to bring a restricted food?
11. ...the veteran says that he/she is missing money or an item since your last visit?
12. ...the veteran or the primary caregiver asks you to do something that you do not want to do?

■ *Understanding Other Cultures*

It is important for volunteers to be sensitive to and prepared for cultural difference they may encounter when providing support to primary caregivers, care recipients and their families. Cultural concepts of “personhood” and self in relation to others in a family and norms of interpersonal morality may dictate how caregiving roles and responsibilities are assigned and accepted within a given culture.

Cultural differences that may affect caregiving have been categorized by anthropologists as follows:

Eastern cultures tend to:

- ❖ Have an interpersonal moral code that stresses responsibilities to kin and clear gender distinctions that impose a noncareer-oriented, homemaking, caregiving role on women.
- ❖ Care for older relatives in the household until they die.
- ❖ View caretiving as a natural role with a commitment to all generations in the family and, therefore, not a burden.
- ❖ Have extended kinship families, so they are better able to share the caretiving burden among many family members.

Western cultures tend to:

- ❖ Most often prescribe the caregiving role to women.
- ❖ Have a nuclear family structure with the roles of men and women less defined by gender distinctions for career and family responsibilities.
- ❖ No longer require women to sacrifice their own needs to only serve others in the family.
- ❖ View caregiving of older adult family members as a necessary but difficult burden.
- ❖ Can be overwhelmed by the added responsibilities of caring for older adult family members because there usually is no extended family available to help share the caregiving burden.

Minority American cultures tend to:

- ❖ Often have extended kinship families as a source of strength and support in sharing caregiving responsibilities. This is true of African Americans, Hispanic Americans and native Americans. These family roles change somewhat as younger family members move away from their parents' and grandparents' communities.
- ❖ Believe they may lack equal access to the larger society's benefits, so ethnic minority groups often feel they have to rely on their own resources, such as religious institutions and extended families, to provide reciprocal assistance in times of need.
- ❖ Manage caregiver responsibilities with less stress, but primary caregivers still need acknowledgment from family, friends and others, and support in receiving respite and other help.
- ❖ Have more realistic expectations, more familiarity with adversity and social support as a buffering mechanism within their own ethnic communities.

■ *Cross Cultural Communications*

A volunteer often can meet the challenge of overcoming of language and cultural barriers by:

- Treating the primary caregiver, care recipient and other family members with courtesy and respect for any different cultural attitudes or ways of doing things.
- Recruiting a younger family member to be an interpreter when the volunteer is trying to communicate with the primary caregiver, the older care recipient or other family members.
- Learning about cultural differences from the family and the contact person at the assigning organization.
- Honoring lifestyle practices and traditions, such as dietary restrictions or modesty requirements for women.

- Being aware of the primary caregiver's and other family members' possible feelings of social isolation and discussing ways to find activities that enable them to meet people who share their values, beliefs and interests.

EXERCISE 2: Appreciating Our Differences

Overview: As volunteer caregivers, individuals need to have an understanding of the influence of culture, ethnicity and family values in order to provide quality support. It is essential for each individual to become aware of his or her own attitudes and biases and how these might influence him or her as a volunteer. This activity provides volunteers with the opportunity to explore their own cultural identities, gain an understanding and appreciation for the difference among the group and to discuss past experiences that have influenced their attitudes and beliefs.

EXERCISE 2: Appreciating Our Differences

Divide into small groups and discuss the following questions:

- What is your cultural/ethnic identity? How does your family define this identity?
- When you were growing up, what did your parents and relatives say about people who were different from your family?
- What experiences have you had with people from other ethnic groups, socioeconomic classes, religions, age groups or communities?
- What were these experiences like? How did you feel about them?
- What personal qualities do you have that will help you establish interpersonal relationships with persons from other cultural groups? What personal qualities may be detrimental?

■ *Dealing with Problems*

It is imperative that you report any problems in your volunteer caregiving assignment immediately. Be sure to document any problems on the Reporting Form (see *Forms* section) The more time that elapses between the occurrence of an incident and when corrective action is taken, the more difficult it is to resolve the situation. Matters of safety related to the veteran care recipient or to you personally are extremely critical.

Even when safety is not an issue, be sure to inform a VA staff member of issues of concern regarding your assignment. These may include:

- The veteran or caregiver continually putting off a visit or not being home when you arrive
- The veteran or primary caregiver reporting that money or items are missing following your visits.
- Being asked to do something that you are not comfortable with or prohibited

■ *Relating to the Primary Caregiver's Family*

The dynamics of each family are unique. Some families are more functional and pull together when members of the family need help. Other families are more dysfunctional and have ongoing problems in family relations. These problems make family members less able to help each other cope with the burdens of caring for an older relative. A volunteer should be prepared to observe a range of attitudes, reactions and behaviors from various family members about caring for a sick older adult relative.

It can be helpful for volunteers to know about basic concepts and principles of family systems' theory as they relate to caregiving families.

■ BASIC CONCEPTS AND PRINCIPLES OF FAMILY SYSTEMS

1. Family members are closely interconnected.
 - A situation or action of one family member affects all other members and the family as a whole.
 - Each family member is both proactive and reactive within the family system.
 - Whether geographically local or distant, each family member acts according to the actions and reactions of other family members.
2. Families operate under explicit or implicit norms, assigned roles and prescribed interaction patterns for family members.
 - Norms include all family attitudes, beliefs, taboos, expectations and labels.
 - Common family roles include the "mover" or "leader," the "follower," the "bystander," the "opposer," and the "caregiver."
 - The usual role of "caregiver" in the family system is in the context of a parent who cares for dependent children.
 - The expectation of marriage partners within the family system is one of mutual support and interdependence. Spouses are expected to depend upon each other for care when one of the other is seriously ill or debilitated.

- Assigned family roles change when an adult child becomes a primary caregiver for one or both parents and, therefore, is also assigned the role of the “mover” in the family even when the adult child is not comfortable in the role.
 - Family systems strive for constancy and consistency, even when established family norms, roles and prescribed interaction patterns are dysfunctional.
 - Stress and conflict result when family norms, roles and prescribed interaction patterns change significantly.
 - Stressful changes are caused by a major adverse family event or crisis, such as a father having a sudden heart attack, or a grandmother having a stroke or debilitating fall.
 - Greater changes within the established family system cause higher levels of stress and conflict. For example, it is acceptable within the family system for one spouse to care for another. However, when a married adult child with children accepts the responsibility as primary caregiver for an aging parent, certain family norms, roles and interaction patterns among the primary caregiver, older care recipient, spouse and children can break down and must be re-established over time.
3. The role change to primary caregiver puts one at risk.
- Spouses accepting the role of primary caregiver experience role losses in other aspects of their lives and are vulnerable to developing a codependent relationship with the care recipient spouse.
 - When caregiving becomes one’s only identity and life’s purpose, the emotional well-being of the primary caregiver is at risk when the care recipient is put in a long-term care facility or dies.
4. Boundaries between the family system and the community at large affect the family’s ability to accept help from outsiders.
- A family system with rigid boundaries tends to reject outside assistance when it believes accepting help from outsiders is a sign of weakness or failure of the family to handle all needs.
 - Families with flexible boundaries are more likely to ask and accept help from friends, neighbors and community organizations.

NOTE: Consider how these basic concepts and principles play out within the families of veterans, both older and those returning soldiers from our Nation’s recent military conflicts.

Safety Issues

No matter how limited or extended the duties of a volunteer assignment are, a volunteer should be aware of precautions required to make a living environment safer. In general, it is important for the living environment to be clean, controlled to prevent infection and transmission of disease and kept free of hazards that cause falls or burns. In addition, food should be handled with care to prevent contamination.

Most accidents happen in the bathroom and kitchen. Accidents also are more likely to happen when someone is angry, tired or stressed. Heightened (or dulled) emotions can reduce one’s attention to the possibility of an accident. A calm environment is more

likely to promote safety than a home where stress levels are high. By providing on-site assistance with important tasks, a volunteer can help reduce stress in the household and promote safety.

Making a home safe may mean paying attention to details that have never before been considered, such as the placement of furniture and large items of glass (coffee tables or sculptures, for example). It may mean removing furniture with sharp edges and blocking direct access to large picture windows. Unstable rocking chairs can be a hazard, as can fragile antiques.

In the bathroom, carpet may be better than a floor mat because it absorbs spills and doesn't get slippery. Outdoor pools pose a threat to older adults (particularly those with sight problems) and should be well gated and locked. Older adults who live in high-rise buildings should have security locks installed on windows and balcony doors.

Smoking can pose a serious hazard for the veteran care recipient, because of both health considerations and the danger of starting a fire. If they smoke, it should only be with supervision and never in bed.

Poor eyesight, dull hearing, poor balance, side effects from multiple medications, slower reaction times and difficulty moving all put older adults and others with compromised medical conditioning at risk for accidents.

A volunteer can assist both an older care recipient and a primary caregiver by checking the living environment for any hazards and bringing these to their attention. If there is agreement that changes should be made, the volunteer can offer to help, as long as such efforts fit within the volunteer's assignment and limits.

■ *Advocacy*

A volunteer support caregiver who regularly visits the living environment of a veteran care recipient, primary caregiver and family has the opportunity to observe gaps in needed services and to act as a liaison with the assigning organization and advocate for identifying and arranging for additional community services to fill these gaps.

The care recipient, primary caregiver and family can benefit from the volunteer's ongoing observations and assessment of the situation while on assignment.

The volunteer support caregiver can assess the home environment, the veteran care recipient, primary caregiver and family for:

- Cleanliness, safety and risk.
- Proper nutrition and meal planning and preparation abilities.
- Medical, social psychological or spiritual problems or issues.
- Financial deficiencies.
- Transportation inadequacies.

Any deficiency, risk or additional needs should be reported promptly to the contact person at the assigning organization.

If the program staff at the assigning organization agrees with the volunteer's observations and assessment, highlights of these may be discussed with the primary caregiver and/or care recipient, as appropriate.

When the primary caregiver or care recipient agrees with the assessment and is interested in gaining access to additional services and resources to fill gaps identified by the volunteer, further steps should be taken. The assigning organization can provide additional services or arrange for referral to other appropriate local social service agencies or health care providers.

HOUSEHOLD SAFETY

- Chemicals, harsh cleaners, insecticides, medications, paints, etc. should all be labeled with big, clear letters. If the older person has dementia, these items should be moved completely out of sight.
- Rooms and hallways used by an older person should be adequately lighted. This helps the care recipient to see the details of a room more clearly and avoid accidents and obstructions.
- At least two flashlights, with working batteries, should be ready to use and easy to find if the lights go out. One should be put by the care recipient's bed and one should be put on a kitchen table. If there is a blackout, several large flashlights are safer than candles. A volunteer should know where to locate flashlights in case of emergencies.
- Bathroom and kitchen outlets should have working circuit breakers.
- In the kitchen, the burners and the oven should work properly. Outlets should not be overloaded and wires should not rest on hot appliances. If the older adult is apt to reach for equipment located above the hot stove, then such items should be rearranged to avoid this.
- Because of their thinner skin and slower reactions, older people are at greater risk of scalding. Hot water heaters should be set so the temperature of the water doesn't rise above 120 degrees F.
- If the care recipient gets cold easily, he or she should be dressed with extra layers and the heat should be set at a higher temperature level for comfort. However, extreme care should be taken with space heaters and electric blankets, as they can cause burns and fires if not used properly.
- Smoke detectors should be checked monthly to make sure they work. An older adult's waning sense of smell makes a smoke detector more important.
- Easy escape routes in case of fire should be located. An older adult won't be able to climb out of a window easily, so escape routes that are easy to see must be planned before an emergency. Is the back door wide enough for the care recipient's wheelchair? Is there a back stairway that an older person can manage? If a bedridden care recipient won't be able to escape, the local fire department should be called and asked for safety instructions in care of emergency. If the care recipient is disabled, the local fire department should be notified of the person's health status, so that they can respond quickly and appropriately in emergency situations. A volunteer should become familiar with whatever fire escape procedures are required at the assigned living environment.
- A small fire extinguisher that is easy to handle should be kept in a convenient place, preferably near the kitchen where fires are most likely to start. A volunteer should ask for instruction on how to use a fire extinguisher.
- A list of clearly written, large-print emergency phone numbers should be kept by every phone, or programmed into the telephone's memory for quick dialing. Telephone memory codes to emergency numbers should be labeled or listed by each phone. The list should include police, fire, poison control, ambulance, the care recipient's doctors, the primary caregiver's home and work numbers and the phone number of a nearby relative or neighbor. It should not be assumed that the care recipient will remember these numbers or even 911. A volunteer should be able to locate and access any of these numbers in care of emergency.

Guidelines for Preventing Falls

Serious injuries from falls often require older care recipients to be moved to nursing homes or other long-term care facilities. The following are fall-prevention guidelines that can be used to check the living environment of the veteran care recipient.

GUIDELINES FOR PREVENTING FALLS

FOR FLOORS, HALL, DOORWAYS AND PATHWAYS:

- Remove all obstacles to safe passage, such as trash, wiring, wastebaskets, footstools, magazine racks, books, magazines, shoes and clothes.
- Repair worn or ripped carpets.
- Tape or tack down curled carpet corners or edges.
- Place non-skid pads under throw rugs or remove them.
- Repair loose floorboards.
- Remove thresholds at doorways.
- Buff waxed floors thoroughly and use nonskid wax.
- Install handrails.
- Adjust the location of hanging plants to prevent having to duck when passing, and still permit watering without having to reach.

FOR STAIRS:

- Install an electric-powered lift to carry the care recipient up and down the stairs in a chair, build ramps on short stairways or create a bedroom/bathroom suite on the first floor to eliminate the need for the care recipient to use stairs.
- Install sturdy handrails, as necessary, on both sides of the stairs, including those leading to entrances and the basement.
- Make sure there is adequate lighting by the stairs.
- Consider removing stairway carpeting. It makes footing more risky by shortening the depth of each step and rounding off step edges.
- Use non-skid treads on stairs.
- Mark step edges with brightly colored adhesive tape so each can be seen clearly.
- Make sure that steps are no more than six inches high.

FOR BEDROOMS:

- Make sure the bed is at a height that permits the care recipient to get in and out easily.
- Replace unlocking wheels with wheels that can be locked to make furniture more stable.
- Replace or repair broken or unstable furniture, such as tripod tables.
- Replace furniture with legs that curve outward creating a tripping hazard.
- Use chairs easy to get into and out of, with strong armrests and high backs for support.
- Keep a walker or can by the chair or acquire an electric-powered pneumatic chair that lifts and lowers the care recipient.
- Make sure there is adequate light for reading and the light switches are easy to use.
- Make sure a telephone is within easy reach of the care recipient.

FOR BATHROOMS:

- Keep the bathroom free of spills and litter.
- Install a special raised toilet seat for easier use by the older care recipient.
- Install grab bars near toilets and bath tubs.
- Replace bar soap with a wall-mounted, liquid soap dispenser in the shower.
- Install nonslip strips on the bottom of the tub or shower floor.
- Avoid using bath oils that can result in slippery conditions.
- Use a secure rod screwed into the wall to hang shower curtains.

■ *The Importance of Cleaning a Home for Germ Control*

With a care recipient at home and the responsibility of maintaining the household for the rest of the family, a primary caregiver is likely to need help from a volunteer to keep the living environment neat and clean.

It is important for a volunteer to take proper measures to assist a primary caregiver and care recipient in preventing the spread of infections. Proper cleaning of the living environment and good personal hygiene for the care recipient will go a long way toward ridding a home of major infectious germs.

If the care recipient is chronically ill or frail, is taking certain types of medications or receiving special therapies for a life-threatening illness, such as cancer, he or she may have a weakened immune system and, therefore, be more vulnerable to infection. The

primary caregiver, other family members and the volunteer also need to be protected from infections that may prevent them from providing care.

Infections are the result of the body being invaded by germs. These cause an adverse reaction – directly by damaging cells or indirectly by releasing poisonous substances (toxins) into the body. Germs are spread directly by a person touching something that is contaminated, or indirectly by breathing in airborne germs, by eating contaminated food, or by being contact with contaminated clothing, equipment or insects. The symptoms will depend on the type of infection, where it is located and whether it has spread throughout the body.

An infection is only dangerous if it is given a suitable environment in which to flourish. People and animals are the sources of most infections, as carriers to many bacteria and viruses. Anyone can become infected, but the most vulnerable are those who have low immunity, such as someone in poor health.

The four basic kinds of cleaning products are all-purpose cleaning agents which can be used on many surfaces; soaps for bathing, washing dishes and laundry; cleansers for scouring and hard-to-clean areas and specialty cleansers for tasks such as cleaning windows or ovens. Directions for their proper use should be followed, and they should be stored in a safe place.

FOUR SETS OF TASKS FOR HOUSEHOLD CLEANING CHORES

1. **DUSTING AND STRAIGHTENING.** Dusting is probably a once-a-week chores, while straightening may be necessary a few times a day.
2. **CLEANING FLOORS AND RUGS.** With the exception of wood floors, which should be cleaned with a mixture of vinegar and water, floors can be washed with warm sudsy water after loose dirt has been swept away. Wet floors are slippery, so they should be dried quickly to avoid accidents. Rugs and carpets should be vacuumed at least weekly.
3. **CLEANING THE KITCHEN.** Particular attention should be paid to cleaning food preparation surfaces, storage areas and the refrigerator. Dishes should be washed in hot, soapy water, rinsed in hot water (rinsed in boiling water if someone in the house has an infectious disease) and allowed to air dry. If there is a dishwasher, one should learn how to use it properly and what should not be put in it. Special cleaners should be used inside the oven. Garbage receptacles should be emptied frequently and recyclables should be rinsed, as their residue can attract insects and rodents.
4. **CLEANING BATHROOMS.** It is important to maintain a high level of cleanliness in the bathroom. If this is not done, germs and odors can grow to dangerous levels. Bathroom surfaces, especially floors, tubs, shower stalls and toilets should be scrubbed with disinfectant to keep germs under control.

For quick clean-up jobs, a bucket with cleaning items, such as paper towels, sponges or rags, a scrub brush, a multi-purpose cleaner, a disinfectant and carpet cleaner, may be stored in the care recipient's bathroom.

■ *Hand Washing*

There is a reason why we were taught at a young age to wash our hands after using the toilet and before and after meals. Hands are the principal transferral for germs and the most likely way that infections will pass from one person to another.

Volunteers should always wash their hands before providing assistance to an older care recipient. Hands should be washed when entering the living environment, after handling soiled articles and before and after handling food. A volunteer who is recovering from a cold should wash his or her hands more often, but especially after coughing or sneezing. In the living environment of an older care recipient with an infectious disease, special care should be taken to wash hands after contact with the older person.

To wash the hands correctly, one should remove jewelry, roll up the sleeves and run water over a bar of soap to clean it. Hands should be wet and lathered up with soap. The entire surface of the hands, between fingers, around and under the fingernails and above the wrist should be washed thoroughly. Under the nails should be scrubbed if a nailbrush is available. Hands should be rinsed and washed again.

Hands should be elevated to drain water from fingers to wrist (clean to less clean) and dried thoroughly with a clean towel. Moisturizer should be added to keep the skin from becoming dry and cracked, because germs can get into cracks in dry skin.

■ *Additional Precautions Against Infection*

Disposable gloves should be used by a volunteer as added precaution when coming into contact with moist body substances or fluids, such as blood, urine, pus, feces, saliva or a wound drainage of any kind.

To avoid spreading droplets when sneezing or coughing, a volunteer should cover his or her mouth with a tissue or handkerchief. A volunteer may be asked to wear a mask if coughing or sneezing is persistent.

Moisture-resistant gowns or aprons should be used on occasions when the volunteer anticipates the soiling of his or her garments with a body substance. A mask or protective eyewear also may be used.

■ *How to Dispose of Body Waste*

Body wastes from the care recipient's room may carry infection and should be disposed of carefully in a way that does not spread infection. Wearing latex gloves and an apron when disposing of body wastes is recommended. Wastes include used paper tissues, sputum, dirty dressings, uneaten food, urine, feces or vomit. When assisting with the disposal of wastes, a volunteer should use the following guidelines:

- Use disposable gloves.
- Pick up solid wastes with tongs, a spring clothespin, a tissue or paper towel. • Place waste in paper or plastic bags and dispose of it in covered containers.
- Place liquid wastes in a container with a lid or pour them down a toilet. Discard disposable gloves safely. Wash tongs and containers with hot water and soap.

REMEMBER: Wash hands immediately after handling body waste.

■ *Hygiene in the Kitchen*

To avoid contamination, food must be purchased wisely, stored and refrigerated quickly and prepared and cooked properly. If a volunteer assists in the kitchen, he or she should follow guidelines for proper kitchen hygiene.

TIPS FOR PROPER KITCHEN HYGIENE

- Keep pets away from all food and kitchen surfaces.
- Wash hands properly before and after preparing food.
- Wash utensils and cutting tools thoroughly with hot water and dishwashing liquid.
- Change and launder dishtowels and cloths regularly. Use clean dishtowels and cloths when working in the kitchen to prepare food.
- Do not wipe hands on an apron or cloth. Do not use dishtowels as hand towels.
- Cover any cuts or sores on hands with a bandage.
- Do not use or eat food if it comes from damaged containers or has passed its expiration date.
- Store fruits and vegetables in the bottom of the refrigerator and wash them thoroughly before eating.
- Do not use the same knife and chopping board to prepare cooked and uncooked foods at the same time.
- Do not prepare foods too far in advance.
- Follow frozen food guidelines and directions on the package carefully. Store meat and fish in the coldest part of the refrigerator and cook them thoroughly.
- Do not taste food with fingers.
- Follow cooking guidelines and directions on all products exactly as described on the package.
- When reheating food, check it to make sure it is thoroughly hot. It should not be reheated more than once.
- Serve and eat cooked food while it's hot.
- Do not give chronically ill older people the following foods: soft cheeses, which may contain listeria bacteria; raw or undercooked eggs or undercooked meat, especially poultry, which can cause salmonella poisoning.

■ *Nutrition and Meals*

There is growing evidence that shows the quality of diet can play a major role in preventing or contributing to five of the leading causes of death in the U.S.: heart disease, cancer, stroke, diabetes and atherosclerosis (narrowing of the arterial wall). A balanced diet provides a combination of nutrients, including vitamins, minerals, proteins, carbohydrates, fats and fiber.

During illness, the body requires an even more balanced diet. It also needs vitamins, such as vitamin C, to fight the deterioration from emotional and physical stress by supporting the immune system. Surgery and illness can cause tissue loss and weaken the immune system, requiring more protein from the body. Diet plays a crucial role in supplying the nutrients the body needs.

High-protein supplements, such as protein drinks, and adding cooked meat, fish or poultry to vegetable dishes may be required for good nutrition. Getting enough calories is critical to good health. When too few are consumed, the body draws first on its stores of fat for fuel and then on protein.

Proteins supply the body with amino acids, which are required to build new protein. Protein from foods, such as meat, poultry, fish, eggs, milk and cheese, provide essential amino acids, while vegetables need to be combined with beans, peas or nuts to provide complete protein.

Carbohydrates, which are starches and sugars, are the body's main source of energy. Starches include potatoes, pasta, bread, rice and some fruits. Sources for sugars include table sugar, candy, pastries, jams and jellies.

Fats also are a good energy source and are an essential component of the body's cells. However, saturated fat should be eaten in moderation because of the risk of heart disease and obesity. Sources of unsaturated fat are oily fish, some vegetable oils and margarine. Sources of saturated fat include red meat and poultry, whole milk and other dairy products.

Vitamins and minerals help the body function properly and contribute to overall good health. These are found in fruits, vegetables, whole grains and some animal proteins.

Fiber passes through the body and helps prevent bowel and digestive problems. Fiber is found in whole meal bread, cereals, potatoes, peas, bananas, oranges and green leafy vegetables.

A major responsibility of a primary caregiver is to plan, arrange and/or serve the care recipient at least three meals daily that include a variety of foods and servings for proper nutrition.

Older adults and those with certain medical conditions may have special dietary restrictions, such as a low salt diet for people with high blood pressure or a sugar-free diet for diabetics.

Volunteer support caregivers familiar with the basic requirements of a regular balanced diet and aware of an older care recipient's dietary restrictions can be helpful in planning and preparing meals.

A regular nutritionally balanced diet includes a variety of foods that should be consumed daily to provide the minimum amounts of vitamins, minerals, carbohydrates, fats and proteins. Following are guidelines for meeting the daily minimum nutritional requirements for older adults.

DAILY MINIMUM NUTRITION REQUIREMENTS FOR OLDER ADULTS

FOOD GROUP	NUMBER OF SERVINGS
Bread group (bread, pasta, cereal, rice)	6 for women, 9 for men
Vegetable group	3 for women, 4 for men
Fruit group	2 for women, 3 for men
Milk group (milk, yogurt, cheese)	2 for women and
men Meat group (poultry, meat, fish, beans, eggs, nuts)	2 for women and men
Fats, oils and sweets	Only to be used sparingly
Following are examples of one serving size from each food group:	
<p>Breads, Cereals, Rice and Pasta</p> <p>1 slice of bread ½ cup of cooked rice or pasta cheese ½ cup of cooked cereal 1 ounce of ready-to-eat cereal</p> <p>Fruits</p> <p>1 piece of fruit or melon wedge ¾ cup of juice ½ cup of canned fruit ¼ cup of dried fruit</p> <p>Vegetables</p> <p>½ cup of chopped raw or cooked vegetables 1 cup of leafy raw vegetables</p>	<p>Milk, Yogurt and Cheese</p> <p>1 cup of milk or yogurt ½ to 2 ounces of</p> <p>Meat, Poultry, Fish, Dry Beans, Eggs and Nuts</p> <p>2 1/2 to 3 ounces of cooked lean meat, poultry or fish 1 egg or 2 tablespoons of peanut butter count as 1 ounce of lean meat</p> <p>Fats, Oils and Sweets</p> <p>Limit butter, cream, margarine, candy, soft drinks, sweet desserts and alcohol.</p>

Medication Issues

Medications have important uses in preventing illness, maintaining health, relieving pain and treating other symptoms of chronic illnesses and conditions. To be used appropriately, safely and effectively, however, medications must be taken as directed, stored properly, used for their intended purpose and only by the person for whom they were prescribed.

Often, a veteran care recipient and even the primary caregiver are prescribed several different medications to treat a number of illnesses and conditions. In most cases, the primary caregiver is responsible for helping the care recipient adhere to taking medications on time and as prescribed by a doctor. Care recipients may not be able to adhere to multiple prescription drug regimens on their own for a variety of reasons, including the complexity

of the medication regimen, poor memory and lack of understanding about why and how to take the medications.

To a great extent, volunteer support caregivers are limited in what they can do to help older care recipients and primary caregivers take medications properly. For instance, they should not touch medications. If a veteran has a bad reaction to a drug, chokes on a pill or in some other way is injured by medication, the person who administers the medication - or even just handles it - maybe held accountable. Volunteers may hand the veteran care recipient the container that holds the medicine, but they should never touch a medication directly.

Taking medication out of a bottle to give to a veteran care recipient or primary caregiver is considered to be "controlling dosage." Putting medication in a person's mouth is considered to be "administering" the medication. These two things should never be done by a volunteer support caregiver. Only the primary caregiver who is with the older care recipient on a daily basis should administer medications with the guidance of doctors, pharmacists and other professional health care providers.

However, volunteers can help by reminding the care recipients and primary caregivers to take their own medications, take them on time, in the correct dosages and according to the doctor's instructions. They also can make sure that medications are stored properly. Volunteers also may be helpful in obtaining information about medicines - the purpose of a medicine, side effects to watch out for, special precautions and foods to avoid - but this information must come from a reliable source, such as a physician or pharmacist.

■ **Medications: Questions To Ask**

Whenever a care recipient is prescribed a new prescription, the primary and volunteer support caregivers, as well as the care recipient should understand what the medication is for, what it will do and what its side effects are, alone and in combination with the other medications the care recipient is taking. Following are common questions to ask a doctor and pharmacist:

- What is the medication intended to do? Is it treating the cause of the illness or condition or its symptoms? Is there an additional way to treat the problem, such as a change in diet, exercise or lifestyle?

REASONS WHY SOME PEOPLE REFUSE MEDICATIONS

- The care recipient may have difficulty obtaining medicines because of transportation problems or financial limitations.
- The care recipient may not understand the doctor's instructions about the medicines prescribed or may be confused about which medicines to take and when.
- The care recipient has disabilities (e.g. difficulty walking, seeing or remembering) which make it difficult for the care recipient to get or to open the medicine bottle or container or to take, apply or swallow the medicine.
- The care recipient does not take medications as prescribed but, because of limited financial resources, take less of each medication so the monthly supply will last longer.
- The care recipient may not believe the medications are helping, dislike the side effects, is depressed and not motivated to get well or feel better.

- When and how should the older care recipient and/or primary caregiver take this medication?
- When is the best time of day to take this medication?
- Is it safe to take it with the other medications, vitamins, herbal products and/or foods?
- Should particular foods, liquids, nutritional supplements or activities be avoided while taking this medication or any other medication already being taken?
- What is the proper dose for someone the older care recipient's age or primary caregiver's age? Older adults tend to be more sensitive to medications because of body changes, such as water loss or fat gain, decreased ability of the liver and kidneys to process and clear medications from the body, a greater difficulty maintaining normal blood pressure and adapting to changing temperature. Also, older people are more likely to have illnesses or conditions that alter their response to medications.
- How long does it take for this medication to have an effect, and how will one know if it is working?
- How long should the older care recipient or primary caregiver use this medication? Should he or she continue to take it even after feeling better? The older care recipient or the primary caregiver should check regularly with the doctor-perhaps every few weeks, depending on the potency of the medication and the side effects-to find out if the medication is still needed or if the dose can be lowered.
- What are the possible side effects? What should be done if the older care recipient or primary caregiver has a bad reaction? There are usually trade-offs to be made in treating older people - for example, a care recipient may need to take a medication that worsens confusion in order to eliminate more troubling hallucinations or paranoia. All the pros and cons should be discussed with the doctor.
- What should be done if the care recipient or primary caregiver forgets to take this medication?
- Is this medication habit-forming? Will it be difficult for the care recipient or primary caregiver to stop taking it?
- Can a generic version be prescribed that will act in the same way, but is less expensive? Or is the branded medication better for this particular condition?

■ *Volunteer Assistance with Medication*

A volunteer can help a veteran care recipient or primary caregiver take medications as directed on the label or as prescribed by a doctor by:

- Reminding the primary caregiver and the veteran care recipient to take their medications according to the instructions on the labels.
- Reminding the veteran care recipient or primary caregiver to be aware of allergies in relation to all medications, vitamins, herbal products and other nutritional supplements being taken, including any non-prescription drugs.
- Reminding the primary caregiver and the veteran care recipient that they are the only ones able to touch or administer the medications.

- Helping the primary caregiver and care recipient to understand the directions on the prescription labels.
- Observing any misuse, abuse or non-compliance in using the medications and reporting these observations to the contact person at the VA medical facility.
- Urging the primary caregiver or the veteran care recipient to ask the prescribing physician or pharmacist any questions they may have about the medications.
- Suggesting how to avoid errors in taking their medications.
- Recommending that the care recipient or primary caregiver use a special pillbox available to make it easier to take medications on schedule. These include daily and weekly compartmented boxes with reminder beepers. However, some medications need to be kept only in airtight containers; they lose their potency in a pillbox.
- Reminding the care recipient or primary caregiver to sit up when taking pills or capsules.
- Suggesting that a doctor be consulted before crushing tablets or opening capsules and mixing the contents with soft food. Long-acting tablets should not be crushed. Doing so may endanger the person taking the medicine. With a doctor's permission, a tablet can be crushed between two spoons by putting the pill in one spoon, nesting the other on top and pressing down on the top spoon with the thumb. Pill-crushing devices also are available at many pharmacies.
- Informing primary caregivers or care recipients that many pharmacists give away dosage spoons with liquid prescriptions. The primary caregiver or care recipient should ask the pharmacist for one. These make it easier to give accurate dosages.
- Reminding the primary caregiver or care recipient that dentures generally interfere with chewable tablets.
- Suggesting that the veteran care recipient or primary caregiver may tolerate a bad-tasting liquid medicine better by sucking on an ice cube before taking the medicine to numb the taste buds.
- Suggesting how to store medications properly.
- Suggesting how to dispose of old medications correctly.
- Informing the contact person at the sponsoring organization of any adverse reactions observed in the care recipient or primary caregiver.
- Paying attention to changes in physical, mental and psychosocial functions of the older care recipient after a medication has been prescribed. These changes may be caused by the medication and may be reduced if a dosage change is made or if a different medication is prescribed. The volunteer can report these observations to the older care recipient's primary caregiver.

■ *Reading the Label*

Labels are placed in a prominent place on the containers of all prescription medications. Labels should include the following information:

- The name and address of the person for whom the medicine is prescribed.
- The name of the physician who prescribed the medication.
- The name and form, such as tablet size, of the medication.

- The dosage amount and directions for taking the medication; for example, "three times a day with food."
- The date the prescription was filled.
- The prescription number used by the pharmacy as a reference.
- The name, address and phone number of the pharmacy and name of the pharmacist.
- The number of times the prescription can be refilled.
- The expiration date when the medication should be discarded.
- The amount of medicine in the prescription bottle, such as the number of tablets, patches, or capsules; ounces, mls, or ccs for liquids and ounces or grams for solid dosage forms.

■ *Medication Record*

It is a good idea for the primary caregiver and older care recipient to keep a medication record to note all of the prescription and non-prescription medicines they are taking.

The medication record should be kept in the older care recipient's wallet or purse and shown to all doctors, nurses and pharmacists involved in the health care of the older person. The medication record must be updated whenever a change in the medication regimen occurs.

The medication record also is a place to help keep track of any bad reactions to specific medications or explain why a medication is not being taken as prescribed. For example, an older care recipient may be told to take a diuretic twice a day, but is only taking it once a day because of increased frequency of urination.

The volunteer should remind the primary caregiver and care recipient to inform their doctors of all medications - both prescription and over-the-counter - and nutritional supplements they are taking.

A volunteer support caregiver is in a good position to help observe when a care recipient or primary caregiver may not be taking prescribed medications as directed or at all.

After gentle urging, one should try to learn why a medicine is not being taken. If the person prescribed the medicine cannot answer this question, then he or she should be observed to determine why the medicine isn't being taken. Observations and other factual information should be recorded in the medication record and reported to the contact person at the VA medical facility. This information also can be useful to physicians and nurses caring for the person when hospitalized.

■ *Storing Medications*

To help ensure the effective and safe use of medications, volunteers can assist primary caregivers and care recipients in storing and discarding them properly by using the following guidelines:

- All medications-including prescription and over-the-counter medications and herbal remedies-should be kept out of reach of anyone who might misuse them. If there are older adults who are not responsible for their actions or children in the home, medications should be locked in a cabinet or kept in bottles with safety lids.

- Some medications must be stored in the refrigerator. These should be stored in an area where they won't freeze and children can't reach.
- Medications should be stored away from moisture, light and heat. These factors can change a medicine's chemical composition and, therefore, its effectiveness or strength. Do not store medicines in the bathroom or kitchen because these rooms are often moist and warm.
- Medicine should be discarded if it has no label, has a label that cannot easily be read or is no longer potent because it is beyond the expiration date on the medicine bottle or package. If medications are being discarded, they should not be placed in the garbage where children and/or animals can get to them. Instead, a physician or the local health department or poison control center should be contacted for instructions regarding how to dispose of drugs properly.
- Clear medications that look like water or soft drinks should not be put in containers from which children or others might drink.
- An emergency telephone list should be created with numbers of significant family members and friends, the emergency room of the nearest hospital, the local poison control center, the police or fire rescue squad, all doctors and other professional care providers, emergency medical services and local pharmacies that are open on weekends and holidays."

■ *Dealing with Relationships and Losses*

Whether short-term or long-term, infrequent, intensive or on-going, the services provided by volunteer support caregivers for primary caregivers and care recipients create a personal relationship that will eventually end. This section was developed to help prepare volunteers for these endings and for the related closure, so they can be positive and meaningful experiences for both the volunteers and for the families they serve.

■ *Preparing for Endings*

Volunteer support caregivers need to be prepared for the end of relationships after long-term assignments of assisting care recipients and/or their primary caregivers. This preparation should help volunteers handle these transitions as comfortably as possible. Appropriately prepared volunteers are more likely to enjoy their support caregiving experiences and look forward to the next volunteer assignments when their current volunteer relationship ends.

The objective is to have "positive closure" when a relationship with a care recipient and/or primary caregiver ends. Positive closure occurs when the volunteer completes an assignment and everyone involved feels comfortable, without any negative or unresolved feelings.

**If we cut our emotions off,
we don't heal.**

Daniel Dworkin, Ph.D. affiliate Professor of Psychology,
Colorado State University and co-author of *Helping the
Bereaved*, Basic Books, 1992.

■ *When a Care Recipient Recovers*

The good news of a care recipient's recovery back to a more independent lifestyle can be disconcerting for a volunteer who is unprepared to face this change in the relationship with the care recipient.

The anticipated end of relationships, especially long-term, intense supportive relationships, can cause a range of emotions for volunteers, primary caregivers and care recipients.

These emotions may include:

- **Ambivalence** - Showing mixed reactions can be confusing to others who are reacting differently to the ending.
- **Resentment** - The primary caregiver may resent losing control of the caregiving role as the recovering care recipient gains more independence. •
- **Avoidance/Denial** - By delaying or blocking discussion of the ending, one also delays preparing for it. By delaying the reaction, one may actually increase and prolong the pain of an ending or separation.
- **Grief** - Memories of past endings and permanent losses may magnify pain when unprepared for an ending.
- **Anger** - An ending can generate anger from the care recipient who is losing ongoing care and from the primary caregiver who is losing the companionship of the volunteer.
- **Joy** - The recovery of the care recipient and changes in the relationship with the primary caregiver and volunteer should be celebrated by all as a positive development.

“Joy” is listed last because it is achieved by preparing well for and addressing the other emotions on this list.

A recovered or recovering care recipient may be upset by the volunteer moving on to another assignment. Anger also can result when the relationship appears to have been based only on the care recipient's incapacitation or illness.

A primary caregiver protected by denial or ambivalence may become unfriendly or resent the dedicated volunteer.

Understanding how this range of emotions may be shown also helps volunteers prepare themselves for their own responses and feelings. This understanding should help volunteers react more positively to others as relationships end.

■ *The Benefits of Introspection and Self-Knowledge*

The VA staff and trainers can help volunteers prepare themselves to deal more effectively with the ending of volunteer relationships. Endings tend to trigger feelings of past losses. How a person reacted to a family member or a friend moving away or a sibling going away to college may have established a pattern for reacting to future changes or endings.

In this section, we will work in small groups to discuss and employ useful exercises to share experiences and feelings about past relationships that have ended or changed

significantly. How did you react when this happened? Has this been a pattern? How did you feel when the person ending the relationship seemed indifferent or unaffected by this change? Each person's issues with endings and changes in relationships can affect feelings about future endings or changes.

Advance preparation will not you of your feelings about endings. Preparation can only help reduce counterproductive reactions to those feelings and increase the opportunity for you to understand and communicate your feelings in a positive way when ending support for care recipients or primary caregivers.

PREPARING FOR A MAJOR CHANGE OR ENDING TO THE VOLUNTEER RELATIONSHIP

- Plan for the ending and discuss it with the Home Health Coordinator, the recovering care recipient and/or the primary caregiver, as appropriate.
- Understand what is ending. Is it the end of the relationship? Or is it merely the end of the caregiving support relationship? Volunteers may remain friends with recovered care recipients and their primary caregivers. But a prolonged support relationship may be used to avoid saying “good-bye,” and it may be resented or delay the recovery of the care recipient.
- Clarify the form of the new relationship, if there is to be one. What will be the same and what will be different? Will it be a friendship? Will the volunteer role end? When will it end? It will be important to clarify what changes will occur in frequency, form and length of future contacts? Will any level of caregiving still be needed or will the relationship be more like other friendships?
- Plan the ending so that it is clearly understood by everyone, including the volunteer, care recipient, primary caregiver, other family members and the Home Health Coordinator.
- Try to end the volunteer relationship with a positive attitude. A negative attitude can mean that there are unresolved issues about endings that may surface in the future. Discuss these with the Home Health Coordinator. Disappointments may come from unmet goals, self-doubts or other problems in the relationship. The Home Health Coordinator can arrange for someone to help a volunteer understand and resolve disappointments and prepare for more positive future volunteer experiences.
- Position the planned change or ending as positive for everyone. All should be looking forward to something new. For the care recipient and the primary caregiver, the volunteer can help by focusing on the new independence and opportunities. For the volunteer, it may mean assisting someone else who needs volunteer support, or some welcome time off or a vacation trip before starting a new volunteer assignment.
- Have a final discussion with the Home Health Coordinator after each assignment ends to review the experience, attitude about the experience and to reflect on the growth and learning achieved from the volunteer experience.

RECOMMENDED STEPS FOR PREPARING FOR THE END OF CAREGIVER SUPPORT ASSIGNMENTS

ONE TO TWO MONTHS BEFORE ENDING THE ASSIGNMENT:

- Set the ending date with the contact person at the assigning organization, the primary caregiver and the care recipient.
- Discuss with the VA Home Health Coordinator, the primary caregiver and the care recipient the remaining tasks that need to be completed and the timetable for their completion.
- Have preliminary discussions with the care recipient, primary caregiver and family members, as appropriate, about the end of the assignment and preparations for the last day of service.
- Identify dealings, issues and needs that must be dealt with in saying “goodbye.”
- Discuss with the VA Home Health Coordinator:
 - the anticipated impact of leaving the care recipient and/or primary caregiver.
 - how to respond to the emotional and behavioral reactions of the care recipient and/or the primary caregiver.
 - how to handle the end of the assignment, including how to transfer useful information to the primary caregiver and/or care recipient.
- Be prepared to discuss:
 - What was most enjoyable about the assignment?
 - What areas of personal growth can be recognized from the assignment?
 - What barriers and challenges were faced and how were they overcome?
 - What skills were used most often? What new skills were developed?

- What major strengths were used or developed?
- What kind of relationship will continue with the care recipient and/or primary caregiver?
- How should the next volunteer assignment differ from this one?

- Determine and discuss with the VAVS staff member plans for a new assignment.
- Identify and inform others who need to know about the ending of the current volunteer assignment.
- Schedule a final post-assignment meeting with the Home Health Coordinator and a VAVS staff member.

FINAL DAYS BEFORE ENDING THE ASSIGNMENT:

- Have discussions with the care recipient, primary caregiver and other family members, as appropriate, about the end of the assignment and preparations for the last day of service.
- Arrange and prepare for a post-assignment meeting with the Home Health Coordinator and a VAVS staff member.

ON THE LAST DAY OF THE ASSIGNMENT:

- Return any keys that were provided during the assignment.
- Celebrate the new independence and positive changes for the care recipient and/or primary caregiver.
- Share plans for the future.
- Say “goodbye.”

■ Preparing For the End of the Relationship When the Care Recipient is Dying

We will take a brief look at volunteer support for veterans who are near death. In most instances, volunteers in the *Caregiver Support Network* will not be assigned to those veterans known to be in hospice care. This type of volunteer assignment requires additional training, however, the situation may certainly arise when a care recipient dies suddenly or transitions to a physical state where death becomes more probable. Volunteer support caregivers who assist chronically ill veterans nearing the end of their lives need to be prepared to understand and provide helpful assistance in a particularly sensitive manner to care recipients, primary caregivers and other family members during this difficult period.

KÜBLER- ROSS: FIVE REACTIONS TO TERMINAL ILLNESS

When people die suddenly from accidents or are stricken by a heart attack or stroke, often there is no time to prepare for death. But when people are terminally ill, there usually is time to prepare.

At this time, people often draw upon their religious and ethnic beliefs and their cultural and individual backgrounds for understanding, perspective, comfort and strength.

One's understanding and preparation for death also depends upon one's age. Young adults may see death as something far off, to be dealt with at a later time. As may be the case for many of our returning military personnel, many young people see themselves as having most of their lives ahead of them. Pressing issues may include family, career, and recent military experience. Middle-aged

persons often view their impending death as an ending of family and career responsibilities with the primary concern being the welfare of loved ones being left behind. Adults in their 70s or 80s may be more accepting of death as a natural part of life, but they still need help to live as long and as fully as possible.

Individual reactions to impending death also may vary over time. It helps to be aware of the stages of reactions to death and dying, as described by Dr. Elisabeth Kübler-Ross, who made a lifelong study of these issues (*On Death and Dying*, New York: Macmillan Publishing Co., 1969 and 1970).

EMOTIONAL REACTION CHARACTERIZED BY:

- **Denial and isolation** Avoiding all discussion about the illness. Discussion focuses instead on the future, as if the illness doesn't exist.
- **Anger about reality** Expressing anger when the reality of the illness is recognized and no longer can be avoided; posing the questions: "Why me? What have I done to deserve this?"
- **Bargaining** Making promises to a higher power to change one's life or do special good works in exchange for a cure or a longer life.
- **Depression** Becoming too weakened by the illness and/or feeling a deep sadness about the inability to perform simple tasks or function in the way to which one has been accustomed. Awareness of the approaching end of life.
- **Acceptance** If time permits, preparing for death from a religious, philosophical, social or emotional standpoint-almost becoming detached from the terminal illness.

Dying persons and their family members may follow these stages in sequence or, more frequently, they may revert back and forth between stages.

NOTE: Supplemental materials are available for those volunteers assigned to patients receiving hospice care.

■ Seven Fears Faced by the Dying

(By Dr. Thomas Leicht, Director of Bellin Hospice Unit, Green Bay, Wisconsin)

Patients who are dying want more than anything else to go on being themselves, to go on living. It therefore becomes the task of those people in touch with the dying to help enable such a process. In caring for patients with a life-threatening illness, I find it helps to focus on three tasks: listen, help and stay.

Those of us in hospice care move about our patients and families with a prescription for care that includes the whole person: physical needs, spiritual needs, emotional needs, relational needs and financial needs. Our ministry is best described by a 15 century folk saying, "To cure sometimes, to relieve often, to comfort always."

I am often asked, "How do you talk to a dying patient?" The more appropriate question is "How do you listen to a dying patient?" If you know how to listen, you will know how to talk. It takes sensitivity to understand what is behind a patient's words. It is only as we listen that we will be able to identify the needs of the dying person. And listening means involvement. You will not only hear what is being said, you will feel what the dying person is feeling. Listening is an active process, not a passive exercise.

To help patients with life threatening illnesses, it is well to know the fears that they may experience and how to respond to them. Our staff has been able to determine seven key fears faced by the dying person.

1. Fear of the Process of dying. "Will death be painful?", "Will it be frightening?", "What will happen to my body?" These are real concerns faced by the dying and their families. Body image creates fear of the kind of death ahead, especially if the patient has cancer and has experienced severe weight loss. The good news that has come out of the hospice movement is that pain can be relieved in ways that allow patients to continue to function in their home environments and death is not a frightening experience, but a peaceful event.

2. A Second Fear of the Dying Is That of Loss of Control. Life-threatening illness gradually makes the patients more dependent. The father can no longer provide for his family, the mother can no longer care for her home, the child can no longer play with his/her friends. As the disease progresses, the patient is thrust into a health care system which creates dependency. This is especially true in the hospital where we frequently make patients wait in admitting rooms, taking their clothes and medication away when they are finally admitted. We tell them who can visit and when. They are told when meals will be served and shy they will receive personal care. Patients and families need a health care system that supports them in the home through a 24-hour a day, seven days a week hospice home care program. If hospitalization becomes necessary, it should take place in an environment which exists for the convenience of the patient and family and not take place in an environment which exists for the convenience of the hospital and staff. Patients and families must be allowed to be active participants in the treatment program and in the decision-making process to the extent they are comfortable being involved.

3. Patients Fear for Their Loved Ones. They are concerned about what is going to happen to them. "Will there be sufficient money to put the children through school?" "Will my wife have to return to work?" "How will my family get along in my absence?" It is reassuring if the family can demonstrate their ability to function as a family unit while the patient is still living.

4. Patients Are Fearful of the Aloneness of Dying. They sense isolation by the decreasing frequency and length of visits of medical personnel and friends, by the

body language of those around them and by the superficial content of our conversations with them. This is where it becomes important to stay. Even though as death approaches patients may not respond, they can be made aware of the presence of another human being through touch and voice. Hearing and touch are the lost two sensations we lose and a loved one's presence can alleviate the aloneness of dying until the moment of death which we must all pass through alone.

5. The Fifth Fear is Reflected Fear. Ted Rosenthal who died at age 33 of leukemia wrote in his book, *How Can I Not Be Among You*, "I never knew what fear was until I saw it in the eyes of the people taking care of me." Patients read how we are reacting to their illness more clearly than we can imagine. Non-verbal communication is very difficult to respond to so it becomes important to be free to experience and share what we are feeling. This is especially true as patients and families relate to each other. Grief is the price we pay for loving relationships which come to an end and we must be free to share the emotions that go with grieving.

6. The Sixth Fear Is That Life Will Have Been Meaningless. Ted Rosenthal said death is "the time when the mind's own camera is forever turned on self." It is the time we look back at our life to see what meaning it had. Has the world been better because I was part of it? It is important to help patients identify those positive aspects of their lives. If a person feels life has been meaningless and moves into questioning the reason for his or her creation, the process can be devastating.

7. The Final Fear Is That of the Unknown. It is here that one's faith system comes into play. Patients wonder if there is life after death and if there is, what it is like. Hope is part of life and must be maintained until the last breath of life (as long as it is a realistic hope). Patients go through a spectrum of hope: from hope of cure, to hope of extension of life, to temporal hopes. These hopes may be living to see the flowers come up in the spring, the leaves turn in the fall, a grandchild born or a holiday celebrated, to living the rest of their lives without pain, or perhaps the hope of eternal life as they understand it in their specific faith.

In relating to patients spiritually, we must be free to share our faith without imposing it. If we are sensitive to what patients say and are open to spiritual direction, we will know how to minister to patient's needs at each point in time.

■ ***Grief and the Aftermath***

Every year, more than 11 million adults lose a parent. It is the single most common cause for bereavement in the U.S. Survey results published in the *U.S. News and World Report* in 1997 reported that the death of a spouse is considered to be the most stressful life event.

As common as bereavement is among adults who lose close family members or friends, it still is a lonely personal experience. Adults often are judgmental about their own feelings of grief. This makes it more difficult for some adults to discuss their grief with others.

EACH GRIEF EXPERIENCE IS UNIQUE

Those who have shared their experiences and feelings of grief after the loss of a loved one may understand better than others how unique the grief experience is for each person. Nobody can know exactly how the grieving person is feeling. One family member may express grief differently than another. There is no hard and fast rule about when grief begins. And some say that grief about the death of a loved one never really ends. It just gets easier to cope with over time.

Each of us has the right to mourn in his or her own way. Grief has no formula. Others should not try to impart a formula or any other limits on a grieving person.

As an older person's condition gets progressively worse, the primary caregiver, close family members and friends, and, even the volunteer on long-term assignment will begin the grieving process long before the older person dies.

This is particularly true when the illness creates changes in the older person's personality, memory, mental capacity and general vitality. These deteriorations may change the older person so much that the primary caregiver, family members and friends can no longer relate to the older person as he or she was before the changes occurred. Everyone in the older person's social network becomes aware, over time, that the older person is getting closer to death.

With this awareness comes the grief of "losing" the older person as he or she once was, and the hopes, dreams and plans for the future to the illness or condition.

As personal as the grieving process is, it is generally accepted that there are three stages of grieving: Denial, Disorganization and Survival. Memories, milestones, anniversaries of the death and familiar locations each may cause a person to shift from one stage to another. Sometimes the stages can overlap until emotional healing occurs.

It is important for volunteers to recognize the stages of grieving and understand what impact grieving may have on the attitudes and behavior of the primary caregiver, the dying care recipient and other family members and friends.

■ *Coping With Grief*

The feelings of grief are emotional, not logical. Coping with grief is a different experience for each person. Some may try to avoid grief by staying very busy and not having time to think about the loss. Suppressing grief does not make it go away. At some point, it still will come to the surface.

Grieving family and friends need support from others who will listen. It is not necessary to offer them helpful advice or have answers. By just listening and showing empathy, a volunteer may be providing the kind of help that people who are grieving need most.

CRYING

Family members and friends should be encouraged to express their emotions. Crying is a natural "release valve" for those who are feeling intense grief. This is true for both men and women.

Anyone mourning who feels like crying should be encouraged to do so. A volunteer may be helpful at these times by showing acceptance of these emotions and compassion by offering hugs or just gently putting an arm around those who are crying.

GUILT

Grieving sometimes brings a sense of guilt for those surviving the loss of a close family member or friend. A spouse may express guilt for still being alive. A primary caregiver may have feelings of guilt for not having "done enough." When these feelings are being expressed, it is important to listen and remind those grieving that survival is a natural part of life and that they did all they had the power to do.

RELIEF

Primary caregivers, other family members and friends may express relief when the older person dies after suffering from a long, painful or debilitating illness, such as cancer or Alzheimer's disease. Relief comes from knowing that the older person is finally at peace and from an awareness that the burden of caregiving responsibilities is now over. The primary caregiver should be reminded that feelings of relief are natural and right, not wrong. For the primary caregiver, relief can be one of the first steps on the path toward healing and moving forward with life beyond caregiving.

The Stages of Grief

Following are examples of behavioral symptoms associated with the three stages of grief and what a volunteer can do to help during these stages:

DENIAL

- A person is willing to discuss only topics related to plans for the future, instead of getting personal affairs in order, such as preparing or updating a will or providing health care directives or a “living” will.
- The primary caregiver and close family members refuse to accept the impending death of the loved one.
- After death occurs, surviving family members and friends have difficulty accepting that the person has died and continue to discuss the deceased in the present tense, as if he or she is still alive.
- After death, the primary caregiver and other close family members may lose a sense of daily dates and times and ignore personal and work obligations. It is as if everything else, except the death of the person has been put “on hold.”
- Close family members may experience feelings of anger, guilt, helplessness and confusion about what to do and where to go next.

What to do:

- Before the death, a volunteer might encourage the person who is dying to discuss what his or her wishes are for an advance health care directive, “living will,” and any other final documents or plans with family members or an attorney.
- Before the death, a volunteer might encourage the primary caregiver and other family members to discuss with the person who is dying the status of a will and other important documents, as well as what his or her wishes are for an advance health directive or “living will.”
- After the death, a volunteer might encourage family members and friends to describe memories of experiences with the deceased.
- After the death, a volunteer might encourage family members and friends to express their feelings about the loss and share these feelings with each other. It is important to let them know that by sharing their feelings in a safe and supportive environment, the pain of their grief may be reduced and feelings of familial love and support may emerge.
- A volunteer might suggest steps for the grief-ridden family to take toward getting back control of their daily lives, such as paying attention to personal hygiene, laundry and regular times for meals and sleep.
- A volunteer might encourage family members to engage in enjoyable activities again, such as in reading a good book, seeing a movie with another family member or taking children or grandchildren to the zoo.
- A volunteer might suggest that family members participate in a local bereavement support group.

What to Do”

SURVIVAL

- Over time, the intensity of the pain of grieving diminishes, as the survivors focus more on the routines of living and on plans for the future.
- Mourning may continue for a year or more with feelings of sadness from time to time. With survival comes the ability to remember cherished moments with the deceased in a positive light without being overcome with grief.

What to Do:

- A volunteer might keep in touch with family members to encourage them to share their feelings, describe positive memories of the deceased and discuss new developments in their own lives and how far they have come in their healing.
- A volunteer might suggest that the primary caregiver consider helping others through a community-based volunteer program.

DISORGANIZATION

- The primary caregiver and other close family members may become disoriented and disorganized in their own lives as the person gets closer to death.

EXERCISE 3: Self-Assessment of Your Beliefs about Death and Dying

Overview: Individuals who volunteer to provide care to other adults need to acknowledge their own expectations and perceptions about death and dying. It is important for volunteers to explore their own fears and beliefs about dying and understand the influence of spirituality, family and past experiences on their feelings about death. This self-assessment activity provides volunteers the opportunity to gain greater insight about their own expectations about death and dying which will enhance their ability to assist others.

EXERCISE 3: Self-Assessment of Your Beliefs about Death and Dying

Answer the following questions, then discuss with the group.

1. To the best of your memory, at what age were you first aware of death?
 - Under the age of 5
 - Age 6 to 9
 - Age 10 to 15
 - Age 16 or older
2. When you were a child, how was death discussed in your family?
 - Openly
 - As though death were a forbidden subject
 - With some discomfort
 - Don't remember any talk about death
 - Only when necessary and not in front of children
3. Which of the following most influences the way you think about death now?
 - Death of someone else
 - TV, movies, radio
 - Books or articles you have read
 - Length of time family members have lived
 - Religion
 - Funerals
 - Own health
 - Other _____
4. Has religion played an important part in the way you think about death?
 - Very important
 - Important
 - Not very important
 - No part at all
5. How often do you think about your own death?
 - At least once a day
 - Frequently
 - Sometimes
 - Never or almost never

6. What does death mean to you?
- To end of life
 - End of physical life, but the spirit lives on
 - Endless sleep and peace
 - A new beginning of life after death
 - Don't know
 - Other _____
7. What aspect about your own death bothers you the most?
- Loss of life and relationships
 - I am not sure what will happen to me when I die.
 - I could no longer provide for my family.
 - My relatives and friends would grieve.
 - The process of dying might be painful.
 - Other _____
8. What do you believe causes most deaths?
- Most deaths happen because the person wants to die.
 - The will of a greater power
 - Most deaths happen because of the way people lived their lives.
 - Most deaths just happen without explanation.
 - Other _____
9. If your doctor knew that you were dying from a disease and had a limited time left to live, would you want to know?
- Yes
 - No
- Why or Why Not? _____
10. If it were possible, would you want to know the exact date on which you were going to die?
- Yes
 - No
- Why or Why Not? _____

■ *Getting the Most out of Your Volunteer Assignment*

It is important to consider what motivates you to accept an assignment as a volunteer support caregiver in order to gain satisfaction from your assignment and continue your commitment for the agreed upon time. Be sure to let the VAVS staff know your primary reason for volunteering, so that they may closely match you with an assignment to meet your needs.

Once you have volunteered for an extended period of time, you may begin to experience “burnout” or disinterest in your assignment. Service in the *Caregiver Support Network* can be a very emotionally draining position. You would be wise to check in with your thoughts and feelings periodically to be sure that you feel comfortable continuing in the assignment. If you find yourself experience any level of stress, “burnout” or disinterest, consider these possible solutions:

- Take some time off, a vacation or a sabbatical.
- Move to a different assignment that may be of more interest.
- Request a temporary move to a short-term assignment just for brief break from the volunteer caregiving responsibility.
- Ask if you can assist in training or recruiting volunteers for the Caregiver Support Network.

Any of these solutions can help you determine what direction you would like to go in your volunteer service, while giving you a much-needed “break.”

You should also be aware that within VAVS and the using department, open-door communication is encouraged. Do not hesitate to speak with a member of the VAVS or Social Work staff when you are seeking support.

EXERCISE 4: The Case of Mr. Ruiz

Overview: The volunteer support caregiver will confront many interesting and challenging care recipients. The role of family and the influence of culture on beliefs, attitudes and behaviors about health and health issues are important considerations when providing care. This case study provides an opportunity for volunteers to further their understanding of their roles, identify strategies for delivering effective support and care to difficult care recipients, reinforce the need for sensitivity to ethnic and cultural issues.

EXERCISE 4 : The Case of Mr. Ruiz

The VA received a call from Victor Ruiz, the son of Juan Ruiz, age 76. Victor states that he is very concerned about his father. Since the death of his mother, six months ago, his father has really started to deteriorate. He no longer has an appetite and eats very little. He shakes and trembles from time to time and has become very forgetful. He is not talking very much and he hardly sleeps at all. He doesn't take care of himself and forgets to take his medication. He refuses to go to see his doctor, because of suspicions that his wife's doctor was the cause of her death. In fact, he only leaves his house to go to church which is one block away.

The son has told the Home Health Coordinator that his father emigrated from Puerto Rico to the U.S.A. with his wife 30 years ago. He has an 8th grade education, but learned enough English to get a job as a laborer. He is retired from work and has very little family nearby. Victor is his only son, but he lives 150 miles away and is not able to visit often.

Victor states that he feels that his father needs help with day-to-day activities, personal care, medications and meals. He requests the services of a volunteer support caregiver. His father expresses that he does not need any help and does not want any strangers in his house.

- What is the role of the volunteer support caregiver?
- How would you prepare for your first visit?
- What do you expect Mr. Ruiz's reaction to be to you?
- What do you know about Mr. Ruiz's culture that you should take into consideration when you provide care for him?
- What other kinds of services do you feel Mr. Ruiz needs? How might he react to these? How would you handle his reaction?

■ ***Recognition and Rewards***

The motivations for becoming a volunteer were discussed earlier. We are aware that volunteers are motivated by their personal beliefs, values and traditions. Their work is rewarding and demanding. As a volunteer in the Caregiver Support Network, you should know that the VA staff and leadership support you and that your volunteer work is not taken for granted.

Voluntary Service and the using departments will make every effort to provide formal and informal volunteer recognition to help reinforce the need and value of volunteer support caregiving. As a volunteer you are entitled to:

- Receive the volunteer newsletter or any other special correspondence related to the VAVS Program at your VA facility.
- Join any special events or activities designed for volunteers
- Participate in any training programs open to volunteers.
- Regular “thank you’s” from VA staff members grateful for your service.

■ ***Getting a Veteran Involved***

A primary caregiver, other family member, member of a veteran’s treatment team, or the veterans him/herself can begin the process of getting a veteran registered in the ***Caregiver Support Network***. As a volunteer in the program, you should always recommend that veteran patients and family follow the proper guidelines for acquiring a volunteer support caregiver and make no effort to circumvent the process by making personal referrals or special requests on behalf of veterans. The Caregiver Support Network will work diligently to ensure that veterans and their caregivers are assigned volunteer support caregivers in the order in which they are referred, unless otherwise indicated.

Step 1: Request is made by the primary caregiver/family member/treatment team member/veteran and forwarded to Caregiver Support Network Coordinator.

Step 2: *Veteran Referral Form* (see ***Forms*** section): completed by the Home Health Care Program Coordinator

Step 3: *Caregiver Support Network Application* (see ***Forms*** section): Sent to the primary caregiver and contains ***Consent Form, Patient Information Form, Emergency Information Form*** (see ***Forms*** section).

Step 4: *Initial Visit Form* (see ***Forms*** section): completed by the Home Health Care Program Coordinator to determine suitability for the ***Caregiver Support Network***.

■ *Beginning Your New Assignment*

Following the completion of each of these steps the name of the veteran and the caregiver will be given to the Program Manager for Voluntary Service to assign a volunteer and set the schedule (see Volunteer Schedule in **Forms** section). Before any volunteer is assigned to the Caregiver Support Network, they must complete a volunteer application and submit to a criminal background investigation (see **Forms** section). Upon acceptance, the volunteer must sign the Memorandum of Understanding (see **Forms** section) , which briefly outlines or role as a volunteer support caregiver, your willingness to undergo training and provides important contact information for VA officials responsible for the program.

Congratulations! You have entered into a very rewarding volunteer assignment. We take great pride in the opportunity to offer this valuable service and recognize the tremendous ability of the ***Caregiver Support Network*** to impact the quality of life for veterans and their families. ***Thank you for caring enough to make a difference!***