

# SINCE YOU CARE

A Series of Guides from **MetLife** in Cooperation with the National Alliance for Caregiving

## Becoming An Effective Advocate for Care

### About the Subject

Now at the beginning of the 21<sup>st</sup> century, we are more than ever a nation of caregivers. As Rosalynn Carter has said, “There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.” Extraordinary advances in medical care allow people with significant health problems and disabilities to extend their lives for many more years than ever dreamed possible. Treatments for both physical and mental illness have improved. Nursing and rehabilitation as well as a variety of social and psychological services and community based programs have been created to assist the chronically ill, the disabled and their family caregivers.

Yet, despite the many changes in health care delivery, caregivers



**MetLife**

*Caregivers face many challenges as they search for information and make decisions about how best to provide care to their loved ones. To help meet their needs,*

*MetLife offers SinceYouCare® — a series of guides which provide practical suggestions and useful tools on a variety of specific care-related products.*

often experience stress and frustration in trying to obtain adequate help and care for their loved ones. Services are not always easy to find and access, and information is not always readily available. For caregivers, being an advocate is one of the most important and often most challenging roles they will assume in trying to best meet the needs of the person to whom they are providing care.

## Things You Need to Know

It may seem difficult to find the information, guidance or help you seek as a caregiver. There are multiple reasons why and many are beyond your control. If you understand the realities of the situation, you will reduce some of your frustration and then find you are more successful in advocating for what you need. As a caregiver, you are working within a health care service system that is complex and often fragmented. Varying sets of instructions and opinions from physicians, insurance companies, media and other professionals may cause confusion. The person you are helping may have chronic health problems and complex treatments that require costly care. There may be a shortage of workers such as nurse's aides and companions in your area to

assist those who need care and assistance with daily activities such as bathing, dressing, shopping and housekeeping. As a family member you may find yourself responsible for locating, organizing and providing care, a role you were not expecting and in which you may, at first, feel inadequate. Advocating, like caregiving itself, is a process, not an event. We learn from each experience along the way. Knowledge, confidence and skill will come to you step by step. Feeling capable, competent and effective in advocating takes time.

### General Guidelines for Advocating

To help yourself be an effective advocate for someone you care about, consider the following general guidelines which can be applied in many caregiving situations and care settings:

- **Determine what information you need; explore one topic at a time.**  
The kinds of information a caregiver may need are numerous and may include, among other things, medical, legal, financial and insurance issues, community resources, housing options and care choices either at home or in a facility.
- **Learn the language and definitions of care.**  
Health care facilities, insur-

ance companies, pharmacists, health services personnel and physicians often speak a language unfamiliar to many. To improve your ability to find answers to your questions and obtain appropriate care for your family member, you will need to speak in a way that the providers can hear.

- **Learn what questions to ask and be prepared.**  
Decide what information is most important to you and ask those questions first. Write down your questions prior to any conversation. Write down the responses you receive to your questions as well.
- **Learn how to ask.**  
Be concise. Phrase your questions clearly so you get the information you want. First state what you need to know and then why you need to know it.<sup>1</sup>
- **Be persistent and follow up.**  
Multiple phone calls may be required to find the information you want. Sending a letter or an email is another method to get what you need. Do not give up. Repeated attempts do produce results.
- **Write things down.**  
Do not assume you will remember all you have been told. Effective advocating requires attention to facts and details. Keep a log of contacts, phone

numbers, names, dates and information obtained. Keep a notebook so you can find the information you have received.

- **Determine your strengths as a caregiver and the strengths of your family member.**

What things can you realistically do and what activities can the person you are helping perform? After you decide what each of you can do, determine what kind of help you need from others.

- **Develop a plan of action.**

To get what you need, take one step at a time. Set realistic goals, that is, ones you feel you can achieve. Each piece of information you receive helps in the decision making process.

- **Form a care team.**

Your team can include health care workers, volunteers, members of your faith community, family, friends, co-workers, community agency personnel, drivers, care managers and/or visitors. Recognize that help comes in many forms, sometimes from sources you least expect.

- **Communicate with your family member.**

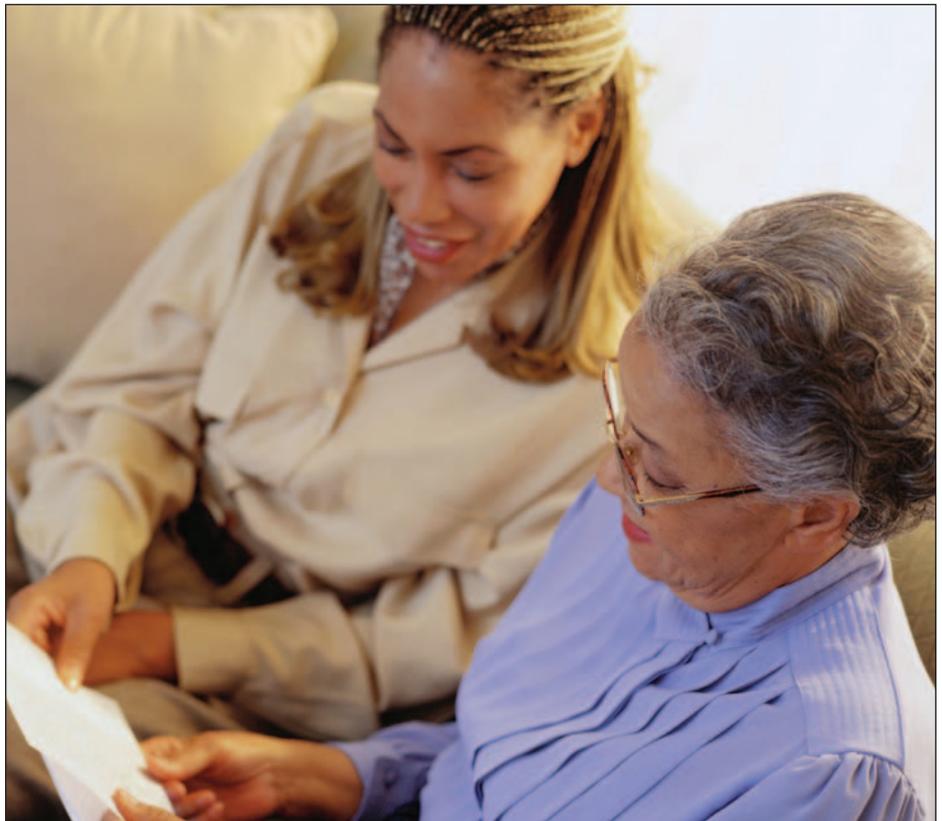
Remember the first rule of caregiving: include care recipients to the fullest extent possible in conversations and decisions affecting their lives. Keep in mind your family member's wishes as you work to advocate on his or her behalf.

- **Do not compare yourself to any other caregiver.**

Some emotions, frustrations and satisfactions of caregiving are experienced by many caregivers but each caregiving relationship is unique. Caregivers' abilities, skills, commitment, responsibilities, personal feelings, cultural expectations, mental and physical health, finances and overall circumstances, vary markedly. Give yourself credit for what you are doing.

As you adapt the above general guidelines to special situations and circumstances, keep in mind an underlying reason for your advocating activities: the desire for respect, comfort, safety and

dignity for the person you care about. You and your family member are central members of the care team. Your points of view are valuable, important and need to be heard. There are a number of specific situations or circumstances where you as a caregiver may need to serve as an advocate when caring for a family member. These include talking with physicians, communicating with insurance company personnel and speaking with a variety of health care providers when your loved one is in the hospital, receiving care at home or in a nursing home or assisted living facility or considering or receiving hospice care. Each of these specific situations will be discussed below.



## Talking with Physicians

Talking with a physician about the condition of someone you care for is sometimes difficult. Not only may doctors speak a language different from what we generally use, they also approach the patient's condition from a different point of reference. Because of the multiple demands on their time, physicians today are often forced to spend less time with each patient, when what most family caregivers and patients need is more time to understand the nature of their illnesses, treatments and care options.

To make the most of your brief encounters with physicians:

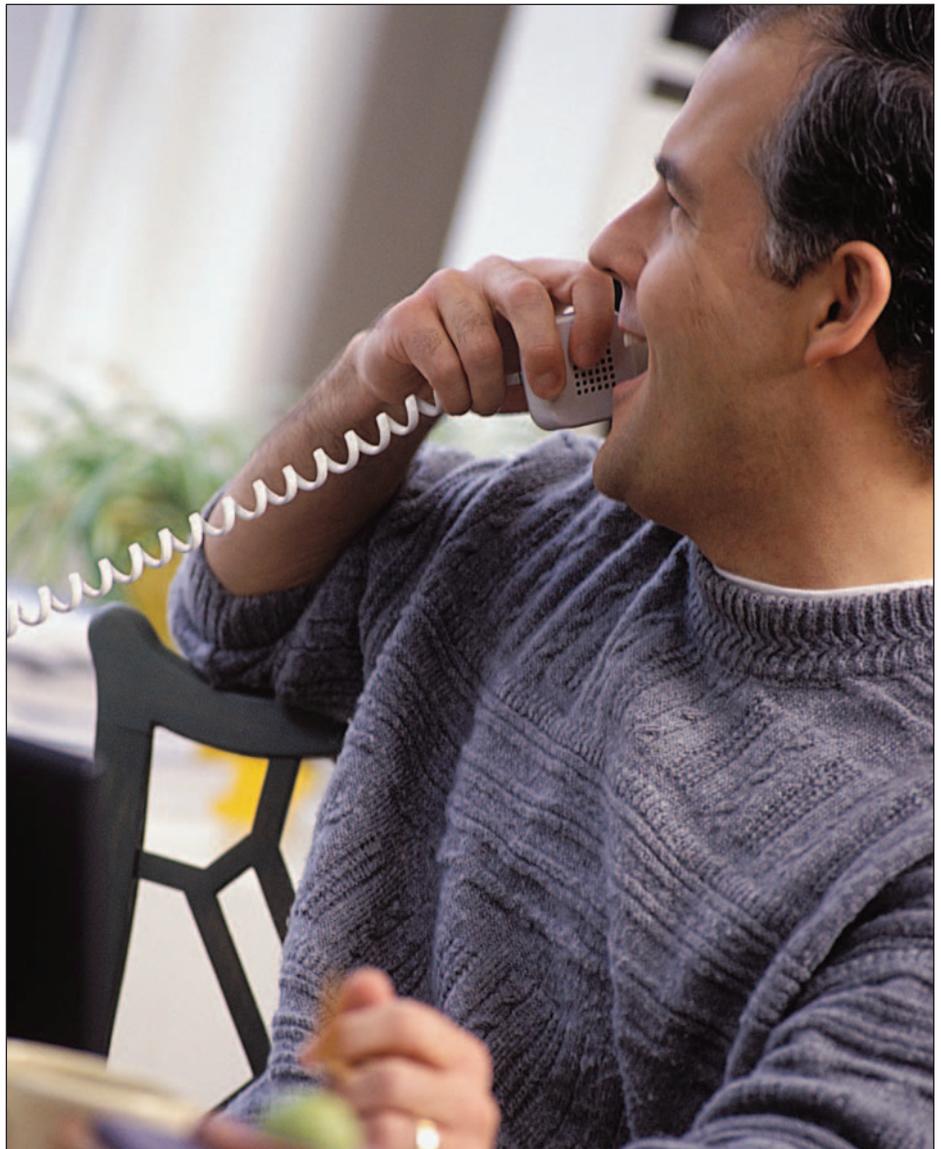
- Be prepared. Make a list of your concerns and specific questions prior to a conversation.
- Share your point of view. Physicians will not know what you think or want to know unless you say it aloud.
- Clearly state your reason for wanting to talk. Ask your questions. Stick to the point. Try not to wander in your conversation. Focus your conversation on what you need to know now.
- When you hear something you do not understand, ask for clarification.
- Avoid assumptions. Do not jump to conclusions. Allow the doctor to finish speaking and listen to what is being said.

- Consider having another family member or a friend join the conversation. It helps when two people hear the same information. Sometimes we do not correctly recall what was said, especially when we are upset.
- If you cannot write down what is said while the doctor is speaking, jot notes to yourself immediately after the conversation.
- Ask the physician to put in writing any instructions, explanations,

tions, resources, medications or information that is important to your loved one's care.<sup>2</sup>

## Communicating with Insurance Company Personnel

Gone is the era when one could ask a physician, hospital discharge planner, visiting nurse or admission department member whether a particular health insurance plan covers specific costs and for how long. Health insurance coverage



is now extremely varied; there are no standard answers. It usually falls to patients and/or caregivers to research the answers to their questions. Plan in advance for any encounter with insurance company personnel. These conversations usually take place on the telephone.

- Make these calls when you are not extremely rushed. Most calls take time. Expect you may go through automated telephone menus, be placed on hold or have your call transferred from one person to another before you reach the person able to help you. Be patient.
- At the beginning of the conversation, ask the name and phone number of the person you are speaking with in case you are disconnected and need to call back.
- Before you place the call, have in front of you the name, date of birth, insurance policy numbers for the insured person and any bills or explanation-of-benefits forms in question.
- State clearly and concisely your question or concern, what you need to know and what you expect from the person answering your call.
- Be considerate and polite but be assertive; you are the customer.

- Keep good notes - the date of the conversation, the name of the person to whom you spoke, what was said. If there is something you need to follow up on, do it as soon as possible.
- Call again. Write letters. Send emails. Do whatever it takes to get the issue resolved or questions answered to your satisfaction. Keep a record of all written correspondence and phone calls in your notebook. Persistence pays off but it does take time.<sup>3</sup>

## **When your Family Member is in the Hospital**

When an individual with chronic illness and either physical or cognitive limitations needs to be treated in a hospital, it is important that attention is given to the ongoing difficulties and limitations this person may have as well as the specific problem for which he or she is hospitalized. The failure to recognize and attend to these ongoing needs may complicate recovery or lead to additional problems. For instance, a person with limited mobility could develop skin breakdown if he or she is bedridden and attention is not paid to the need to either turn the person in bed or get a special mattress. An individual with Alzheimer's disease may become more confused in the hospital. He or she could potentially wander or

fall and get hurt getting up during the night in unfamiliar surroundings. You as a caregiver can help the hospital staff to recognize your loved one's needs beyond the immediate problem which led to the hospitalization.

Understanding the language and operation of a hospital may at first seem daunting. You will learn quickly by not only keeping notes of what you are told but also by keeping track of what you observe about the way things are done. Find out whom to ask for updates about your family member, about hospital procedures and then be sure to ask your questions. You will also discover with whom to share important information you have about your family member.

You may also be able to get valuable information from the staff. For instance, the nurse may know the time your family member's doctor usually makes rounds. This is helpful information if you would like to speak with the doctor about your loved one's condition. When the doctor is visiting with your family member, he or she will have all of the information from the chart, will be able to check on specific concerns you may have and evaluate any symptoms you have observed that may be a worry for you. This is especially important if your loved one

is unable to let the doctor know how he or she feels.

When a family member goes into a hospital, if you have been taking care of her or him at home or know his or her routines at a nursing home, assisted living facility or in any other living arrangement, it is important for you to share with hospital staff information you have that could be important during the hospital stay. Be sure to tell them about any limitations in the person's hearing, vision, ability to move around, capacity for self-help. Make them aware if your family member has cognitive problems which may interfere with his or her ability to follow directions or call for help in an emergency. Let them know about food preferences, allergies and/or any other things that are useful for them to know about your family member. Your input can assist the staff in providing the best possible care to your loved one and help to prevent problems which could delay or complicate his or her recovery.

## Getting Ready for Discharge<sup>4</sup>

Hospital care is usually for a brief period of time. Patients do not stay in hospitals until they are fully recovered or able to function as they did prior to admission. Patients only stay in hospitals until

their conditions are considered medically stable and therefore no longer in need of the level of care provided in hospitals. What is determined by physicians and insurance companies as medically stable establishes the timing of a patient's discharge. Patients' and caregivers' opinions about the right time for discharge may differ considerably from what actually occurs.

- Every hospital has a designated discharge planner responsible for planning a coordinated, smooth move for a patient from the hospital to another place of care. The title of the person may differ; it can be a nurse, a social worker or other health professional but the function remains the same.
- Since hospital stays are often short ones, the discharge planning process should begin as soon after admission as possible to avoid making major decisions under extreme time pressure.
- Find out who the discharge planner is for your loved one. Contact that person and set a specific time to talk.
- As an important member of the discharge planning team, you have knowledge that no one else on the team has. If your family member had been receiving home health care services prior to hospitalization and you want, or you do not want, to use the

same agency when he or she returns home, let the discharge planner know.

- If your family member has been receiving care from someone he or she trusts and likes, it is important to do what you can to be certain that care provider is not forgotten in the discharge plan. In addition to speaking to the discharge planner, you may want to call the agency, if the person comes through an agency, and let them know about the impending discharge and your wish to have the same person if at all possible.
- Determine how care outside the hospital will be paid for. Will insurance cover any or all of it? What will be the out-of-pocket expenses?
- If care in a nursing home or rehabilitation facility is needed after discharge, the discharge planner can make the referral and arrangements. If time permits, you may want to visit any facilities you are considering to evaluate whether you feel they will meet your loved one's needs. Be prepared that the facility you would most prefer may not have beds available at the time of your loved one's hospital discharge. Nursing homes often have a limited number of beds that are used for short-term rehabilitation

following a hospitalization. If your first choice of a facility is not available at the time of discharge, you can always consider a transfer at a later time should your family member not have his or her needs met at the facility to which he or she is admitted from the hospital. Additionally, if a longer or more permanent nursing home stay is required and your loved one wishes to move to another facility, you can always make a change when a room becomes available at the facility he or she would most prefer.

- The discharge planner can provide assistance with the admission process to a nursing home and arrange for any specialized transportation which may be needed following a hospital stay. However, you may want to make calls yourself to find out what may and may not be covered by your family member's insurance, what the full cost of care will be, what proportion will be out-of-pocket and what the admission requirements are.
- If your opinion about discharge plans differs from the hospital team members, share your thinking with them. Try to remain calm as you state the facts from your viewpoint. Every hospital should have a Patient Advocate available to help you with any really difficult situation.



- When speaking with the discharge planner, ask about new needs your loved one may have. Do you as the caregiver need any training prior to discharge? You might, for example, need instructions from a physical therapist if your family member needs more help with daily activities.
- Make certain you are aware of any medication changes. Ask the discharge planner to write down the medications, the doses, and when they should be taken. If you are unfamiliar with any of the medications, ask what they are for and what the side effects are. If the discharge planner is unable to answer

these questions, you may need to speak with the nurse on the floor or your loved one's doctor. Also, if there are medications your loved one took before coming to the hospital and they are not on the list, ask why they are missing. Don't assume they have been stopped unless you confirm it. They may have just been forgotten. It is best to have the hospital staff check whether or not the medication should still be taken prior to discharge from the hospital.

## When your Family Member is Receiving Care at Home

Home health care may involve many kinds of helpers: nurses (RN or LPN), nurse's aides (certified nursing assistants, home health aides), homemakers, physical, occupational or speech therapists, social workers, chaplains, psychologists, volunteers and others. Home health care providers who are professional and considerate always remember they are guests in the home and behave accordingly.

When care begins:

- Find out the name of the person at the agency whom you should contact and the best time to do so when you have information to share or questions to ask. Usually the home care nurse is the main contact, responsible for coordi-



- nating the team of agency personnel in the home, for establishing a plan of care for your family member and the person to call should you question the type or quality of care being given.
- Let the nurse know how you want to be involved with the care provided. Find out what information the home care team needs from you to help them give care to your loved one and support to the family.
- Ask to be part of the periodic care planning conferences or discussions that are often

required by regulations and are an essential part of quality care.

- Establish a system of communicating with the nurse and other helpers who come into the home. Having a written communication log, that remains in the home, can be one effective method for assuring accurate, two way transmission of information.
- The team member who often has the most personal and sustained contact with a patient is the home health aide. Learning to speak and work effectively



with that person and his/her supervisor is key to receiving the kind of care you desire for your loved one.

- Make certain you leave emergency contact information with your phone number(s) and that of another family member/friend if possible who can be contacted in the event of an emergency.
- It is also important to have a document available to all care providers which lists pertinent information about the family member for whom you are caring, including whether he or she has a

living will (copy should be available to provide to emergency personnel), allergies, medications, health problems, preferred hospital, family contacts and physician information in the event that he or she should need emergency care. The sheet can be provided to emergency personnel.

- Do not be afraid to ask questions or voice concerns with the supervisor if you feel you loved one's care needs are not being met.
- Always keep care providers updated on any changes in your loved one's condition or medications.

### **When your Family Member is Receiving Care in a Nursing Home or Assisted Living Facility**

Your family member may receive care or other assistance in different places at different times. When considering a move from one care setting to another, particularly to a new living environment, it is usually advisable, if possible, to visit the residence prior to making a decision. Some caregivers prefer to make the initial visit without the family member, then return for another look with the person who will be living there. Once a place has been chosen, your advocating skills are critically important during the transition period. Do not assume that information about

your family member's health conditions, personal likes, abilities or style of living have been passed along to the staff at the new site, even if you are told they were. It is better to give information twice, particularly about medications and the person's abilities.

With any move, there is always a period of adjustment. Give your family member time. Have realistic expectations. Most people do adjust with understanding and encouragement. Extra help can be given to those who require additional support to adjust.

When your family member moves to a residential facility, there are a number of things you can do to make a positive difference in the kind of care she/he receives.

- Learn the personnel structure of the facility and the name of person(s) to contact for giving and getting information about your family member.
- Develop good communication with staff. It is helpful to get to know the head nurse on the floor or wing where your loved one is residing as well as the nurse on the evening shift. Also introduce yourself to the social worker and other members of the care team including the therapists and nursing assistants who are caring for your loved one.

- Find out the procedures for sharing your concerns.
- Be sure to praise good work and show appreciation to staff.
- Visit on a regular basis at different times of the day if possible.
- If you live at a distance, maintain regular telephone communication with a staff member familiar with your loved one's care. Be certain to also identify an alternate staff member should your usual contact person be unavailable.
- Attend care planning conferences or ask for one if you feel it is needed.
- Don't be afraid to speak with the appropriate staff if your loved one expresses any concerns about the care he or she is receiving, if you feel your loved one's needs are not being met or if you feel there are specific things that need to be done for him or her.
- Let the staff know if you see changes in your loved one that concern you.

Individuals whose families are involved in a positive way generally have higher morale and receive better care. You are the link, "the personalizer," the one who can assure that your family member is recognized, known and treated as an individual.

## **When Your Family Member Has a Terminal Illness**

Hospice is a philosophy of care. By definition, hospice/palliative care is a specialized way of treating people with terminal illnesses. It is care designed to achieve the best quality of life for individuals at the end of life by controlling their pain and other symptoms and maximizing their ability to continue doing things that give meaning to their lives. A hospice program assists both the individual in need of care and his or her family. Medical treatment of the underlying life threatening disease may continue even as a person receives palliative care.<sup>5</sup> Hospice care usually does not include active treatment of disease.

Hospice and palliative care are provided in hospitals, long term-care facilities, assisted living residences, hospice facilities and/or at home by a specially trained team of caregivers. The team may include physicians, nurses, physical and occupational therapists, chaplains, trained volunteers, pastoral care workers, nurse's aides, homemakers, social workers, psychologists, dieticians, transportation personnel and pharmacists.

End of life decisions related to treatment and care are rarely clear cut and are often made in the

midst of multiple emotions and opinions. Physicians, nurses, social workers and clergy can help the caregiver, the care recipient and other family members sort out or clarify the decisions to be made. Prior to making a decision about hospice care, it may be helpful to ask the physician what the likely outcome of this illness is and what the probable consequences of a certain treatment plan are. You can request in this situation, as in most others, a second opinion. You and your loved one should openly explore all of your questions and concerns regarding choosing to enter hospice care with professionals who can provide you with the information needed to make an informed decision to best meet your loved one's needs and wishes.

- Making these decisions is best done through conversations and dialogue with all of the people involved, most importantly, the individual facing a terminal illness.
- Consider what your loved one wants and what is in his or her best interest. Wherever possible involve him or her in all discussions and treatment decisions.
- Your loved one, along with you and other family members, should be the ultimate decision makers in this situation.

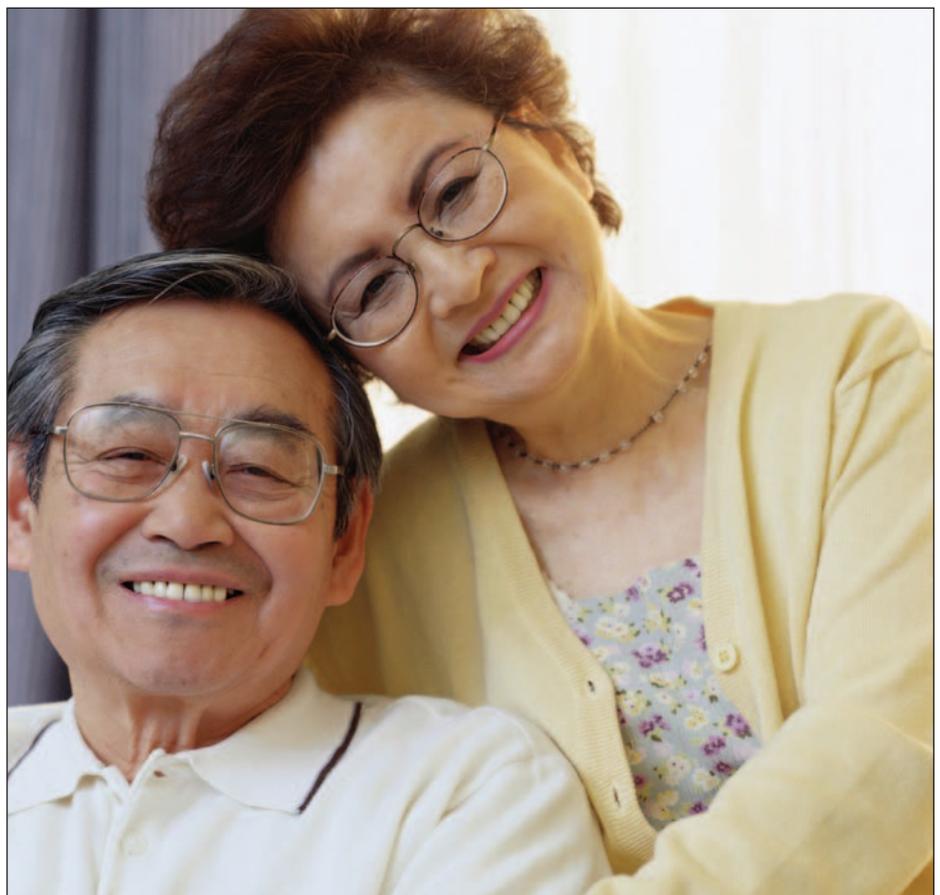
## Helpful Hints

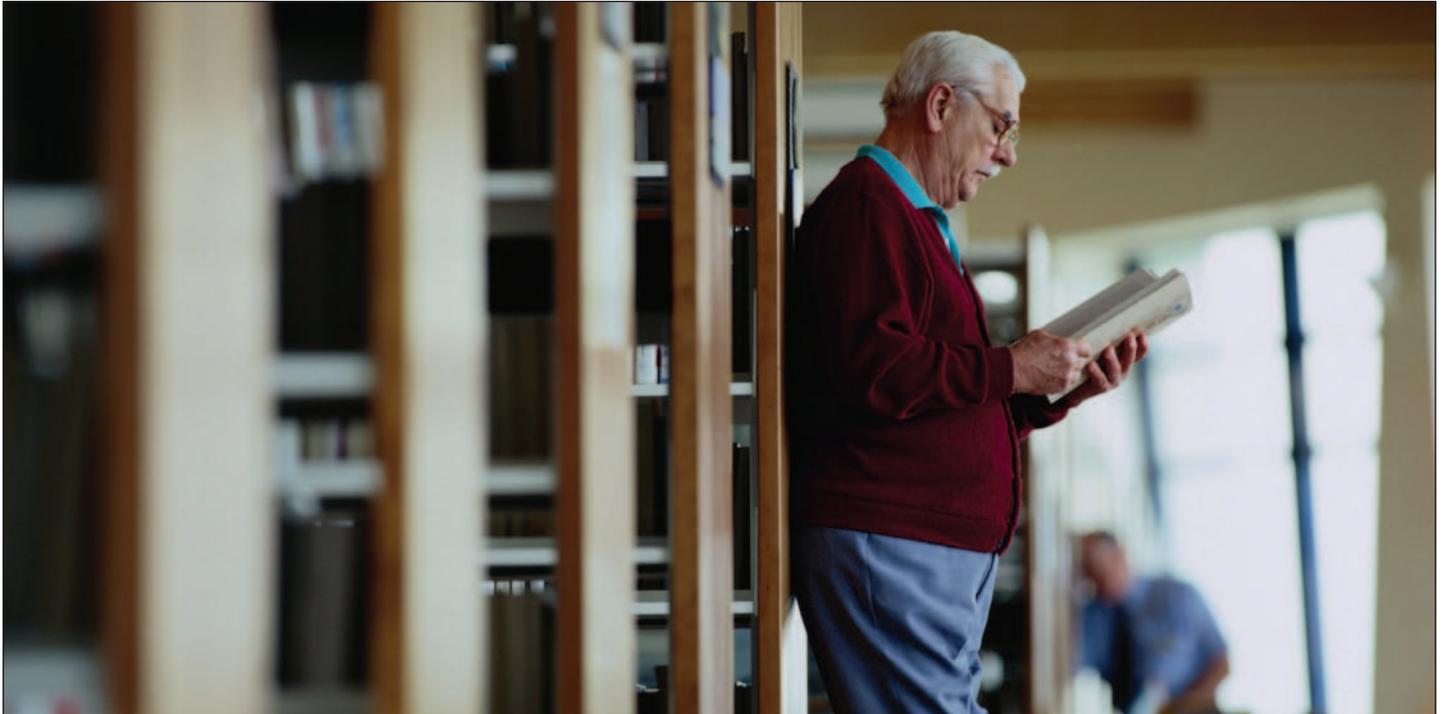
- Current privacy laws may prevent you from obtaining information related to your loved one from health care providers unless your loved one has given you authorization to do so. If your family member is able to make decisions and wishes for you to advocate on his or her behalf and to have access to insurance and health care information, he or she will need to sign authorizations which allow health care providers to share information with you.
- Your loved one should also consider consulting an elder law attorney to discuss options which will allow him or her to:
  - make certain his or her wishes related to health care decisions are documented and
  - appoint someone to act on his or her behalf regarding health care matters if he or she is unable to do so at some future time.

This would include such things as completing a living will and appointing a durable power-of-attorney/health care proxy for health care matters. Your loved one should additionally consider a durable power-of-attorney for financial matters so that you or someone else that he or she designates can complete financial

transactions on his or her behalf when he or she is unable to do so. This might include receiving and cashing claim payments to cover health care expenses and being able to manage your family member's income to meet his or her living and health care needs appropriately. It is important to recognize that these legal documents must be completed when an individual has the capacity to make such decisions. If, for instance, someone has Alzheimer's disease, he or she should consult an attorney early in the illness while he or she is still able to understand and make clear his or her wishes.

- Always remember, the knowledge you possess about your family member's treatments, daily functioning, personality, lifestyle, values, culture, beliefs and preferences, when shared, can help improve the quality and the safety of the care received.
- Don't be afraid to ask questions or let health care professionals know when you have concerns about the care he or she is receiving or changes in his or her condition. Sometimes people are anxious about questioning health care professionals. You, as the caregiver for your family member, are an important part of the health care team





and a resource for others who provide care to him or her. If you do not speak up when you feel there is a problem, the rest of the team will assume everything is going well.

- In any conversation you have with health care staff on behalf of your loved one, regardless of where it takes place, try to remain calm and confident that what you have to say is important to the care he or she is receiving. Feeling angry or helpless at that moment will only get in your way. Remain polite, positive and open in all discussions.
- You may want to consider a caregiver support group. It is often helpful to discuss your concerns with others in a similar situation. They may have suggestions from

their experience which will help you in your efforts to advocate for your loved one. You can usually find out about groups in your area from the local area agency on aging or you can contact the Eldercare Locator which is listed in *Resources to Get You Started*.

## Resources to Get You Started

### *Books and Publications*

**The Caregiver Helpbook: Powerful Tools for Caregiving**  
This book seeks to provide guidance and support tools for caregivers in the realms of personal stress, communication, boundaries, seeking help, dealing with

the emotions of anger, guilt, etc. Schmall, V.L. PhD, Cleland, M. R.N., Sturdevant, M. RN, M.S.W., L.C.S.W. (2000). Legacy Health System 1st Edition, \$6.31, ISBN: 0967915546.

### **Complete Eldercare Planner: Where to Start, Which Questions to Ask & How to Find Help, 2nd edition**

The author draws upon her years of consulting experience to provide caregiver support and precise, practical and accessible caregiving advice. She provides a step-by-step approach to many areas of elder care. The book contains instructions, checklists and lists of resources. Loverde, Joy, Three Rivers Press, 2000, Paperback, \$19.95, ISBN: 0812932781.

## **How To Care for Aging Parents**

This book is a useful starting point for those finding themselves in a caregiver's role for parents or any other older relative. It provides information on health care issues, caregiver concerns, community and facility based services as well as an extensive listing of helpful agencies and organizations, with contact information that assists caregivers. Morris, Virginia, Workman Publishing Company; October, 2004, \$18.95, ISBN: 0761134263

## **Love, Honor, & Value: A Family Caregiver Speaks Out About the Choices & Challenges of Caregiving**

This book is about and for family caregivers, written primarily for family members, friends and partners giving care. It combines personal accounts of caregiving with practical advice and tips. Mintz, Suzanne Geffen, Capital Books, Inc., 2002, Paperback, \$14.95, ISBN: 1892123568.

## ***Internet Sites***

### **Administration on Aging (AOA)**

AOA is part of the U.S. Department of Health and Human Services, and provides resources, news and developments, and information for older adults. AOA funds the Eldercare Locator, a service that gives information to callers about state and community resources

that provide assistance to older persons and their caregivers. The AOA's home page may be accessed at: [www.aoa.gov](http://www.aoa.gov). The Eldercare Locator may be accessed at: [www.eldercare.gov](http://www.eldercare.gov), or by calling 1-800-677-1116, M-F, 9 a.m.-8 p.m. EST.

### **American Bar Association Commission on Law and Aging**

The Commission on Law and Aging seeks to support and maintain quality of life issues amongst elders. The Commission functions within the American Bar Association. The site provides a very helpful resource for consumers entitled *Law and Aging Resource Guide*, which contains information on a variety of topics, including health care decision making tools as well as state specific contact numbers and resources for legal assistance for older adults. Access the site at [www.abanet.org/aging](http://www.abanet.org/aging).

### **The American Geriatrics Society Foundation for Health and Aging (FHA)**

The FHA is a national non-profit organization established in 1999 by The American Geriatrics Society to advocate on behalf of older adults and their special health care needs. The website contains a comprehensive on-line guide entitled *ElderCare at Home*. The guide addresses physical problems, mental/social problems and prob-

lems in managing care. The site also contains a *What to Ask* series with questions to ask healthcare providers about various care issues. [www.healthinaging.org/](http://www.healthinaging.org/)

### **Beth Israel University Hospital & Manhattan Campus of the Albert Einstein College of Medicine.**

These two organizations have developed an on-line *Caregiver Resource Directory* which provides practical assistance for caregivers related to a variety of caregiving situations, including communicating with health care professionals and issues related to financial and insurance situations. The guide can be downloaded or a hard copy can be ordered on-line at [www.netofcare.org](http://www.netofcare.org).

### **Family Caregiver Alliance (FCA)**

The Family Caregiver Alliance provides information, education, services, research and advocacy for the nation's caregivers. Based in California, it is a resource for national, state and local levels of support. FCA produces informational fact sheets for caregivers. These and other publications are available on-line or they may be ordered from FCA. The site also has on-line support groups available to caregivers. Access the site at: [www.caregiver.org](http://www.caregiver.org) or call 1-800-445-8106 M-F, 9 a.m. - 5 p.m. PST.

## Family Caregiving 101

This is an educational website for caregivers which is co-sponsored by the National Alliance for Caregiving and the National Family Caregivers Association with support from Eisai Inc. It provides assistance and information for family caregivers on a variety of issues related to caregiving as well as resources for locating needed services. The website can be accessed at [www.familycaregiving101.org](http://www.familycaregiving101.org).

## National Academy of Elder Law Attorneys (NAELA)

This is the website for attorneys

that deal with the many issues facing older adults and the disabled. NAELA attorneys can assist their clients with estate planning, long-term care issues, power-of-attorney, wills and trusts. Within the site is a search field to find an elder law attorney in your area. There is also a very helpful question and answer section that will assist in the search for an elder law attorney. Access the main site at [www.naela.org](http://www.naela.org) and the specific question and answer site at [www.naela.com/public/index.htm](http://www.naela.com/public/index.htm). If you do not have access to a computer you may reach NAELA by phone at 520-881-4005

or via mail at: NAELA, 1604 N. Country Club Road, Tucson, AZ 85716-3102

## National Alliance for Caregiving (NAC)

The NAC website, [www.caregiving.org](http://www.caregiving.org), contains research on caregiving as well as practical assistance for caregivers including a guide to hospital discharge planning, a guide for caring for aging parents and a guide specific to palliative care. The website also has a database called the *Family Care Resource Connection* that can be accessed



in the “Caregiver Tips & Guides” section of the website. This database allows caregivers to search for information on specific topics and includes reviewed and rated books, videos and websites related to a wide variety of caregiving issues.

## National Family Caregivers Association (NFCA)

The NFCA is committed to support, educate and speak up for family caregivers. Its website, [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org), provides a number of practical tip sheets and checklists for caregivers. Topics include caregiver tips for: talking on the phone, improving doctor caregiver communication, advocating when your loved one is hospitalized and communicating effectively with healthcare professionals.

## National Institute on Aging (NIA)

The National Institute on Aging produces a number of publications related to health issues that affect older Americans. Publication categories include sections on healthy aging, caregiving, planning and decision making, making sense of health information and a variety of disease specific conditions. The website currently offers a new publication called *Talking With Your Doctor* which is a guide for older people to help them to get the information they

need when seeing the doctor. This and the other publications can be downloaded or ordered from [www.niapublications.org/](http://www.niapublications.org/).

For help with ordering publications you may also call 1-800-222-2225.

## Useful Tools

Enclosed are tools to help you start a written record of information:

- **Personal Health Information** – This tool provides a checklist of important information to share with health professionals involved with your family member’s care. It can be especially helpful if he or she has several doctors so that all have basic information including the other doctors your loved one is seeing and any medications that he or she may be taking. It is also important in an emergency situation to provide to emergency and hospital personnel.
- **Important Information for Caregivers** – This tool contains information for caregivers who may be assisting your loved one at home on a day to day basis. It includes health information pertinent to your family member’s care needs and key phone numbers.

## Endnotes

<sup>1</sup> Houts, Peter S., editor, *Eldercare at Home*, The American Geriatrics Society Foundation for Health in Aging, 2003, [www.healthinaging.org](http://www.healthinaging.org).

<sup>2</sup> National Family Caregivers Association, [www.nfacres.org](http://www.nfacres.org) & *Talking with your Doctor*, NIH Publication No. 94-3452, September 2000, [http://www.healthandage.com/html/min/nih/content/booklets/talking\\_with\\_your\\_doctor/talking\\_with\\_your\\_doctor.htm](http://www.healthandage.com/html/min/nih/content/booklets/talking_with_your_doctor/talking_with_your_doctor.htm).

<sup>3</sup> National Family Caregivers Association, [www.nfacares.org](http://www.nfacares.org).

<sup>4</sup> *A Family Caregiver’s Guide to Hospital Discharge Planning*, National Alliance for Caregiving & United Hospital Fund; [www.caregiving.org](http://www.caregiving.org).

<sup>5</sup> Partnership for Caring, [www.partnershipforcaring.org](http://www.partnershipforcaring.org).

## *About the Authors of Since You Care®*

*Since You Care* guides are prepared by the MetLife Mature Market Institute in cooperation with the National Alliance for Caregiving and MetLife's Nurse Care Managers.

**MetLife Mature Market Institute®** is the company's information and policy resource center on issues related to aging, retirement, long-term care and the mature market.

### **MetLife Nurse Care Managers**

are available to MetLife's long-term care customers and their caregivers, on a daily basis, to help identify and resolve caregiving questions and concerns through counseling and referral.

**National Alliance for Caregiving** is a non-profit coalition of 38 national organizations that focuses on issues of family caregiving.

### **Mature Market Institute**

#### **MetLife**

57 Greens Farms Road

Westport, CT 06880

E-Mail: [MatureMarketInstitute@metlife.com](mailto:MatureMarketInstitute@metlife.com)

[www.maturemarketinstitute.com](http://www.maturemarketinstitute.com)

### **National Alliance for Caregiving**

4720 Montgomery Lane,

Fifth Floor, Bethesda, MD 20814

[www.caregiving.org](http://www.caregiving.org)

MetLife, a subsidiary of MetLife, Inc. (NYSE:MET), is a leading provider of insurance and other financial services to individual and institutional customers. The MetLife companies serve approximately 12 million individuals in the U.S. and provide benefits to 37 million employees and family members through their plan sponsors. Outside the U.S., the MetLife companies have insurance operations in 12 countries serving approximately 8 million customers. For more information about MetLife, please visit the company's website at [www.metlife.com](http://www.metlife.com)

*This booklet offers general advice, however, it is not a substitute for consultation with an appropriate professional. Please see a health care professional, attorney, or other appropriate professional when determining how the information and recommendations discussed in this booklet apply to your specific situation.*

## Personal Health Information

Personal Health Information (This tool is intended to be kept at the care recipient's home. It contains contact information and important information about the care recipient's health. It should be kept in a place that is easily accessible, one that all caregivers are aware of, so that it can be retrieved and given to healthcare professionals if emergency treatment is needed or the individual is seeing a new doctor.)

**Name:** \_\_\_\_\_ **Date of Birth:** \_\_\_\_\_

**Address:** \_\_\_\_\_ **Phone:** \_\_\_\_\_

**Primary Emergency Contact:** \_\_\_\_\_ **Relationship:** \_\_\_\_\_

**Phone (Home):** \_\_\_\_\_ **(Work):** \_\_\_\_\_ **(Cell):** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

**Residential Address:** \_\_\_\_\_

**Secondary Emergency Contact:** \_\_\_\_\_ **Relationship:** \_\_\_\_\_

**Phone (Home):** \_\_\_\_\_ **(Work):** \_\_\_\_\_ **(Cell):** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

**Residential Address:** \_\_\_\_\_

**Primary Physician:**

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Other Physician (Specialist):** \_\_\_\_\_

**Specialty:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Other Physician (Specialist):** \_\_\_\_\_

**Specialty:** \_\_\_\_\_

**Phone:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Preferred Hospital for Admissions:** \_\_\_\_\_

**Phone (Admitting):** \_\_\_\_\_ **(Emergency):** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Person DOES** \_\_\_\_\_ **OR DOES NOT** \_\_\_\_\_ **have a Living Will\***

**Person DOES** \_\_\_\_\_ **OR DOES NOT** \_\_\_\_\_ **have a Health Care Power of Attorney\***

# SINCE YOU CARE

**Insurance Plan Name:** \_\_\_\_\_

- Member Number: \_\_\_\_\_
- Group Number: \_\_\_\_\_
- Medicare: Part A: \_\_\_\_\_ Part B: \_\_\_\_\_
- Insurance Cards: Yes\* \_\_\_\_\_ No \_\_\_\_\_

**Current Medications:** (include nonprescription/over the counter):

Medication: _____	Dose: _____	Frequency: _____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

**Vitamins/Herbal Supplements:** \_\_\_\_\_

Allergies: Drugs: \_\_\_\_\_ Food/Other: \_\_\_\_\_  
\_\_\_\_\_

Pharmacy: (Name): \_\_\_\_\_ (Address): \_\_\_\_\_  
Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

**Existing Medical Conditions:**

- 1) \_\_\_\_\_
- 2) \_\_\_\_\_
- 3) \_\_\_\_\_
- 4) \_\_\_\_\_
- 5) \_\_\_\_\_
- 6) \_\_\_\_\_

**Other Notes** (May include special diet, hearing or vision problems, cognitive or ADL difficulties)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**ALL INFORMATION WAS LAST UPDATED ON:** \_\_\_\_\_

\*Copies of these documents should be kept with this form and given to healthcare professionals if emergency treatment is needed or the individual is seeing a new doctor.

## Important Information for Caregivers\*

This tool is intended to provide pertinent information to individuals who are giving direct care to your family member on a day to day basis.

### Patient Information

#### Demographic:

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Address: \_\_\_\_\_ Phone: \_\_\_\_\_

#### Health:

Primary Medical Conditions: \_\_\_\_\_

Allergies (Include Food and Drug): \_\_\_\_\_

Current Medications: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Need for Assistance (Includes activities such as bathing, dressing, toileting, shopping, laundry, etc. - List any assistive devices, e.g. cane.) \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Special Concerns or Precautions: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Particular Likes and Dislikes: \_\_\_\_\_

\_\_\_\_\_

**Important: Know Location of Personal Health Information Form, Living Will, Powers of Attorney, Medical Insurance Cards, Other Documents, as applicable: IN THE EVENT OF AN EMERGENCY THESE SHOULD BE GIVEN TO EMERGENCY PERSONNEL.**

# SINCE YOU CARE

## Useful Telephone Numbers

### Family Contacts:

Name	Relationship	Phone Number(s)
_____	_____	_____
_____	_____	_____

### Health Contacts:

Doctor(s):	Name	Phone Number(s)
_____	_____	_____
_____	_____	_____

Pharmacy: \_\_\_\_\_

Preferred Hospital: \_\_\_\_\_

Medical Equipment Company: \_\_\_\_\_

Home Care Agency: \_\_\_\_\_

Nurse: \_\_\_\_\_

Home Health Aide: \_\_\_\_\_

Others: \_\_\_\_\_

\_\_\_\_\_

### Insurance Company:

Name	Type of Insurance	Phone Number	Policy #
_____	_____	_____	_____
_____	_____	_____	_____

### Other:

Name	Relationship	Phone Number(s)
_____	_____	_____
_____	_____	_____

\_\_\_\_\_

Directions to the Individual's Home (Include cross streets etc.): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\*This document is adapted in part from Caregiver Resource Directory, Online Version, Beth Israel University & Manhattan Campus for the Albert Einstein College of Medicine, [www.netofcare.org](http://www.netofcare.org).