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Cares & Concerns

CAREBOOKLET  
For the New  
CAREGIVER

ELDER ABUSE IS AGAINST THE LAW. REPORT IT!

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# CAREGIVER'S CAREBOOKLET

## CARE AND CONCERNS FACING THE NEW CAREGIVER

### CAREGIVERS

There are some things in this life we are not prepared for in our maturing process, and becoming a Caregiver is usually one of those things. When faced with an aging or ill parent, we find ourselves with mixed emotions, physical limitations and changeable desires as to how to handle life's circumstances. We also find that Caregiving is not limited to the older generation, but can also apply to the necessary care of incapacitated children.

As there are only a few textbooks or reference guides to deal with the many facets involved with being a Primary Caregiver (in my view that is the individual who does the everyday care), accomplishment by the "experience method" ensues. The notes and information included in this Carebooklet are intended to only highlight the phases and some of the details that a Primary Caregiver must approach. It is the hope that the information provided is beneficial as a primer for your journey and experience.

The Caregivers involved in the care of any individual may be more than just of a medical nature. It is of the utmost importance that cooperation, communication and coordination be maintained by all the caregivers for the benefit and comfortable transition of the Caregiven. Create a Caregiving Management Team to cover all the facets.

## CARENOTES

The role of the Caregiver is one of constant change, as the needs of the Caregiven change, for the better or the worse. The relationship of the Caregivers to the Caregiven is very important, as the Caregiven (patient) must realize that the Caregiver is there to assist, not to serve; and requests made of them (the patient) are in their best interest and not given to harm them.

The better prepared the Caregiver is for the physical and emotional demands of the effort, the more effective in the effort. The family or other caregivers should be diligent in assisting the primary Caregiver. A sense of compassion (and a sense of humor) help everyone involved to enjoy a new and rewarding relationship with the Caregiven and each other.

## CONCERNS

As the Caregiver, you have the opportunity to see the patient every day, so your observations can be useful in the overall care of the Caregiven. A checklist of the important personal information of the Caregiven is helpful in dealing with healthcare offices; and a personal health log of the daily activities and conditions can be helpful to the doctors and healthcare aides. A checklist and log similar to the one in this booklet can easily be used, as well as a list of prescription medicines and dosage information.

In the following pages are notes of areas of concern to the Caregivers. As you read each area, you may find that there are many questions that you want to ask. There are many people willing to answer your questions in the different agencies available to you. It is suggested that you write down your questions so that you will not forget the most important ones. If you don't ask, they can't answer.

With the assistance of the checklist, prescription list and a daily log, should a medical emergency arise, you can be prepared with the necessary information and assistance for the emergency personnel and hospital staff.

**CAREGIVERS** – are the people involved in the care of an individual who requires assistance in their life, due to accident or the aging process and/or debilitating disease. The Primary Caregiver is normally thought to be responsible for the daily medical and dietary care of the Caregiven and is usually a spouse, adult child or relative that can take on the daily care and assistance of an individual, without payment for services. Other caregivers are usually other family members, doctors, or those named by a court to administer to the welfare of an incapacitated individual, (whether on a temporary or permanent basis). These individuals can be Primary Caregivers, but usually are the financial coordinator and/or hold the power of attorney to act on behalf of the Caregiven should the need arise.

HOME PREPARATION- should be considered as to the easiest and most utile way to care for an individual with limited capacity for the everyday living experiences.

Things as simple as furniture placement and door space/swing become important because of necessary accessibility for the Caregiver and the Caregiven. Little things can make a big difference in the care and handling of an individual. These things can also enhance a positive and cheerful attitude.

FAMILY PREPARATION- may seem to be unnecessary, but the family has to realize the changes and transition that their loved one is going to have to make. The family must realize that the caregiver, if not already one of the family, must somewhat become as one of the family; and are not household servants. They are there to assist in the care of their loved one. As the condition of their loved one changes they must adapt, and be willing to assist as much as possible; if only in cooperation and possible limited access to their loved one. They must remember, however, that their visits are important. Though perhaps sometimes limited, they should visit as often as is comfortable and convenient to the Caregiven and the Caregiver, while remembering the daily schedule of the Caregiven is important. They should not try to give orders to the caregiver for care, unless they are prepared to take over the responsibility of the daily Caregiver should the need arise. Family members should remember that most patients are excellent actors and actresses, and can appear to be better or worse than their actual condition, depending on what they want believed. Watch for game-playing of family against a caregiver. It happens!

PHYSICAL DEMANDS- for the Caregiver can change, depending on the mobility of the Caregiven. If there is a reduction in the mobility of the patient, the caregiver may find themselves lifting and handling the individual physically; assisting in rising/sitting, in and out of bed, walking, up and down stairs, etc. The Caregiver should be taught the proper lifting and assistance techniques. Improper handling can result in injury to the patient and/or caregiver. Check with the hospital Social Services or other healthcare agencies for possible course available. First Aid Courses usually include some basic instruction, and a Cardiopulmonary Resuscitation Course (CPR) can be invaluable.

EMOTIONAL DEMANDS- cannot really be anticipated, but only handled as required. Both the Caregiver and the patient will experience changeable emotions, based on the situation and events of the hour. The roles tend to change into the Caregiver becoming a parental figure. At all times, the Caregiven must be given the proper respect and attention to maintain their self-esteem. They have not become children, so don't treat them as such. Elder Abuse is against the law, report it to the proper authorities if it happens.

PHYSICIANS, SURGEONS & SPECIALISTS- make up a major caregiver's group. The list of doctors involved depends on the condition and level of care necessary for the patient. It is suggested that the Caregiver be familiar with the name and phone number of the primary physician and those

surgeons and specialists that may need to be contacted in the care process. A listing is suggested as noted on the Carenotes checklist for easy access to the needed physician or specialist.

HOME HEALTH AIDS- should be made available as required by the condition of the Caregiver. The medical industry is constantly finding new and innovative ways to help the physically limited to stay mobile for as long as possible. Things such as beds, bathroom accessories, canes, wheel-chairs, walkers have been designed that allow the patient greater freedom and self-reliance.

HOME HEALTH SUPPLIES-are those things that make the Caregiver comfortable in their general personal care; such as bed pads, adult diapers, deodorizers, dressings, clothing and shoes, and general medications. Innovative design is helping to maintain self-esteem and comfort.

HOME HEALTH CARE- is often described with more than one meaning. The two major meanings are an agency that performs personal and medically necessary procedures in the home of the patient as determined by the physician; and the actual functions necessary for the care of the patient who need assistance in their daily life to remain in familiar living conditions. A home health care agency is usually called in by the physician where the patient must receive medications and treatment or therapy by a licensed professional, but that can be performed in the home. This may include injections; medications and dressings; physical therapy; speech therapy; occupational therapy; and assistance by an aide where the physical limitations of the caregiver might warrant the need.

The caregiver usually assists the patient with additional bathing and personal care; tends to the dietary concerns; and arranges for the transportation for physicians visits or emergency situations. It is often beneficial if the caregiver can perform simple checks of the patient, such as blood pressure, glucose levels, and maintains general notes on regular intervals as to patient condition.

TRANSPORTATION- is usually required for visits to the physician and other appointments, as well as grocery store visits. The condition of the Caregiver determines the mode of transportation necessary. It is quite beneficial when the Caregiver can provide the necessary transportation and assist the patient in and out of facilities. However, when that is not possible, other modes of transportation may be necessary (cabs, emergency vehicles, and ambulance services), fees for some of which are not covered by Medicare or insurance. The Caregiver should try to remember their own physical limitations should an emergency arise and call for the proper assistance, rather than risk injury to themselves or the Caregiver.

HOSPITALS & INSTITUTIONAL CARE- when the Caregiver's condition requires the transfer to a hospital or institutional care facility, the Primary Caregiver becomes one of emotional support where possible. Entrance into one of the facilities is usually ordered by the primary care physician. Depending on the physical and mental condition of the patient the transfer may be to a hospital,

transitional hospital, convalescent center, assisted-living center of nursing home, or hopefully to return home for continuing care.

FINANCIAL AFFAIRS- of the Caregiven may be handled in some cases by the Primary Caregiver, or by another family member, attorney or court-appointed individual (if the condition of the Caregiven warrants). The Primary Caregiver must be aware of who the responsible party is for handling various financial matters, and which insurance policies are in force for emergencies and physician visits.

The Caregiven is best served when a trusted individual can act in his/her behalf. This may mean a power of attorney, or names being included on accounts so that their signature is recognized by the financial institutions. The individual should be aware of bank accounts, safe deposit boxes, stocks and securities, property holdings, other assets, income sources, living wills, funeral/burial plans, and insurance.

Because of our changing times, this is good advice for the elder citizen and the younger generation, as we cannot predict our mental/physical incapacitation. We all need someone that we can rely on for help should be faced with the situation.

LEGALPAPERS AND DECISIONS- should be discussed and understood early in the relationship of the Caregiven and the Caregivers. It is especially important in cases where the Caregiven could reach a point of being incapable of speaking or decision making. The Caregiven should make known verbally and in writing where possible to all involved with their care, their feelings on some very sensitive issues that may involve life or death decisions and directives. The caregiver should listen carefully to the wishes and directives of the Caregiven and follow them, whether they agree or not. The dignity of the Caregiven is very important in life and in death. The Caregiven should provide property and asset disposition wills where necessary, a health care directive outlining their wishes for their care, organ donor directives, deceased arrangement directives, living wills and authorization of a surrogate (or preferably a durable power of attorney) for the individual should the patient be incapacitated. If these things aren't prepared in advance, decisions may have to be made in a court of law by someone not familiar with the desires and wishes of the Caregiven. It's always better to know than to guess what is wanted so that it can be done within the limits of the laws. Most of the forms are available from a bookstore or on-line. Just be sure that you understand the requirements and that it is legal in your state.

PROGRAMS & INFORMATION SERVICES- are available to broaden the Caregiver's understanding of the Caregiven's changing health conditions; care of the Caregiver and the Caregiven; insurance programs and what the policies mean- Medicare, Medicaid, HMO's, Hospice, Medigap, and any other terms that have been dreamed up to apply to healthcare for the Caregiven. Organizations and associations dedicated to specific problems of the Caregiven can offer information along with programs that might assist in the care of the patient. These include, but are not limited to: Alzheimer Disease, Diabetes, Kidney Disease, Cancer, Parkinson's Disease ( to mention only a few).

The American Association of Retired Persons (AARP) offers a wealth of information for the Caregiver and the Caregiver and families to understand the transitions and changes for living, and area associations to assist where possible.

“The Merck Manual of Health and Aging” can be found in the local library that is informative on specific conditions, insurance programs, and some of the legal and financial concerns involved in healthcare, and an excellent resource list of phone numbers and addresses. It can also be purchased on line thru my site of [www.eldercaregiverinfo.com](http://www.eldercaregiverinfo.com) at Amazon.com, along with other Merck Manuals.

Theodore Miller’s book “The Day I Died” is a fictional story but with a lot of details on the benefits of organ donors and the harvesting sequence that is crucial for transplants to be successful. It can be purchased thru my site of [www.eldercaregiverinfo.com](http://www.eldercaregiverinfo.com) at Amazon.com.

Funeral homes can provide details of the steps to follow at the completion of the Caregiver’s journey. They include things like who to contact, how to handle arrangements, and a lot of details you never think of. It is helpful if these are discussed when the decisions can be made for the future and not the “right now” situation. Just ask for help. Search and you will find!

HOBBIES- are the unsung medicines as the longer the mind is kept sharp and the body able to participate, the overall health and attitude of the both partners in the care process is easier. It is in becoming idle that the mind turns inward.

Arts and crafts, sports and reading are the easy ones. My mother used crocheting and knitting to keep her arthritic hands more limber. My dad used gardening.

Family history in a family tree and the stories that are the family lore can refresh the spirit and a treasure created for future generations. When the older generations are gone we have no verbal or written history of family progression unless it’s shared by the ones who remember the truth.

There’s a lot of activities that can be considered hobbies, and if it works to keep us younger, than go for it. Don’t do discouraged. Do Determined!

ENCOURAGEMENT AND CONCLUSION – Now is only really the beginning for you the Caregiver and you the Caregiver. The relationship you enjoy will probably be shared the rest of your lives. A partnership in dealing with every day and a good sense of humor can make life’s changes easier to accomplish the best possible travels down this path of caregiving.

Share what you learn with others that are taking the same path, you might make their transition a little easier, as hopefully this booklet has made it a little easier for you. Share your experiences with the author of the booklet, so greater information can be shared in future editions. To say that you could “write a book” on the subject is a truth, as after you experience the adventure you will be well qualified to add to the cares and concerns of the caregiver.

It is only in having experienced being a Caregiver that these Cares and Concerns have been offered to shed a little light on your new path. It is hoped that this booklet has given you insight and a beginning for your path of Caregiver or Caregiver. Life is short, but death is but a temporary parting for some, but caregiving is daily; often twenty-four hours a day. Do it in love, that the load might be easier for all.

Vicki Risener was asked what qualified her to write this booklet. Her response is that when you have experienced it twenty-four hours a day for several years, you are qualified beyond any educational training. Compassionate physicians, excellent hospital staff and social workers and cooperative healthcare and insurance agencies make a world of difference. Sometimes it is the warm and friendly attitude toward them that helps in gaining their help. Hopefully the reader can gain through this experience.

Thank You for your interest in this Carebooklet. Visit our website

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