

A Guide for Caregiving

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Last October, a young mother and her husband looked at each other and said, "It's time. Let's go out. The baby will be fine."

So they did. They worried about leaving their five-year-old in someone else's care. What if something happens? No matter that the child was in excellent and capable hands, they worried anyway.

To tell the truth, they did not have a very good time. They kept thinking about their daughter and all of the things that might happen - and had happened in the past, nobody can look after our daughter as well as we can.

But they did it. They had an evening out by themselves, the first one in four and a half years. The mother told me that the big thing is not to feel guilty. If the child is in good hands, if she is with someone who knows about her illness and what to do in case of an emergency, then fine. It is safe to have some time away. The mother says now that the time was long overdue. "We need to leave her and we need to get out." We need to have our own life too.

FOREWORD

Anyone at any time can find themselves dependent on others for care. The causes are too numerous to list. Older people are more likely to be disabled or dependent due to medical problems, younger people through birth defects, accidents, or illness. Whatever the reason, the person's relationships with family and friends change dramatically. A husband, son, daughter, or friend may find that he or she is now also a "caregiver," the person primarily responsible for seeing that another person's physical, psychological, and social needs are met. Another person now will depend on them for things they once could provide for themselves.

Regardless of the cause of the disability-- a chronic illness or condition such as severe epilepsy, heart or lung disease, stroke, dementia, arthritis, or the combined effects of multiple medical and social factors, the caregiver role is a profound change for both people. Adjustment to this change is stressful. Old patterns of behavior and old relationships must be given up and new ones developed. There are opportunities for both great personal growth and the risk of great emotional turmoil and distress. Caregiving is rewarding, but physically and emotionally draining.

This booklet is directed primarily to the caregiver. It is not a "how to" booklet full of practical advice on how to address specific problems of disease or dependency. Instead, the focus is on practical approaches to problems shared by people in the new role of caregivers. Staying healthy and active, avoiding depression, making friends, and having time to enjoy at least some of the pleasures of life are an essential part of any complete and meaningful existence. Serving as the primary caregiver for a dependant loved one must not become the sole purpose or activity of a life.

Caregivers and carereceivers should read this booklet. Caregivers, family members, friends, neighbors, and carereceivers will find the information useful in improving their own and each other=s lives.

1. INTRODUCTION TO CAREGIVING

Introduction--You, the Caregiver, Are Important!

Few of us are prepared for the task of becoming a caregiver. To make the job easier, you need a plan. You need to know where you are headed and how you are going to get there. This guide may serve as a sort of roadmap to caregiving. It is also a strong reminder that those who care for other people can do a better job if they take the time and the effort to look after their own needs.

The success of the caregiving depends on how well the caregiver cares for himself, or more often, herself. If the caregiver gets sick, who will care for the carereceiver?

The topics that follow can make the role of caregiver easier, and at the same time, help the person receiving the care. In what follows the "caregiver" is the person giving the care, and the "carereceiver" is the person getting it.

The two checklists below focus first on the carereceiver and, second, on the caregiver. They should be seen as general guidelines to help insure the health, safety and comfort of both the carereceiver and you, the caregiver.

Give yourself time to settle in to the new job of being a caregiver. If after a month or so, things are not going smoothly, find help.

Checklist For the Carereceiver

- Legal and financial papers are in order and available?
- Medical appointments are made and kept as needed?
- The home is clean, safe and pleasant?
- Nutritional needs, exercise, sleep and social activities are maximized to the degree possible?
- Personal hygiene and grooming are done daily?
- Respite services are used monthly/weekly?
- Level of care is reviewed monthly to ensure carereceiver is able to remain in the home?

Checklist For the Caregiver

- I get out or exercise at least once a week?
- I get at least seven to nine hours of sleep every night?
- I talk to or see up to three friends or relatives a week?
- I keep annual medical and dental appointments?
- I take my medications as prescribed?
- My legal and financial papers, including my will, are in order and available?
- I check a new resource regarding caregiving at least once a month?
- I have read and understand the Caregiver's Bill of Rights?
- I eat three balanced meals a day?

Common Problems in Caregiving

List of Needs

The first step in organizing a plan of care is to make a list of needs. As family members or friends think about a person with a continuing need for care, several questions come up:

- What are his or her needs?
- What kinds of care does the person need to be able to stay at home in the community?
- Who is going to provide the care? When? How?
- Should the carereceiver stay in his or her own home, live with the children, parents, or other relatives, or move to other surroundings (retirement apartments, residential care, intermediate care, skilled nursing facility or other)?
- How can living arrangements be changed to help the person stay in the home and become more independent?
- If outside services are needed, does the carereceiver have the resources to pay for them? How can they be obtained?
- How can care be given to the person in need without denying attention to others (spouse or children) for whom the caregiver is also responsible?
- Do you as the caregiver feel tired or frustrated?

In answering these questions you are developing an important list of the needs of the carereceiver and, at the same time, addressing your own needs. The questions do not have easy answers. People are different, their needs and the ways to meet those needs will depend upon the people involved and the help they receive.

Being a caregiver can be stressful. This stress will affect his or her ability to keep on giving necessary levels of care. The stress may be physical, financial, environmental, or emotional. Or, more likely, a combination of all four.

Physical Stress: Providing physical care for another person can cause physical stress. General homemaking and housekeeping activities such as cleaning, laundry, shopping, and meal preparation take energy and can be tiring, particularly when added to the caregiver's existing responsibilities in her or his own home.

The care needed to supervise medications and maintain hygiene can also be stressful, particularly if the person acts out, is incontinent (loss of bladder or bowel control), or needs assistance in bathing. Lifting and transferring individuals with limited mobility is tiring and can result in injury to the caregiver, the care receiver, or both. Sometimes there is the additional responsibility of making sure that wheelchairs, walkers, or hospital beds are safe and working properly.

Financial Stress: Providing care is never free and can be expensive. Services that cannot be provided by family members and the caregiver (medical, pharmaceutical, therapeutic, etc.) must be paid for. Decisions will have to be about where these services will come from and how they will be paid for. When money is limited, families often help as much as they can. This does help, but it puts a financial burden on everyone. The heaviest cost usually falls on the caregiver.

Environmental Stress: The proper home setting must be chosen. If the care receiver wants to stay in his or her own home, modifications such as railings and ramps may have to be installed. If the care receiver has seizures or is unsteady simple changes can make the home safer. If this is not possible, alternative arrangements must be sought, such as moving in with a friend or relative or specialized housing (retirement homes, senior apartments, residential care homes, assisted living facilities, or nursing homes). If the care receiver is to remain in the home, some major adjustments in the living arrangements may be necessary.

Social Stress: Providing personal care for up to 24 hours a day can isolate the caregiver from friends, family and a social life. The caregiver may feel too tired to have an evening out once a month or even once a week. This can result in a build up of anger or resentment toward the person receiving the care.

Emotional Stress: All of these factors can produce tremendous emotional stress. The stress is compounded by the difficulties the caregiver has managing her or his own time, juggling multiple responsibilities, and feeling the pressure of the increased dependency.

For family members providing care, stress can result in indifference, anger, resentment and bitterness about the constant responsibilities, deprivation and isolation can result. This can also be a time when many of the old unresolved conflicts between parents and siblings resurface and intensify. This only raises the level of anxiety and frustration. There might even be the unspoken desire to be released from the burden through the institutionalization or even death of the care receiver. This desire is quickly followed by feelings of remorse and guilt. All of these emotions may be felt and then denied because they seem unacceptable and selfish.

The caregiver needs to know that these feelings are common to most caregivers even though they are usually not expressed. There is help and there are resources. Keep reading. Join or form a support group, find out what resources are available in your community and use them, take care of yourself and your own needs.

Types of Help Available

Through Family or Friends

First make a detailed inventory of any assets individual family members and friends can contribute, including the assets of the person needing the care. These assets include available time, skills, space, equipment, the strengths of the person in need care, and, most important, money. Sit down with all the family members (or at least as many as are agreeable) and work

out a plan for giving help. This involves defining and agreeing upon what needs to be done, and who can and will do what and when they will do it. For example, Aunt Martha can cook, Uncle Peter can mow the lawn, and Mary can check on Mom twice a day.

Caregiving Exchanges: Some situations may allow for exchanging support services such as the Caregiver Exchange through the Area Agency on Aging. A friend who has similar caregiver responsibilities may care for both impaired individuals one day a week in exchange for your providing the care on another day. Another exchange situation might include making a spare room available for a student in exchange for his/her help in providing care.

When Community Agency Help is Needed

When family or other volunteer help is not available or cannot meet your needs, caregivers or carereceivers may wish to seek help from agencies. A wide range of help may be available. Some may be covered by private insurance, Medicare and/or a state supplemental program. All of it can be purchased. Service costs may be based on the income of the carereceiver. Each agency has its own fee structure. Ask about costs before you order the service. See the appendix for some providers.

Kinds of Services Available

Adult Day Care: This is for people who are physically and/or mentally frail. It offers a range of therapeutic, rehabilitative, and support activities, including nursing, rehabilitation, assistance with activities of daily living, social work services, meals, and possible transportation, provided in a protected setting for a portion of the day, one to five days a week, usually during weekdays.

Chore Workers/Handypersons Services: Includes heavy-duty housecleaning, minor home repairs, yard work, installing safety devices, and winterizing homes.

Companionship Services: Companions visit isolated and homebound individuals for conversation, reading, letter writing, and general light errands.

Transportation/Escort Services: These services provide personalized transportation and sometimes accompaniment to provide personal assistance.

Geriatric Assessment Units and Special-Care Units: Specialized geriatric units, both inpatient and outpatient, exist in some hospitals and medical centers. They provide coordinated multi-disciplinary diagnostic services to older patients.

Home Delivered Meals: Some nutritional programs as well as specialized meals-on-wheels programs deliver meals to the handicapped and frail, homebound aged.

Subsidized programs ask for voluntary contributions, while others may require full payment cost for delivery of a hot, well-balanced lunch, and sometimes a cold evening meal.

Home Health Aides: Provide personal care to individuals at home (These services may be covered by health insurance if skilled services are needed and ordered by a physician.) Aides assist with eating, dressing, oral hygiene, bathing, colostomies, administering medications, etc., as well as light household tasks.

Home Health Care: Organized programs of nursing, social work, occupational therapy, physical therapy, and other rehabilitation services to individuals in the home.

Homemaker Services: Provided by non-medical personnel, services include shopping, laundry, light cleaning, dressing, preparation of meals, and escort services on medical visits. Homemakers can be of great help in supplementing help provided by family members, or providing relief when family caregivers need a break. Homemakers can be secured through in-home health care agencies, the Area Agency on Aging, the Department of Social Services, religious groups and organizations. Some agencies provide bonding and training for their homemakers while others provide only a registry of homemakers' names and phone numbers, in which case you must thoroughly check references and draw up a contract for the required services.

Hospital and Surgical Supply Services: Supply houses rent or sell medical supplies and equipment like hospital beds, canes, walkers, bath chairs, oxygen and other equipment. Consult your Yellow Pages.

Housekeeping Services: These usually include cleaning, shopping, laundry, and meal preparation.

Housing Assistance: Housing assistance programs exist to help in the search for housing, shared housing, or finding emergency shelters. The Area Agency on Aging (see appendix) can be a place to start. Remember that the Area Agency on Aging is not just for the elderly. Their services are also for the handicapped. The Department of Housing and Urban Development may also be helpful.

Nutritional Programs: Group meal programs feed many older adults as a group in a senior center, community center, or school. A noonday meal is provided, containing one-third of the recommended USDA dietary allowance, usually for a voluntary contribution. Additionally, some centers provide recreational and educational activities.

Occupational Therapy: Occupational therapy, or OT, is restorative, to enhance or restore skills necessary for daily living. It should be provided by a qualified occupational therapist who is referred by your doctor or the Department of Rehabilitative Services.

Physical Therapy: Physical therapy, or PT, is rehabilitative therapy to maximize mobility. It should be provided by a qualified physical therapist, recommended by your doctor or hospital.

Respite Care Services: Respite care programs provide temporary and in some instances up to twenty-four hour care to give relief to primary caregivers. The care may be provided in the

person's home, at an adult day care center, or other facility.

Skilled Nursing Services: These specialized services are provided for specific medical problems by trained professionals through local home care agencies. Your doctor must prescribe nursing services.

Speech Therapy: Speech therapy is provided by a qualified speech therapist to overcome certain speech and communication problems. The doctor usually recommends this.

Social Day Care: Provides supportive, but not rehabilitative services in a protected setting for a portion of the day, one to five days a week. Services may include recreational activities, social work services, a hot meal, transportation, and occasionally, health services.

Telephone Reassurance: Friendly telephone calls are provided by agencies or volunteers offering reassurance, contact and socialization. Telephone reassurance can be a lifeline for people who are home alone during the day.

Transportation: Transportation services provide travel by automobile or specialized vans to and from medical care. Call county and community agencies and service providers such as the Red Cross, the United Way, and the Cancer Society for information.

2. CARING FOR THE CAREGIVER

Caring for the Caregiver

Caregivers experience mixed emotions. Love for your family member and the satisfaction you derive from helping may coexist with feelings of resentment about the loss of your privacy and frustration at believing you have no control over what happens. You may find it hard to accept the decline of the special person for whom you are giving care. Such feelings will depend in part on your prior relationship with your carereceiver, the extent of your responsibilities as a helper, and daily activities in your life (professional, social, and leisure pursuits). Your conflicting emotions may cause guilt and stress.

To guard against becoming burnt out, physically and emotionally drained, you must take care of yourself.

You need to maintain your health and develop ways to cope with your situation.

Caregiver's Self-Rating Scale

Below is a scale to evaluate your level of caregiving. It has been adapted from an article in *Co-op Networker; Caregiver of Older Persons*, by Judy Bradley. It is a good way to provide some guidelines for caregivers and to evaluate the level of care and value you give to your carereceiver and to yourself.

The scale is a 1-10 continuum which describes the various styles of caring. Circle the number or numbers that best describe your level of care.

1 2 3 4 5 6 7 8 9 10 Scale of Caregiving

1. Abandonment: to withdraw protection or support or actively abuse your carereceiver.
2. Neglect: to ignore life-threatening situations or to be consistently cold or angry.
3. Detachment/Aloofness: to maintain an air of detachment or being aloof, perfunctory in your care, no genuine concern, only obligation. Concerned only with physical well-being of your carereceiver.
4. General Support: given freely, with a careful degree of warmth and respect, occasional feelings of manipulation. Concerned with both emotional and physical well-being of

carereceiver.

5. Expressed empathy: the ability to feel what your carereceiver feels, a good relationship where feelings are freely expressed and positively received.

6. Sympathy: feeling sorry for carereceiver, giving sympathy, focusing on the losses experienced by carereceiver.

7. Occasional over-involvement: care characterized by periodic attempts to *do for* rather than *be with*.

8. Consistent Over-involvement: carereceiver is regarded as the object of a series of tasks which must be performed.

9. Heroic Over-involvement: care characterized by sometimes frantic and desperate attempts to provide for every possible need your carereceiver has; increased dependence, carereceiver not allowed independence.

10. Fusion of personalities: between caregiver and carereceiver. The caregiver's needs no longer have any value or meaning; the caregiver has abandoned him/herself to needs of the carereceiver.

Put yourself on the one to ten scale to see how you value your carereceiver and how you value yourself. Low numbers give little or no value or respect to the needs of your carereceiver. The high numbers (8, 9,10) give little or no value to your own needs as an individual and as a caregiver. The numbers in the middle are where you find a balance between too little care and too much. Neither of the two extremes is healthy; neither is good for you or for the person receiving your care.

What Can I Do To Help Myself?

Acknowledge your feelings: Your feelings have a lot to do with the way you deal with caregiving. All feelings are legitimate, even those that may seem disturbing to you (including anger, frustration, and sadness). Recognizing and accepting your emotions is the first step toward solving problems of guilt and stress. Learn to express your feelings to family members, friends, or professionals. Take the following caregiver Stress Test; determine how much stress you are under.

CAREGIVER STRESS TEST

The following test will help you become aware of your feelings, and the pressures and stress you feel.

1 Seldom, 2 Sometimes, 3 Often, 4 Usually True, 5 Always True

- I find I can't get enough rest.
- I don't have enough time for myself.
- I don't have time to be with other family members beside the person I care for.
- I feel guilty about my situation.
- I don't get out much anymore.
- I have conflict with the person I care for.
- I have conflicts with other family members.
- I cry everyday.
- I worry about having enough money to make ends meet.
- I don't feel I have enough knowledge or experience to give care as well as I'd like.
- My own health is not good.

If you answered usually *true* or *often true* more than once or twice, it may be time to look for help with caring for the carereceiver and for yourself.

Find Information

Check your public library for books, articles, brochures, videotapes, and films on caregiving. Some hospitals, Area Agencies on Aging, Adult Education Centers, the Red Cross, and social services offices have additional information on resources which can help. Help is available, find it and use it.

Join a Caregiver Support Group

In addition to offering useful information, these groups provide a place for caregivers to come together and share their feelings in a supportive environment. Groups help caregivers feel less isolated and can create strong bonds of mutual help and friendship. The most important thing a support group does is to let you know that you are not alone, that other people are doing the same things you are doing and that they are having the same problems you have.

Participating in a support group can help reduce stress, share experiences, and improve your skills as a caregiver. Sharing the way you cope with problems in a group lets you help others while helping yourself. It may also help you to realize that some problems have no solutions and that accepting the situation is in reality, all you can do.

Set Realistic Goals

Caregiving is only one of the many conflicting demands on your time. It is important to set realistic goals. Recognize what you can and cannot do, define your priorities, and act

accordingly. Get help - your family, friends, and neighbors. Prepare a list of jobs for anyone who may offer assistance. The list might include:

- running an errand for you,
- preparing a meal,
- taking your carereceiver for a ride,
- taking your children after school one day.

Do Not Be Afraid to Ask for Help

Do not expect people to ask if you need help. It is up to you to ask for it.

Communicate with your Family and Friends

Turning to family members or friends for emotional support and help can be a mixed blessing. Yes, their visits may make you feel less alone and better able to deal with caregiving responsibilities. And, yes, they can give you a break by giving you some time away from your carereceiver. But, relatives or friends can also be critical of the way you provide care. They may feel the house is not clean enough; or they may not like the way your carereceiver is dressed. Recognize that they are responding to what they see at the time and do not necessarily understand the whole picture and any gradual changes in your carereceiver's condition. Harsh criticism may be a response to their own guilt about not giving you more help. Try to turn this criticism to some positive end. Say something like, "Yes, you are right. The house is untidy, or the bathroom could be cleaner...Could you come over one day a week to help?"

If this does not work, try to listen politely to what they say (this might not be easy). However, if you and your carereceiver feel comfortable with the way you are managing the situation, continue to do what meets your needs. Have a meeting from time to time to help other family members understand the situation and to involve them in sharing the responsibilities for caregiving.

Use Community Resources

Investigate community resources that might be helpful. Consider using in-home services or adult day care. Employ a homemaker to cook and clean, or an aide to help your carereceiver bathe, eat, dress, use the bathroom or get around the house.

Use Respite Care Services

When you need a break from providing care to your carereceiver, consider respite care. For example, a companion can stay with your carereceiver for a few hours at a time on a regular basis to give you time off. Or your carereceiver can participate in an adult daycare program where he or she can socialize with peers in a supervised setting; this gives your carereceiver a necessary break. Hospitals, nursing homes, and particularly residential care homes can place

older or disabled relatives in their facilities for short stays. Your doctor, the local Area Agency on Aging, your town social services office, your church, The United Way, and the Red Cross, to name just a few of your resources, can help with information and arrangements.

Stay Healthy

Your own health and well-being affects your outlook on life and your ability to cope. Taking care of yourself is important and involves:

- ! eating three balanced meals daily,
- ! exercising daily,
- ! getting enough sleep/rest,
- ! allowing yourself leisure time.

Food is fuel. Skipping meals, eating poorly, or substituting too much coffee and too many cigarettes for food is bad for you. Learn to prepare and eat simple, nutritious, well-balanced meals. Do not drink more than 2-3 ounces of alcohol a day.

Being physically active is relaxing and makes you feel good. Stretching, walking, jogging, swimming, or bicycling are only a few examples of exercises you can do. Consult your doctor before starting an exercise routine. Your doctor can help design a program that fits your individual needs.

Leisure time is time off. You will feel better and more able to cope, if you have some time off. Having time to read a book, visit a friend, or watch TV can give you pleasure and relaxation, and break the constant pattern and pressure of caregiving.

Sleep refreshes and enables you to function throughout the day. If your carereceiver is restless at night and disturbs your sleep, talk to your doctor and other caregivers about ways to handle the situation. You may need to have outside help in the evenings to allow you time to sleep.

If you are too tense to sleep, practice relaxation exercises. Deep breathing or visualizing pleasant scenes can be helpful. Continued sleep disturbance may be a sign of major depression, which needs medical attention.

Relaxation Exercise

- ! Sit or lie down in a comfortable position. Close your eyes. Let your mind wander, go with the flow. Wiggle your fingers and toes, then hands and feet, ankles and wrists. Loosen tight clothes. Rock your head from side to side, gently, gently. Now you have prepared yourself to relax physically and psychologically.
- ! Now concentrate, still with your eyes closed, on one nice thing you really want to think about; maybe it is a place you visited once, or your own ideal place. This might be the

seashore, or a hilltop, or a field of grass and flowers. Become totally immersed in the place. Smell the smells, see the sights, hear the sounds. Feel it, whether it is a hilltop, the beach, or a snowy mountainside. Make it real. If it is a sandy beach in the summer, run the warm sand through your fingers, smell the saltiness of it, hold the sand to your cheek, listen to the gulls and terns, watch the puffy clouds and their shadows on the water. You are weightless. You are in control of this scene, it is yours, you are breathing slowly, peacefully. This is YOUR place and no one can take it from you.

- ! If this works for you, whenever you have a chance, go back to your special place, close your eyes again, tune in, relive those moments in the world of your choice where everything is perfect and everything is yours. This relaxation exercise can benefit you all day. Check your local library or bookstore for books, audiotapes, videotapes or films on relaxing and managing stress.

Keep Your Sense of Humor

Laughter is the best medicine. This is an old expression popularized by Norman Cousins's book *Anatomy of an Illness*, in which he describes his battle with cancer and how he *laughed* his way to recovery. He is not the only one to suggest that laughter, a sense of humor is a good thing. Positive effects may be releasing tension, reducing pain, improving breathing, and generally elevating moods. It sounds silly and has not been scientifically proven, but studies continue. In short, humor therapy is valuable and it helps us through difficult or stressful times.

Try it. It can do no harm.

- ! try to see the humor in being a caregiver;
- ! write on a card *Have you laughed with your carereceiver today?* And put it in a conspicuous place in the bathroom or kitchen; -- read funny books or jokes, listen to funny tapes or watch humorous movies or videos that make you laugh;
- ! share something funny with your carereceiver, a friend, or relative; -- go to social groups that are fun, where people laugh; -- be aware of how often you smile.

If you find that you are feeling hopeless, and humor or laughter is not helping, get in touch with a counselor. And remember, laughter is the best medicine. Try it, you'll like it!

Avoid Destructive Behavior

Sometimes people handle stressful situations in ways that are destructive. Instead of openly expressing feelings, they get angry, sulk, withdraw, overeat, use alcohol, drugs, or cigarettes to mask their difficulties. This does not solve the problem, it just adds one more. If the strain results in neglecting or abusing the carereceiver, get help fast.

Get Help

You do not have to go it alone. Turn to family members, friends, clergy members, professional counselors, or a caregiver support group for help and support.

Build Your Self-Esteem

Pursue activities and social contacts outside your home. Do what you enjoy. Go to a movie, play a musical instrument, or get together with friends. It may not be easy to schedule these activities, but the rewards for having balance in your life are more than worth the trouble. Taking care of yourself helps you and the person you are caring for. Meeting your own needs will satisfy you and give you extra strength and enthusiasm for your caregiving.

You have rights, too.

Below is a Caregiver's Bill of Rights. After you read it, post it somewhere where you can see it.

A Caregiver's Bill of Rights

I have the right . . .

- ! To take care of myself. This is not an act of selfishness. It gives me the ability to provide better care.
- ! To ask for help even though my relatives may object. I recognize and respect the limits of my own endurance and strength.
- ! To do things and have interests that do not include the person I care for, just as I would if he or she did not need my care. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- ! To occasionally get angry, be depressed, and express other difficult feelings.
- ! To reject any attempts by my relatives or carereceiver to manipulate me through guilt, and/or depression.
- ! To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one for as long as I offer these qualities in return.
- ! To take pride in what I am accomplishing and to appreciate the courage it sometimes takes to meet the needs of my relative.
- ! To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- ! To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides must be made towards aiding and supporting Caregivers.
- ! To appreciation and emotional support for my decision to accept the challenge of providing care.
- ! To protect my assets and financial future without severing my relationship with my relative.

- ! To take time off during emergencies in order to care for my own health, spirit, and relationships.
- ! To expect all family members, men and women both, to participate in the care I provide for their relative.

Modified by the Epilepsy Foundation of Virginia

3. PERSONAL CARE

Personal Care

Personal care activities

These include: eating, bathing, shaving, caring for the skin, hair and mouth, and transferring (moving from chairs, toilets or bed). We take these activities for granted until weakness or a disability makes them difficult to accomplish independently or safely. Providing assistance requires knowledge, patience, skill and physical strength. Remember that the carereceiver may be able to do or learn to do more to help him or herself.

- ! Bathing: Giving somebody a bath may require strength, special equipment and skills. Caregivers should ask the carereceiver's doctor and, or physical therapist, for advice and instructions.
- ! Shampooing and Shaving: Visits to a barber or hairdresser are usually positive enjoyable experiences. If going out to the barber or hairdresser is not practical, many will come to the home. Wetting hair with alcohol or cream rinse helps to remove the snarls. Dry shampoos are available if your family member is bed bound. People who are diabetic or on an anti-coagulants (Coumadin) should use an electric razor to reduce the risk of cuts. It is much easier and safer to shave another person with an electric razor.

Skin Care:

- ! Keep skin clean and dry, especially when people are having problems with bowel and bladder control. When washing, use a mild soap, rinse well, and dry thoroughly.
- ! Keep bedding clean, dry and free of wrinkles. Disposable bed pads can be purchased at a drug store and can keep sheets dry so that the caregiver does not have to change sheets so often.
- ! Massage skin gently using a light, circular motion. Change the carereceiver's position at least every two hours, particularly for those confined to a bed or wheelchair. Encourage them to shift their weight between position changes to redistribute pressure.
- ! Encourage good nutrition and adequate fluid intake. As a supplement to your family member's diet, give a multi-vitamin every day to ensure proper nutrition. Check with the physician as to appropriate supplements.
- ! Use mattress and chairs that are soft and form-fitting rather than rigid and hard. (Example: egg crate mattress and sheepskin). This spreads the weight over a larger skin area, decreasing the pressure under the bones.
- ! Encourage movement or mild exercise to stimulate circulation. Combing hair and helping with bathing and dressing are good ways for frail people to get exercise and be more independent.

- ! Watch for possible sources of pressure or anything that would interfere with good circulation, such as tight shoes, elastic cuffed socks or tight undergarments.
- ! Heels, feet, backs of the knees, hips, buttocks, sacrum, elbows and shoulder blades are prone to skin breakdown. An air mattress may prevent skin breakdown.
- ! Watch for any redness or a break in the skin and report it immediately to the doctor or nurse, and keep the carereceiver off the affected side.

Toileting

- ! Safety features in the bathroom, such as grab-bars and raised or padded toilet seats, make a bathroom safer and easier to use.
- ! A commode or urinal may be necessary when distance to the bathroom is a problem. They may be especially helpful at night.
- ! Loss of control over bowel or bladder functions can be embarrassing and people may try to hide it from caregivers and professionals. Be sensitive to the person's feelings, and mention this to the doctor.
- ! For the carereceiver with bowel and/or bladder problems it may help to take him or her to the bathroom every two hours. Check with your doctor or nurse for a program in your area.

Constipation or Irregularity

Many people become constipated due to side effects of medications and inactivity. If your carereceiver is experiencing this problem, talk to the doctor or pharmacist.

Other important factors are:

- ! Eat plenty of fresh fruit, vegetables and foods high in fibers. -- Drink at plenty of water and juice.
- ! Avoid constipating foods like cheese, rice, bananas, etc. -- Exercise as much as possible.
- ! Be sure your doctor is aware of all the medications being taken.

Assistance with Eating

Eating can be time-consuming, especially if the carereceiver must be fed. Encouraging independent eating saves time for caregivers, and promotes the independence and self-worth of the older person. Try to relax yourself and enjoy the time spent with your carereceiver. Here are some suggestions for encouraging independence:

- ! Schedule regular visits to the dentist. Dentures may not fit correctly; tooth decay can make chewing uncomfortable.
- ! Provide adaptive equipment such as plate guards or special silverware with built-up handles.

These can be purchased from medical supply houses (listed under Hospital Equipment and

Supplies in the Yellow Pages). An occupational therapy evaluation can recommend the best for each individual. -- Finger food may be easier to eat than food needing knives and forks.

- ! Straws, cups with two handles, or glasses with a ribbed surface are easier for independent drinking.
- ! Reminder: Treat people you are feeding as adults, not children. If they are not interested in eating, find out why. Maybe they are thirsty, or not feeling well, or maybe they do not care for the food.

Transferring

Moving people who cannot move safely by themselves requires skill, knowledge, and some strength. For every type of disability, there is a specific technique to use. Ask a doctor or therapist or get caregiver training for specific techniques. Remember:

- ! When lifting, do not add your own weight to whatever you are lifting-get close and stay balanced.
- ! Do not use weak back muscles to lift - use your leg muscles, they are much stronger.
- ! Do not twist when you are lifting - change the position of your feet so that you face the person you are lifting. Keep your spine straight. Spread your feet to keep your balance.

Rest and Sleep

Sleep patterns change as we age. Older people may need less sleep, but it may take longer for them to fall asleep. Also, awakenings during the night increase. Younger people, too, may have trouble sleeping because of sleep disorders, medication, or anxiety. Scheduled rest times are important. A few naps during the day can refresh and revitalize the carereceiver. If you notice that your carereceiver is only sleeping for brief periods during the night, it could indicate a problem. Notify your doctor and discuss your concerns.

Tips for Encouraging Self Care

Encourage the carereceiver to do as much as possible; provide only as much help as is needed. When people manage all or part of their own personal care, it is an exercise that will help maintain strength as well as promote independence. No matter how small the activity (holding the soap, combing the front of the hair, etc.) it is important that the person be encouraged to participate.

Adapt the home to allow the carereceiver to do more things. Install grab rails in the bathroom, wheelchair-accessible sinks and mirrors, a bath bench for the shower or tub, and lights with switches that can be easily reached.

- ! Therapists or nurses can teach you to perform personal care tasks safely and effectively.
- ! Learn about the carereceiver's disability and what you and others can do to help him/her

function as independently as possible. If he or she cannot perform a certain activity, see if there is another activity that they can do. For example, one might be able to independently dress the upper body, if sitting, but need help in dressing the lower body.

4. MEDICAL ASPECTS OF CAREGIVING

Medical Aspects of Caregiving

Overview

As a caregiver, you are in a position to help your carereceiver by encouraging routine physical examinations. You can be very helpful in dealing with doctors and other medical personnel. You can follow through with medical treatment at home.

But remember that the primary responsibility for treatment is with the doctor and the patient. If there is any doubt about what you should or should not do, ask the doctor. You can help your carereceiver to understand his/her medical treatment and encourage the carereceiver to be involved in making decisions. Though it may be tempting for you to decide what is best for the patient, resist the impulse. People need control over their own lives. This is especially true for a person who needs the help of others. If you have serious concerns, talk about them openly with the doctor.

Keeping Records and Managing Medications

- ! Caregivers can help the carereceiver maintain medical records for use by the doctor. Arrangements can be made through the doctor's office to send for previous records that could be helpful in treatment. You also should keep a list of all medications (both prescribed and over-the-counter) being used. If the carereceiver has seizures, keep a seizure calendar. Keep a simple journal of relevant events and any changes in medications or the carereceiver's reaction to them.

- ! Many people needing caregivers are taking several medications. There may be drug interactions. It is important for every doctor prescribing medications for the carereceiver to know all of the drugs being taken. When the patient sees a new doctor, he or she should bring all of their drugs in a paper bag. Having one pharmacist who fills all of your prescriptions is a good way to avoid problems with drug interactions. Over-the-counter or non-prescription drugs also can cause problems. Talk with your pharmacist before giving them to your carereceiver.

Below is a sample of "current medication list" which includes the essentials: name of medication, sample of the medication taped beside its name, the reason for the medication, the dosage and the time the medication is taken:

Current Medications List

Medication Name	(Tape or Draw Pill Here)	Reason	Dosage	Take At...

If your carereceiver is taking medications at different times throughout the day, it may be helpful to develop a second list to help with daily medication set-ups; this list may be color coded, or may have the names of the medications grouped in the times to be taken each day. If medications are taken several times a day, their names will appear several times on your list.

Keep the list someplace where you will see it and remember it--on the refrigerator door, on the bathroom door. Remember to keep the medications out of reach of children.

Your local drugstore has a variety of compartmentalized pillboxes. They can hold a day's supply or a week's supply of pills with different compartments for each pill or each time of day that the pills are given. These make it very easy to remember what pills were given at what time.

Remember that many medications work by maintaining a steady level of medication in the blood. This makes it very important to give the right amount of medication at the right time. Too much or too little medication can cause problems. Talk to the doctor about what to do if a dose of medicine is forgotten or doubled. Remember to refill the prescriptions several days before you run out of pills. Ask for a good supply of medication. If possible get a three-month supply.

Seeing the Doctor

If the visit is for a specific problem, have the following information for the doctor:

1. The symptoms,
2. How long they have been present,
3. How often they happen,
4. How bad they are.

Reviewing this information before the visit will help. And remember, it is important that the patient have a chance to see the doctor privately to discuss confidential information. Before leaving the doctor's office, meet with the doctor or the nurse to find out how you can help with treatment and what your role as caregiver should be. Do not be afraid to speak up if you disagree with the advice.

It is useful to look at the following three areas:

1. What can be done now to help in the treatment of current medical problems,
2. How to recognize new problems that may arise,
3. What to do in emergencies.

Planning For Emergencies

Having an emergency plan is critical, especially if a substitute caregiver occasionally takes your place. (Post phone numbers next to your telephone or in a conspicuous place. Point them out and explain them to any substitute caregivers.

1. 911 number for emergencies (Medical, Fire or Police),
2. The physician's number (emergency and office number),
3. The name and number of the hospital the physician and the patient prefer,
4. The number of the home health agency, if one is currently making visits to the home,
5. The poison center number.
6. The 24-hour number of the medical or oxygen supplier, if one is being used,
7. The telephone number where you, the caregiver, can be reached.
8. Any special instructions for specific emergencies. For example what to do in case of a seizure, instructions for when and how to use Diastat or Cyberex for seizures, how and when to use epinephrine for extreme allergic reactions.

Remember, be alert for changes in behavior and signs of illness in the care receiver. They can help reveal a medical problem. If you have any questions, call the doctor for advice.

Side Effects

All medications can have side effects. Some side effects are more likely to happen when a new drug is started. They may go away fairly quickly. Other side effects may be the result of an interaction between one drug and another. A third reason may be because the person is taking too much or too little of the medication. Each drug has its own list of possible side effects. Talk to the doctor if you suspect your care receiver is having trouble with side effects.

5. EMOTIONAL AND INTELLECTUAL HEALTH

Emotional and Intellectual Well-Being

People may have powerful emotional responses to the events in their lives. Some people seem cheerful and happy most of the time, others may be anxious and depressed. People who suddenly find themselves in the difficult new role of either giving or needing care usually may have great difficulty dealing with their new role.

Depression: Signs and Causes

Depression is a common and understandable response to a major change in life and daily routines. Some things to look for are:

- ! inability to concentrate or make decisions,
- ! lack of enjoyment, or enthusiasm, even for things that were once favorite activities.
- ! loss of interest in eating, or weight loss or gain.
- ! lack of interest in being with other people, or loss of sex drive.
- ! feeling unwanted and worthless.
- ! sadness or crying spells for no apparent reason,
- ! problems with sleeping (sleeplessness during the night or excessive sleep during most of the day),
- ! feeling tired most of the time, regardless of adequate rest.

If people brood about their unhappiness, much of their energy is focused on worry. Part of that worry may relate to the fear that they will be unable to manage their affairs. This worry can lead down the path to more depression, which may cause physical problems.

In exploring the cause of depression, the following questions should be asked:

1. Is there a physical or medical problem causing the depression?
2. Have there been changes in hearing, seeing, moving, or other body functions?
3. What social contact does the carereceiver have?
4. Is there anything, which makes the person feel useful?
5. What kind of personal losses (death of friends, relatives, or pets) have there been?
6. Is the person getting proper nutrition?
7. What kind of mental stimulation is the person getting?
8. Is the focus entirely on the past, or is there some enthusiasm about coming events?
9. Is there a possibility of reaction to medications?
10. Is there a dependency on alcohol or drugs?

Once these questions have been answered, steps can be taken to relieve the depression. It will take work from both the caregiver and the carereceiver to change habits and routines.

Prolonged depression causes biochemical changes in the brain, usually requiring treatment with medication. Talk to your doctor to find help for treatment of depression.

Other resources are County Mental Health Centers, psychologists, counselors or clergy.

Suicide Prevention

It is critical that caregivers know and recognize the warning signs of suicide.

- ! Depression - feelings of sadness, hopelessness, a sense of loss and statements such as "Life isn't worth living" are common before a suicide.
- ! Withdrawal and isolation - suicidal people may pull away from family, friends and others close to them.
- ! Behavior changes - sudden changes such as irritability, aggressiveness or changes in eating and sleeping habits can signal problems. Making final arrangements - a suicidal person may give away valued possessions, make out a will, make a plan for suicide, or write a suicidal note in preparation. They may purchase weapons or stockpile medications.

Suicide may be prevented. If the person you care for shows any of the warning signs:

- ! Ask - don't be afraid to ask directly if the person is thinking about suicide. It is not a taboo subject. You will not be putting ideas into the person's head. It can be a relief for suicidal persons to talk openly about their feelings.
- ! Listen - let the person express his/her feelings and concerns. Don't worry about saying the right things - just listen.
- ! Show you care - tell the person you care and want to help. Take active steps to make sure the person is safe; remove weapons, pills, etc., and stay with him/her.
- ! Get help fast- make sure the suicidal person talks to a counselor or other helpful person who will know what to do.
- ! Suicide prevention and crisis hotlines are usually in the front of the phone book. A crisis counselor can help figure out the best way to handle the situation and give referrals to other resources.

If you think that the person you are caring for may be suicidal, you must do something about it quickly. Simply getting the person to talk to you about it is not enough. With the role of Caregiver comes responsibility. Suicide awareness and action may be your highest priority. Not reacting strongly enough to the threat of suicide can result in death. Overreacting can be embarrassing, uncomfortable, and may offend your carereceiver, but it is not fatal. Caregivers can learn to fine-tune their vigilance.

Promoting Emotional Well-being

It is important for the carereceiver to be involved in decision-making. You must stress that needing help with everyday activities does not mean that he or she cannot make decisions for themselves. Also, granting others the right to decide does not mean you are ignoring or abandoning them. Caregivers need to be sensitive to giving enough care, but not too much.

Ways to promote mental health

- ! encourage socializing with friends and relatives through visits, phone calls or letters.
- ! arrange fun times such as parties or outings.
- ! help start new hobbies or revive old ones.
- ! listen, talk, and share feelings.
- ! assure privacy.
- ! treat with respect, as you would any other person.
- ! encourage movement and exercise.
- ! help find ways to be as useful as possible.
- ! keep the lines of communication open.

Memory Problems

Memory loss can be one of the hardest problems for both the carereceiver and the caregiver. Some memory problems are treatable, some are not and some may be a side effect of medication. Talk to the doctor. Forgetfulness, even inability to recognize familiar faces and places, might result from such treatable causes such as malnutrition related to improper eating habits, alcohol, side effects of medications, loneliness, isolation, few chances to socialize with others, sensory impairment (decreased vision, decreased hearing), surgery, accident, viral infections or other illness, or depression or other mental illness. (See the Epilepsy Foundation of Virginia's pamphlet on memory.)

Some illnesses can cause memory problems, which may or may not be permanent. These include epilepsy, fever, heart disease, lung disease, thyroid problems, anemia, diabetes, Parkinson's, Alzheimer's, and infections. If you suspect illness or medication is causing the problem, talk to the doctor. Problems with side effects may be solved by changing medications or changing the times the medications are taken.

Behavioral Problems

It is usually best not to antagonize or confront people who are acting out or being disruptive. Instead, temporarily go away from the person, leave the room. The message you want to give is "I care for you, but not your behavior right now."

Below are some suggestions:

1. Avoid confrontation. If disrobing is an issue, offer brightly colored clothes which make the

person feel good.

2. Don't argue. If the person becomes too agitated, change the subject to something completely different.
3. Reduce stimulation. Lower lighting, reduce noise, turn down the television or radio, minimize clutter.
4. Walk slowly with the person to reduce anxiety and ease the stress of muscle tension.

Mental Stimulation

Share stories. Talk about current interests and events. Play games or solve puzzles. Bring friends to visit the carereceiver. Consider getting a pet, or, if that is impractical, you or a friend could bring a pet for visits. Animals, a dog, cat, or even a canary can make a surprising difference.

People are happier and feel more productive if they are doing something that is fun and stimulating. Below are just a few examples of possible activities:

- ! sew or knit,
- ! be a friendly telephone caller,
- ! be a foster grandparent,
- ! be a pen pal,
- ! be a reader to children at an elementary school,
- ! save stamps for collectors,
- ! write favorite recipes on cards and share them with others, -- read books, magazines, newspapers,
- ! do puzzles (jigsaw, crossword),
- ! try artwork (calligraphy, painting, drawing),
- ! write or record memoirs, poetry, thoughts,
- ! keep a joke book,
- ! care for pets or plants,
- ! listen to soothing music,
- ! take correspondence courses,
- ! play musical instruments,
- ! start or re-arrange a family photo album,
- ! volunteer, at libraries, hospitals, museums, or schools
- ! bake
- ! plan a potluck or brown-bag lunch at home,
- ! tutor or visit with children and youth,
- ! type for self and others,
- ! participate in radio call-in shows,
- ! learn to use a computer.
- ! get connected to the internet
- ! keep a diary

In addition, everyone who is physically able should be encouraged to participate in swimming, bowling, gardening, dancing, miniature golf, nature walks, mall-walking, jogging, shuffleboard

and other activities outside the home.

Drawing, writing, reading, crafts, taking classes, and other hobbies encourage creativity. Indoor games including chess, checkers, monopoly, cards, billiards and Parcheesi provide interesting relief from boredom as well.

6. LEGAL AND FINANCIAL AFFAIRS

Legal and Financial Affairs

People needing a caregiver continue to be concerned about management of their assets and property. However, they may be unable to participate because of illness, confusion or loss of memory. Diminishing responsibility is an issue that needs to be thought about and addressed before it becomes a problem.

Compiling an Inventory

Make an inventory listing all of the assets and liabilities of the care receiver. Include bank accounts, pass books, certificates of deposit, money market funds, stocks, bonds, jewelry, real estate deeds, promissory notes, contracts, insurance policies, safety deposit boxes (including location of the key), and retirement or pension benefits. Include the location of the records for each asset and liability. Other important documents, such as birth and marriage certificates, social security numbers, divorce decrees and property settlements, income tax returns (state and federal), death certificate of spouse (if any), and wills (including the attorney's name and executor) or trust agreements, should be listed and the locations noted. If he or she is able, the care receiver should compile the list. If he or she is unable to make the list, a family member, attorney, banker, accountant or certified financial planner can help with the inventory. The inventory should be copied and kept in a safe, obvious place. Perhaps with a friend or relative. The inventory should be updated every year.

Managing a Will and Financial Affairs

The point of financial and estate planning for adults is to plan the orderly distribution of the estate upon their death. People need a will, which incorporates the above inventory and says how they wish their property to be disposed of. Everyone over the age of 18 should have a will.

If there is no will, an attorney should be consulted immediately. Proper planning is essential and powers of attorney or trust agreements should be executed while one is still competent. Otherwise, transfer of responsibility for management of the financial affairs to someone else must be completed through a court action, and costs spent in clearing up Probate problems come directly out of the assets.

Remember, as a caregiver concerned about the financial affairs of a care receiver, you should not get directly involved without legal authority. Acting without clear legal authority, even with the

best intentions, can cause serious problems.

The book, Planning for the Future, published by the American Publishing Co., Evanston, Ill., is a comprehensive guide to help parents assure the future quality of life for their disabled child. If you are caring for a child, you may find this book helpful. Estate Planning for Persons with Disabilities, a division of the Protective Life Insurance Co. (1-800-448-1071) offers free seminars for support groups, school staff, local organizations, etc.

The legal mechanisms available for surrogate decision-making are: durable power of attorney (DPA), probate conservatorship, and durable power of attorney for health care (DPAHC).

Durable Power of Attorney is a written legal document giving someone other than the "Principal"-the carereceiver, the authority to handle the Principal's financial decisions. It must be signed by the Principal while the Principal is still legally competent. The DPA is valid without time limit until the Principal either revokes the DPA or dies, or the court revokes the DPA due to mismanagement. The preferences of the Principal regarding the management of assets should be specified. This power to manage assets can be transferred immediately or can be designated to go into effect when it is determined that the Principal has become mentally incapacitated. Financial decisions made by an individual given DPA by the Principal are binding on the Principal and his/her successors, so caregivers and carereceivers should get legal advice.

Probate Conservatorship, or Conservatorship of Estate, allows for the management of the Principal's money and other property when the Principal does not have the capacity to make decisions or appoint someone to act on his or her behalf. Court proceedings are needed to name a conservator. This is a difficult emotionally trying experience, but it may be necessary if the carereceiver is already incapacitated.

Durable Power of Attorney for Health Care (DPAHC)

This is a written document, which must be signed by the Principal while he/she still has the capacity to make decisions. The DPAHC delegates the authority to make medical treatment and health care decisions on behalf of the Principal. It allows a person to state how he or she wants their health care decisions made. Wishes regarding extraordinary supportive care, including breathing machines and tube feeding, should be addressed in the Durable Power of Attorney. All adults should have a Durable Power of Attorney for Health Care.

Choosing a Lawyer

Pick a lawyer who knows about estate planning, writing wills, probate or conservatorship. Get recommendations from friends or professionals, or contact the local Bar Association, the Department of Rights for Virginians with Disabilities, or ARC. Before hiring a lawyer, ask if he or she has enough experience to do what you need.

Planning Checklist

Do you have a written plan stating what you want in the future?
Have you asked someone to serve as an advocate or guardian?
Do you understand the government benefit programs that are available for basic care and supervision?
Have you set aside any funds for your carereceiver?
Have you prepared written plans for your carereceiver's final arrangements?
Do you and your spouse have wills?
Do you have a Special Needs Trust?
Have you met with your relatives and friends to let them know of your plans?
Have you reviewed your plan in the last year?
Do you feel that you have done everything in your power for your carereceiver's future?

LIABILITY OF CAREGIVING

Anyone who accepts the responsibilities of a caregiver must also understand that there are legal duties or liabilities that come along with the position. Most states have elderly abuse laws as well as child abuse laws. Caregivers are bound by these laws in two ways: They must not abuse the person they are caring for (physically, mentally or financially) and they must report any incidents of abuse or suspected abuse.

As a caregiver, you must provide a clean and safe environment, nutritious meals, clean bedding, and clothes. At the same time, if you are in charge of the elderly person's finances, you must use that money properly, purchasing necessary services for the benefit of the person to whom care is given. Failure to provide, to get, or to purchase care are all forms of abuse or neglect.

In addition, caregivers may not physically, sexually or psychologically abuse the person receiving the care. Yelling, screaming, withholding affection, etc., are as much an abuse as hitting. If you are thinking about becoming a caregiver, or are one now, you have to accept the physical, psychological and legal duties to provide the necessary care. If you are reaching a point where you are no longer able, physically or emotionally, to provide the proper care, we urge you to consider the alternatives and to get help fast.

7. WHEN IS IT TIME TO STOP CAREGIVING?

Caregiving is stressful. Stress either causes or exacerbates some 70 to 90 percent of all medical complaints, including tension and migraine headaches, seizures, high blood pressure, asthma, nervous stomach, bowel problems, and chronic lower back pains. Research suggests that stress can play a role in susceptibility to heart disease, stroke, and cancer.

Stress has also been implicated in psychological disorders such as anxiety reactions, depressions and phobias, as well as poor work performance, drug and alcohol abuse, insomnia, and unexplained violence. If you are experiencing any of these, it is extremely important that you learn and use techniques to reduce stress. Again, get help fast. The help is for your own well being and the well being of the person you are caring for.

Below are some telltale signs which can indicate when you have reached your limit, when it is time to get help professional help, utilize more stress reduction methods, or stop caregiving:

- ! constantly snapping at the carereceiver, being constantly irritated,
- ! seldom laughing,
- ! feeling constantly tired or pressured,
- ! losing sleep, having difficulty falling asleep, sleeping restlessly,
- ! frequent yelling, screaming, crying, or rages, -- withholding affection from the carereceiver, -- withholding food, baths, dressing changes, etc.,
- ! constantly blaming the carereceiver for your situation,
- ! refusing to go out, even for a walk because "He or she needs me."

These are not the only signs of "burn out," but they are typical. The treatment for burnout is simple -- get help and get away for extended periods, either through stress management, respite help or through a complete change in caregiving.

No one can be a full-time caregiver forever; the job is much too strenuous and stressful. The point is to know your limits. Be honest with yourself, and when your limit has been reached, STOP. Find alternatives, get help from qualified professionals, and do not feel guilty. You have done the right thing.

CHOOSING A RESIDENTIAL CARE FACILITY

First talk to the carereceiver's doctor. The doctor is your best ally since most facilities require a complete physical exam and the physician can assess the level of care your carereceiver needs. This is important in order to determine which type of licensed care facility you will need.

Nursing homes or residential facilities for elderly: The residential care facility is for non-medical

care and supervision which may include personal services (help in bathing and grooming, guidance in dressing, aid in taking self-administered medications) and help with other daily living activities. Managed home care provides in-home care and case management for the elderly or physically or mentally disabled of all ages.

Find a licensed facility, people who need care and supervision are often defenseless against abuse or exploitation. The law requires that care facilities be licensed. So when you select a care facility, check for the license to assure the protection provided by law and quality care for your loved one.

What Should I Look for When I Visit a Care Facility?

Ideally, both you and your carereceiver will visit a number of facilities and then choose the one which best met the needs of the carereceiver. Before and during the preview process you will have plenty of time to talk about the decision. You will have a lot of information to get during the visit. Writing down the questions you want to ask and the information you need beforehand will organize the visit and make it much less stressful. Carry this checklist during your visit and make notes while you look around and talk to people. Some items you may want to cover during your initial visit to insure quality care are:

- ! Ask to see the facility license,
- ! Look closely at the building and grounds,
- ! Talk to some facility residents,
- ! Talk to the administrator in charge of daily operations and to staff members.
- ! Ask to see a copy of the Admission Agreement.

Contact your County or State Department of Social Services for more information. Also contact nonprofit organizations. The Epilepsy Foundation of Virginia has done a survey specifically geared to the needs of people with Epilepsy. Other organizations may also have information for people with specific needs. Call the United Way for more information and referrals.

APPENDICES

An Overview of Aging Services and Programs in Virginia

Virginia's Department for the Aging

The Virginia Department for the Aging is the Commonwealth's designated state unit on aging as required by the Older Americans Act and the federal Administration on Aging. As one of America's 57 state units on aging, the department is responsible for planning, coordinating, funding, and evaluating programs for older Virginians which are made possible through funding from both the Older Americans Act and from the Virginia General Assembly. These programs include a full range of nutrition, transportation, health, education, and social services to improve the quality of life for older Virginians. The Commissioner of the department is appointed by, and serves at the pleasure of, the Governor and has overall responsibility for a biennial budget of more than \$50,000,000. Services are available for the elderly and the physically or mentally handicapped of any age.

The Department for the Aging had its beginnings in 1958 as the Commonwealth's Commission to Study Facilities and Services Available to the Elderly. By 1970, responsibility for developing and coordinating programs for the elderly was housed in what was then called the Division for State Planning and Community Affairs. In 1973, the General Assembly appointed a Commission on Aging and in 1974 they established the Virginia Office on Aging as an independent agency reporting to the Governor. This same year saw the creation of the Governor's Advisory board on Aging. In 1979, the Director of the Office on Aging reported to the newly established Secretary of Health and Human Resources. In 1982, the General Assembly recognized the significance of programs for older Virginians by upgrading the Office on Aging to full departmental status.

25 Local Area Agencies on Aging

Virginia also has a network of 25 local agencies established under the auspices of the Older Americans Act which are prepared to assist older persons and their families. These organizations are called Area Agencies on Aging or AAAs. AAAs are designated by the Virginia Department for the Aging, with the sanction of local governments, to plan, coordinate, and administer aging services at the community level. Some AAAs are private nonprofit organizations, others are a part of local government, and still others are jointly sponsored by counties and cities. AAAs in Virginia serve a specific "planning and service area" which usually corresponds with the boundaries of one of Virginia's planning districts. Planning districts organize counties and cities along common geographic, demographic, and economic boundaries.

AAAs prepare plans for providing services and programs to those older persons who live within the boundaries of their service area. Each AAA has an advisory board of local citizens who are knowledgeable about the unique needs of their local communities and who assist in the preparation of their plan of services. Older persons and their families are also provided with an opportunity to comment on these services and programs through public hearings held by their local AAA.

AAAs are financed with Older Americans Act and other federal funds, state funds, private funds, and appropriations from local governments. Older persons who participate in the programs or use the services provided by their AAA are offered the opportunity to contribute to the cost of these programs. Although those services funded through the Older Americans Act are available free of charge to those older Virginians who are in greatest social and economic need, some AAAs offer other services on a sliding-fee scale to those elderly or handicapped individuals and their families who can afford to purchase them.

Area Agencies on Aging in Virginia

PSA 1 - MOUNTAIN EMPIRE OLDER CITIZENS, INC. P.O. BOX 888 BIG STONE GAP, VA 24219 MARILYN PACE MAXWELL, EXEC. DIRECTOR PHONE: 540-523-4202 FAX: 540-523-4208 e-mail: meoc@mounet.com
JURISDICTIONS SERVED *Counties of Lee, Wise, & Scott. City of Norton.*

PSA 2 - APPALACHIAN AGENCY FOR SENIOR CITIZENS, INC. BOX 765 CEDAR BLUFF, VA 24609 DIANA WALLACE, EXEC. DIRECTOR PHONE: 540-964-4915 or 963-0400 FAX: 540-963-0130
JURISDICTIONS SERVED *Counties of Dickenson, Buchanan, Tazewell, & Russell.*

PSA 3 - DISTRICT THREE GOVERNMENTAL COOPERATIVE 305 SOUTH PARK STREET MARION, VA 24354-2994 MIKE GUY, EXEC. DIRECTOR PHONE: 540-783-8158 or 1-800-541-0933 FAX: 540-783-3003
JURISDICTIONS SERVED *Counties of Washington, Smyth, Wythe, Bland, Grayson, Carroll. Cities of Galax & Bristol.*

PSA 4 - NEW RIVER VALLEY AGENCY ON AGING 141 EAST MAIN STREET PULASKI, VA 24301 DEBBIE PALMER, EXEC. DIRECTOR PHONE: 540-980-7720 OR 639-9677 FAX: 540-980-7724 e-mail: nrvoadp@aol.com
JURISDICTIONS SERVED *Counties of Giles, Floyd, Pulaski, & Montgomery. City of Radford.*

PSA 5 - LOA - AREA AGENCY ON AGING, INC. PO BOX 14205 ROANOKE, VA 24038 SUSAN WILLIAMS, EXEC. DIRECTOR PHONE: 540-345-0451 FAX: 540-981-1487 e-mail: loaaa@roanoke.infi.net
JURISDICTIONS SERVED *Counties of Roanoke, Craig, Botetourt, & Allegheny. Cities of Salem, Roanoke, Clifton Forge, & Covington.*

PSA 6 - VALLEY PROGRAM FOR AGING SERVICES, INC. PO BOX 817 WAYNESBORO, VA 22980-0603 ANN BENDER, EXEC. DIRECTOR PHONE: 540-949-7141 or 1-800-868-8727 FAX: 540-949-7143 e-mail: vpas@cfw.com
JURISDICTIONS SERVED *Counties of Rockingham, Rockbridge, Augusta, Highland, & Bath. Cities of Buena Vista, Lexington, Staunton, Waynesboro, & Harrisonburg.*

PSA 7 - SHENANDOAH AREA AGENCY ON AGING, INC. 207 MOSBY LANE FRONT ROYAL, VA 22630-2611 CATHIE GALVIN, DIRECTOR PHONE: 540-635-7141 or 1-800-883-4122 FAX: 540-636-7810 e-mail: galvin@shentel.net
JURISDICTIONS SERVED *Counties of Page, Shenandoah, Warren, Clarke, & Frederick. City of Winchester.*

PSA 8A - ALEXANDRIA AGENCY ON AGING 2525 MOUNT VERNON AVENUE - UNIT 5
ALEXANDRIA, VA 22301-1159
ROBERT EIFFERT, DIRECTOR
PHONE: 703-838-0920
FAX: 703-836-2355
JURISDICTIONS SERVED *City of Alexandria.*

PSA 8B - ARLINGTON AGENCY ON AGING 1801 NORTH GEORGE MASON DRIVE
ARLINGTON, VA 22207-1999
TERRI LYNCH, DIRECTOR
PHONE: 703-358-5030
FAX: 703-358-5073
e-mail: tlynch@co.arlington.va.us
JURISDICTIONS SERVED *County of Arlington.*

PSA 8C - FAIRFAX AREA AGENCY ON AGING 12011 GOVERNMENT CENTER PARKWAY, Suite 720
FAIRFAX, VA 22035
CARLA PITTMAN, DIRECTOR
PHONE: 703-324-5411
FAX: 703-803-8150
e-mail: cpittm@co.fairfax.va.us
JURISDICTIONS SERVED *County of Fairfax. Cities of Fairfax & Falls Church.*

PSA 8D - LOUDOUN COUNTY AREA AGENCY ON AGING 102 HERITAGE WAY, NE, SUITE 102
P.O. BOX 7000
LEESBURG, VA 20177
ANNE EDWARDS, ADMINISTRATOR
PHONE: 703-777-0257
FAX: 703-771-5161
JURISDICTIONS SERVED *County of Loudoun.*

PSA 8E - PRINCE WILLIAM AREA AGENCY ON AGING 7987 ASHTON AVENUE, SUITE 231
MANASSAS, VA 22110
LIN WAGENER, DIRECTOR
PHONE: 703-792-6400
FAX: 703-792-4734
JURISDICTIONS SERVED *County of Prince William. Cities of Manassas & Manassas Park.*

PSA 9 - RAPPAHANNOCK-RAPIDAN COMMUNITY SERVICES BOARD P.O. BOX 15681
5631 BRADFORD ROAD
CULPEPER, VA 22701
BRIAN D. DUNCAN, EXEC. DIRECTOR
PHONE: 540-825-3100
FAX: 540-825-6245
e-mail: morgans@citizen.infi.net
JURISDICTIONS SERVED *Counties of Orange, Madison, Culpeper, Rappahannock, & Fauquier.*

PSA 10 - JEFFERSON AREA BOARD FOR AGING 674 HILLSDALE DRIVE
CHARLOTTESVILLE, VA 22901
GORDON WALKER, CEO
PHONE: 804-978-3644
FAX: 804-978-3643
JURISDICTIONS SERVED *Counties of Nelson, Albemarle, Louisa, Fluvanna, & Greene. City of Charlottesville.*

PSA 11 - CENTRAL VIRGINIA AREA AGENCY ON AGING, INC. 3225 OLD FOREST ROAD
LYNCHBURG, VA 24501
JO NELSON, EXEC. DIRECTOR
PHONE: 804-385-9070
FAX: 804-385-9209
JURISDICTIONS SERVED *Counties of Bedford, Amherst, Campbell, & Appomatox. Cities of Bedford & Lynchburg.*

PSA 12 - SOUTHERN AREA AGENCY ON AGING, INC. 433 COMMONWEALTH

BLVD.MARTINSVILLE, VA 24112-4228TERESA CARTER, EXEC. DIRECTORPHONE:
540-632-6442 or 1-800-468-4571FAX: 540-632-6252e-mail: saaa@neocomm.net
JURISDICTIONS SERVED*Counties of Patrick, Henry, Franklin, & Pittsylvania. Cities of
Martinsville & Danville.*

PSA13 - LAKE COUNTRY AREA AGENCY ON AGING1105 WEST DANVILLE
STREETSOUTH HILL, VA 23970-3501GAY CURRIE, EXEC. DIRECTORPHONE:
804-447-7661 or 1-800-252-4464FAX: 804-447-4074e-mail: lakecaaa@aol.com
JURISDICTIONS SERVED*Counties of Halifax, Mecklenburg, & Brunswick. City of South
Boston*

PSA 14 - PIEDMONT SENIOR RESOURCES AREA AGENCY ON AGING, INC.PO BOX
398BURKEVILLE, VA 23922-0398RONALD DUNN, EXEC. DIRECTORPHONE:
804-767-5588FAX: 804-767-2529
JURISDICTIONS SERVED*Counties of Nottoway, Prince Edward, Charlotte, Lunenburg,
Cumberland, Buckingham, & Amelia.*

PSA15 - CAPITAL AREA AGENCY ON AGING, INC.24 EAST CARY
STREETRICHMOND, VA 23219-3796MARY C. PAYNE, EXEC. DIRECTORPHONE:
804-343-3000 or 1-800-989-2286FAX: 804-649-2258
JURISDICTIONS SERVED*Counties of Goochland, Powhatan, Henrico, Chesterfield, Charles
City, Hanover, & New Kent. City of Richmond.*

PSA 16 RAPPAHANNOCK AREA AGENCY ON AGING, INCBOWMAN CENTER, 11915
MAIN STREETFREDERICKSBURG, VA 22408CAROL DAVIS, EXEC. DIRECTORPHONE:
540-371-3375FAX: 540-371-3384
JURISDICTIONS SERVED*Counties of Caroline, Spotsylvania, Stafford, & King George. City of
Fredericksburg.*

PSA17/18 NORTHERN NECK-MIDDLE PENINSULA AGENCY ON AGING, INC.PO
BOX 610URBANNA, VA 23175ALLYN GEMERER, EXEC. DIRECTORPHONE:
804-758-2386FAX: 804-758-5773e-mail: bayaging@inna.net
JURISDICTIONS SERVED*Counties of Westmoreland, Northumberland, Richmond, Lancaster,
Essex, Middlesex, Matthews, King & Queen, King William, & Gloucester.*

PSA19 - CRATER DISTRICT AREA AGENCY ON AGING23 SEYLER
DRIVEPETERSBURG, VA 23805DAVID SADOWSKI, EXEC. DIRECTORPHONE:
804-732-7020FAX: 804-732-7232e-mail: craterdist@aol.com
JURISDICTIONS SERVED*Counties of Dinwiddie, Sussex, Greensville, Surry, & Prince George.
Cities of Petersburg, Hopewell, Emporia, and Colonial Heights.*

PSA20 - SOUTHEASTERN VIRGINIA AREAWIDE MODEL PROGRAM, INC.
(SEVAMP)7 KOGER EXECUTIVE CENTER - SUITE 100NORFOLK, VA 23502-4121JOHN

SKIRVEN, EXEC. DIRECTORPHONE: 757-461-9481FAX: 757-461-1068e-mail:
services@ssseva.org

JURISDICTIONS SERVED*Counties of Southampton, & Isle of Wight. Cities of Franklin,
Suffolk, Portsmouth, Chesapeake, Virginia Beach, & Norfolk.*

PSA21 - PENINSULA AGENCY ON AGING, INC. 739 THIMBLE SHOALS BOULEVARD,
EXECUTIVE CENTERBUILDING 1000, SUITE 1006NEWPORT NEWS, VA
23606-3562WILLIAM MASSEY, EXEC. DIRECTORPHONE: 757-873-0541FAX:
757-873-1437e-mail: wmassey@learninglink.org
JURISDICTIONS SERVED*Counties of James City & York. Cities of Williamsburg, Newport
News, Hampton & Poquoson.*

**PSA 22 - EASTERN SHORE AREA AGENCY ON AGING - COMMUNITY ACTION
AGENCY, INC.**PO BOX 849 MARKET STREETONANCOCK, VA 23417GEORGE V.
PODELCO, EXEC. DIRECTORPHONE: 757-787-3532FAX: 757-787-4230e-mail:
esaaacaa@shore.intercom.net
JURISDICTIONS SERVED*Counties of Accomack & Northampton.*

The Community Transportation Association of Virginia, Inc.
PO Box 1282
Richmond, VA 23210

The Community Transportation Association of Virginia, Inc. (CTAV), exists to promote transportation services in all areas of the State, with special emphasis on specialized transportation for elderly persons, persons with disabilities, and rural public transportation. The goal of the Association is to be a strong advocate for the transportation disadvantaged of Virginia. One million Virginians do not drive and CTAV seeks to build the infrastructure to serve these persons. CTAV has a database of all specialized transportation providers in the State to promote a comprehensive "best practices" exchange to more efficiently deliver transportation and training services.

CTAV's membership includes Individuals, Area Agencies on Aging, Community Service Boards, Section 5310 and Section 5311 providers. Private For-Profit Cab and Charter Operators, Direct Provision and Subcontractor Operators, Nonprofits and Planning District Commissions.

CTAV is governed by a sixteen-member board that is elected by the membership in accordance with the Bylaws.

How did CTAV get started?

As a result of the Commission to Study Needs of Persons with Physical and Sensory disabilities within the Commonwealth, (chaired by Lt. Governor Don Beyer and known as the Beyer Commission) the Specialized Transportation Council (STC) was founded to deal with specialized transportation needs in Virginia. Rural Public and Specialized Transit Operators and other

interested individuals formed a statewide organization to address issues facing the diverse needs of the transportation disadvantaged. The STC sponsored the first meeting in February 1994, which was attended by more than one hundred participants. The Community Transportation Association of Virginia was formed in April 1994, and became formally incorporated in 1996.

Specialized Transportation Services

Central Virginia Transportation 804-492-3600

Charlottesville Transit System 804-296-RIDE 804-971-3350

Greene County Community Transportation System 804-985-5205

JAUNT, INC. 804-296-6174

JABA Transportation Services 804-978-3644 800-277-5222

Ride Share (804) 295-6165 (804) 979-1597 (fax)

Thomas Jefferson Planning District Commission P.O. Box 1505 Charlottesville, VA
22902-1505 e-mail: Tina Sherman

Resources for Caregivers of Elders

UVA Physicians/Health Professionals

For General Care:

University Physicians at "CARE" - Center for Adult Rehab and Eldercare
804-964-1333
Dr. John Gazewood
Dr. Kimberly Baumann
Alicia Martinez-Spencer, Geriatric Nurse Practitioner

Colonnades Medical Associates 804-924-1212
Dr. Diane Snustad
Dr. Mary Preston

For Alzheimer's and other Memory Disorders:

UVA Memory Disorder Clinic 804-243-5420
Dr. Robert Brashear

For Neuro-Psychiatric care:

Dr. Suzanne Holroyd- 804-243-4646

For Parkinson's Disease and other Movement Disorders:

UVA Movement Disorders Center
Dr. Frederick Wooten., Jr. 804-924-5304

UVA has many general practitioners and specialists serving the elderly population including cardiologists, ophthalmologists, orthopedists, and internists. For more information call: 804-924-DOCS.

Additional Senior Services at UVA:

Kathleen Fletcher- Director, Geriatric Services 804-924-0098

Diabetes Community Network.:

Evelyn Nyong'a, Nurse Educator 804- 2434620

Cardiovascular Prevention and Rehabilitation

Anne Hedelt- Program Director
804-243-4600
Laura Knotts- Program Nutritionist 804-243-4600

Continuum Home Health Care

UVA Hospital West and Kluge Children's Rehab Center A consumer health information-nation center designed to provide you and your family easy access to health and medical information explained in everyday language. Requests

may be phoned in and mailed to your home or you may come in and browse the library.

Free of charge. Open 9:30 AM to 4:00 PM weekdays

JABA and Jefferson Eldercare Caregiver's Library #804-978-3644

674 Hillsdale Drive

Charlottesville, Va. 22901

An on-site library containing a variety of resources addressing caregiver issues.

Charlottesville-Piedmont Alzheimer's Chapter

804-973-6122 or 888-809-7383

500 East Westfield Road, Suite 14

Charlottesville, Va. 22901

Provides a 24 hour helpline to talk you through problems as they arise, caregivers' file of articles and ideas related specifically to living with AD, a book and video lending library for more in depth info on Alzheimer's and a chapter newsletter.

American Parkinson's Disease Association Information and Referral Center UVA

Miriam Hirsch, Health Educator, 804-982-4482

Located at the University of Va., offers information and educational materials for patients, their families and caregivers. Makes referrals to medical and rehab specialists.

American Association of Retired Persons

800-424-3410

601 E. St., NW

Washington, D.C. 20049

A lobbying and educational organization serving individuals 50 and older.

Provides free booklets and money-saving programs for members.

ARCH National Resource Center 800-7RELIEF (1-800-773-5433) 8:30a.m. - 5:00

p.m.

Respite, temporary relief for families and caregivers, is a service in which care is provided to children with disabilities, chronic or terminal illnesses, and to children at risk of abuse and neglect. A nationwide service to help parents, caregivers, and professionals find respite services in their local area.

Eldercare Locator: 800-677-1116

Runs a helpline that will tell you how to reach the area agency on aging that oversees services to the elderly in your parents', hometown.

Lovingston Health Care Center

Overnight respite care, no minimum or maximum stay
Where: Nelson County
Phone Number: 804-263-4823, Tiffany Brogan

Piedmont Health Care Center
Overnight respite care, no minimum or maximum stay
Where: 1214 Jefferson Park Blvd. Charlottesville, Va. 22903
Phone Number: 804-295-1161, Janice Shifflett

Manorhouse at University Village
Overnight respite care up to 30 days
Where: 491 Crestwood Drive
Charlottesville, VA 22903
Phone Number: 804-971-8889, Linda Broadbent, Admissions Director

Culpeper Baptist Retirement Community
Overnight respite for minimum of 2 weeks
Where: 12425 Village Loop
Culpeper, VA 22701
Phone Number: 540-825-2411, Valarie Diamond, Marketing Director

Geriatric Care Managers

A professional Geriatric Care Manager(GCM) is a professional in the field of human services trained and experienced in assessment, coordination and monitoring of services for older adults and their families.

Jefferson Elder Care, affiliate of the Jefferson Area Board for Aging (JABA)
Where: 674 Hillisdale Drive
Charlottesville, Va. 22901
Phone Number: 804-978-1417, Victoria Stow, Care Management Team
Coordinator

Advocates, Inc.
Where: P.O. Box 7108
Charlottesville, Va. 22906
Phone Number: 804-293-4508, Lundi Palmer

Library and Information Resources

Body Talk- Health Information Services at UVA
#804-924-5000 or 1-800-251-3627

Interim Healthcare
2114 Angus Road
Charlottesville. Va. 22901 Intake Nurse: Debbie Roach

804-295-5501 or 800-876-0984

Martha Jefferson Home Care/ The Third Age
2409 Ivy Road
Charlottesville, Va. 22903
Intake: Melissa Stultz
804-982-8295

Medshares Home Care of Virginia
1300 Branchlands Drive
Charlottesville, Va. 22901
804-978-1997
Intake Coordinator: Cheryl Roberts
800-596-2285

Adult Respite and Daycare Services

Center for Adult Rehab and Eldercare (CARE), an affiliate of JABA
Adult daycare and overnight respite, 1-21 nights
Where: 674 Hillside Drive Charlottesville, Va. 22901
Phone Number: 804-978-7168, Ellen Phipps

Eldercare Gardens
Short-term overnight respite care, 1-3 nights
Where: 1150 Northwest Gardens
Charlottesville, Va.
Phone Number: 804-973-7933, Linda Shortridge

Martha Jefferson House
Short-term overnight respite care depending on bed availability
Where: 1600 Gordon Ave. Charlottesville, Va. 22901
Phone Number: 804-296-1470, Sylvia Davis

Village Nursing Center
Overnight respite care, no minimum or maximum stay, dependent on bed availability
Where: Fork Union, Virginia
Phone Number: 804-842-2916, Angela Davis

Maggie Short, Director
Sarah Giballa, Intake Nurse 804-984-2273

Center for Hospice and Palliative Care 804-924-9082
Community Care Manager
Cindy Westley
804-243-2870

UVA Senior Services Caregiver Helpline
Windy Forch, GNP
804- 982-1090

Caregiver Support Groups

It is always a good idea to call prior to attending to confirm dates and times.

"Parenting Your Parent"

Where: Focus Women's Resource Center
1508 Grady Ave., Charlottesville

When: Second Thursday of each month, call for exact time

Contact: Lynn Reynolds- 293-2222

Caregiver's Support Group

Where: JABA's CARE Center

624 Hillsdale Drive, Charlottesville

When: Second Tuesday of each month, 5:30-6:30 PM

Contact: Ellen Phipps-804- 978-7168

The following are support groups provided through the Charlottesville-Piedmont Alzheimer's Chapter. For more information, call 804-973-6122 between 9:30 AM and 1:00 PM or 888-809-7383 or the number listed with the specific group.

Where: Senior Center

1180 Pepsi Place, Charlottesville, Va. 22901

When: Fourth Monday of each month, 1:00 PM

Phone Number: 804-973-6122, Dela Alexander

Where: Jefferson Park Baptist Church

2505 Jefferson Park Ave. Charlottesville, Va. 22901

When: Third Tuesday of each month, 7:00 PM

Phone Number: 804-973-6122 daily between 9:30 AM and 1:00 PM

Where: Evergreene Meadows

Stanardsville, Va. 22973

When: Fourth Tuesday of each month, 2:00 PM

Phone Number: 985-448 1, Barbara Berger

Where: Louisa Healthcare Center

21 0 Elm Street Louisa, Va., 23093

Phone Number: 540-967-0269, K. Beverly to confirm times and dates.

Where: Martha Jefferson Health Wise Building

509 Locust Avenue

Charlottesville, Va.

When: September 15 through October 20 from 1:00 PM to 2:30 PM

Phone Number: 804-982-7009, call Sue Winslow to reserve a space

ADDITIONAL UVA SERVICES

UVA Women's Center

Where: The Comer Building

14th Street & University Ave. Charlottesville, Va. 22908

Phone Number: 804-982-2361

Services: Provides individual , short-term personal counseling free of charge.

Services available to women and men, UVA faculty, staff, and members of the Charlottesville Community

The Women's Place Midlife Health

Where: Northridge, 2955 Ivy Road, Suite 104 Charlottesville, Va. 22903

Phone Number: 804-243-4720, Catherine Zuver, Nurse Educator Services: a medical and educational resource for midlife women. Provides interdisciplinary team

medical care, support programs, health screens, educational programs and more.

Home Health Care Agencies

Medicare and Medicaid will cover home care when the care is provided by a certified agency and prescribed by the individual's doctor. The individual must have a skilled need such as diet or medication teaching, wound care, or physical therapy to qualify for this type of care. The care provided is part-time. not continuous . Each agency will evaluate the individual at home to determine how often and for how long home care should be provided.

UVA, Continuum
2205 Fontaine Ave., Suite 204
Charlottesville, Va. 22903
804-984-2273 or 800-336-4040
Intake Nurse: Sarah Giballa

101
Charlottesville, Va. 22901
804-973-1420
Intake Nurse: Marcia Hickory

Augusta Home Care
PO Box 215
Fishersville, Va. 22939
From Waynesboro, Va.: 540-932-4900
From-1 Staunton, Va.: 540-332-4900

Comprehensive Home Care/Home Health, Inc.
PO Box 177
Arvon, Va. 23004
804-581-3245
Director: Charlotte Avis
Louisa, Va.: 800-858-9412

Intake Nurse: Patsy Rinehart

Family Care Home Health & Hospice
PO Box 592
Culpeper, Va. 22701
540-825-2273

Care Advantage Plus
23 00 Commonwealth Drive, Suite

Director: Jane Wayland

Health Reliance
PO Box 1209
Louisa, Va. 23093
804-295-9573
Director: Henry B. Walsh

Commonwealth Catholic Charities
1512 Willow Lawn Drive
Richmond, VA 23230
804-285-5900

Hospice of the Piedmont
1290 Seminole Trail
Charlottesville, Va. 22901
Director: Jerry Bailey
804-975-5500
terminal patients only)

Virginia State Resources for Children and Youth with Disabilities

State Department of Education: Special Education

H. Douglas Cox, Director
Office of Special Education and
Student Services
Department of Education
P.O. Box 2120
Richmond, VA 23218-2120
(804) 225-2402
E-mail: dougcox@pen.k12.va.us

Programs for Children with Disabilities:

Ages 2 Through 5

Linda Bradford, Specialist
Office of Special Education
Services, Department of Education
P.O. Box 2120
Richmond, VA 23218-2120
(804) 225-2675
E-mail: lbradfor@pen.k12.va.us

Programs for Infants and Toddlers with Disabilities: Ages Birth Through 2

Shirley Ricks, Manager
Children/Family Services
Office of Mental Retardation
Services
Department of Mental Health,
Mental Retardation & Substance
Abuse Services
P.O. Box 1797
Richmond, VA 23214
(804) 786-0992

State Vocational Rehabilitation Agency

John Vaughn, Commissioner
Margaret S. Walsh, Education
Services Manager
VA Department of Rehabilitative
Services
8004 Franklin Farm Drive
P. O. Box K300

Richmond, VA 23288-0300
(804) 662-7000

Office of State Coordinator of Vocational Education for Students with Disabilities

Neils W. Brooks, Director
Office of Vocational & Adult
Education
Department of Education
P.O. Box 2120
Richmond, VA 23218-2120
(804) 225-2847
E-mail: nbrooks@pen.k12.va.us

State Mental Health Agency

Richard E. Kellogg, Acting
Commissioner
Department of Mental Health,
Mental Retardation & Substance
Abuse Services
P.O. Box 1797
Richmond, VA 23218
(804) 786-3921

Nancy Bullock, Director
Division of Child and Adolescent
Health
Virginia Department of Health
P.O. Box 2448
Richmond, VA 23218
(804) 786-7367
E-mail:
nbullock@dvhmail.state.va.us
URL:
<http://www.state.va.us/nhr/dvh>

State Agency for the Visually Impaired

W. Roy Grizzard, Jr., Commissioner
Department for the Visually
Handicapped
397 Azalea Avenue

Richmond, VA 23227
(804) 371-3140
E-mail:
slonnegr@dvhmail.state.va.us
URL:
<http://www.state.va.us/nhr/dvh>

**Programs for Children and Youth
Who Are Deaf or Hard of Hearing
Regional ADA Technical
Assistance Agency**

Mid-Atlantic DBTAC
TransCen, Inc.
451 Hungerford Drive, Suite 607
Rockville, MD 20850
(301) 217-0124 (V/TTY)
E-mail: adainfo@transcen.org
URL: <http://www.adainfo.org>

Disability Organizations

Attention Deficit Disorder
To identify an ADD group in your
state or locality, contact:

Children and Adults with Attention
Deficit Disorders (CHADD)
499 NW 70th Avenue, Suite 101
Plantation, FL 33317
(954) 587-3700
(800) 233-4050 (Voice mail to
request information packet)
URL: <http://www.chadd.org>

Attention Deficit Disorder
Association (ADDA)
9930 Johnnycake Ridge Road,
Suite 3E
Mentor, OH 44061
(216) 350-9595
(800) 487-2282 (Voice mail to
request information packet)
E-mail: NatIADDA@aol.com
URL: <http://www.add.org>

Cecilia Kirkman, Director of
Prevention & Children Services

Ronald L. Lanier, Director
Ratcliffe Building, Suite 203
1602 Rolling Hills Drive
Richmond, VA 23229-5012
(804) 662-9502 (V/TTY) (800) 552-
7917 (V/TTY)
E-mail: VDDHH@aol.com

Department of Mental Health
Mental Retardation & Substance
Abuse Services
P.O. Box 1797
Richmond, VA 23219
(804) 371-2185

**State Health Department
Representative for Child &
Adolescent Health**

Cecilia Barbosa, Director
Division of Child & Adolescent
Health
VA Department of Health
P.O. Box 2448
Richmond, VA 23218
(804) 786-7367
E-mail: cbarbosa@vdh.state.va.us
URL: <http://lwww.vdh.state.va.us>

**State Mental Retardation
Program**

Janet Hill, Director
Office of Mental Retardation
Services; Department of Mental
Health,
Mental Retardation and Substance
Abuse
P.O. Box 1797
Richmond, VA 23219
(804) 786-1746

**State Developmental Disabilities
Planning Council**

Brian S. Parsons, Director
Virginia Board for People with
Disabilities
202 North Ninth Street

Ninth Street Office Building, 9th Floor
Richmond, VA 23219
(804) 786-0016 (V/TTY)
(800) 846-4464 (In VA)

Protection and Advocacy

Sandra Reen, Director
Department for Rights of Virginians with Disabilities
Ninth St. Office Building, 9th Floor
202 North 9th Street
Richmond, VA 23219
(804) 225-2042 (Voice/TTY); (800) 552-3962 (In VA)
1-800-372-3900

Autism

To find autism group in your state, contact:

Autism Society of America
79 1 0 Woodmont Avenue, Suite 650
Bethesda, MD 20814
(301) 657-0881; (800) 3-AUTISM
URL: <http://www.autism-society.org>

Colleen Quinn, Program Administrator
Autism Training and Family Support Program
The Arc of Virginia
6 North 6th Street, Suite 403-A
Richmond, VA 23219
(804) 649-8481

Charlotte Crane, Program Administrator
VA Autism Resource Center
134 W. Piccadilly Street
Winchester, VA 22601
(540) 667-7771

Brain Injury

Harry Weinstock, Executive

URL: www.state.va.us/hhr/drvd

Client Assistance Program Contact **Protection & Advocacy Agency**

Programs for Children with Special Health Care Needs

Alzheimer's Disease

To find the nearest chapter of the Alzheimer's Association call:

The Alzheimer's Association
919 Michigan Ave.

Chicago, IL 60611-1676

Director

Brain Injury Association of VA
3212 Cutshaw Avenue, Suite 315
Richmond, VA 23230

(804) 355-5748; (800) 334-8443 (in VA)

Cerebral Palsy

Kathleen Prendergast

UCP of Southeastern Virginia
1709 Colley Avenue, Suite 306

Norfolk, VA 23517

(757) 627-2326; (757) 497-7474

Epilepsy

Suzanne Bischoff, Executive Director
Epilepsy Foundation of VA
The Highlands Center Box BRH,
Drawer E

UVA Health Sciences Center
Charlottesville, VA 22908

(804) 924-8678; (804) 982-6327
(TTY)

Learning Disabilities

Justine Maloney, President
Learning Disabilities Association of VA
VA 3115 North 17th Street

Arlington, VA 22201

(703) 243-2614

E-mail: Jwmla@aol.com

Mental Health

Lori Lester, Coordinator
Mental Health Association of VA
6 North Street, Suite 403A
Richmond, VA 23219
(804) 649-8481

Valerie Marsh, Executive Director
VA Alliance for the Mentally III
P.O. Box 1903
Richmond, VA 23218-1903
(804) 225-8264; (888) 486-8264

Joyce Kube, Executive Director
Parents & Children Coping Together
8032 Mechanicsville Turnpike
Mechanicsville, VA 23111
(804) 559-6833; (800) 788-0097 (in
VA only)

Mental Retardation

Steve K. Waldron, Executive
(804) 751-0829

Visual Impairments

Karen E. Walker, Director
American Foundation for the Blind-
Southeast
100 Peachtree Street, Suite 620
Atlanta, GA 30303
(404) 525-2303
E-mail: atlanta@afb.org

University Affiliated Program

Fred P. Orelove, Executive Director
Virginia Institute for Developmental
Disabilities
Virginia Commonwealth University
301 West Franklin Street, Box
843020
Richmond, VA 23284-3020
(804) 828-3876 (V/'TTY)
E-mail: forelove@saturn.vcu.edu

Technology-Related Assistance

Kenneth Knorr, Project Director
Virginia Assistive Technology

Director
The Arc of Virginia
6 North 6th Street, 4th Floor
Richmond, VA 23219
(804) 649-8481
E-mail: ARCVA@richmond.infi.net

Speech and Hearing

Karen Corso
Speech-Language-Hearing
Association of VA, Inc.
P.O. Box 35653
Richmond, VA 23235-0653
(804) 794-7117

Spina Bifida

Karen Anderson, President
Richmond Area Spina Bifida
Association
5307 Great Bridge Terrace
Richmond, VA 23237

System
8004 Franklin Farms Drive
P.O. Box K300
Richmond, VA 23288-0300
(804) 662-9990; (800) 435-8490 (in
VA only)

**Parent Training Information
Project**

Cherie Takemoto, Executive
Director
Parent Educational Advocacy
Training Center (PEATC)
10340 Democracy Lane, Suite 206
Fairfax, VA 22030
(703) 691-7826; (800) 869-6782
E-mail: peatcinc@aol.com
<http://www.members.aol.com/peatcinc/index.htm>

Parent Resource Centers

Anita Swan, Coordinator
Office of Special Education Services
Virginia Department of Education
P.O. Box 2120

Richmond, VA 23218-2120
(800) 422-2083; (804) 371-7420
E-mail: aswan@pen.k12.va.us

Roanoke, VA 24004
800-354-3388

Parent-To-Parent

Elizabeth Fletcher, Coordinator
Parent to Parent of Virginia
Family and Children's Service
1518 Willow Lawn Drive
Richmond, VA 23230
(804) 282-4255

Parent Teacher Association (PTA)

Lois Cumashot, President
Virginia Congress of Parents and
Teachers
1027 Wilmer Avenue
Richmond, VA 23227
(804) 264-1234

Other Disability Organizations

F. Robert Knight, President
Easter Seal Society of VA
4841 Williamson Road
P.O. Box 5496
Roanoke, VA 24012
(540) 362-1656; (800) 365-1656 (In
VA)

The United Way

Information and Referral

Charlottesville	804-972-1701
Hampton Roads	757-629-0500
Newport News	757-873-9328
Norfolk	757-625-4563
	800-223-2086
Peninsula	757-838-9772
Richmond	804-275-2000
	800-544-2155
Roanoke	540-365-7351

USDA Adult and Child Food
Program
PO Box 598

Virginia Elected Officials

These people are your elected representatives. They work for you. Call them or write to them if you need their help.

Governor

James Gilmore
State Capitol
Richmond, VA 23219
(804) 786-2211

United States Senators

Honorable John Warner (R)
United States Senate
Washington, DC 20510-4601
(202) 224-2023
(202) 224-6295 (Fax)
E-mail: senator@warner.senate.gov

Honorable Charles S. Robb (D)
United States Senate
Washington, DC 20510-4603
(202) 224-4024
(202) 224-8689 (Fax)
E-mail: senator@robb.senate.gov

House of Representatives

District	Name	Home Town
1	Herbert H. Bateman	Newport News
2	Owen B. Pickett	Virginia Beach
3	Robert C. Scott	Newport News
4	Norman Sisisky	Petersburg
5	Virgil H. Goode, Jr.	Rocky Mount
6	Bob Goodlatte	Roanoke
7	Tom Bliley	Richmond
8	James P. Moran	Alexandria
9	Rick Boucher	Abingdon
10	Frank R. Wolf	Vienna
11	Thomas M. Davis	Falls Church

Virginia State Resources for Adults with Disabilities

THE DEPARTMENT OF REHABILITATIVE SERVICES

The Department of Rehabilitative Services (DRS) is the agency of Virginia State Government offering assistance to persons with physical, mental and emotional disabilities in order that they may become self supporting and as independent as possible. Through the provision of vocational rehabilitation services, persons with disabilities are appropriately prepared for suitable jobs and placed in gainful employment. DRS offers comprehensive training and placement services.

DRS has developed broad contacts with employers and can refer clients to them. It will also arrange appointments and set up interviews.

DRS works with businesses, organizations, communities and other groups to accommodate persons with disabilities and integrate them into the mainstream of society.

Persons with disabilities may receive assistance from DRS if it is determined that employment is probable after rehabilitation. Independent living training is available regardless of employment potential.

Every applicant's case is studied by a trained professional. Once it is determined that services may be provided, a counselor and the person with the disability plan a rehabilitation program specifically tailored to the person's specific needs.

There is no charge for DRS services. Once it has been determined that a person is eligible for services, they may be asked to contribute to the cost of their services if they are financially able. No one is denied services if they are unable to pay.

You may apply for services by calling, writing, or visiting the nearest DRS office. On contact, a rehabilitation counselor will schedule an appointment or, if necessary, arrange a home visit to determine your eligibility.

Programs and Services for Persons with Disabilities

DRS offers a wide range of services including:

- Personal Assistance Services (PAS)
- Physical and psychological examinations
- Guidance counseling
- Vocational evaluation and training
- Employment services
- Occupational licenses, tools, equipment, and supplies
- Job placement services, and
- Job follow-up services.

Specialized programs include:

Long term rehabilitation case management
School-to-work transition programs
Personal assistance services
Supported employment programs, and
Independent living services.

Disability Determination Services

The Disability Determination Services division of DRS adjudicates claims for Social Security Disability Insurance (SSDI) benefits and Supplemental Security Income (SSI) for persons with disabilities. SSDI pays benefits to workers under 65 who have worked and paid Social Security taxes. Previous work is not necessary for SSI, but claimants must have limited income and assets. DRS also provides assistance for determining eligibility for Social Security work incentives.

Low Interest Loans for Adaptive Equipment

The Assistive Technology Loan Program is now being planned to provide low interest loans to finance adaptive equipment. The task force developing the plan will make its recommendation to the Governor and General Assembly in 1996.

DEPARTMENT FOR RIGHTS OF VIRGINIANS WITH DISABILITIES

The DRVD is the state protection and advocacy agency for people with disabilities. The DRVD can help if you or your child:

face discrimination because of a disability or illness, or
are illegally denied a service by an agency or program, or
are physically or psychologically harmed (abused) and/or are not given proper care (neglected).

If you or your child has a disability, the DRVD can explain your rights and responsibilities, relevant laws and regulations, and explain any benefits available to you. DRVD will investigate abuse and neglect, rights violations, and denial of services and will provide representation if you have been denied services or if the services have been inappropriate.

Call DRVD if you or your child has been denied opportunities because of a disability in:

Employment and Promotions
Housing
Transportation
Education or training; or,
The use of public places.

SOCIAL SECURITY ADMINISTRATION WORK INCENTIVES

These programs are subject to change. Please contact your nearest SSA or DRS office for up to date information.

PASS

PASS (Plans for Achieving Self Support) enable individuals to set aside income/resources for a vocational goal. Goals can include:

- Education
- Vocational training
- Starting a business, or
- Job coach services.

PASS can make it possible for an individual with a disability to hire a job coach. Support services could include job development, job site training, and follow-up support.

PASS is available for a maximum of 48 months. The first PASS is for 18 months and requires extensions after that.

A PASS must include five components:

- Individualized attainable vocational goals;
- A schedule for meeting the goals;
- Identification of income or resources to be set aside;
- An explanation of how the money will be spent; and
- A written plan.

Income or resources set aside in a PASS are not counted in determining SSI eligibility or benefits. PASS can help a supported employee:

- Qualify for SSI;
- Maintain current SSI; or,
- Increase SSI.

IRWE

An IRWE (Impairment Related Work Expense) is an expense for an item or service which is directly related to enabling an impaired person to work and which is incurred because of a physical or mental impairment. An IRWE allows a person with a disability to recover money spent as a result of their disability. The money must be needed to support work activities and related to the disability.

An IRWE can be used for a variety of expenses, including:

- Drugs and medical services;
- Adaptive equipment;
- Special medical devices;

Attendant care services;
Some transportation costs; and
prostheses and other equipment.

To be eligible for deduction, the person claiming an IRWE must meet the SSA definition of disability and must be able to:

Prove that the expense is work related;
Prove that the money has been paid; and,
Show that the expenses were reasonable.

Deducting the cost of an IRWE can reduce gross monthly earnings to meet SSI and SSDI application requirement and to maintain or increase SSDI and SSI benefits.

SUBSIDIES

Subsidies allow a part of a person's wages to be excluded when determining if substantial work is being done by an SSDI or SSI applicant or recipient.

A supported employee can qualify for a subsidy if he or she:

Gets extra training and support at work;
Needs extra supervision; or
Has documented proof that his or her production is below company standards.

To be eligible, the employer must verify that the employee is being paid more than is reasonable for the value of their work.

A subsidy may allow a supported employee to become eligible for SSI and SSDI benefits.

These programs may change. Contact your nearest Department of Rehabilitative Services or Social Security office for current information.

The Epilepsy Foundation Virginia would like to thank Crestar Bank for their donation in support of this booklet.