THE

CAREGIVER'S HANDBOOK

For the wonderful people caring
For those in need of caring people

Developed by the Caregiver Education and Support Services, Seniors Counseling and Training, Case Management Services of the San Diego County Mental Health Services, 1250 Moreno Blvd., San Diego, CA 92110, Robert Torres-Stanovik, LCSW, Editor (first printing January 1990, second printing July 1990).

Edited, updated and formatted for printing by
Robert S. Stall MD, Geriatrician

The Caregiver's Handbook

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What Should You Expect At Your Age? A Lot! ***TM***

A *Grassroots Geriatrics*TM Publication

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Preface by Robert S. Stall MD, Geriatrician

I became acquainted with the original on-line Caregiver's Handbook several years ago as a nine part series posted to the Web by Mr. Mike Moldeven, with permission from the Caregiver Education and Support Services, Seniors Counseling and Training, Case Management Services of the San Diego County Mental Health Services, 1250 Moreno Blvd., San Diego, CA 92110.

Many requests have come to me over the years for written copies of the handbook, which I've copied and happily mailed out free of charge. I have also taken the liberty to grant permission for the handbook's non-commercial use to educators, not-for-profit organizations, and caregiver support groups.

On behalf of the caregivers I work with directly or become aware of from afar, I personally congratulate and thank the people at the San Diego County Mental Health Services who put together the original Caregiver's Handbook.

Robert S. Stall MD
Geriatrician
February 16, 2004

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This 9-part online posting of the *<u>Caregiver's Handbook</u>* *is made with permission from The Caregiver Education and Support Services, Seniors Counseling and Training, Case Management Services of the San Diego County Mental Health Services, 1250 Moreno Blvd., San Diego, CA 92110. Questions concerning the Handbook's content should be referred to that agency or to Dr. Robert S. Stall.*

The titles of the San Diego County government and private sectors entities in the original publication, and their locations and telephone numbers have been, in most cases, deleted from this version as they would not be ordinarily available as resources to readers who are outside of San Diego County. Instead, most entities were identified as functions or in some other manner to facilitate identification of counterparts where the handbook might be used.

Readers are reminded that this handbook was prepared in 1990 or earlier and much has happened since in caregiving and other social services. It is therefore suggested that the HB be referred to as a general guide, and specifics checked, as appropriate, with physicians, healthcare providers, state and community social services, and caregiving resources generally for more up-to-date information.

Produced by The Caregiver Education and Support Services Seniors Counseling and Training Case Management Services of San Diego County Mental Health Services1250 Moreno Blvd. San Diego, CA 92110(619) 692-8702, Robert Torres-Stanovik, LCSW, Editor First Printing - January 1990; Second Printing-July 1990.

Acknowledgments by Robert Torres-Stanovik, LCSW

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Thank you to my family, Maida, Shawn and Sylvia for their loving patience for allowing me the time/energy to complete this handbook; thank you to my support staff of students Karen Zaustinsky and Laurie McFarland for their assistance with the initial stages of this handbook, and the typists Heidi Peters, Fatima Ruiz, and Ewald Brieske for their many revisions and rerevisions in order to arrive at this handbook; thank you to the San Diego County Senior Teams, the Southern Regional Resource Center, Frank Dwinnell, MD, Stanley Rest, Ph.D., Donna Pasanen, the Telephone Friends, several caregivers and care receivers for their assistance in editing, advising and encouraging me with this handbook. Special thanks to Mimi Campbell-Goodman for the bear graphics (Note from Mike: I deeply regret not being able to include the graphics. They are excellent.) Very special thanks to Ray Schwartz, my supervisor, editor, and above all encourager who was always close at hand with his red pen and some kind words.

Caregiver Education Support Services (CESS) wishes you the very best of care. We care! CESS, a program under Seniors Counseling and Training Program, Case Management Services, would like your comments regarding our Caregiver's Handbook. If we can offer further services or if you have any comments or improvements regarding this manual, write us at: Seniors Counseling and Training Program, Case Management, DHS, 1250 Moreno Blvd., San Diego, CA 92110.

Foreword

Older citizens are more likely to be disabled or dependent due to medical problems. These problems change a person's relationships with family and friends. A husband, daughter, or friend may find that they are now also a caregiver, the person primarily responsible for seeing that a patient's physical, psychological, and social needs are met. Another person now depends on them for basic physical needs.

Regardless of whether the disability is due to progression of a chronic illness such as 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. These adjustments are often stressful, as well-established patterns must be abandoned, and new adaptations developed. This provides opportunities for personal growth, but also, invariable causes emotional turmoil and distress. Being a caregiver is rewarding, but also can exhaust a person physically and emotionally, leading to illness and inability to further provide care.

This book is directed primarily at the caregiver. This is not a how-to book focused on problems of the ill patient. Rather, it offers practical approaches to common caregiver problems. Staying healthy, avoiding depression, remaining active, making friends, enjoying pleasurable activities are an essential part of any human life, including those of caregivers. Serving as the primary caregiver for an ill loved one should not make life meaningless.

Caregivers for frail and ill older people should read this book. Family members who are not primary caregivers should also read this book to become more aware of the problems facing caregivers. Caregivers, other family members, and care receivers will find the resources, tables, and questions useful in improving the quality of life for all concerned.

"Mr. Torres-Stanovik and staff of the San Diego County Mental Health Services have performed an important service for the frail elderly and their caregivers."

J. Edward Jackson, MD, Director, Seniors Only Care Clinic and Alzheimer's Disease Diagnostic and Treatment Center University of California, San Diego

Chapter 1 – Introduction to Caregiving

You, the Caregiver, Are Very Important!

Few people are prepared for the responsibilities and tasks involved in caring for the aged. To help make the task easier, it is important to have a game plan in life which helps determine where we are headed and how we are going to get there. This guide will help to serve as a road map which gives optional paths for caregivers. It is also an emphatic reminder that those who care for other people can do a better job of caregiving if time and attention also are given to their own personal needs. It can not be stated strongly enough; the caregiver is a very important part of the caregiving equation. The success of this equation and the continuance of its success are actually dependent on how well the caregiver cares for him/herself. In other words, if the caregiver becomes ill, who will care for the care receiver? Before you get to that place, please read this handbook.

This handbook explores a number of different topics which can make the role of caregiver easier, and at the same time, help the person receiving the care. Throughout this handbook, “caregiver” refers to the person giving care, and “care receiver” the elderly person receiving the care.

Below are two checklists, one focusing on the care receiver and the other on the caregiver. They are included as general guidelines to help insure an optimal level of health, safety and comfort for both your care receiver and yourself, the caregiver.

Checklist for the Care Receiver

__ All legal and financial matters are in order and available

__ Physical and dental appointments are kept annually or more often if needed

__ The home environment 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 have been utilized monthly/weekly

__ Level of care is reviewed monthly to ensure care receiver is able to remain in the home

Checklist for the Caregiver

__ I am getting out/exercising at least once a week

__ I am getting at least seven to nine restful hours of sleep a night

__ I talk with or visit up to three friends or relatives weekly

__ I keep annual medical and dental appointments

__ I am taking only the medications as prescribed to keep up my health

__ My legal and financial papers, including wills, are in order and available

__ I have checked a new resource regarding caregiving each week

__ I have read and am aware of the Caregiver's Bill of Rights

__ I am eating three balanced meals a day.

Chapter 2 – Common Problems in Caregiving

List of Needs

The first step in organizing a rational care plan is making a list of needs. As family members or friends care for an impaired elderly person, several questions present themselves:

-- What are his/her needs?

-- What kinds of care are needed to allow the elderly/impaired person to remain in the community?

-- Who is going to provide the care? When? How?

-- Should the care receiver remain in his/her own home, live with the children 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 or become more independent?

-- If outside services are needed, does the impaired person 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 also has responsibility?

-- Do you as the caregiver feel tired or frustrated from caring for an older person?

In answering these questions you are developing an important "List of Needs" of the impaired elderly person, and bringing into perspective the caregiver's needs as well. The questions do not have easy answers and the solution may vary in every situation. The care of an impaired older person can create stress that affects the ability of the caregiver to continue giving necessary levels of care. The stress experienced may be physical, financial, environmental and/or emotional in nature.

Physical Stress

Providing physical care to an impaired older person can cause physical stress. General homemaking and housekeeping activities such as cleaning, laundry, shopping, and meal preparation require energy and can be tiring, particularly when added to existing responsibilities in one's own home.

Personal care required for the supervision of medications and the maintenance of hygiene can also be stressful, particularly in situations of acting-out behaviors, incontinence (loss of bladder or bowel control), colostomies, or assistance with bathing. Lifting and transferring individuals with limited mobility is not only tiring, but also can result in injury to the caregiver or the impaired person. In some instances there is the additional responsibility of maintenance of equipment such as wheelchairs or hospital beds.

Financial Stress

The care of an impaired elderly person has many financial dimensions. For those services that cannot be provided by family members (medical, pharmaceutical, therapeutic, etc.), decisions will have to be made as to where service will be secured and how they will be paid. When money is limited, many families assist with the cost of care, causing financial burdens on all family members.

Environmental Stress

The proper home setting has to be chosen. If the care receiver elects to remain in his/her own home, modifications such as railings and ramps may have to be installed. If the person cannot remain in his/her own home, alternative arrangements must be sought, such as moving in with a friend or relative or specialized housing (retirement hotels, senior apartments, residential care homes, intermediate care facilities, or nursing homes). If the care receiver is to remain in the home, some major adjustments in the living arrangements and patterns of daily living will be necessary.

Social Stress

Providing personal care up to 24 hours a day can cause social stress by isolating oneself from friends, family and a social life. The caregiver may find himself/herself becoming too tired or unable to have “an evening out” even once a week, or once a month. What can result is a build-up of anger and resentment toward the very person receiving the care, as the care receiver is the cause of the lost socialization.

Emotional Stress

All of these factors often result in tremendous emotional stress. Compounding these sources of stress are the difficulties in managing one's time, juggling multiple responsibilities, and feeling the pressure of the increased dependency.

For family members providing care, the various forms of stress can result indifferent feelings. Anger, resentment and bitterness about the constant responsibilities, deprivation and isolation can result. This is also a time when many of the unresolved conflicts from parent-child relationships resurface and can intensify, causing anxiety and frustration. There might even be the unspoken desire, at times, to be relieved of the burden through institutionalization or even death of the care receiver. This desire is frequently and swiftly followed by feelings of guilt. All of these can be felt, and then denied because they seem unacceptable. The person giving care needs to be assured that, in fact, these feelings are common even though they may not be expressed. There are resources that can help caregivers. The remainder of this book will address those resources, such as joining a caregiver support group, using community resources and above all, caring for you, the caregiver.

Chapter 3 – 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 impaired elderly person needing the care. Assets include available time, skills, space, equipment, the strengths of the person in need care, and most importantly, 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 tasks will be performed, by whom, on which days, and so forth. 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 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 to a college student for his/her help with care of the care receiver, in return for free room and board.

When Community Agency Help in Needed

When family or other volunteer help is not available or cannot meet your needs, caregivers or care receivers 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 supplemental program of your State). All of it can be purchased. Sometime the service costs may be based on the income of the care receiver. Each agency has its own fee structure; you may want to ask about their arrangements before ordering the service.

Services Available to Impaired Elderly

Adult Day Health 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 life activities, 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.

Escort Services for the Elderly: These services provide personalized accompaniment to service providers as well as personal assistance.

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

Home Delivered Meals: Some nutritional programs as well as well as specialized "meals-on-wheels" programs offer home delivered meals to the 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 cold evening meal.

Home Health Aides: Provide personal care to individuals at home (These services may be covered by health insurance if 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, and 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 senior housing, shared housing, and finding emergency shelters, such as Heartland Human Relations and Area Agency on Aging.

Nutritional Programs: Congregate 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.

Physical Therapy: Physical therapy, or PT, is rehabilitative therapy to maximize mobility. It should be provide by a qualified physical therapist, usually 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.

Senior Service Teams: Regional/County Mental Health teams working together to provide mental health screening, needs assessments, and short-term counseling services to seniors.

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: Provide 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 older people who must be left at home alone during the day.

Transportation: Transportation services provide travel by automobile or specialized vans to and from medical care. Community agencies and service providers such as Dial-a-Ride, Red Cross Wheels, Cancer Society, and LifeLine are but a few.

Chapter 4 – 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 care receiver, 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 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 “Coop Networker: Caregiver of Older Persons” by Judy Bradley. It is an excellent effort to provide some guidelines for caregivers and to evaluate your level of care and value which you give your care receiver and yourself.

The scale is a 1-10 continuum which describes the various styles of caring. Circle the number or numbers which 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 to actively abuse your care receiver.

2. Neglect: to allow life-threatening situations to persist or to display consistent coldness or anger.

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 care receiver.

4. General Support: given freely, with a guarded degree of warmth and respect, occasional feelings of manipulation. Concerned with both emotional and physical well-being of care receiver.

5. Expressed empathy: the ability to feel what your care receiver feels. A quality relationship where feelings can be freely expressed and caringly received with non-judgmental positive regard.

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

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

8. Consistent Over-involvement: care receiver regarded as object of 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 care receiver has; increased dependence, care receiver not allowed independence.

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

You can place yourself on the Scale of Caregiving to determine how you value your care receiver as compared to yourself. The low numbers give little or no value (honor) to the needs of your care receiver. 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 undercare and overcare. Neither of the two extremes is healthy; they represent positions where you are not helping your care receiver.

What Can I Do To Help Myself?

Acknowledge your feelings: Your feelings have a lot to do with the way you view and cope with caregiving. All feeling are legitimate, even those that may seem disturbing to you (including anger, frustration, and sadness). Recognizing and accepting your emotions are the first step toward resolving 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.

Caregivers Stress Test

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

Seldom Sometimes Often Usually True 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 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 the response to one or more of these areas is “usually true” or “often true” it may be time to begin looking for help with caring for the care receiver and help in taking care of yourself.

Seek Information

Check your public library for books, articles, brochures, videotapes, and films on caregiving. Some hospitals, Adult Education Centers, the Southern Regional

Resource Center and CESS offer courses on caregiving and additional information on resources that you can turn to for help. Help is available!

Join a Caregiver Support Group

In addition to offering useful information, such groups provide a unique forum 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.

Participating in a support group can help mange stress, exchange experiences, and improve skills as a caregiver. Sharing coping strategies in a group setting 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 reality.

Set Realistic Goals

Caregiving is probably 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. Turn to other people for help - your family, friends, and neighbors. Prepare a list of tasks for anyone who may offer assistance. The list may include:

Running an errand for you
Preparing a meal
Taking your care receiver for a ride
Taking your children after school one day.

Practice Good Communication Skills

Do not expect that others will ask if you need help. It is up to you to do the asking.

Communicate with your Family and Friends

Turning to family members or friends for emotional support and help can be a mixed blessing. Their visits may make you feel less alone and better able to deal with caregiving responsibilities. They can give you a break by spending time with your care receiver.

However, other relatives or friends can be critical of the way you provide care. They may feel the house is not kept clean enough; or they may not like the way your care receiver is dressed. Recognize that they are responding to what they see at that time and are lacking the benefit of experiencing the whole picture and any gradual changes in your care receiver's condition. Harsh criticism may be a response to their own guilt about not participating more in the care process.

Try to listen politely to what is being said (even though this might not be easy). However, if you and your care receiver feel comfortable with the way you are managing the situation, continue to do what meets your needs. Schedule a family 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 care receiver 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 care receiver, look at respite care. For example, a companion can stay with your care receiver for a few hours at a time on a regular basis to give you time off. Or have your care receiver participate in an adult daycare program where he or she can socialize with peers in a supervised setting; this gives your care receiver a necessary break from staying home all the time. Hospitals, nursing homes, and particularly residential care homes offer families the opportunity to place older relatives in their facilities for short stays. The Residential Bed Availability Hot Line, your doctor, and the Area Agency on Aging can assist with arrangements.

Maintain Your Health

Your general 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,
- enough sleep/rest,
- allowing yourself leisure time.

Food is fuel for your body. Skipping meals, eating poorly, or drinking lots of caffeine is not good for you. Learn to prepare and eat simple, nutritious, well-balanced meals. Avoid alcohol above 2-3 ounces daily.

Being physically active can provide you with an outlet that is relaxing and makes you feel good.

Stretching, walking, jogging, swimming, and bicycling are examples of invigorating exercises. Consult your doctor before starting an exercise routine. Your doctor can help design a program that fits your individual needs.

Leisure time allows you to feel better and more able to cope with your situation. Having time to yourself to read a book, visit a friend, or watch TV can also bring enjoyment and relaxation, and break the constant pattern and pressure of caregiving.

Sleep refreshes and enables you to function throughout the day. If your care receiver is restless at night and disturbs your sleep, consult your doctor and fellow caregivers on possible ways to handle the situation. You may need to have outside help in the evenings to allow you time to sleep.

If you are unable to sleep because of tension, 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. Allow your mind to drift a few seconds, go with it wherever it goes. Wiggle your fingers and toes, then hands and feet, ankles and wrists. Loosen tight clothes, belts, ties. Sway 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 some one pleasant thing you really want to think about; maybe it is a place you have visited in the past, or your dream place of your own imagination. It might be the seashore, or high on a hill, or in a field of grass and flowers. Become totally immersed in the place. Smell the smells you best remember. See the sights it offers. Hear the sounds. Feel it, whether it be water or sand or soil or snow. Fully realize this place or situation you are in: if it is on the sandy beach, sift your fingers through the warm sand and smell it, hold the sand to your cheek, smell the salt of the sea, search the skyline for gulls and terns

and low clouds in the distance. Your body is totally weightless. You are totally in control of this scene. It is so relaxing and pleasant and beautiful, you are breathing slowly, peacefully. This is YOUR place and no one can take it from you.

- After you have sufficiently experienced your peaceful imaging, whenever you have a chance, return to your special place, close your eyes again, tune in, relive those these special few moments in the world of your choosing where everything is perfect and everything is yours. This relaxation exercise can benefit you all day. Check your local library or book store for books, audio tapes, videotapes or films on relaxing and managing stress.

Laughter Is the Best Medicine

This is an old expression popularized by Norman Cousin's book “Anatomy of an Illness”, in which he describes his battle with cancer and how he “laughed” his way to recovery. His hypothesis and the subject of many studies suggest that there are positive effects to be gained from laughter as a great tension-releaser, pain reducer, breathing improver, and general elevator of moods. It sounds miraculous, is not proven, but studies continue. Groups such as the International Conference on Humor and many hospitals use “positive emotion rooms” and “humor carts”. In short, humor therapy is valuable and it helps us through difficult or stressful times.

So for yourself and your care receiver:

- try to see the humor in being a caregiver
- write on a card “Have you laughed with your care receiver today?” and place 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 humorous with your care receiver, a friend, or relative
- attend social groups where there is a lot of camaraderie, joy and fun
- be aware of how often you smile; it takes much less energy to smile than to frown

If you find that you are feeling hopeless, and humor or laughter is not affording you the up-lift you want, contact 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 overeat, use alcohol, drugs, or cigarettes to mask their difficulties. Such escapes do not solve the problem and are harmful to health. If the strain results in neglecting or abusing the care receiver, it is a very serious problem. It is also against the law!

Seek 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

Continue to 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 for a card game. It may not be easy to schedule these activities, but the rewards for having balance in your life are great. Taking care of yourself benefits you and your care receiver. Meeting your own needs will satisfy you and give you additional strength and vigor to bring to your caregiving tasks.

Chapter 5 – Caregiver's Bill of Rights

You have rights, too. Below is a Caregiver's Bill of Rights. After you read them, post and keep them fresh in your mind.

- Caregivers have the right to receive sufficient training in caregiving skills along with accurate understandable information about the condition and needs of the care recipient.
- Caregivers have the right to appreciation and emotional support for their decision to accept the challenge of providing care.
- Caregivers have the right to protect their assets and financial future without severing their relationship with the care receiver.
- Caregivers have the right to respite care during emergencies and in order to care for their own health, spirit, and relationships.
- Caregivers have the right to expect all family members, both men and women, to participate in the care for aging relatives.
- Caregivers have the right to provide care at home as long as physically, financially and emotionally feasible; however, when it is no longer feasible caregivers have the obligation to explore other alternatives, such as a residential care facility.
- Caregivers have the right to temporarily alter their premises as necessary to provide safe and livable housing for care receivers.
- Caregivers have to right to accessible and culturally appropriate services to aid in caring for aging care receivers.
- Caregivers have the right to expect professionals, within their area of specialization, to recognize the importance of palliative (ease without curing) care and to be knowledgeable about concerns and options related to older people and caregivers.

Caregivers have the right to a sensitive, supportive response by employers in dealing with the unexpected or severe care needs.

Chapter 6 – Personal Care

Personal care activities

Include: eating, bathing, shaving, caring for the skin, hair and mouth, and transferring (moving from chairs, toilets or bed). During the course of our daily lives these activities are taken for granted until weakness or a disability makes them difficult to accomplish independently or safely. Providing assistance requires knowledge, patience, skill and physical strength.

- Bathing: Bathing an older person may require strength, special equipment and skills. It is advised that caregivers ask the elderly person's doctor and/or physical therapist for special instructions on how to safely bathe the care receiver.
- Shampooing and Shaving: Visits to a barber or hairdresser are very positive experiences. Individuals who provide this service will often 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 medication to thin the blood (anti-coagulants, i.e., Coumadin) should use an electric shaver 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 bed linens 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 position of older people 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 onto other areas.
- 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 the appropriate supplement.

- Use mattress and chairs that are soft and form-fitting rather than rigid and hard. (Example: egg crate mattress and sheep skin). This spreads the weight over a larger skin area, decreasing the pressure under the bones.
- Encourage movement or mild exercise; this helps stimulate circulation which is good for the skin. 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 on anything that would interfere with good circulation, such as tight shoes, elastic cuffed socks or tight undergarments.
- Bony prominences are prone to skin breakdown. They are heels, feet, behind the knees, hips, buttocks, sacrum, elbows and shoulder blades. A special air mattress may be ordered by the doctor to 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 care receiver off the affected side.

Toileting

- Safety features in the bathroom, such as grab bars and raised toilet seats, make using the bathroom safer.
- A commode or urinal may be necessary when flexibility and distance to the bathroom are a problem. They may be especially helpful at night.
- Lack of control over bowel or bladder functions can be embarrassing and older people may try to hide it from caregivers and professionals. Be sensitive to the older person's feelings, and mention this to the doctor. Loss of bowel and bladder control is not a part of normal aging and often can be controlled.
- For the care receiver with bowel and/or bladder problems it may help to take them to the bathroom every 2 hours. Specialized programs exist to retrain a bladder and bowel function. Check with your doctor or nurse for a program in your area.

Constipation or Irregularity

Many elderly become constipated due to medications and inactivity. If your care receiver is experiencing this problem, the doctor or nurse can suggest a stool softener. Other important factors are:

- Eat plenty of fresh fruit, vegetables and foods high in fibers
- Drink at least 8 glasses of water a day

- Avoid constipating foods like cheese, rice, bananas, etc
- Exercise as much as is tolerated
- Be sure your doctor is aware of all the medications being taken

Assisting with Eating

Eating can be very time-consuming, especially if the older person 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 care receiver. Here are some suggestions for encouraging independence:

- Check gums for areas of redness. Dentures may not fit correctly and cause the family member pain when chewing.
- 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.

- Prepare finger foods which may be easier to eat than those requiring utensils.
- Encourage older people to use a straw, cups with 2 handles, or a glass with ribbed surface for independent drinking.
- If the older adult has limited vision, consistent place setting of food and utensils helps to know where to find silverware, beverage, etc. Using the "clock" method to locate food may be helpful; for example, "Your meat is at 9 o'clock, your potato is at 12 o'clock and your carrots are at 3 o'clock."
- Reminder: Treat older people who are being fed as adults, not children. Disciplining poor eating habits should be avoided. When they lack interest in food, try to learn the reason. For example, ask if they are thirsty or not feeling well, or if the food in not appetizing on this occasion.

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, therapist or attend caregiver training for specific techniques. In all cases, remember:

- When lifting, do not add your own weight to whatever you are lifting-get close and keep balance centered.
- Do not use weak back muscles to lift - use your leg muscles because they are much stronger.
- Do not twist when you are lifting - instead, change the position of your feet so that you face the older person, keeping your spine straight.
- Balance is vital - spread your feet to serve as a base for support.
- Your doctor can refer you to a physical therapist who can teach you to transfer safely.

Rest and Sleep

As we age, our sleep patterns change. The elderly require less sleep time. It takes longer for them to fall asleep. Also, awakenings during the night increase. Scheduled rest times are important. A few naps during the day can refresh and revitalize the care receiver. However, if you notice that your care receiver is sleeping for brief periods during the night, it could indicate a problem. Notify your doctor and discuss your concerns.

Tips for Encouraging Self Care

- Allow the care receiver to do as much as possible; provide only as much help as needed.

When older people do all or part of their own personal care, it is a form of 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 able to participate.

- Adapt the home to allow the care receiver to do more things. Install equipment such as grab rails in the bathroom, wheelchair-accessible sinks and mirrors, bath bench for the shower or tub, and lights with switches that can be easily reached.
- Seek the aid of therapists or nurses to teach you how to perform personal care tasks safely and effectively.
- Learn about the care receiver's disability and what you and others can do to help him/her function as independently as possible. If the older person cannot perform a certain activity, see if there is a part that can be done. For example, one might be able to independently dress the upper body if sitting, but require help dressing the lower body.

- Whenever possible, include the care receiver in making plans for his/her care. Take suggestions and feelings into consideration and encourage involvement in his or her own care. Sometimes, slowing the pace of an activity allows older people to do more for themselves.

Be aware of changes in the care receiver's health and abilities. Your plans for care will change as the care receiver changes.

Chapter 7 - Nutrition

Good nutrition is important in order that people live life to its fullest. Good nutrition is a balance of proteins, carbohydrates, fats, vitamins, minerals and water in the foods we eat. A healthy diet helps to (1) provide energy; (2) build, repair, and maintain body tissues and (s) regulate body processes.

When meals are eaten in the company of others, people not only benefit from the nutritious foods, but also enjoy the chance to socialize. This encourages good eating habits and promotes good mental health.

The table that follows summarizes essential nutrients (which you may also find listed on food labels) and their functions:

Nutrients on Food Labels and their Function

- Protein: For preservation and repair of tissue; formation of antibodies to fight infection.
    - Carbohydrates: For energy; fiber to help prevent constipation.
    - Fat: For energy; healthy body and skin.
    - Vitamin A: For healthy eyes, skin, hair; resistance to infection.
    - Vitamin C: For healthy gums, skin; healing of wounds, bones; resisting infection.
    - Thiamin (B1): For digestion; healthy nervous system.
    - Riboflavin (2): For healthy eyes, skin, mouth; use of oxygen from air.
    - Niacin: For healthy digestive tract and nervous system.
    - Calcium: For preservation and repair of bones, teeth; muscle contractions; blood clotting.
    - Iron: For building red blood cells to carry oxygen to all parts of the body.

To simplify daily meal planning, foods are grouped according to the nutrients they supply. Plan your diet to include the recommended number of servings from each group.

Adapting Meals for People with Dietary Restrictions

If an individual is on a special diet (low salt, diabetic or low saturated fat), the Basic Four Food Groups Guide (which follows) can still be used.

However, because diets are prescribed to control a specific medical condition, certain foods may have to be eliminated, modified in the preparation, or limited in their intake. It is important that caregivers obtain specific instructions from a registered dietitian or their doctor on which foods are allowed, how much, and how they should be prepared.

Since some foods or medications may interact with other medications and/or foods in a harmful way, check with the pharmacist as to restrictions in any medications' use before it is applied.

The Four Basic Food Groups

Meat Group: Provides protein, niacin, iron, and Thiamin-B1 (2 servings daily). Dry beans and peas, soy extenders, and nuts combined with animal or grain protein can be substituted for a serving of meat. 2 ounces of cooked, lean meat, fish or poultry have the same amount of poultry as: 2 eggs; 1 cup cooked dry beans, peas, or lentils; 4 tablespoons peanut butter; ½ cup cottage cheese.

Grain Group: Provides carbohydrates, Thiamin-B1, iron, and niacin (4 servings daily). Whole grain, fortified, or enriched grain products are recommended. 1 adult serving is: 1 slice bread; 1 cup ready-to-eat cereal; ½ cup cooked cereal, pasta, cornmeal, rice or grits; 1 small muffin or biscuit, 5 saltines, 2 graham crackers.

Milk Group: Provides calcium, riboflavin-B2, and protein (2 servings daily). Foods made from milk contribute part of the nutrients supplied by a serving of milk. 1 cup milk has the same amount of calcium as 1 cup yogurt, 1 and ½ slices (ounces) cheddar-type cheese, 1 and ¾ cups ice cream, 2 cups cottage cheese.

Fruit-Vegetable Group: Provides vitamins A and C (4 servings daily). Dark green leafy or orange vegetable and fruit are recommended 3 or 4 times weekly for vitamin A. Citrus fruit is recommended daily for vitamin C. 1 adult serving is: 1 cup raw fruit or vegetable, ½ cup cooked fruit or vegetable, 1 medium fruit, such as an apple or banana, ½ cup juice.

Common Problems Interfering with Good Nutrition

Illness, disability and depression can affect an older person's desire and ability to eat properly. The following suggestions deal with common problems that interfere with good nutrition.

When the care receiver says the food tastes strange, it might help to:

- Check teeth for tooth decay or gum infection
- Avoid alcohol
- Marinate meat, poultry and fish in sweet fruit juices, Italian dressing, or sweet or sour sauces
- Drink plenty of fluids or suck on candies to get rid of bad tastes
- Serve foods at room temperature or cold
- Try milk-shakes or cheese
- Use stronger seasonings such as basil, oregano, rosemary, tarragon, lemon juice or mint when cooking
- Try new foods.

CRAMPS, HEARTBURN, BLOATING

- Eat slowly
- Eat small meals frequently
- Avoid gas-forming foods, e.g., cabbage, onions, nuts, beer, cola drinks
- Avoid lounging immediately after eating; stand or sit upright for one hour after eating
- Avoid fried, greasy and heavily spiced foods
- Try bland, low-fat, easily digested foods
- Chilled antacid may help (CHECK with your doctor regarding the brand of antacid to use).

CONSTIPATION

- Take high-fiber foods and plenty of liquids
- Exercise
- Add bran when cooking or baking (1 - 2 tablespoons of bran for each cup of flour)
- Drink hot beverages which act as stimulants

DIARRHEA

- Eat small meals frequently
- Drink clear liquids
- Avoid high fiber and greasy foods
- Replace fluid loss with liquids between meals

NAUSEA & VOMITING

- Avoid unpleasant odors
- Eat small meals frequently
- Chew slowly and thoroughly
- Sip cool, clear liquids between meals
- Rest after meals with head elevated
- Avoid hot, spicy, strong-smelling foods or fried, greasy foods
- Try foods which are cold or at room temperature, and low-fat food
- Eat dry or salty food
- Try fresh air and loose clothing

DRY OR SORE MOUTH

- Drink plenty of liquids
- Suck on ice chips
- Suck on popsicles made of milk or non-acid juices
- Dunk or soak foods in liquids
- Use extra gravies, sauces, salad dressing
- Rinse mouth frequently
- Suck hard candies or chew gum
- Eat sweet or tart foods if no sores in mouth
- Artificial saliva can be used

General Tips for Helping the Older Person to Eat Well

- Plan meals and snacks to include the person's favorite foods
- Use a variety of foods from each of the four food groups
- Prepare foods that provide a variety of texture, color, and temperature
- Provide a pleasant setting, i.e., flowers, place mats, matching dishes, good lighting.

In addition to books, recipes and literature, the organizations listed below are valuable in providing tips, ideas, counseling, and reminders that you are not alone. They can help make the gradual transition to improved eating habits. Addresses listed were local San Diego. For same or counterparts in your locality check your telephone directories or contact the United Way, American Heart Association, American Diabetes Association, American Cancer Society, Arthritis Foundation, American Dietetic Association, and the United Ostomy Associates.

Chapter 8 – Medical Aspects of Caregiving

Overview

As a caregiver, you are in a position to help your care receiver along the road to good health care by encouraging routine physical examinations. You are valuable in helping the care receiver talk to their doctors and other medical personnel. You can follow through with their medical treatment at home.

However, it is important to remember that the primary responsibility for medical treatment rests between the doctor and the patient. If there is any doubt about what you should or should not do, the doctor should be consulted. You can help your care receiver to understand his/her medical treatment and encourage the care receiver to be involved in making decisions. In medical treatment, it is often tempting to decide what is best for the patient, but it is best to recognize the care receiver's need to choose. We all need control of our lives, and this is especially true for a person who needs the help of others. If there are serious concerns about decisions being made, caregivers should discuss the matter openly with the doctor.

Keeping Records and Managing Medications

- Caregivers can help older people 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. This may require getting Releases of Medical Information signed by the care receiver. You also should keep a list of all medications (both prescribed and over-the-counter) being used. The same medications that are helpful in easing pain, stopping infection, controlling heart rate and keeping people healthy can also cause serious problems.
- Because many older adults take several medications at one time, it is possible that these drugs can interact with one another and be a danger. If more than one doctor is prescribing medications, it is important to keep each doctor aware of the drugs that are being taken. You can keep them informed by taking all your drugs in a paper sack or a list of all your drugs to each doctor. Having one pharmacist that fills all of your prescriptions is a way to prevent taking drugs that interact and cause problems. Over-the-counter or non-prescription drugs also can cause problems. Talk with your pharmacist before using them.

- If you find the medicine schedule confusing or difficult to follow, ask your pharmacist about preparing all medicines in blister packs.

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 Pill Here)	Reason	Dosage	Take At...
Estrogen		Osteoporosis		Morning
Acetaminophen		Joint pain		Each meal and bedtime
Warfarin		Atrial fibrillation		Bedtime
Calcium		Osteoporosis		Morning

If your care receiver is taking several medications at different times throughout the day, it may be helpful to develop a second list to assist you 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. For medications taken several times a day, their names will appear several times on your list as in the example below:

Daily Medication Set-up

- Time of Day Medication is given, AM + PM
- List all Medications for Each Time

Morning

Noon

Evening

Bed Time

Choosing a Doctor

- If you don't have a doctor, choose one carefully. There are several referral sources you can utilize:

  1) a friend who is satisfied with his/her physician for a referral
  2) your County Medical Society
  3) Physician Referral Service
  4) A neighborhood hospital (some offer a physician referral service)

- The doctor is a valuable resource. If you are having a difficult time managing your care receiver at home, or an acute illness occurs, the doctor may assist with related health care concerns. Your care receiver may have to be hospitalized. The doctor may assist by making a home health care referral. Once hospitalized, the doctor can assist in placement issues or home health care upon discharge. If he/she doesn't offer it, you may request it.

- If you are dissatisfied with your doctor, consider:

  1. What do you want from your doctor?
  2. Are these wants realistic (e.g., cure of an incurable disease)?
  3. Have you discussed them with your doctor and/or staff?
  4. Do you have a primary physician (usually internist or family practitioner) who oversees your overall medical care? Often, sub-specialists such as cardiologists or orthopedists focus on one organ system, and do not try to coordinate the patient care.
  5. Do you keep your appointments?
  6. Do you take medications as prescribed, contact the doctor if you change, and discuss your concerns with him/her?

Remember, physicians are human beings, with individual personalities, enormous responsibilities, and only 24 hours in one day. No doctor will be right for all patients. Find a doctor whose skills and style of practice suits your current needs. All patients should have one physician to coordinate their care. Frequently changing doctors is likely to result in poor quality care of chronic or complex problems.

Older individuals with multiple medical problems or difficulties with memory or intellectual functions may benefit from a comprehensive geriatric assessment program. This guide identified one program in the San Diego area as the UCSD Seniors Only Care Program (SOCARE). Your physician or local Area Agency on Aging may have information on comparable programs in your community.

Arranging the Doctor’s Appointment

Some questions to ask when you make a first appointment:

- What are the office hours?
- How are the bills handled?
- Who will answer my questions if the doctor is unavailable? -- How does the office handle emergencies?
- How is co-payment handled?
- What hospitals does he/she go to?

On the first visit to the doctor, the patient's list of current medications (Table 4) and previous medical records should be given to 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, how bad they are

Reviewing this information before the visit will help. And remember, it is important that the patient have a chance to visit with 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.

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 problems that may arise

3) What to do in emergencies

Planning For Emergencies

Having an emergency plan is important, especially when a substitute caregiver occasionally takes your place in the home. (Post phone numbers for the following agencies next to your telephone or a conspicuous place where they can easily be seen by anyone. This sentence modified for readers outside San Diego County.)

1) The 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 phone number
6) The 24-hour number of the medical or oxygen supplier, if one is being used
7) The telephone number where you (caregiver) can be reached.

Remember, observe changes and signs of illness in the care receiver. They can help detect a medical problem.

But if any doubts about health arise,

CALL THE DOCTOR FOR ADVICE - DO NOT PROCRASTINATE!

Chapter 9 – Emotional and Intellectual Well-Being

Each human being is a combination of body, mind, and spirit; we should be aware of how these parts interact. For example, people may have powerful emotional responses while facing the many challenges which life presents. Thus, some may often appear cheerful and optimistic while others are anxious and unhappy. In later years, we usually continue our basic moods, but the ways we express our feelings often become more obvious.

Depression - Signs and Causes

In the midst of losses, such as physical changes, death of friends or loved ones and reduction of income, older people may begin showing signs of depression. Some things to look for are:

- inability to concentrate or make decisions
- lack of feelings of enjoyment, or enthusiasm even for doing those things that were favorites
- little interest in eating (causing weight loss) or changes in eating habits (overeating causing weight gain)
- lack of interest in being with other people, or loss of sex drive (libido)
- feeling unwanted and worthless, sometimes leading to the thought that life is not worth living
- 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 older 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 become forgetful and 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 care receiver have?
4. What are the opportunities for usefulness?
5. What kind of personal losses (death of friends, relatives, or pets) have there been?
6. Is the older person getting proper nutrition?
7. What kind of mental stimulation is the person getting?
8. Has there been a difficult adjustment following retirement?
9. Is the focus entirely on the past or is there some enthusiasm about coming events?
10. Is there a possibility of reaction to medications?
11. 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 some work from both the caregiver and the care receiver to change habits and routines. Prolonged depression causes biochemical changes in the brain, usually requiring treatment with medication. The doctor is a good person the contact to find help for treatment of depression. Other resources are County Mental Health Centers, psychologists, counselors or clergy.

Suicide Prevention

Suicide among the elderly is a significant and ever increasing problem. Statistics show that 27 percent of all suicides in San Diego County (1985-87) were committed by people 60 years of age and older. Nationally, elderly (65+ years) made up 12.3 percent of 1987 population and committed 21.0 percent of suicides. Elderly complete one suicide every 1 hour and 21 minutes, or each day 17.7 seniors committed suicide.

Unlike other segments of the population, the elderly do not often make threats or mention suicidal thoughts to others. Therefore, it is important that caregivers also know other warning signs:

- Depression - feelings of sadness, hopelessness, a sense of loss and statements as "Life isn't worth living" are common before a suicide
- Chronic or terminal illness
- 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, making out a will, make a plan for suicide, or write a suicidal note in preparation. They may purchase weapons or stockpile medications.

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

- 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 to the suicidal person 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 - make sure the suicidal person gets in contact with a professional counselor or other helpful person who will know what to do. Or have the suicidal person call suicide prevention/crisis intervention Hotline in your community. Telephone numbers for such local resources should be at the front of your telephone directory. A crisis counselor can help figure out the best way to handle the situation and give referrals to other resources.

Death and Dying Interventions Elderly terminally ill encounter anxiety and fear regarding death:

- fear of the process of dying (e.g. will there be pain?)
- fear of losing control (e.g. will I be at another's mercy?)
- fear of letting go (e.g. I can not leave family and friends to an uncertain future)
- fear of seeing how others will avoid me
- fear of losing my caregiver (e.g. will he/she be turned off emotionally to me?)
- fear of the unknown after death
- fear that my "life's script" has been meaningless, unfulfilled, a waste

You may wish to ease these fears through an open discussion of these fears and intervening:

- Regarding the death process, a "faith system" may be of great help; if you can get the person involved in his/her religious faith, the subject of death is well covered

- Regarding the fear of letting go and isolation, assist then person to get his/her "house in order”

This entails a will, funeral arrangements, burial plot, etc. Also attempt to have the person and family involved discuss the situation.

- Regarding meaninglessness of one's life, have the person do a "Life Script," whereby he/she writes all the good things done for others, all accomplishments, etc. Then discuss with the person that had he/she not been there to do what he/she did at that time, no one else would have, and society would have been the worse for it. So he/she did make a difference. Truly, no person is an island!

Promoting Emotional Well-being

It is important to help the elderly remain involved in decision-making as long as possible. You must stress that needing help with everyday activities does not mean that they 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 the right combination of giving just the right amount of assistance and no more.

Ways to promote good mental health in the elderly:

- 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, not as little children unable to think for themselves
- encourage movement and exercise
- help find ways to be as useful as possible
- strive to keep the lines of communication open

The Importance of Lifetime Learning

Research shows that reaction time may be slower in older people but they can still learn. Families and friends may need to be patient in waiting for responses. It is also important to remember that short-term memory may not be as good as it was.

The brain helps link people to the world. If we are able to process and understand what we see, hear and absorb from our senses, our experiences will become more meaningful.

Sometimes older people are incorrectly labeled as "senile"; the misconception is that they are no longer able to think for themselves. However, for the most part, older people continue to make good use of their creative powers, and as is true for all parts of the body, the brain usually will function better if it is used regularly.

Lifetime learning means exploring new ideas, whether this is from reading, listening to radio or television, trying a new hobby, or trying a new recipe. It can include lively conversation with friends and family. What it boils down to is a willingness to keep exploring the many adventures that life has to offer. The benefits of lifetime learning include more enthusiasm for life, less boredom and depression, increased feeling of self-esteem and self-respect, more interest in the surrounding world, and new ideas to share with family and friends.

Memory Problems

Memory loss can be one of the hardest problems for both the care receiver and the caregiver. Some memory problems are treatable, some are not. Therefore, it is important for the doctor to determine the causes of memory loss in the individual. 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 or accident resulting in injury to body, viral infections or other illness, or depression or other mental illness.

Sensory Problems

People who have losses in hearing and vision may have trouble understanding things consequently negatively affecting their emotional well-being. Basic aids to hear and see are vital. At times an older person may be cut off from the world because of wax in the ears or worn out hearing-aid batteries. Glasses may need to be adjusted or perhaps just cleaned. Good lighting, without glare, is important. Magnifying glasses or large print can make reading easier.

Confusion

For people who are confused, the following tips can be useful:

- Make changes in routines gradually
- Be clear about reminders for appointments or meetings
- Write simple directions in large, clear print
- Use large labels (words or pictures) on drawers and shelves to identify contents
- have clocks and calendars clearly visible and mark off passing days
- Make certain that medicine is being taken regularly
- Confused or forgetful patients must have assistance with their medications
- Encourage consumption of nutritious foods
- Encourage movement and/or exercise as this will increase circulation of the blood and help improve bodily functions, including the ability to think

Behavioral Problems

For people who are acting out, being disruptive, or have other undesirable behaviors, it is best to not antagonize or confront but to temporarily remove your presence from the person, giving the message that "I love/care for you but not this behavior".

Below are some suggestions to minimize undesirable behaviors:

1. Avoid confrontation. If the behavior deals with disrobing, offer brightly clothes which make the person feel good.

2. Don't argue. If the person becomes too agitated, change the subject/object to something completely different.

3. Reduce stimulation. Lower lighting, reduce noise (radio, TV) to soothing music, minimize items in the area to a few possessions known to the person, and avoid clutter.

4. Promote familiar objects, pictures.

5. Walk slowly with the person to reduce anxiety and stress the muscle tension.

Mental Stimulation

Because many older people enjoy recalling events from past years, families and friends should encourage the sharing of stories. Activities which stimulate the brain (visiting with others) can contribute to the goal of continued lifetime learning.

Often, older people can become happier, more productive individuals when they are encouraged to perform fun, brain-stimulating activities. The following activities are especially good for homebound elderly:

- 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 rearrange a family photo album
- volunteer, at libraries, hospitals, museums, schools, Retired Senior Volunteer Program (RSVP)
- bake for self and others
- 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

In addition, older people who are 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.

Chapter 10 – Legal and Financial Affairs

Older people 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. It is important to involve them whenever possible.

Compiling an Inventory

Develop an inventory which lists all assets and liabilities of the older person. The following items should be included: bank accounts, pass books, certificates of deposit, money market funds, stocks, bonds, precious metals, jewelry, real estate deeds, promissory notes, contracts, insurance policies, safety deposit boxes (including location of the key), and retirement or pension benefits. Location of the records for each asset and liability also should be included. 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 designated. If able, the older person should compile the list. If unable, a family member, attorney, banker, accountant or certified financial planner can help compile the inventory which should be copied and kept in a safe, obvious place, possibly with a relative or friend. It is important that the document be updated every year.

Managing a Will and Financial Affairs

An objective of financial and estate planning for older people is to plan for the orderly distribution of the estate upon their death, according to their desires. Consequently, it is important for people to have a will drafted, which incorporates the above inventory and states how property is to be disposed of upon death. Everyone over the age of 18 should have a will or a similar legal document.

If a person does not have a will, an attorney should be consulted immediately. Proper planning is essential and powers of attorney or trust agreements should be executed while a person is still competent. Otherwise, transfer of responsibility for management of the person's 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 person's assets, diluting whatever estate is left after death.

Remember, as caregivers 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 legal mechanisms available for surrogate decision making are: durable power of attorney (DPA), probate conservatorship, durable power of attorney for health care (DPAHC) (California only - check to determine if your State has comparable laws).

Durable Power of Attorney is a written legal document giving someone other that the “Principal” 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 can 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 caregiver and care receiver are urged to seek the advice of an attorney.

Probate Conservatorship or Conservatorship of Estate allows for the management of the Principal's money and other property when the Principal presently lacks the capacity to either decide or appoint another to decide financial decisions in his/her behalf. Court proceedings to designate a conservator are required. This is a difficult and extreme procedure but may be necessary if the care receiver is already incapacitated to the extent that he/she is unable to manage personal financial affairs.

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 gives someone other than the Principal authority to make medical treatment and health care decisions on behalf of the Principal for up to the maximum of seven years after the document is signed. It allows one to specify ahead of time how he/she wishes these decisions to be made. Wishes regarding extraordinary supportive care, including breathing machines and tube feeding, can be addressed in the Durable Power of Attorney. All adults should have a Durable Power of Attorney for Health Care.

Lantern-Petris-Short (LPS) Conservatorship

(California only - check for comparable laws in your State) or conservatorship of person is a court-ordered process which enables a person to get the psychiatric and/or medical care needed but by reason of mental illness is refused. The court determines if the Conservatee, in addition to receiving the necessary psychiatric treatment, may also retain or be denied the right to vote, possess a driver's license, enter into contracts, or refuse non-psychiatric medical treatment. The Conservator may be a relative, friend or an appointee from the Conservator's office. The Conservator may be given the right to require and authorize the conservatee to receive involuntary psychiatric and/or medical treatment and supervises and assists in making proper living arrangements, including placement in a Residential Care or a nursing home when indicated by the doctor. In order to start the process, one consults either with his/her attorney or calls the Office of the Counselor in Mental Health. An individual has to be adjudicated to be gravely disabled before being placed on an LPS conservatorship. Grave disability is defined as the inability to provide for one's food, clothing, shelter and proper medical care due to a mental disorder.

Selecting an Attorney

It is important to select an attorney who is knowledgeable in the areas needed (estate planning, will drafting, probate or conservatorship). Ask friends or other professionals for recommendations, or contact a Lawyer Referral Service, County Bar Association, or Senior Citizens Legal Services. Before agreeing upon a particular attorney, ask if he/she has previously done what you require.

Chapter 11 – Liability of Caregiving

Anyone who accepts the responsibilities of a caregiver must also understand that there are a number of legal duties or liabilities that come with it. Many states including California have passed elderly abuse laws. Caregivers are bound by these laws in two ways: not to abuse the elder person (physically, mentally or monetarily) and report any incidents of abuse or suspected abuse to (California residents only) the Adult Abuse Reporting line 476-6266 or 1-800-523-6444.

(Residents of states other than California: Check you local telephone directory for the Adult Abuse Reporting telephone number or contact your county mental health services for guidance)

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 care, failure to get care, and failure 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 of the person as is striking the person with the hand or with objects. Therefore, if you are contemplating becoming, or are now a caregiver, you must be ready 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 to personal caregiving and to seek help with this decision from a counselor or one of the resources available in Appendix A.

When is it Time to Stop Caregiving?

As we have stated repeatedly throughout this booklet, caregiving is a very stressful situation. Stress either causes or exacerbates some 70 to 90 percent of all medical complaints, including tension and migraine headaches, high blood pressure, asthma, nervous stomach, bowel problems, and chronic lower back pains. There is research evidence indicating stress plays a role in a person's 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 the above, it is extremely important that you learn to use various techniques for stress reduction (some are mentioned in this booklet), contact one of the professionals in Appendix A or come to the decision, both for your well-being and that of your care receiver, that it is time to stop caregiving.

Below are some telltale signs which can help you assess when you have reached this fork in the road; seek help professional help, utilize more stress reduction methods, or stop caregiving:

- snapping at the care receiver constantly even over little things
- being constantly irritated
- seldom laughing anymore
- feeling constantly tired or pressured
- losing sleep, failing to fall asleep for hours, sleeping restlessly all night long
- yelling or screaming, or having crying fits, or rages frequently
- withholding affection, feelings of goodwill from the care-recipient
- withholding food, baths, dressing changes, etc
- constantly blaming the care receiver for your being in this situation (his/her isolated caregiver)
- refusing to go out anymore, even for a walk because “he/she needs me”
- withholding expenditures for goods or services he/she needs because he/she is going to die soon and it is wasted money

While these are not exclusive, they indicate a classic picture of “caregiver burnout”. The treatment for caregiver 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 remain a full-time caregiver forever; the job is much too strenuous and stressful. When should you say “I’ve reached my limit - I can’t do this anymore”? Just be honest with yourself, and when that “limit” has been reached, STOP! Research alternatives, request help from qualified professionals, and rest easy, because you did the right thing! And you’re not alone in having to take a step back and seek help.

Chapter 12 – Choosing a Residential Care Facility

In making the decision to seek an alternate living arrangement for your care receiver you will first need to consult with your physician. The physician can be your best ally since most facilities require a current complete physical exam and the physician can assess the appropriate level of care your care receiver needs. This is important in order to determine which type of licensed care facility you will be seeking. These may include the hospital (for urgent problems), subacute care (for convalescence and rehab), skilled nursing facility, assisted living facility, dementia care residence, senior apartments, or even staying at home with home care.

Seek licensed facilities and agencies, since 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?

It is ideal if both you and your care receiver could preview a care facility prior to deciding. Both prior to and during the preview process you have the opportunity to further discuss your feelings in making the decision. Since you have many things to do during your visit, you will find the outing less stressful and easier afterward to evaluate if you organize your thoughts beforehand, write down the questions you wish to ask, carry this checklist during your visit and make notes while looking around and talking to different people. Some items you may want to cover during your initial visit to insure quality care are:

- Ask to see the facility license
- Ask to see the most recent State Survey report, if available
- Look closely at the building and grounds
- Talk to some facility residents
- Talk to the facility administrator who is in charge of daily operations
- Talk to some facility staff members
- Ask to see a copy of the Admission Agreement

In California, a booklet entitled “A Consumer's Guide to Community Care Facilities” details a 6-page checklist for facility visits. A copy may be obtained from: The California Health & Welfare Agency, Department of Social Services, 744 P Street, Sacramento, CA 95814 (916) 445-4500. Contact your local County or State Department of Social Services for a copy an equivalent document.

Chapter 13 - Conclusion

This handbook was originally made available from San Diego County through the efforts of many collaborators. I hope it will serve as a reference tool for the new and veteran caregiver. It can never be said often enough that that YOU, the caregiver, are incredibly important!

The welfare of another person, the care receiver, depends on you. If you are not in good health, the care receiver also may suffer. If you have taken on the role of a caregiver you have also accepted a special responsibility to take care of yourself. So, good luck and good caring (for both yourself and your loved one).

YOU, THE CAREGIVER, ARE VERY IMPORTANT!

Chapter 14 – Examples of Caregiver Resources

This Appendix lists examples of resources for the caregiver by county locality, resource title and telephone number. The specific titles of the activities and their telephone numbers would be of little use outside the county. For the purpose of this copy the resources were identified by functions as a guide for preparing a list suitable to your needs. Specific titles, locations, telephone numbers, times open for calls, etc., may be available from your County Mental Health Services, United Way directory, or telephone directory. An excellent resource would be the indices in the public and academic libraries in your city and county. The following examples include several not listed in the handbook:

- EMERGENCY (Large print. Post near telephone)
- Your physician(s)
- Ambulance Services
- Hospital to which care receiver would be taken
- Oxygen Support
- Suicide Prevention/Crisis Intervention
- Poison Control Center
- Pharmacist
- Police
- Fire Department
- Neighbors you can count on in emergencies
- Domestic Violence Hotline
- Elder Abuse Hotline
- E-mail: Samaritans (UK) Suicide Prevention
- E-mail: Survivors of Suicide (Australia)

General Information and Referrals

- Area Agency on Aging - Senior Hotline
- American Association of Retired Persons (AARP)
- Alzheimer's Association Help Line
- State/County Self-Help Center
- Medical Information Service
- Older Women's League (OWL)
- Senior Citizen's Centers (near your home)

- INTERNET/World Wide Net (WWW) (e.g. GERINET, HOSPIC-L, LTC-LIST, SeniorNet and AARP forums (America OnLine), Dr. Stall's WWW Home Page, various newsgroups dedicated to general health and well-being)

Specific Services

Aging Services

Legal Services

Adult Day Health Centers

Alzheimer’s Centers – Social Day Care

Senior Centers

Caregiver Support/Training Groups

(check with your County Mental Health Services)

Nutrition Information Centers

(e.g. Meals on Wheels)

Health Information

(Hearing aids maintenance, MedicAlert, prostheses maintenance and repair, etc.)

In-Home Care Support Service

(Homemakers, Hospice, Visiting Nurses, etc.)

Clergy

Chapter 15 – Additional Reading

A. Calder and J. Watt, **I LOVE YOU BUT YOU DRIVE ME CRAZY**, a guide for caring relatives, Forbez, Vancouver, Canada, 1981

D. Cohen and C. Eisodorfer, **THE LOSS OF SELF**, a family resource for the care of Alzheimer's Disease and related disorders, NAL Penguin, Inc. New York, 1987

Norman Cousins, **ANATOMY OF AN ILLNESS**, Bantam, New York, 1981

H. Edwards, **WHAT HAPPENED TO MY MOTHER?** Harper and Row, New York, 1981

D.R. Eyde and J. A. Rich, **PSYCHOLOGICAL DISTRESS IN AGING**, a family management model, Aspen, Rockville, MD, 1983

J. Halpern, **HELPING YOUR AGING PARENTS**, a practical guide for adult children, Ballentine, New York, 1987

Julie Tallard Johnson, **HIDDEN VICTIMS**, an eight-stage healing process for families and friends of the mentally ill, Doubleday, New York, 1988

N.L. Mace and P.V. Rabin, **THE 36-HOUR DAY**: a family guide to caring for person with Alzheimer's Disease, related dementing illnesses, and memory loss in later life, Johns Hopkins University Press, 1981

Jacqueline Marcell, **ELDER RAGE, OR TAKE MY FATHER… PLEASE!: HOW TO SURVIVE CARING FOR AGING PARENTS**, 2nd edition, Impressive Press, April 2001.

L. Mortain et al., **WHO CARES?** helpful hints for those who care for a dependent older person, U.S.C., Los Angeles, CA 1985

B. Shulman and R. Berman, **HOW TO SURVIVE YOUR AGING PARENTS**, so you and they can enjoy life, Surrey, Chicago, 1988

B. Silverstone and A. Burack-Weiss, **SOCIAL WORK PRACTICE WITH THE FRAIL ELDERLY AND THEIR FAMILIES**, C.C. Thomas, Springfield, IL, 1983

B. Sloan, **THE BEST FRIEND YOU'LL EVER HAVE**, Crown, New York, 1980

Updated! *Chapter 16 – Online Caregiving Resources*

Powerful Tools for Caregivers Online Course
abcdependentcare.com/docs/pto.shtml

The Caregiver's Army
caregiversarmy.org

National Alliance for Caregiving
caregiving.org

CareGiving
caregiving.com

New! **Caregiver Support Program**
(Jewish Community Healing Project, Buffalo, NY)
stallgeriatrics.com/jchp/

New! **CareConscious – Educating Family Caregivers**
careconscious.com