



AND THOU SHALT HONOR...

Viewers Guide

October 9, 2002 • 9 p.m. ET on PBS



Dear Reader,

Some years ago, both of us experienced one of those profound events that blessed, saddened, enlightened and honored us—and changed our lives forever. We each found ourselves in the position of being the primary caregiver for a frail, chronically ill parent.

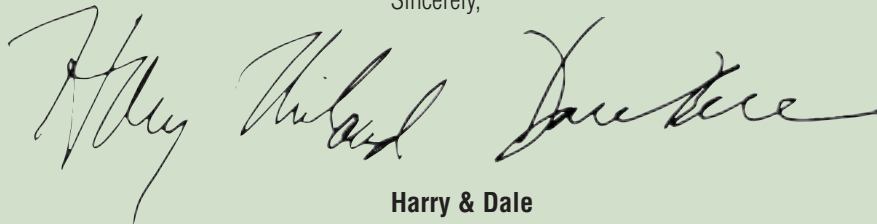
In sharing our stories with each other, we came to realize that, despite our different family histories, our experiences were similar. Eventually we learned that they were reflective of other caregivers as well. Together we learned how unprepared we were for assuming that awesome responsibility with its spiritual rewards. We didn't notice the signs of "creeping" caregiving that are so obvious when we look back and see how our role as caregiver gradually crept up on us. Nor did we have a clue as to where to turn for help. "Caregiver burnout" was not simply an expression; it was very real and always a threat. One day while we were sharing our experiences with each other, it occurred to us that our nation needed a wake up call to pay attention to the growing phenomenon of caregiving. Asking ourselves the proverbial "Why not?" we decided to produce *And Thou Shalt Honor...*

And Thou Shalt Honor... and its companion pieces—the outreach campaign, Web site, database of local resources, video, professional educational curricula and book, *And Thou Shalt Honor... The CareGiver's Companion* published by RODALE Inc.—are all designed to help others find answers to the questions we had when we were caregivers. We also hope that these resources and this project will provide the basis for a new movement to support caregivers.

A critical thing, that neither one of us did—something that would have made an enormous difference in our caregiving experiences—was talk with our parents when they were still healthy about the probability that they would, at some point in the future, need some kind of caregiving. Like all of us, they might not be able to lift that fork to feed themselves anymore. We believe that had we done this in advance—while we and our siblings could plan—our caregiving experiences would have been substantially less stressful. That's exactly why we've prepared this Viewers Guide—in the hope that you can take it and use it to have the conversations we didn't. It is not possible to make this a one-stop-shopping guide, but we hope that you will be able to use the facts, the stories and the thoughts contained within to start you and your family on a journey of discussion with those you wish to "honor" through your care.

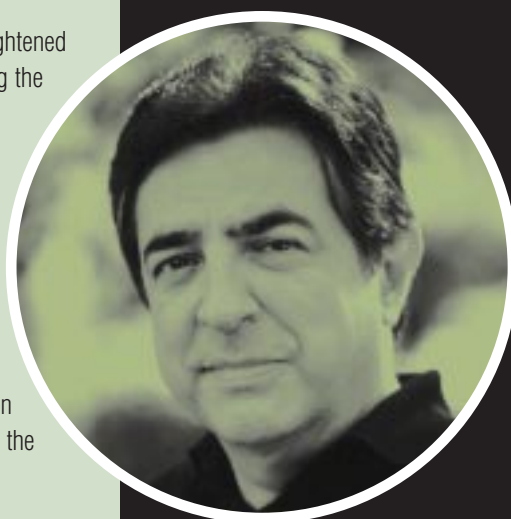
In addition, please use this Guide and the other *And Thou Shalt Honor...* resources for small group discussions: at your place of worship, in your workplace, in schools, among your friends. We hope that our efforts will make a difference in the lives of caregivers—and we are convinced that you will.

Sincerely,



Harry & Dale

Harry Wiland and Dale Bell
Producers



Although I was busy filming a weekly TV program, "First Monday," when Harry & Dale asked me to be the host for *And Thou Shalt Honor...*, I seized the opportunity. Caregiving has been a personal journey for me, too, and I hope that the program, the outreach materials, the book and this Viewers' Guide will provide you with some insights and help you to engage your family, your friends, and your community in making a difference for caregivers in America.

Joe Mantegna

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OUTREACH OVERVIEW

In her introduction to *And Thou Shalt Honor... The Caregivers Companion*, Pulitzer Prize-nominated author Beth Witrogen McLeod writes, “Often I’ve been asked what one thing I would have done differently ‘if only I knew then.’ Honestly, there is no one thing. I wish I had known that services for the aging—many free or low-cost—can provide education, respite and support. I wish I had known that many talented professionals are ready and able to help. I wish I had known that I was not weak or incompetent just because I was unable to be all things to all people. I wish I had known that my feelings of guilt and exhaustion were not mine alone but are shared universally in the caregiving arena. I wish I had known that what I was experiencing was the leading edge of an unprecedented and historic phenomenon, not merely my personal cross to bear.”

Beth, who cared for two dying parents simultaneously, poses an obvious question: Why wasn’t she better prepared for her role as a caregiver? Why aren’t more of us planning for the near-inevitability of our role as caregiver? A study of caregiver attitudes released by the National Family Caregivers Association and the National Alliance for Caregiving in March 2002 pointed out that most people do not identify themselves as caregivers until they are well along the caregiving path because of a fear that doing so will change the nature of their relationship to their loved ones. The word “caregiver” is too clinical and impersonal.

The producers of *And Thou Shalt Honor...* intend this program to raise awareness of the needs of caregivers and caregiving issues. Their hope is that watching the two-hour special will prompt those of us who are providing care to a loved one to recognize that we have become a “caregiver”, that we are not alone, and that there are services and resources to call on for help. Above all they hope that their production will prod those of us who are not yet caregivers to prepare for that eventuality.

To help convert this awareness into action, the producers have enlisted more than fifty national membership organizations to promote awareness of the program to their membership (see p. 13) and to encourage their members to join or form caregiving coalitions in their community. Concurrently, at the local level, these same coalitions have been teaming with their Public Television Stations to engage their communities in discussion and action.

All materials produced for the outreach are available in downloadable format on the Web site. If you are interested in finding out more about the outreach campaign, send an e-mail to ThouShaltHonor@BBallard.com or check the “grass roots” section at www.thoushalthonor.org (after 10/1/02, www.pbs.org/thoushalthonor).

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For information on purchasing And Thou Shalt Honor... videotapes, books or resource libraries, turn to page 15.

TABLE OF CONTENTS

How to Watch the Show	
How to Use the Guide.....	2
Conversations with your Loved Ones Who May Need Care	
The Journey Begins	
Questions for Conversations with Ill or Elderly Loved Ones	
Creeping Caregiving.....	3
Involving Your Siblings	
Hints for Sibling Discussions	
In It Together—Talking With Your Siblings.....	4
Questions for Your Family Discussion.....	5
Keeping Your Loved One at Home	
Caregiving at Home	
“Respite: A Key to Caring for the Caregiver”.....	6
Information on Respite	
Questions to Ask Yourself.....	7
When You Need Professional Caregiving	
Finding Homecare and Evaluating Nursing Homes	
Making the Move	
“The Caregiver Crisis”.....	8
Questions for Your Loved Ones When Discussing a	
Nursing Home or Assisted Care Facility	
“Addressing the Caregiver Crisis:	
improving the quality of direct-care jobs.....	9
The Global Picture	
Hints for Talking with Your Employer	
The Economic Impact of Family Caregiving.....	10
Questions for You and Your Spouse	
New Services Help Caregivers.....	11
Honor	
Moving Up the Grief	
Reflections on Honor	
Honor: Coming to Terms.....	12
Eulogy for Harlan Nation	
National Outreach Partners.....	13
Making A Difference	
Affecting Change	
Questions for Employers and Employees	
Questions for Elected Officials and	
Government Workers.....	14
Questions for High School and College Students	
Questions for the Faith Community	
Program Resources	
Credits.....	15
Checklists	
Is Your Loved One’s Personal Information	
In Order?.....	16
Does Your Loved One Require Care?.....	17
Acknowledgements	
Board of Advisors.....	Back Cover

HOW TO WATCH THE SHOW

The challenge of *And Thou Shalt Honor...* is to engage viewers in applying what we see on the screen to our own lives. We encourage you to watch the caregivers' stories as they unfold and then ask yourself "what if." What would your life be like if you were faced with caring for the intimate daily needs of a loved one? Where would you get the information you need to do it? Where would you find the strength? How would your family react if you were to say to them one day, "Mom needs to move in with us because she just can't safely care for herself anymore and I can't juggle managing two households?" How would you take care of yourself while taking care of everyone else? If you watch the show with your loved ones, talk about the connections to your own life. "That's what happened to Joe at the office." Or, "Do you remember when Aunt Maureen was taking care of Grandma?" Lead the conversation to the "what if" questions: "What if we needed to care for our frail and elderly loved ones? What would be the impact on our lives and how can we prepare for that eventuality?" "What if something happened to one of us?"

If you watch it with a group of friends or a group from church, encourage people to talk about their caregiving experiences. Talk about parents and loved ones, and what your hopes and fears are for their future. When it's over, ask yourself how you might better prepare to become a caregiver. Whether your role as caregiver is sudden or creeps up on you, it's important to be prepared.

"I came home from work one day and he thought he was having a stroke. I asked him why he didn't go to the hospital; he didn't know where the hospital was and I asked him why he didn't call me at work and he couldn't remember where I worked. He just knew that this was home and that I would be there pretty soon. And it started from there."

— Mary Ann Nation

HOW TO USE THIS GUIDE

This Viewers Guide is built around the stories told in *And Thou Shalt Honor...* and is designed to help facilitate discussions with your loved ones and others who may make a difference in your ability to care for those you love. Hopefully, the checklists and questions we've provided will promote thought and assist you in your conversations and planning.

The Guide is presented in seven stand-alone sections. Pages 2-3 are designed to help you begin the conversations with your parents or loved ones who may need care now or in the future. Questionnaires from *And Thou Shalt Honor... The CareGiver's Companion* will help you gather the information needed for your planning. (This book is now available in bookstores or can be ordered on-line at www.thoushalthonor.org or www.pbs.org/thoushalthonor after 10/1/02)

Caregiving demands the involvement of your family. On pages 4-5, we provide some helpful hints for engaging your siblings in discussion. On pages 6-7, we start with questions about maintaining independence and what can be done to help your loved ones stay in their homes. We then move to a discussion of what to do when that's no longer possible. An essay on the importance of respite care reminds you to prepare for caring for yourself as well as for your loved one

When the time comes that you are unable to take care of your loved one at home, discussions of assisted living facilities, professional caregivers and nursing homes can be very difficult, and it's hard just to know what questions to ask. We provide some guidelines and hints on pages 8-9 and an essay on the caregiver crisis offers both insight and food for thought.

The impact of caregiving can be overwhelming and it's never too early to sit down and make plans. If you are married, talking with your spouse is crucial to addressing financial issues. Read pages 10-11 for thoughts on the budgetary impact of caregiving and questions to address. There's also an essay on the short and long-term economic impact of caregiving.

This program is about "honor." Engage in some self-reflection with us on page 12. Then on page 13, share Mary Ann Nation's tribute to her husband, Harlan.

Finally, how do we promote greater awareness and support for caregivers and how do we affect change? For thoughts on carrying these conversations into other venues, review the questions on pages 14-15. Also, look there for *And Thou Shalt Honor...* program resources.

YOU'RE NOT ALONE

Remember, when having these conversations, use all of the resources you have available. In addition to the materials found here and elsewhere, those who live in your loved one's world—other family members, friends, doctors, spiritual advisors, caregiving professionals—are also valuable resources for you. Ask them for their guidance for handling the conversation. Also, ask them to broach the subject with your loved ones themselves.

A final piece of advice, "Never ask a question unless you really want to know the answer." Recognize that, in order to have an open and honest conversation, you must be willing to hear answers you may not like, but need to know.

Good luck.



And Thou Shalt Honor...

THE JOURNEY BEGINS

A single event in Mary Ann Nation's life (page 2) dashed her hope for the long and happy retirement she and her husband, Harlan, had planned. Instead, the dream of relaxing and travelling that is held by so many of us slipped away from her, and arguments with the hotel desk clerk over a room-service charge were replaced by pleas to the utility company to keep the electricity on. Who among us can not relate to Mary Ann—that mother, wife, sister, daughter—struggling to do the right thing, the honorable thing, for her husband? Do you worry as we do that Mary Ann will reach the point where she is so financially, physically and emotionally exhausted that she can no longer function? The frightening thing about Mary Ann's story is that it is not unique—it's not even unusual. And it can happen to any one of us.

TAKING THE FIRST STEPS

In the case of Mary Ann and Harlan Nation, their caregiving situation came upon them suddenly. This is common when your loved one has a stroke, heart attack, or serious accident. However, in many cases, caregiving seems to creep up on the caregiver. Regardless of your situation, preparing for the eventuality that you will be a caregiver will make all the difference in the world. Take stock of your situation and that of your loved one. For instance, are your loved ones within a reasonable driving distance? If not, although the basic issues remain the same, you will experience and need to plan for the complications wrought by being far from each other. Other factors to consider are the size of your family, their reaction to you being a caregiver, or to the thought that they might also become caregivers. Other details are also important. You'll need to think about your parent's or loved one's medical and financial situation, as well as your own. PLEASE BE CERTAIN TO PLAN FOR YOUR OWN HEALTH AND WELL-BEING AS A CAREGIVER, as well as for the health of your loved ones!

There is no easy way to do this, but if you and your loved ones are going to live comfortably in the inevitable caregiving relationship, you need to prepare and you must have answers to some basic questions. The form, "Is Your Loved One's Personal Information in Order?" found on page 16 of this Guide, on page 104 of *And Thou Shalt Honor... The Caregiver's Companion*, and at www.thoushalthonor.org [after 10/1/02 - www.pbs.org/thoushalthonor], is a model to use for recording critical information about your loved ones. This is a good first step, and it also can be used to trigger conversations about the future. As for the conversations, speak gently. Honestly invite your loved ones' input, and remember that everyone might be feeling terribly vulnerable during this conversation.

"Creeping" Caregiving

In most cases, the amount of time and energy that we devote to taking care of an aging parent or loved one starts off small and increases slowly. That's why we frequently refer to "creeping" caregiving in this Guide. Here are some of the signs:

"Creeping" caregiving stage I

- Calling your parent or loved one daily just to "check-in"
- Worrying about whether they remembered to take medicine as scheduled
- Stopping by regularly or asking someone else to stop by to check on them
- Taking them shopping or to the doctor because they no longer can go by themselves

"Creeping" caregiving stage II

- Their health generally deteriorating
- Calling or stopping by several times a day
- They've lost ability to clean their home or themselves
- Occasional but increasing need to for you to stay overnight with them or to arrange for someone to do so

QUESTIONS FOR CONVERSATIONS WITH ILL OR ELDERLY LOVED ONES

[Hint: Begin by telling them that you've been thinking about the future and want to be in a position to meet their needs as they get older, but to do so means that you need to have a serious conversation about it now. You could even ask them if they are as nervous about this conversation as you are!]

- Dad/Mom/Honey, I've been thinking about my own long term care needs and I've been talking about it with the kids. Have you given any thought to what you would want for yourself?
- Have you ever thought of the possibility that you might become debilitated? Would you please share those thoughts with me?
- What do you imagine would be the things that would worry you if you were to become unexpectedly ill for an extended period of time?
- Who would you like me to notify if you became ill or are hospitalized?
- If you become debilitated, what arrangements would you like to make to be sure that your checks are deposited and your bills are paid?
- If you were to need rehab, do you have a preference for a particular facility?
- Are all of your medical records in one place? Where are they?
- Where is your insurance information, both the policy and the card?

Hints for Sibling Discussions

1. Set a schedule for the meeting and keep to it.
2. Keep your expectations realistic.
3. Rid yourself of preconceived notions about what should be done.
4. Invite dialogue.
5. If anyone is participating by phone, arrange to have a speaker phone so all can hear.
6. Make certain that everyone speaks.
7. Be knowledgeable about caregiving and your relative's prognosis.
8. Recognize that the only control you have is over your own reactions and no one else's.
9. Meet each other on the common ground of your affection and sense of responsibility for your parents.
10. Tell them, honestly, that you need them. Practice saying the four words that all caregivers must learn to be healthy: "I need your help."
11. Share your worries about your parents and your situation, not your judgements about your siblings and their capabilities.
12. Play to each other's strengths when divvying up responsibilities.
13. State the obvious—everyone knows it's there and saying it aloud (whatever "it" may be) creates an environment of openness and invites discussion. Keeping the obvious to yourself isolates you and everyone else at the table.
14. Love the family comic. Everyone needs to laugh from time to time.

IN IT TOGETHER— TALKING WITH YOUR SIBLINGS

As we've seen in *And Thou Shalt Honor...* and as we've experienced in our own lives, certain situations can, like no other, bring out the warts as well as the halos in a family. Caregiving is one of those situations. Perhaps it's because, when faced with the reality of needing to provide care for an elderly or ailing parent or loved one, it can seem a daunting task. It's at times like these that we tend to fall back on familial patterns. The little boy or girl who was always the "leader" in the family will, as an adult, step up to the plate to figure out what needs to be done and who can do it. The "child" in the family may revert to being a little kid once again, distancing himself or herself from responsibility. The "comic" may try to see some humor in the situation, whereas the "troublemaker" will be stirring up family animosities or knocking down trees to put up roadblocks. These are all behavioral patterns they employed as children and are the facades behind which they sought and may again seek refuge.

So, then, how in the world can you address potential or current family caregiving situations with all of this "baggage?" The first thing to do is to recognize where you are as a family. You each carry the weight of generations of expectations and family rituals that may be unspoken yet still present in your family culture. Recognize that, as children, you developed patterns of relating to each other and to your parents and now is not the time to judge or attempt to change each other. Stay focused. You each need your energy for working together to provide care for your loved one. Recognize, too, that you don't all have the same emotional connection with your parents, so there may be some additional baggage in the room.

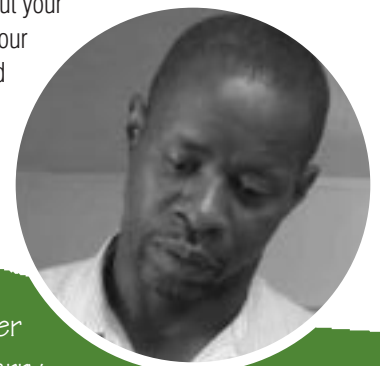
Once acknowledged, put it all behind you. Regardless of your family history, this is a time when you need each other. Play to each other's strengths. And believe it or not, everyone will not be on the same page when it comes to taking care of Mom or Dad, possibly even disagreeing that Mom or Dad needs a caregiver!

DO YOUR HOMEWORK

Begin to raise your concerns with your siblings before you actually sit down with them so that they don't feel hi-jacked by the topic of the meeting. Be sure to include your parents and even your extended family—those who are so close to your loved ones that they are *de facto* family. Just don't invite the whole neighborhood or your productive meeting could end up more like a family reunion—worthwhile, but not appropriate to the occasion. Let everyone know if Mom or Dad will be there. Ask if there is anything in particular anyone would like to know so that you can gather the proper information and have it available when you get together. Circulate an agenda in advance and ask for input. Anything can be discussed as long as the focal point is making sure your loved ones' caregiving needs are met.

Before this initial planning session, ask your parents to go with you or give you permission to talk with their doctors. Find out what to expect as their condition (including aging) progresses. Ask the doctors to direct you to more information and possible resources in your community to help your family provide for their caregiving needs.

Take a personal inventory. Look candidly at yourself and your financial situation. If you have a spouse or children, talk with them about your concerns for your parents and your desire to talk with your siblings. Ask for their input and be in tune with their needs and expectations.



"Well, I guess it all started when one of my other sisters was keeping her. And that didn't work at all. And then other people tried to keep her, and it wasn't working for one reason or another... We were against putting her in a home. And then the best way we thought was, we'll rotate. But then, well, Larry had her for a year. And that was a lot on him. It started out with six of us, and then boiled down to us three."

“It ain’t always peaches and cream - you know - even between us three. We have our little fights, our disagreements, but we know the one single thing we have in common is looking out for our mother and that outweighs anything”

—Milton Boykin

Take an honest, but private, look at your siblings and what you know of their personal situations. Think about their strengths as well as their vulnerabilities. Try to imagine what role each of them could realistically play in caring for your parents, but avoid prejudicing your relationship with too many preconceived notions of what they should or shouldn’t be able to do. Ultimately, if you are going to be in this together, each of you must have the leeway to step up to the challenge in a manner that is both comfortable for you and provides the best possible care for your loved ones.

Gather materials, including a list of caregiving resources, to share with your siblings when you get together for the initial planning session. The form, “Does Your Loved One Require Care?” on page 17 of this guide will help to provide perspective for everyone in attendance and allow you to do a candid assessment of your parents’ current or possible situation. It also will help remove some of the unspoken fears your parents might have, even though they may have to acknowledge that they need some help now.

Everyone responds to situations best when they have clarity about both why something needs to be done and what specific tasks need to be performed. Create a detailed list of caregiving tasks to discuss with them, along with their frequency. Circulate this list at the meeting so that it can be modified and responsibility assigned for each task. Remember to include financial responsibility as an option for those who want to participate as caregivers but don’t live near your parents.

WHEN EMOTIONS RUN HIGH

Recognize that everyone’s emotions may be a little bit “off-kilter” and try to keep the conversation focused on taking care of your loved ones. If you are concerned that you might not be able to manage this meeting, there are professional facilitators and experienced “outsiders” who can help. Chapters 4 & 5 of *And Thou Shalt Honor... The Caregiver’s Companion* are extremely helpful on the subject of dealing with your family under difficult circumstances.

Regardless of the kind of response you get from your siblings, remember to keep the lines of communication open. If some of them can’t make the meeting, take notes and fill them in later. If some of them don’t want to participate in caregiving, don’t write them off. Remember that some discussion and planning is better than none. Besides, they may need to let this all sink in before they can take on the mantle of caregiver. This also might be a good time to practice forgiveness, for surely as time progresses you will need a little forgiveness yourself. The meeting, after all, is a metaphor for the caregiving journey. It’s a process with setbacks and rewards, ups and downs, twists and turns, but a process nonetheless.

We’re a matrilineal people so you follow your mother and you’re taught when you get older to take care of your mother and your grandmother.”

—Alene Garcia, Hopi Nation

And Thou Shalt Honor...

Questions for Your Family Discussion

[Hint: Begin by acknowledging that you’re probably all a little bit anxious about this conversation but that everyone’s presence—in person or in spirit—is a testament to the concern and honor you all feel toward your loved ones. Remind them that now is the time to begin these conversations so that you can make proper preparation before a crisis and, if appropriate, while your loved ones are capable of making their wishes known. Recognize too that everyone may not agree—and allow disagreement to be discussed.]

- Why are we here?
- Why is this important to discuss now?
- Does everyone agree that Mom/Dad need care now?
- If not, what are our options?
- Does everyone feel equally capable of participating in caring for our parents?
- Reviewing this list of tasks that we’ve all drafted (“Do your homework”), are there any tasks that you feel you could do?
- What are your sacred cows? Are there things that you are not open to discussing?
- What resources, financial or personal (such as a connection to a respite service), do you have to contribute to this conversation?
- Does anybody know what the models are that our family has traditionally followed when providing care for our frail family members? How have other family members handled similar situations?
- Does anybody have any experience being a caregiver or watching someone being a caregiver? If so, will you share your observations?
- As we look to the future, what is our “worst nightmare” about caring for our aging loved ones?
- As we look to the future, what would be the “ideal dream” of caring for our loved ones?
- Do you (Mom, Dad, Honey) have a preference for how you would like us to care for you?

Making Changes

Sometimes, a catastrophic medical event is the catalyst for moving our loved ones into our homes, or us moving in with them. Other times, it is just their increasing inability to take care of themselves. Whatever the cause, moving a loved one into your home will require changes that could range from setting up a bedroom to making major modifications. It also could mean learning to operate special equipment to bathe or move him or her around the house. In either case, you will experience a substantial learning curve associated with caregiving. Where do you buy specialty products? How do you move someone substantially heavier than you? Where do you go for training or support? How do you deal with the topsy-turvy nature of your relationships? Having been the child of your parents your entire life, how do you now become their parent? And if you're caring for a spouse, how do you retain your spousal relationship when one of you is caring for the other, helping to maintain his or her very existence?

Regardless of the challenges you face, remember to place caring for yourself high on your priority list. Dr. Donna Benton, PhD of the Andrus School of Gerontology offers an important warning: Some caregivers actually die before the person they are caring for dies. Caring for yourself is not a luxury; it's a necessity.

"I'm already giving so much here that I wonder at some point... will there be any of me left?"

—Ethelinn Block

CAREGIVING AT HOME

Independence is a major issue for all of us. We all want to stay at home and take care of ourselves right up until we die peacefully in our own beds surrounded by the warmth and support of our loved ones. Unfortunately, that rarely happens. Now that most of us live longer, we also die longer. In the case of our loved ones, this state of declining health pocked by critical medical events is frequently the reason so many of us find that our role as caregiver just "creeps" up on us. During this time of "creeping" caregiving, we tend to layer our caregiving responsibilities on top of the rest of the commitments in our lives. We call or stop by to check on Mom more frequently; we take Dad to his doctor's appointment; we do the grocery shopping for Aunt Margaret. We try to honor and respect their independence even as they become more dependent on us.

What happens when a critical medical event intervenes in this fragile balance of caregiving/work/home life? In *And Thou Shalt Honor...*, we see four generations of a Hopi family engaged in a caregiving situation. A terrible automobile accident transformed Alene Garcia from caring for her mother into a woman cared for by her mother, daughter and granddaughter. Although special equipment and substantial modifications to their home were necessary, this extended family was able to keep their loved one home.

In other cases, such as that of Lorraine Watson who is caring for both of her parents and sister in their home, there is no extended family. There might not even be any outside help. Lorraine takes all three of her loved ones shopping. She tends the garden and does the cooking, cleaning and laundry. We see her mounting stress, and the relief she receives through a county respite program. Ethelinn Block, whose father suffers from Alzheimer's Disease, has moved him into her home. We see the challenges this presents to her family. And we hear her worry that "there will be nothing of me left." Lorraine Watson could certainly voice that same concern. These stories underscore one of the biggest challenges of caregiving: taking care of yourself.

The toll of caregiving can be significant.

RESPIRE: A KEY TO CARING FOR THE CAREGIVER

Courtesy of the ARCH National Respite Network and Resource Center www.archrespite.org

What exactly is respite?

The simple definition is "relief." It is a break from the 24-7 responsibilities of caring for a loved one.

We assume that everyone gets to take a break from time-to-time, but sometimes when you're caring for someone else you may not have those opportunities—not even for a short break to have a shower.

Often caregivers feel guilty about taking a break and even think they don't need it. They wait until they find themselves drained of energy, depressed, and in poor health, and at that point—hopefully—realize that they must have some time off to rest, regroup, and rejuvenate in order to continue their caregiving. Thinking ahead and planning for regular and periodic breaks make an enormous difference to the caregiver and help avoid such things as depression, burn-out and, in some cases, serious illness.



And Thou Shalt Honor...

Who can provide respite?

Many times friends and family members who know the care recipient can be the best people to provide respite. Sometimes fellow members of a church or synagogue will volunteer to help. Care for a loved one might be available through an adult day care facility, a nursing home, or an assisted living facility. Respite can also be provided in your own home. Local social service agencies may be able to match your family with a provider.

Some issues to consider...

Explore what kind of a caregiver you are or will be. How have you handled caregiving responsibilities in the past?

Think about how much time you would like for yourself in a week, month or year. Some people like to have a few hours several times each week, while others prefer a full day once or twice a month, and still others prefer a week, 2-3 times per year. Planning is important.

What would you do with your time off? You might use the time to go shopping, go to appointments, visit friends, read a book, or simply take a nap.

The respite experience should be a positive one for the care recipient as well as the caregiver. In other words, respite should include activities your loved one enjoys, even if it's as simple as someone reading aloud or having a conversation with him or her.

It is also wise to have a back-up plan for emergencies. When one happens, caregivers who have an established means of obtaining respite can generally access emergency respite much more easily than those who start to look for it in an emergency situation.

Assess your financial resources to see what you can afford if you must hire a respite provider.

Do you want a respite provider to come to your home, or do you want your loved one to leave the home temporarily? You may want different things at different times. Try to keep your options open.

Trust and safety are important. You want your loved one to be in a safe environment with someone who is capable of meeting his/her needs and will not cause harm. When seeking care other than from family and friends, check to see how providers are screened and trained. Ask for references. Visit facility-based programs and check on the status of their license.

Many caregivers experience extreme guilt when they consider taking a break. Remember that periodic breaks can keep you healthy and better able to attend to the needs of your loved one.

What can a church or organization do to help out?

It's often difficult for people to ask for help. If you notice a regular member of your group has been absent lately due to caregiving responsibilities, offer to take turns volunteering to provide relief so that person can participate again. Perhaps you could plan to drop in on a family periodically to offer help.

If your group doesn't know of a person in need, consider a volunteer project to find families that could use some time-out help, and either rally your members to provide care, or explore ways to help families purchase services through donations.

Provide information on the importance of respite to family caregivers through your publications, announcements at meetings, or as part of presentations, lectures, or sermons.

Contact local social service agencies to see what you can do to help. Could you provide space in your facility or transportation to and from activities?



"...I learn from them a lot and it's not just being with them or doing things for them. It's being WITH them and they share things: tell about how to live your life, be a good person, respect other people, respect your self and basically just treat people the way you want to be treated."

— Angela Delgarito

Questions to Ask Yourself

- What can I do to modify my home?
- Will I know what to do if a medical crisis should occur?
- What are the practical daily things that I need to do to adequately care for my loved one?
- What is the emotional temperature of my family?
- How do I expect my loved one to react to living with me?
- How do I expect the rest of the family to participate in my caregiving responsibilities?
- Where can I find respite?

Information on Respite

Looking for more information on respite services? Check out these sources:
The ARCH National Respite Locator Service (1-800-7RELIEF)
The Eldercare Locator (1-800-677-1116)
Your local Area Agency on Aging

Finding Homecare and Evaluating Nursing Homes

The prospect of being a caregiver, perhaps already daunting, becomes even more complex when the loved one who needs your care does not live near you. Under those circumstances, you probably will find yourself dealing with many of the same issues, but distance can make them more difficult. How do you make certain that your loved one is being adequately cared for on a daily basis? For help, finding answers to these questions you can go to the Eldercare Locator on the Web at www.eldercare.gov or call 800-677-1116 Monday through Friday from 9:00 AM to 8:00 PM.

Other checklists to help with the nursing home decision:

<http://www.dhfs.state.wi.us/bqaconsumer/NursingHomes/NHchkListNHtwo.htm>

<http://www.medicare.gov/nursing/checklist.pdf>

MAKING THE MOVE

Moving to a long term care facility or nursing home is the often inevitable outcome of your loved one's overall declining health. In the case of Sal Perrotta, his daughter could no longer provide adequate care for him so they agreed that a nursing home made sense. Giving away his dog was perhaps the hardest part of the move. Howard Frushtick, who now volunteers his time at an adult day care facility, cared for his wife until her Alzheimer's progressed to the point when he could no longer care for her at home. Ethelinn Block is caring for her father at home right now, but we're sure she dreads the day when she can no longer manage.

Nonetheless, many people find that the move to a nursing home can be a blessing in disguise for everyone involved. Two critical elements can make the difference:

- Finding a facility that will provide good care for your loved one
 - Medical care that makes both you and your loved one feel comfortable
 - A facility that meets your standards of cleanliness
 - A warm, caring staff
- Continuing to be your loved one's caregiver
 - Visiting frequently
 - Brushing his hair
 - Putting on her make-up
 - Being there during meals to assist in feeding if necessary
 - Bringing flowers and music and family

THE CAREGIVER CRISIS

By Karen Kahn, Paraprofessional Healthcare Institute (www.paraprofessional.org)

Though the vast majority of people in need of caregiving support rely on family and friends, at least four million elderly, chronically ill and people living with disabilities receive some care from paid caregivers. This care may be provided in the person's home or in a variety of other settings, including assisted living facilities, nursing homes, group homes, or adult day programs. Though many of us would prefer not to rely on the formal caregiving system, in fact, distance from our loved ones and family and career commitments often leave us no choice.

The formal caregiving system employs at least two million "direct-care workers"—home health aides, nursing assistants, personal care attendants and direct support professionals who provide help with a wide variety of activities, from bathing, toileting and transferring to household chores and meal preparation, checking blood pressure and monitoring medical equipment. These workers provide eight out of every 10 hours of paid assistance for long-term care recipients. Thus, the relationship between the caregiver and the long-term care recipient is critical to the quality of care and the quality of life experienced.

Sadly, however, this system is in crisis. Because of lack of attention and funding, the formal care system cannot attract the stable, caring workforce necessary to care for our loved ones.

On average, direct-care workers earn only \$8 per hour, and they often work only part-time hours. Low pay and lack of support leads to high rates of turnover and vacancies.

"She's healthy but she's not very steady on her feet. She falls a lot. I knew she was not going to be willing to leave her apartment because she always said that was the one thing she didn't want. I know we can't have her come live here with us and so I was looking at facilities in the Pittsburgh area. I was looking at some nursing homes and some assisted livings."

—Joni Rabinowitz (Marcia Rabinowitz lives in NYC)



And Thou Shalt Honor...

- Nursing home turnover rates average 76.1% annually, according to the American Health Care Association
- Rates of turnover for home health aides are cited at between 40 and 60% annually
- Nursing home staff vacancy rates for nursing assistants during 2001 averaged 11%.
- Home health providers report turning down clients due to their inability to attract and keep home health aides.

This workforce instability already affects the quality of care for long-term care recipients. Unfortunately, the crisis is expected to worsen over the next decade as the number of elderly citizens increases dramatically. The government predicts a net increase of 780,000 direct-care positions—an increase of 39%—at a time when the workers available to fill these positions—typically women between the ages of 25 and 44—is shrinking.

Fortunately, workers, consumers, and providers are joining together to advocate for public policies that will support a more stable, valued, and well-trained workforce. These coalitions are building a grassroots movement for quality jobs for caregivers, because they recognize that quality jobs are fundamental to delivering quality care to our loved ones.

WILL NURSING HOMES SURVIVE THE BOOMERS?

Let's not kid ourselves. The move to a nursing home is painful for all involved. The very thought of it conjures up images of old people tied to their chairs being cared for by an under-paid, under-trained, un-caring staff. The nursing home industry at one time warranted its terrible image. However, thanks to crusaders like Dr. Bill Thomas and his Eden Alternative, as well as to caregivers who remain caregivers even when their loved ones are in a nursing home, this situation is changing. But, issues remain. Professional caregivers are sorely underpaid and the fastest-growing population in the country is over 85. This number doesn't even begin to reflect the impact of the aging baby-boomer generation. Expect to see more changes in nursing homes and assisted living facilities as the generation that grew up demanding quality grows old expecting more.

QUESTIONS FOR YOUR LOVED ONES WHEN DISCUSSING A NURSING HOME OR ASSISTED CARE FACILITY

[Please have this conversation well before your loved one needs to move to an assisted-living facility. The best time is to do it is now!]

- How do you envision your long-term care situation?
- Would you be comfortable if a paid caregiver came in to help you a little bit?
- Have you explored this possibility?
- Would you like to move to an assisted living facility if you determine that you would be more comfortable or safer than if you were at your home?
- Do you have a specific facility in mind?
- If I can find someone who could answer some of our questions, would you be willing to go with me to talk with him or her?
- Do you know someone who could answer some questions for us and give some referrals?

"I've been doing this kind of work 28 years. I should be making at least \$10.00 an hour."

—Mary Alice Wadley



Addressing the Caregiver Crisis: Improving the quality of direct-care jobs

By Vera Salter,
Paraprofessional Healthcare Institute

The only way long-term care providers can attract stable, competent, caring workers is to improve the quality of their jobs. What is a quality job? One that:

- Pays a living wage,
- Provides health benefits,
- Provides high-quality training and support,
- Provides career advancement opportunities

How can you help improve the quality of jobs for direct-care workers in order to ensure a stable, qualified, and caring workforce in the future? Begin conversations in your community about long-term care. Find people in your community who rely on paid caregivers and ask them about the importance of these workers in their lives. Find out about the direct-care workers in your community: why do they leave their jobs? What would help them stay in these important jobs?

Explore whether your state is already working on this issue and how you and your community might become more involved. Is there a state taskforce or a statewide coalition? The National Clearinghouse on the Direct Care Workforce (www.directcareclearinghouse.org) can provide this information.

Form a coalition that includes the key stakeholders in long-term care: providers, workers, and consumers.

Explore how high turnover rates and job vacancies affect each group. How can you work together to create a more stable workforce? Can you work together to change the way our society values—and therefore pays—direct care workers?

Hints for Talking with Your Employer

The various stresses of eldercare affect employee productivity. In one study: 50% of respondents said they were less productive at work; 51% said they had to take time off during the work day; 7% had to drop back to part-time work; and 11% had to leave the workforce temporarily.

Another survey by the National Alliance for Caregiving said that 10% of caregivers had to give up their jobs entirely.

It is estimated that lost productivity costs businesses at least \$11.4 billion annually. The need for businesses to respond to the caregiving demands on their employees will become more and more critical over the next decade. If your employer doesn't have a caregiver support policy in effect, it can start by offering some of these components:

- Flex time
- Shortened work weeks
- Modified daily schedules based on needs
- Telecommuting
- Dependent life insurance
- Long-term care insurance covering spouse and parents/parents-in-law
- Flexible spending/dependent care accounts
- Access to Employee Assistance Programs for counseling and support

"I'm ragged; I'm tired. I don't have a social life. My life is taking care of my daughter and taking care of my parents plus work full time. ...I get run down. ...and you're expected to be here (at work) 7 o'clock; smile on your face; ready to work..."

— Pam Haddad

A NEW WORLD

How do we keep our world from becoming suddenly topsy-turvy? It's hard. In fact, it may be near impossible. The key is to try to gather as much information and make as many plans as possible in advance of an event that could plunge us into crisis, but doing so takes a lot of effort. In addition to talking with your family and friends, you also need to find out what policies your employer may have in place. You need to scout out resources in the community. Make certain that you're looking at respite as well as professional support. Financial issues such as long-term-care insurance should be addressed if possible. At the very least, you need to plan for the possible impact that caregiving might have on you and your loved ones.

THE ECONOMIC IMPACT OF FAMILY CAREGIVING

By Donna L. Wagner, Ph.D., Director, Center for Productive Aging, Towson University, Towson, MD and Paul Alper, President and Co-Founder, The Caregivers Marketplace, Charlestown, RI

Most people realize that taking responsibility for a relative or friend who needs care and assistance requires an investment of both time and emotional energy. Few realize that a financial commitment is often involved as well.

Many research projects on family caregiving have focused on the personal trade-offs associated with caring for a loved one—less time for friends, other family members, and travel and leisure activities, and time missed from work. Researchers have also measured the burden of stress on family caregivers and the relationship between caregiving and illness. Estimates on the value to society of family caregiving show an astounding \$257 billion a year saved on care for adults and children with special needs.

But less is known about the economic impact of caregiving on the family. Costs to the family caregivers can be long- or short-term, difficult to predict, and vary according to the caregiving situation. When caring for an older person, costs are often unrelated to that person's financial status. Many caregivers report, for example, making purchases for an older person and feeling uncomfortable asking for reimbursement.

The deeper, long-term economic effects of caregiving are usually determined by decisions related to employment. One of the few studies that estimates some of the long-term economic consequences of caregiving is "Juggling Act," conducted in 1999 by the National Alliance for Caregiving (NAC) and the National Center on Women and Aging at Brandeis University.

Looking at a small group of respondents (55 individuals) from a larger NAC/AARP survey of caregivers conducted in 1997, "Juggling Act" suggests that the long-term financial repercussions of caregiving can be far-reaching and significant, particularly in terms of reduced pensions. The study concluded that diminished contributions to Social Security caused lifetime benefit losses of approximately \$25,000 among family caregivers, while reduced contributions to pension plans resulted in average losses of over \$67,000. Overall, the average lifetime loss of wealth estimated for this group totaled \$659,139.



And Thou Shalt Honor...

The short-term costs of family caregiving are related to out-of-pocket spending on two levels: goods and services for the person with special needs, and costs associated with providing care—travel, phone, etc. Research suggests that about half of all caregivers for older adults report spending their own money on essential products or services. The amount and types of expense vary, based on individual needs.

Among family caregivers who participated in a 2001 survey conducted by The Caregivers Advisory Panel, almost 80 % reported that they were the primary purchasers of health products. More than half purchased incontinence products, specialty bathing and skin care supplies, and nutritional supplements. More than a third bought wound care or wound prevention products, while more than one fourth of family caregivers provided home safety accessories. A family involved in caregiving can, for example, expect to spend approximately \$1,500 annually for incontinence products and as much as \$2 a day on nutritional supplements.

The 1997 NAC/AARP survey of caregivers found that those who paid their own money for needed products or services spent an average of \$171 per month; a total estimate of \$1.5 billion per month was spent on a national basis by all caregivers.

For the approximately 6.7 million long-distance caregivers who live at least an hour away from the care recipient, the costs can be even higher. The 1997 study found that these caregivers spent \$1.3 billion monthly to cover their out-of-pocket expenses for travel and phone, and an additional \$222 million monthly in direct purchases of needed products and services.

Today, the individuals who provide essential care to an older adult receive scant support for their important contributions. Their costs for needed services, for example, are not tax deductible unless the older person is a legal dependent. And, although Congress passed the National Family Caregivers Act last year, the companion \$3,000 tax credit proposed by the previous administration has not yet been enacted. Some states have financial support mechanisms for caregivers, but for the most part, caregiving expenses are the sole responsibility of the family.

FUTURE COSTS COULD BE OVERWHELMING

The economic impact of our national caregiving future could be overwhelming if we don't take steps right now to make needed changes in the workplace, in government policy, and in the attitude our society exhibits toward the sick and elderly. Personally, we need to assume that we will have limited access to Federal and state resources and that we must make plans now to prepare for our caregiving future. Those plans include having the appropriate discussions with our family members, identifying local resources, and developing and implementing a financial plan that will provide funding for adequate care for us and our loved ones.

QUESTIONS FOR YOU AND YOUR SPOUSE

[Hint: Long term care can cost \$60,000 annually and financial discussions can become very sticky. Set the proper tone by saying that you've come across some information that has you concerned about your future. You'd like to take some time to sit down and discuss it. Assume the best. Maintain a positive tone.]

- Have you given any thought to what will happen to us financially if we need to pay for long-term care for our parents or each other?
- What will be the toll on our personal finances?
- Does our current insurance/medicare/medicaid cover caregiving costs?
- Should we get long-term care insurance?
- Where can we find information about what long-term care will cost and what our unreimbursed expenses will be?
- Should we establish a savings or investment account to help pay for unreimbursed caregiving costs?
- Do you have some other ideas about how we might plan for the long-term care of our parents and, eventually, ourselves?

And Thou Shalt Honor...

New Services Help Caregivers

The need to address the economic impact of caregiving has spawned a number of businesses including long term care planners, long term care insurance, eldercare and more.

The Caregivers Marketplace is the first discount buying service for caregivers. It offers savings on a wide variety of products for caregivers and helps reduce their estimated \$171 monthly out-of-pocket expenses.

For more information, go to www.caregiversmarketplace.com or call (866) 327-8340.

The National Family Caregivers Support Program

When Congress re-authorized the Older Americans Act in 2000, it established the National Family Caregivers Support Program. The program calls for all states, working in partnership with area agencies on aging and local community-service providers to provide five basic services for family caregivers, including:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling, organization of support groups, and caregiver training to to assist the caregivers in making decisions and solving problems related to their caregiving roles;
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

To access services under the Program and find out the name of the nearest Area Agency on Aging, contact the U. S. Administration on Aging's EldercareLocator at 1-800-677-1116 or www.eldercare.gov.

Moving Up the Grief

Most of us think of grief as being an expression of loss related to a loved one's death, but it's also important to recognize that transitions bring with them a certain sense of loss and grief. Examples of situations that might trigger grief earlier than you expect it are when you first realize that your loved one needs a caregiver, when you move a loved one into a nursing home, or when your loved one receives a diagnosis of a terminal illness. Allow yourself and your family to feel that grief, to mourn the change that you are each experiencing.

Reflections on Honor

- What does "honor" mean to you?
- How does being a caregiver for someone honor them?
- How does being cared-for by someone honor you?
- How do you want to be honored by those you love?
- How do we honor someone we love but don't really like?
- How can each of us fashion a caregiving future that will allow us to honor our loved-one as well as allow them to honor us?

HONOR: COMING TO TERMS

The Oxford English Dictionary offers this as the first definition of the word 'honor': "High respect, esteem or reverence, accorded to exalted worth or rank a) As felt or entertained in the mind for some person or thing, b) As rendered or shown: The expression of high estimation or c) As received, gained, held or enjoyed."

Caregivers, whether highlighted in *And Thou Shalt Honor...* or living down the street from us, understand the complexity and the accuracy of this dictionary definition. They understand that, through their ministrations, they are paying homage to their loved ones. They equally understand that it takes a great deal of humility for their loved ones to allow themselves to receive the care they are offering. In this humility, this act of acceptance, they are being honored by those for whom they care.

If we stand on the outside looking in, we may see only the labor, the frustration, the isolation, and the toll that caregiving exacts. But those who have walked in the shoes of caregivers recognize the sacred nature of the gift of mutual honor that has been bestowed on them. They know it's not easy—that it can be terribly hard—but in the end, they know that they have become an integral part of the mystery of human existence.

How can we assimilate what we've witnessed in *And Thou Shalt Honor...* and adapt it to our own lives? Why is it so hard to acknowledge the transition to caregiver? Is it because we don't want to accept the changes in our lives and our relationships, and because it may mean we have to acknowledge that this is "the beginning of the end?" How in the world can we possibly ask those we love to think or talk about their death? How frightening it is for us to realize that the person who has known us so intimately since the beginning of our lives will be gone and, with their passing, a piece of us will pass too.

"Human beings are the only species on earth who have ever nurtured, tended and honored its frail elders. That is the miracle of human life."

— Dr. Bill Thomas

When our caregivers in *And Thou Shalt Honor...* talk about the experience as being "hard," they are certainly talking about the physical aspects of taking their loved ones to the doctor or shopping, or bathing or dressing him or her. They also are talking about not getting enough rest, about worrying about paying the bills, about isolation. But they are talking about something else as well. And that is the knowledge that all of this is only one dimension of "hard." The other dimension is personal, intimate, and perhaps spiritual, recognizing as Mary Ann Nation did "that the only way out... is for Harlan to die and I don't want that."

Nancy Mairs describes caregiving as "willing into life." George, her husband-caregiver, wills Nancy into life through his devotion, his acceptance, and his need for her. Yet, despite our best efforts, we can't keep those we love alive forever. The beauty of the caregivers filmed for *And Thou Shalt Honor...* is that they know it, and they have come to terms with the fact that the greatest gift they can give their loved ones is being with them, doing for them, loving them, and honoring them with their care until they die.

We can't prevent time from taking its toll on us and our loved ones, but we can make sure that by having open and honest conversations with our families and friends, by responding to the early signs of "creeping" caregiving, by planning for the care of our frail and elderly loved ones, and ourselves, we can make this final transition better than it might have been.

"My mom and dad were so good to me as a child. Not only were they good to me, they were good to my blind sister. And now it's time for me to be quiet and to give back to them."

— Lorraine Watson



And Thou Shalt Honor...

EULOGY FOR HARLAN NATION

by Mary Ann Nation

I loved you most when our children were born
I loved you when you were strong
And more when you weren't
I loved you when you had money
And more when you didn't
I loved you when you smiled
And more when you couldn't
I loved you when you talked
And missed your voice profoundly when you couldn't
I loved you when we argued
But more when we didn't
I loved you when I was with you
And more when I wasn't
I loved you when it was time for you to come home
I loved your ugly old van
But only more when you were in it
I loved you when you were in blue jeans
And more when you weren't
I loved you when you walked
And more when you couldn't
I loved you when you did things for me
And more when you couldn't
I loved you when I dressed you
And when I helped you shave
I loved you with a beard
And more without one
I loved you when you played with your grandkids
I loved the way you loved our sons
And more when you loved our daughters
I loved you when you were forgiving
And more when I wasn't
I loved you when I loved Jesus
And more when you did
I loved you when you wouldn't give up
And more when you had to
But I loved you more when I had to let you go
Harlan, I love you more than all the pebbles in the churchyard
And always will.

Harlan Nation died July 4, 2002. We are all deeply saddened by his passing and grieve with Mary Ann and her family.

And Thou Shalt Honor...

NATIONAL OUTREACH PARTNERS August 6, 2002

AARP
Age Concern
Alzheimer's Association
American Association on Mental Retardation
American Cancer Society
American Network of Community Options and Resources
American Parkinson Disease Association
American Red Cross
American Society on Aging
American Stroke Association
Americans for Better Care of the Dying
ARCH National Respite Network and Resource Center
Catholic Charities USA
Children of Aging Parents
Community-State Partnerships
Easter Seals
Faith in Action
Family Caregiver Alliance
Fifty-Plus Fitness Association
Health Insurance Association of America
Health Ministries, U.S.A., PCUSA
Home Instead Senior Care
Hospice Foundation of America
Interfaith Caregivers Alliance
International Employee Assistance Professionals Association
Little Brothers - Friends of the Elderly
Mental Healthcare Screening
Midwest Bioethics Center
National Adult Day Services Association
National Alliance for Caregiving
National Association of Area Agencies on Aging
National Association of Social Workers
National Association of State Units on Aging
National Committee to Preserve Social Security & Medicare
National Council on the Aging
National Family Caregivers Association
National Friends of Public Broadcasting
National Funeral Directors Association
National Health Council
National Hospice and Palliative Care Organization
National Issues Forums
National Mental Health Association
National Organization For Empowering Caregivers
National Organization of Rare Disorders
National Parkinson Foundation
National Partnership for Women & Families
National Spinal Cord Injury Association
Oncology Nursing Society
Paraprofessional Healthcare Institute
Partnership for Caring: America's Voices for the Dying
Rosalynn Carter Institute for Human Development
Service Employees International Union
Shepherd's Centers of America
Visiting Nurse Associations of America
Well Spouse Foundation

80% of older adults who need long-term care in the US receive that care not in nursing homes, but in their own homes or in community settings from informal caregivers (family or friends) who number 20-25 million.

By 2020, up to 14 million elderly people will need long-term care—double the number of those who need it today.

Approximately 7 million caregivers provide or manage care long-distance (living at least an hour away) and together give approximately 15 million days of work annually.

AFFECTING CHANGE

If we're to change the caregiving experience, we need to:

1. Engage in “caring” conversations with our loved ones
2. Engage our communities in public discussions of caregiving issues
3. Work with our public officials to identify needs and develop appropriate support programs

But that's just the beginning. Many coalitions have formed around the country to use *And Thou Shalt Honor...* as a catalyst to focus community attention on the needs of family and professional caregivers. The challenge for these coalitions and for you, the readers of this Guide, is to move from advocacy to activism. We hope that you will help develop systems to ensure that individuals and families taking care of ill, disabled, or aged loved ones receive information about services available in the community. We hope you will help these individuals, these caregivers, gain access to supportive services. We hope you will make certain that the caregivers in your community receive counseling when they need it, and training to help with their every day tasks as well as their decision making and problem solving. We hope you will develop respite services and reach out to caregivers to make them aware that they can get temporary relief from their labors. Finally, we hope that you will organize support for legislation and government programs that will provide financial relief and support for caregivers.

Please continue your conversations with your families and your community.

Questions for Various Audiences

[Hint: The following are suggestions for the kind of questions you can raise as you promote discussion of caregiver issues in different settings. Adapt them to fit a setting appropriate for you, or come up with your own list of discussion questions.]

For Employers and Employees

- Does our company have a policy that allows employees to deal with a family caregiving situation?
- How does our company envision an employee will meet his or her professional obligations and at the same time juggle family caregiving?
- Would our company be willing to establish an employee task force to look into and develop a company caregiving policy?
- What are the constraints on our company's ability to work with employees who suddenly find themselves in a caregiving situation?

For Elected Officials and Government Workers

- What is the role of government in caring for our frail and elderly?
- What should be the role of government in supporting caregivers?
- What can we do to raise the profile of caregiver issues in our community?
- Do we have, and have we widely disseminated, a list of governmental resources for families dealing with the stresses of caregiving?
- What protections could government provide to cover caregivers who are forced to leave the workforce thereby losing health insurance and other benefits?



“The true moral test of a society is how it cares for those in the dawn of life—the young, those in the shadow of life - the disabled and sick, and those in the twilight of life - the elderly.”

— Senator Hubert H. Humphrey, as quoted by Senator Mark Dayton, MN

- Can we provide an opportunity—such as a town hall meeting—for the community to speak to us about their caregiver concerns?

For High School and College Students

- What are the long-term implications of the aging baby-boomer generation on the cost of caregiving?
- How could more people be encouraged to become professional caregivers?
- How much should professional caregivers be paid to acknowledge the service they provide and to allow them to afford a reasonable standard of living?
- How much would you need to earn if you had to pay for a professional caregiver for your parents for 10 hours a day? Who should pay for the cost of this care?

For The Faith Community

- What can we do to help individuals recognize that they are in a “creeping” caregiving situation?
- Can we develop a system for identifying those in our community who may be in need of caregiving, or caregivers in need of respite?
- How can we involve young people in caring for the caregiver?
- How can we sensitize members of the community to the needs of caregivers?
- What should be our role in supporting caregivers?
- Does our faith require us to provide care for our frail and elderly?

PROGRAM RESOURCE

A plethora of resources for caregiving already exists and we at *And Thou Shalt Honor...* do not wish to duplicate the fine efforts of other organizations working on them. Please refer to the list of National Outreach Partners on page 13 of this Guide and on www.thoushalthonor.org (after 10/1/02, www.pbs.org/thoushalthonor) for links to their Web sites. Each of these organizations offers substantial resources to help you as you proceed on your journey. Also, see the box about new services on page. 11.

In addition, we direct you to a few specific items:

- ***And Thou Shalt Honor... The Caregiver's Companion*, published by RODALE Inc. is truly superb. It can be purchased for \$24.95 at www.thoushalthonor.org (after 10/1/02, www.pbs.org/thoushalthonor) or by calling 1-800-527-8200. Bulk discounts available. It is also available in bookstores.**

(We have borrowed liberally from *And Thou Shalt Honor... The Caregiver's Companion* in writing this Viewers Guide.)

- **The *And Thou Shalt Honor...* video: available in VHS for \$29.95 at www.thoushalthonor.org (after 10/1/02, www.pbs.org/thoushalthonor) and at www.caregivingvideo.com**
- **A CareGiver's Resource Library, based on *And Thou Shalt Honor...* will be available Fall 2002 through Aquarius Productions at www.aquariusproductions.com.**
- www.thoushalthonor.org (after 10/1/02, www.pbs.org/thoushalthonor) offers a substantial amount of information and resources including supplemental information that can be used with this Guide.
- www.caregivers-usa.org (Web-based database of local caregiving resources) Tens of thousands of organizations have registered their services in this database, searchable by topic, type of service and location.

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IS YOUR LOVED ONE'S PERSONAL INFORMATION IN ORDER?

Make a photocopy of this form and fill in the blanks with the requested information. Then file the paper with the rest of your loved one's important documents, so you can find it when you need it. You might want to make a copy to keep in your purse or briefcase as well.

PERSONAL INFORMATION

Full name _____

Maiden name or other names _____

Home address _____

Phone _____

Date and place of birth _____

Social Security number _____

Driver's license number _____

Military ID number _____

Medications _____

Religious affiliation _____

Church or synagogue _____

Phone _____

Clergy _____

Phone _____

HEALTH CARE CONTACTS

Primary care physician _____

Phone _____

Pharmacist _____

Phone _____

Other health care providers _____

Name _____

Phone _____

Name _____

Phone _____

Name _____

Phone _____

Hospital _____

Phone _____

LEGAL AND FINANCIAL CONTACTS

Attorney _____

Phone _____

Accountant/tax preparer _____

Phone _____

Financial advisor _____

Phone _____

Insurance agent _____

Phone _____

Banks

Name _____

Phone _____

Name _____

Phone _____

EMERGENCY CONTACTS

Police department _____

Phone _____

Fire department _____

Phone _____

Ambulance service _____

Phone _____

Poison control center _____

Phone _____

Family members

Name _____

Phone _____

Name _____

Phone _____

Name _____

Phone _____

Name _____

Phone _____

Neighbors

Name _____

Phone _____

Name _____

Phone _____

Name _____

Phone _____

Name _____

Phone _____

Name _____

Phone _____

DOES YOUR LOVED ONE REQUIRE CARE?

In each of the 20 categories below, place a check mark next to the description that best fits your loved one. An A response means all is well, while a B suggests that intervention might be necessary. If you choose C, your loved one clearly requires help, though the nature and scope of that care can vary. A D response means the person requires full-time assistance, perhaps from a home health aide or in an assisted living facility.

Of course, real life is seldom as clear-cut as the choices in this checklist. You may give your loved one an A in some categories but a B or C in others. Even so, the checklist can be a valuable tool when discussing the need for care with your loved one and other family members. Just as important, it can provide some welcome reinforcement and reassurance, should you decide to intervene.

1. Communication

- A. No difficulty speaking, reading, writing, or comprehending.
- B. Occasional trouble recalling words. Reads less. Handwriting is not as legible. Sometimes requests that information be repeated, then comprehends.
- C. Frequent trouble recalling words. Avoids reading; needs help with restaurant menus. Handwriting deteriorates noticeably. Frequently requests that information be repeated, but still may not comprehend.
- D. Significant problems with word recall, reading, writing, and comprehension. Struggles to maintain a conversation.

2. Mental Function

- A. Exercises good judgment. Makes appropriate decisions. No trouble recalling people, places, appointments, directions, or recent events.
- B. Exercises reasonably good judgment, but requires some help or prompting. Experiences occasional memory lapses.
- C. Has noticeable difficulty with judgment. Frequently needs help making decisions. Shows significant memory impairment. Often appears confused.
- D. Judgment and memory substantially unreliable. Needs considerable help making decisions.

3. Mood

- A. Reasonably good morale and self-esteem. Copes well with everyday stress. Grieves losses, then bounces back and carries on with life.
- B. Displays occasional anxiety, depression, irritability, or fear that may interfere with normal functioning.
- C. Increasing problems with anxiety, depression, irritability, or fear.
- D. Mood problems take over. Becomes unmanageable and may cause harm to himself or others.

4. Behavior

- A. Acts as usual in social situations.
- B. Occasionally acts in an unusual way—for example, wearing the same clothes day after day. Finds unreasonable fault with others.
- C. Frequently acts in disturbing ways that draw the attention of others. You avoid social situations with the person because of the potential for erratic behavior.
- B. Erratic behavior predominates. The person no longer can function socially.

5. Mobility

- A. Walks satisfactorily for a person of that age. Needs no help with stairs, escalators, or revolving doors.

- B. Noticeably slower when walking or climbing stairs. Occasionally needs help with escalators and revolving doors.
- C. Avoids walking. Frequently needs assistance; may use a cane or a walker. Climbing stairs is increasingly difficult.
- D. Cannot walk unassisted. Climbing stairs is difficult to impossible.

6. Medications

- A. Takes own medications as directed, with few, if any, lapses.
- B. Sometimes is confused about which medications to take when. Occasionally takes the wrong one(s).
- C. Needs regular supervision to take medications correctly.
- D. Depends on others to manage medications.

7. Meals

- A. Prepares meals satisfactorily. Eats well without assistance.
- B. Eats without assistance but occasionally has difficulty preparing meals. Sometimes lets refrigerator and pantry become bare or allows food to spoil.
- C. Needs some help preparing meals and eating. Cannot maintain refrigerator and pantry without assistance; frequently allows food to spoil.
- D. Unable to prepare meals. Cannot eat unaided.

8. Alcohol Use

- A. Not an issue. Drinks moderately in social situations, if at all.
- B. Liquor bottles appear in the garbage or elsewhere in the home with disturbing frequency, but the person seems unimpaired.
- C. Signs of alcohol use increase. The person smells of liquor and appears drunk.
- D. Alcohol use is out of control. Person displays disruptive behavior.

9. Finances

- A. Needs no help with banking, paying bills, or balancing the checkbook.
- B. Easily makes routine purchases but occasionally struggles with other financial matters, such as paying bills or balancing the checkbook.
- C. Needs help to manage personal finances.
- D. Incapable of managing personal finances.

10. Safety

- A. Maintains a safe lifestyle; remembers to lock doors, turn off the oven, and fasten seat belt.
- B. Experiences occasional safety lapses.
- C. Experiences more frequent safety lapses.
- D. Lacks awareness of safety issues, potentially posing a danger to self and others.

11. Housekeeping

- A. Maintains home at usual levels of neatness and cleanliness.
- B. Can perform most housekeeping tasks, but with occasional lapses in neatness; for example, may allow garbage, mail, and newspapers to pile up.
- C. Housekeeping skills are deteriorating. Needs help to maintain home at usual levels of neatness and cleanliness.
- D. Unable to perform housekeeping tasks. Seems unconcerned about neatness and cleanliness or overwhelmed by the inability to maintain home.

12. Social Life

- A. Maintains usual level of interpersonal relations with family and friends.
- B. Occasionally has difficulty with relationships. May act insensitive or fail to observe expected social graces.
- C. Needs prompting and assistance to maintain usual level of interpersonal relations.
- D. Little remaining aptitude for relationships. Not interested in or concerned about others.

13. Transportation

- A. Travels independently. Drives or arranges for other transportation.
- B. Experiences some lapses in judgment behind the wheel. Sometimes ignores stop signs and traffic lights. Has gotten tickets and/or has been involved in minor accidents. Sometimes struggles to arrange for other transportation.
- C. Experiences frequent lapses in judgment behind the wheel. Makes passengers feel unsafe, especially when driving at night. Often needs help arranging for other transportation.
- D. Can no longer drive safely. Always needs help arranging for other transportation.

14. Toileting

- A. Needs no help.
- B. Occasional accidents; needs some help.
- C. Frequent incidents of wetting and soiling; needs more help.
- D. Can no longer toilet alone.

15. Bathing

- A. Bathes satisfactorily without assistance.
- B. Reports difficulty with bathing. Needs help getting into and out of the tub or shower.
- C. Needs regular assistance with bathing. May try to avoid it.
- D. Cannot bathe satisfactorily, even with considerable help. Seems unconcerned about personal cleanliness.

Continued over

DOES YOUR LOVED ONE REQUIRE CARE?

Continued from page 17.

16. Grooming

- A. Grooms satisfactorily without assistance.
- B. Experiences occasional lapses in grooming; may neglect to comb hair, or may have trouble shaving, brushing teeth, or caring for dentures or glasses.
- C. Needs considerable help with grooming.
- D. Cannot groom without assistance. Seems unconcerned about appearance.

17. Dressing

- A. Dresses without assistance. Makes appropriate choices in clothing.
- B. May struggle with buttons, jewelry, and/or neckties. May need help selecting clothes.
- C. Dresses with assistance. May seem intimidated by the choices in a closet full of clothes and shoes. May rely on someone else to put together outfits.
- D. Needs help with nearly all aspects of dressing.

18. Grocery Shopping

- A. Purchases groceries without assistance.
- B. Less able to shop independently. May forget items, which results in more frequent trips to the supermarket. Pantry may lack some staples but contain multiples of others.
- C. Needs help to shop. Seems intimidated by the supermarket and more forgetful. Pantry is in a worsening state of disarray.
- D. Unable to shop even with assistance.

19. Laundry

- A. Does own laundry satisfactorily. Takes care of clothing without assistance.
- B. Has some trouble identifying items that need to be hand-washed or dry-cleaned.
- C. Needs help to do laundry; seems confused by the task.
- D. Unable to do laundry even with assistance. Relies on someone else to wash clothes.

20. Telephone Use

- A. Converses appropriately. Looks up telephone numbers, maintains a personal phone/address book satisfactorily. Able to manage a cordless phone.
- B. Occasionally seems distracted or confused during conversations. Sometimes has difficulty looking up telephone numbers and keeping track of them. Occasionally misplaces a cordless phone.
- C. Frequently seems distracted or confused during conversations. Shows decline in ability to look up telephone numbers and keep track of them. Frequently forgets to hang up the phone; often misplaces a cordless phone.
- D. Has significant trouble using the phone; may avoid it.

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- "Surviving transition - expected and unplanned," by Carol Levine
- "Elder caregiving - bringing the family together," by Rae Horwitz
- "Caregiving and work - an impossible balance?" by Gail Gibson Hunt

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