



Coming Together:



Shared Wisdom from Door County Caregivers



Rosalynn Carter has said, “There are only four kinds of people in the world—those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who will need caregivers.”

According to the US Census Bureau, there were an estimated 763,395 people age 65 and older living in Wisconsin in 2009. This represents 13.5% of the total population. Although disabilities among older adults are on the decline, many individuals require the assistance of a caregiver as they age. Estimates show that, in 2000, Wisconsin had 549,279 family caregivers who provided 588 million hours of care each year. This informal care was valued at more than 5.8 billion dollars! Within the next five years, population trends suggest that Door County will be one of only two counties in Wisconsin that will have older adults making up more than 27% of our total population. This means that aging and caregiving will continue to play a very prominent role in the lives of Door County's citizens and our community as a whole.

Caregivers and their families are unique and so are the feelings, needs, challenges and rewards that they experience. At the same time, there is a thread of commonality that binds caregivers to one another. For many, this thread is the emotional impact of caregiving. Caregiving forever changes those who provide care and the relationship they have with their loved one. The experience often brings frustration, sadness, anger and grief. Yet, it can also bring new-found strength, unwavering resilience, fresh advocacy and unexpected joy.

Serving the caregivers of Door County is the mission of the Door County Caregiver Coalition. Through the Greater Wisconsin Agency on Aging Resources, Inc. (GWAAR), our coalition applied for and was awarded grant funding to develop a resource to reach out to and support family caregivers. With our grant funds, we developed this publication, entitled “Coming Together: Shared Wisdom from Door County Caregivers”. A courageous and knowledgeable group of family caregivers graciously answered some challenging questions as we recorded their answers. On these pages, you will find their sage wisdom, practical tips and honest feelings. In addition, professional articles complement the various topics and a caregiver's guide to resources is included at the back for your reference. We are forever grateful for the contributions of this group of dedicated Door County caregivers and their willingness to help others.

A project such as this involves a great deal of planning and research along with a spirit of commitment to and respect for the role of caregivers. For their dedication and fine work, I want to thank Erin Szakala, Social Worker with the Door County Department of Social Services and Christy Wisniewski, Program Coordinator with Memory Care Connections. For the excellent professional photography, thanks go to László Szakala for donating his time and talents. I would also like to acknowledge the support and assistance of the Door County Caregiver Coalition as well as the guidance from the caregiver team at GWAAR in bringing this project to fruition.

“Together, we are not alone.” – Caregiver Support Group of Door County

Bev Knutson, Supervisor, Door County Senior Resource Center

Door County Caregiver Coalition Members: Parish Nurse & Parkinson Disease Support Group Facilitator Carol Moellenberndt, HELP of Door County Older Adult Services Worker Orlaine Gabert, UW-Extension Family Living Educator Pam Peterson, Bay Counseling Services Therapist and Caregiver Support Group Facilitator Amy Jahnke, Neighbor to Neighbor Volunteer Caregivers of Door County Executive Director Ann Bennett, Washington Island Community Health Partnership Director and Caregiver Support Group Facilitator Carole Machek, Memory Care Connections Program Coordinator and Caregiver Support Group Facilitator Christy Wisniewski, Door County Department of Social Services Social Worker and Caregiver Support Group Facilitator Erin Szakala and Door County Senior Resource Center Supervisor and Caregiver Support Group Facilitator Bev Knutson

Our Caregivers



Don and Esther Diefenbach

Donald and Esther Diefenbach have been married for 58 years and have two grown children. Don cared for Esther, who has been diagnosed with dementia, at home until February 2010 when she moved to a local CBRF. Don continues to be a loving and attentive caregiver, visiting daily and offering her support. In addition to being a caregiver, he remains active in the community by umpiring baseball games—where he is known to many as “Ducky”—working as a crossing guard for the Sturgeon Bay schools and delivering communion for his church. Like many spousal caregivers, Don has experienced the gamut of emotions that come with the illness and increasing needs of one’s partner. Through it all, he has persevered as Esther’s number one advocate. He has educated himself on her

disease, accessed services on her behalf and advocated with providers to ensure that her needs are met. Don is truly an amazing caregiver.

George and Inga Drastata have been married for 54 years. In 1960, their youngest child, Michael, was born with cerebral palsy and a brain aneurysm. As parents of a child with special needs, the Drastatas advocated tirelessly for Michael to have the best education and opportunities available to him. He graduated from high school and worked at Continental Bank in Chicago for 14 years before his health started to deteriorate. As Michael’s needs increased, George and Inga were joined by their daughter, Annie, in caring for him full-time. For 17 years, the three of them provided almost total care to Michael while ensuring that his life was active, enjoyable and filled with meaning. For the last two years of his life, Michael lived at Florida House, an Adult Family Home, and worked regularly at the Sunshine House, where he thrived. The Drastatas’ wealth of caregiving experience, insightfulness and down-to-earth perspective make them an excellent source of wisdom and support for other family caregivers.



David Drastata, Jeffrey Mark, Annie Drastata, George, Inga and Michael Drastata



Ed and Ellen Looker

Ed and Ellen Looker have been married for 66 years and have four adult children. Ellen is a dedicated caregiver for Ed, who has been diagnosed with dementia for the past several years. They continue to live in their own home, still attend Sunday church services and enjoy taking rides in Door County or short overnight trips when possible. Ellen finds that working in their yard and attending a water exercise class at the YMCA where she can visit with other seniors, helps to minimize some of the stress of caregiving. She is an advocate of educating people about dementia and she seeks out information on dementia through the internet, written materials and also attends a caregiver support group. She has a great sense of humor, finds the positives in challenging situations and, at age 85, is a remarkable caregiver.

and Their Loved



Dick and Terry Wiesner

Dick and Terry Wiesner have been married for 47 years and have three children and three grandchildren. Dick was born and raised in Door County and spent his 43 year career as an Optometrist in Sturgeon Bay. Terry is a Registered Nurse. In addition to being husband and wife, Dick and Terry worked together in his office for 30 years. Just three months after retirement in 2006, Dick suffered a stroke that left him with significant impairments and Terry began her journey as his caregiver. The road has been overwhelming at times and there have been many challenges along the way. But, Terry has educated herself about Dick's illness, discovered untapped personal strengths and found new meaning in her marriage vows. Today, both she and Dick, who has resided at Whispering Pines CBRF since August of 2009, have learned to smile, laugh and have fun again in this new life that they are making for themselves. They are a true inspiration to others.

In 1997, Renny Lea, her husband Dave and two teenage daughters, Ilona and Corinne, moved to Door County from Sheboygan in order to provide increased care for her aging mother, Frances Miller. In order to maintain Frances' independence and routine as much as possible, they moved into her home and built their new lives around providing for her care. Frances, who is now 97 years old, has resided at Good Samaritan Scandia Village in Sister Bay since 2007 and is now in Birchwood, their dementia unit. Frances, who had been a professional musician, still performs on the keyboard, entertaining and bringing pleasure to fellow residents there. Renny continues to be a dedicated and actively involved caregiver, visiting as regularly as she can and paying close attention to the small details that ensure that Frances' life is filled with joy and meaning.



Frances Miller and Renny Lea



Dennis and Dorothy Lindsey

Dorothy and Dennis Lindsey were married for 64 years and three daughters were born to their marriage. Although they lived in Florida, California, Illinois and several other places, their "hearts" were always on Washington Island where they lived and operated several restaurants. As a couple they enjoyed music; Dennis had his own band and sang on the radio. With several agencies helping to provide care in their home, Dorothy was a dedicated caregiver for her husband until he died in December of 2009 at the age of 98. As an advocate of humor and faith—and with a genuine respect for the work of caregivers—Dorothy is a great source of strength and support for caregiver support group members.

What helps you make it through the day?

I start out the day saying to myself "I will do my best". If I ask God for help and have faith, he will help me.

Dorothy—Caregiver for her husband

Stay in the day. Worrying about the future won't help and the past is in the past. I stay focused on what I can do today.

Terry— Caregiver for her husband

I put a list down for the day and week. It helps to stay organized. If there's nothing to do it's a long, slow day.

Don—Caregiver for his wife

A short nap! Even 10 or 15 minutes in the chair really helps me to feel refreshed.

Ellen— Caregiver for her husband

Knowing our son was so thankful and appreciative of our help made caregiving easier.

George—Caregiver for his son

Helping others as a church visitor – giving communion and visiting.

Don—Caregiver for his wife

Keep a positive attitude – for your own sake and your loved one's. You don't want your loved one to be bitter about his condition/disability because you've made him feel this way.

Inga—Caregiver for her son

If in a stressful situation, I walk away. Then I come back and try again later. My husband may be more receptive then.

Ellen—Caregiver for her husband

The internet really helps to get information. In some caregiver chat rooms, you can get good tips.

Ellen-Caregiver for her husband

Time for Hope & Renewal

By Erin Szakala

When you are a family caregiver, it is especially important to take time to refresh your spirit and renew your energy. Here are some suggestions:

- ☐ **Make peace** – In every experience, positive or negative, there is a need to let go of what **was**. Until you do, you can't appreciate what **is**. Life has changed in ways you may never have expected or planned. Your loved one is no longer able to do things that s/he used to do. You are engaged in tasks you never imagined you would – or could – do. Accept this new reality and open your heart to the strengths, relationships and experiences that it brings.
- ☐ **Forgive yourself** – No one is perfect. We all stumble and make mistakes from time to time. Recognize any hurt you may have caused and vow to do what you can to make it right. Forgiving yourself does not mean that you are no longer responsible for your past actions. Nor does it mean that you forget what happened. Forgiveness involves accepting the situation as it was, understanding why it happened and releasing the blame, resentment and anger that accompany the memory of it.
- ☐ **Build your self-esteem** – Picture yourself as positive. Focus on your achievements rather than your mistakes. Make sure that your strengths and not your weaknesses are the major topic of your conversations. If you find yourself becoming negative, change the subject. Surround yourself with positive people whenever possible and identify healthy role models who you can emulate.
- ☐ **Be happy** – Happiness is a state of being that is available to anyone and, like any good habit, it can be cultivated. Somewhere between childhood and being a caregiver, you've probably lost your sense of humor. Did you know that kids laugh an average of 60 times per day while adults laugh less than 10? Start laughing more by finding humor in your daily life. When something "negative" happens, practice turning it into something funny. Your loved one spills his milk – think of a cow that has suddenly sprung a leak. Make a point of enjoying at least one funny thing each day – a comic strip, a humorous TV show, a joke or a silly moment with your loved one. Laughter is therapeutic. It will make you feel good, and feeling good leads to happiness.

high blood pressure, and offers distraction.

- ☐ Reducing stress.
- ☐ Protecting the heart.
- ☐ Improving brain functioning.
- ☐ Elevating mood.
- ☐ Giving you a good workout.
- ☐ A good

What would you advise people not to do or say to caregivers?

“Why don’t you put him in a home?” Family members, friends, people who belong to our church, they’ve all said this and it is very hurtful.

Annie– Caregiver for her brother

“I could never do it” – referring to taking care of a loved one at home. This made me feel as if I was different or weird in some way. The truth is that when faced with a challenge, we all find strength to do what needs to be done. No one can help you to find strength within yourself - you have to do this.

Inga– Caregiver for her son

It doesn’t help when people say: “God doesn’t give you any more than you can handle”. I have a sign in my bathroom that says “God helps you to handle what you have been given.” That means a lot to me. I put it at eye level and look at it every day.

Terry– Caregiver for her husband

People need to realize that the person (with an illness or disability) can hear everything that is said, even if s/he can’t respond. My husband loved company – be sure that you let your friends and neighbors know to include your loved one in the conversation.

Dorothy– Caregiver for her husband

My husband is ignored in conversation because he cannot speak. He’s in there but he can’t communicate. People don’t know how to deal with this so they don’t include him in conversation. Please – don’t talk over him, include him. Make eye contact with him.

Terry– Caregiver for her husband

I always appreciate it when someone comes over and talks to my husband, at least says “hi”. They need to recognize him as a person. Don’t ignore him, include him.

Ellen– Caregiver for her husband

It is hurtful when good friends fall away. They stop visiting because they don’t feel comfortable. That hurts.

Terry– Caregiver for her husband

Guilt—A Common Denominator in Caregiving

By Susan McAninch

Guilt is a common feeling in the world of caregiving. Guilt can be a gift that propels you to be the best that you can be—or it can immobilize you.

For caregivers, painful feelings, such as guilt, sadness and anger, are like any other type of pain. They are your body's way of saying "Stop. Pay Attention." Just as pain from burning your finger pulls your hand away from the stove, guilt guides your actions.

You have a picture of the "Ideal You" with values you hold and expectations of how you relate to yourself and others. Being a caregiver tests those self-proclaimed standards and guilt often arises when there is a mismatch between the day-to-day choices you must make and the choices the "Ideal You" would like to make. The "Ideal You" is a parent who attends all of your child's soccer games. When you miss one in order to take your father to an appointment, you think you are falling short.

You may consider your own needs not a part of the "Ideal You". You may believe that your own needs are insignificant when compared to the needs of your sick loved one. You then feel guilty when you even recognize your needs, much less act on them. How could you possibly take time for yourself, especially when it means leaving your loved one under the care of someone else—and your loved one doesn't want anyone but you?

You may have feelings that are misaligned with the "Ideal You". You may experience anger over the injustice of your loved one's illness—and how that impacts your life. You may feel anger at your loved one for being sick! You may feel a sense of responsibility for your loved one's illness. What if you had called 911, instead of believing your husband when he said his chest pain was just a little heartburn?

Below are some tips for managing caregiver guilt:

- ☐ Recognize the feeling of guilt. Unrecognized guilt eats at your soul.
- ☐ Identify other feelings. Often, there are feelings under the guilt. Name those, too. Be honest with yourself. For example, it may be hard to admit that you resent the reality that your Dad need so much of your time. Once you put your feelings into words, you are open to see your situation from a new perspective. You might see too that you are strong and have what it takes to take care of your loved one, time consuming though it may be.
- ☐ Be kind to yourself. Give yourself permission to have any feeling, so you can stop judging yourself harshly. Do you have an unmet need? Are you feeling impossibly responsible for something that is really not your responsibility? If you determine that your guilt is justified, then change your behavior from that moment on to better fit your values.
- ☐ Revisit and challenge the "Ideal You". Your expectations of yourself may be unrealistically high. Recognize that you are making the best choices based on your resources and knowledge at an given time.

Not all caregivers experience guilt, but if you are among the many, if not most, who do, learn to manage your guilt so that it serves you and does not imprison you.

What have people said or done for you that you found was helpful?

Sometimes you feel you're the only one with these problems. Then you go to the caregiver support group and find out you're not alone.

Inga– Caregiver for her son

We had good neighbors who stopped by and offered help. Getting connected with Neighbor to Neighbor for a peer companion was wonderful too. Our son and the peer companion got along very well – he was a real blessing.

George– Caregiver for his son

It means a great deal to my mom to get mail – letters, cards, photographs. She looks at them and reads them over and over. It is a true source of enjoyment for her.

Renny– Caregiver for her mother

A short term respite stay can do wonders!

Terry—Caregiver for her husband

Laughter – first we laugh at a joke, then we can cry together.

Dorothy—Caregiver for her husband

The Value of Caregiver Support Groups

By Erin Szakala

Remember the old adage, "trouble shared is trouble halved"? This is the value of a caregiver support group. Joining a group offers one way to share your troubles and connect with people who are going through the same experiences that you are living each day. If you can't leave the house, many Internet support groups are available.

A caregiver support group provides information about helpful resources as well as generates camaraderie. Seasoned caregivers can share their collective wisdom and help those who are less experienced to contend with the difficult aspects of caregiving. Finding home care services, pre-planning legal affairs, applying for financial help, or preparing to move a loved one into a care facility can all be daunting events, yet group members can help each other to take these steps. Support groups offer a place for caregivers and families to learn together, deal with feelings of frustration, sadness or isolation, and "link arms" with others who have a mutual understanding. Support groups can also validate a caregiver's identity and give them permission to care for themselves throughout the caregiving journey.

There's another important benefit that a support group can provide. People facing the challenges of caregiving need to find hope for the future, laugh about the "humorous" aspects of their lives, enjoy social activities and have fun together. What better group of people to connect with than those who walk in the same shoes?

Types of Caregiver Support Groups

Community support groups for caregivers: Internet support groups for caregivers:

People live near each other and meet in a given place each week or month. People are from all over the world and have similar interests or problems.

You get face-to-face contact and a chance to make new friends who live near you. You meet online, through email lists, websites, message boards, or chat rooms.

The meetings get you out of the house, provide a social outlet, and reduce feelings of isolation. You can get support without leaving your house, which is good for people with limited mobility or transportation problems.

Meetings are at a set time. You will need to attend them regularly to get the full benefit of the group. You can access the group whenever it's convenient for you or when you need help most.

If your problem is very unusual – a rare disease, for example – there may not be enough people for a local support group, but there will always be enough people online. Since you can access the group whenever it's convenient for you or when you need help most, you can find support and resources.

The advantages of joining a support group are limitless. Some of the best reasons to join include:

- Sharing common experiences and learning coping strategies
- Exploring and sharing solutions to problems
- Finding emotional outlets and receiving support from peers
- Forming new friendships and discovering a sense of community
- Developing new skills through education
- Helping others while still helping yourself

To find a community support group, refer to the Door County Resource Guide for Senior Citizens, Persons with Disabilities and their Caregivers. You can pick it up at the Door County Senior Center or find it online at www.co.door.wi.us or call the Senior Center at 746-2542.

Some local support groups for caregivers include:

Caregiver Support Group of Door County

1st & 3rd Wednesdays of the month 1:00—2:30 p.m. Sister Bay / Liberty
2nd & 4th Wednesdays of the month 1:00—2:30 p.m. Sister Bay
Good Liberty Senior Community Room 2323 Mill Road
Resource Center Cornucopia Room for
Caregivers 832 N. 14th Avenue Sturgeon
Bay

(920) 746-2542

(920) 746-2542

3rd Wednesday of the month
10:30 a.m.—12:00 p.m.
Trinity Lutheran Church
1763 Townline Road
Washington Island
(920) 847-2108

Dementia Caregiver Support Group

1st Monday of the month 1:00 p.m. Good Samaritan
1st Thursday of the month 1:00 p.m. Good Samaritan
Scandia Village 10560 Applewood
Road Sister Bay

(920) 854-2317

Parkinson Disease Support Group

1:00—2:30 p.m. United Methodist
Sturgeon Bay

(920) 743-3476

While traditional support groups offer an opportunity to meet with other caregivers in person, the internet offers many opportunities for individuals to “meet” online, problem-solve, share information and experiences and ultimately receive support. Online support groups can be accessed, 24 hours a day, seven days a week. This is a plus for caregivers and others who can’t find quiet time until the late hours of the night.

Some caregivers report that they prefer the flexibility, convenience, anonymity and value of connecting with and hearing from a large, diverse group of people online. They can find a community of support right at their fingertips from peers and professionals across the nation and even throughout the world.

Another invaluable feature of the computer age is the wealth of knowledge that can be accessed online. Useful resources, newsletters, connections to disease-specific sites, medical and research updates and self-care tips are just a few examples of additional wisdom available on the internet.

No matter what, it is vital that you find support as a caregiver. Unfortunately, the tenacious independence of most Americans does not serve us well when we are faced with the challenges of caregiving. **A caregiver must have support.** Take a chance and find that support in a caregiver support group.

Respite

Sometimes just getting a break is all that you need. Sometimes, getting a break is what makes all the difference in the world. **That's what respite is—a break for caregivers.**

The primary purpose of respite care is to provide temporary relief from the extraordinary and intensive demands of caring for someone with special needs. In turn, this relief strengthens your ability to provide care to your loved one. Respite is planned and proactive. Respite means taking a break before extreme stress and a crisis occur.

Without respite, caregivers themselves may face serious health and social risks as a result of stress associated with continuous caregiving. Three fifths of family caregivers age 19-64 who responded to a recent Commonwealth Fund survey reported fair or poor health, one or more chronic conditions, or a disability, compared with only one-third of non caregivers. In addition, a Commonwealth Fund study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than non-caregivers of the same age.

In turn, a number of studies have proven the value of respite to caregivers and their loved ones. A 2001 paper published in the research journal *Focal Point* explored the benefits of respite for parents of children with emotional and behavioral disorders. This research concluded that respite enhanced the caregivers' capacity to cope with stress, lessened the number of institutionalizations and created greater optimism about the caregivers' ability to continue to provide care. Further, a study of caregivers of Alzheimer's patients published in the *Journal of the American Medical Association* in 1996 showed that respite and counseling lessens depression and helps caregivers avoid nursing home placement for their loved one for as much as a year.

Respite comes in all shapes and sizes. A weekend trip to visit friends, an evening out to a concert or an afternoon to get your hair done. An hour's walk on a country road, 30 minutes reading a good book or five minutes of silent time to relax and clear your head. It's all respite as long as it serves to break your tensions and renew your spirit.

The next time you start feeling guilty about taking a little time for yourself, remember this: Respite isn't just for you. Your loved one will reap tremendous benefit from respite as well. Respite is guaranteed to take the edge off your tension, recharge your batteries and refill your reserve of patience so you can resume your caregiving duties once again. Not only will this make you feel better, it will go a long way toward helping your loved one too. Plus, your loved one will have the opportunity to meet new people, socialize and participate in fun activities as a part of his/her respite time as well. Respite is a win-win situation for everyone involved.

Door County Caregivers



Front row, from left to right: Ellen Looker, Renny Lea, Dorothy Lindsey and Terry Wiesner. Back row, from left to right: Annie Drastata, Inga Drastata, George Drastata and Don "Ducky" Diefenbach



Share Their Wisdom



What factors came into your decision to place your loved one?

Knowing within myself that I couldn't do it anymore – emotionally or physically. It is hard to accept – sure I might do things differently (than facility staff) but I have to let it go. Just because they do it differently doesn't mean that they don't do it well.

Terry– Caregiver for her husband

A crisis precipitated it. It was a very tough decision so it was nice to have support from family, friends and professionals in making it. The home-like setting of Birchwood (the dementia unit at Scand) made a big difference for me. I saw that Mom was getting more there than I could give her at home – stimulation, an opportunity to play her music and a chance to feel useful and productive. This helped me to make the decision for her to stay there.

Renny—Caregiver for her mother

The qualities of the facility. I need to do my homework first – check it out. I know I need to take it all with a grain of salt though, too, and choose the one that seems like the best fit for my husband.

Ellen– Caregiver for her husband

Safety was a factor – our loved one was falling often – he or one of us was going to get hurt.

George, Inga and Annie—Caregiver for their son/brother

A Tough Decision

By Susan McAninch

The decision to place your loved one in a nursing home or other care facility may be the hardest decision you, as a caregiver, have to make in the course of caregiver. How do you make such a decision?

Sometimes, extreme or acute circumstances dictate a decision—you become ill or incapacitated, or your loved one's condition changes dramatically—s/he breaks a hip and needs total care or exhibits violent behavior that creates an unsafe environment for all. These circumstances, while still difficult, can make a decision a little easier because “the situation” decides for you.

At other times, though, the need to make a decision emerges over time. The decision is complex and based on the combination of both your and your loved one's characteristics, community resources (available, unavailable or already exhausted) finances, and much more, all of which are highly individual and ever changing. No wonder there are no simple rules that make this decision easy.

So, what should you consider? In the most general terms, consider nursing home care when your loved one requires too much care to live safely on his own and has become emotionally and/or physically needy to the extent that living with family jeopardizes the safety, health and well-being of you and/or your family. A 2005 caregiver study (Buhr, Kuchibbatla, Clipp; Caregivers' Reasons for Nursing Home Placement: Clues for Improving Discussions with Families Prior to the Transition. *The Gerontologist*, Volume 46, Issue 1. pp. 52-61) showed that the main reasons (in order of prevalence) one places a loved one in a facility are: need for more skilled care, health of the caregiver, the loved one's dementia-related behaviors (specifically hallucinations, unusual motor behaviors, abnormal behavior at night), the need for more assistance, and depression in the loved one. Additionally, when the demands of caring are high and the caregiver's feelings of satisfaction are low, the incidence of placement increases.

Moving a loved one to a care facility is understandably the last decision many caregivers want to make. Caregivers use many strategies to help keep their loved ones at home. Getting help early in the care-giving career, with support from formal resources as well as family and friends, helps to delay placement. Counseling and attending support groups also help to extend the ability to keep managing at home. Caregivers are known to reach their limit, and then go on, providing care at home far beyond their physical and emotional capacity. It is not a surprise, then, that when placement becomes a reality, a myriad of emotions are present.

When all efforts are not enough, a common response is that placement represents a failure: a failure to cope, a failure of caregiving skills, a betrayal of your loved one. Feelings of guilt are prominent. Often promises have been made; there may be a conflicted relationship to start with; family members may not be in agreement; your loved one may adamantly not want to move or may not have the capacity to understand. All of these variables and more make a tough decision even tougher.

Guilt must give way to practicalities sometimes, and this is one of those times. Obsessing about the “what ifs” and “if onlys” may stand in the way of making a clear-headed decision. You must concentrate on your loved one's needs, not on what they—and you—wish could be. To continue to be the best you can be, it is important to be open to grieving the losses inherent in placement: the loss of the person who was, the loss of what you vowed and wanted, and the loss of your role as the primary caregiver. Healing comes from allowing yourself to feel the loss, experience the sadness, challenge the guilt and get support for your decisions.

Tips for communicating with doctors

Be an “actor”, not just a “re-actor” with regard to your loved one’s care. Keep a spiral notebook and write down questions you have for the doctor, symptoms, main points discussed during the visit, etc. This helps you to have it all in one place and ready for the doctor when needed. Write down blood sugar levels, blood pressure readings, etc. so you don’t have to rely on memory when the doctor asks.

Renny—Caregiver for her mother

Keep the primary care doctor’s phone number handy and, when there is a question at a specialist’s office, call the primary doctor and connect them directly. This ensures good care.

Dorothy—Caregiver for her husband

You need to be your loved one’s advocate. I type up a list of information from one doctor to give to the other doctors so they know what is going on.

Ellen—Caregiver for her husband

Call the doctor ahead of your loved one’s appointment to discuss the concerns you have. Ask the doctor to consult with other doctors – like a psychiatrist – if needed for behavioral concerns.

Don—Caregiver for his wife

Before I chose a new doctor for my husband, I interviewed him to see if he was prepared to care for my husband’s complicated medical condition and understood what I wanted for him.

Terry—Caregiver for her husband

A Positive Visit

By Christy Wisniewski

The relationship with a doctor is a very personal one, often evaluated by the strength of communication and level of trust. Following are some tips to assure a productive, positive doctor visit for you and your loved one:

Getting to the doctor – Sometimes a loved one may resist going to the doctor. Some ways to encourage the doctor visit include:

- Assuring your loved one that the doctor just wants to follow up on a last visit, or do a routine check up.
- Limiting the amount of time your loved one has to worry about an appointment by waiting to tell him

- or her about the appointment.
- Emphasize a fun activity afterward, such as visiting a friend or grabbing a bite to eat.
- Utilizing supports that may share a strong bond, such as family, a neighbor, or friend.
- Prepare for the visit in advance with distractions, particularly if you anticipate a long wait.

Snacks,

crossword puzzles, magazines, music and headphones are just a few ideas.

Carry a notebook – even little changes in your loved one's wellbeing can mean an adjustment in medication or a test for something more serious. A small notebook for daily observations can give the doctor a clearer, more comprehensive picture of your loved one.

- Note the date, time and specifics about the change. Some changes might include: unusual mood swings, rash or fever, confusion, pain, loss of appetite, or changes in routine.
- The notebook is also a good place to write notes of test results, medication changes/dosages, and anything else discussed with other doctors involved in care.

Be an Advocate –What you say, how you say it, and the information you give makes a difference in how your loved one is treated.

- Use "I" statements, such as "I need..." "I would like..." or "I'm feeling uncertain..."
- Restate what the doctor is saying or ask for clarification when you don't have complete understanding.
- Request more information about medications, diagnoses, tests; including options, alternatives, risks, and benefits.
- Don't be afraid to discuss costs and economical approaches to treatment.

Get organized. A binder, accordion file, or pocket folder is essential for organization and separation of the volumes of information necessary to manage a chronic illness. Have sections appointed for:

- Emergency information to be grabbed if a crisis occurs. This might include: diagnoses, list of medications, insurance information, social security number, date of birth, physician and hospital contact numbers.

- Future planning information: Power of Attorney documents, financial planning information.

- A section to store past notebooks or care logs
- Contact information for supportive resources.

- A section for any educational information about your loved one's medical conditions.

What helps you cope with the losses associated with your loved one's condition?

Humor and then more humor.

Ellen– Caregiver for her husband

The caregiver book the Senior Center gave me—Daily Comforts for Caregivers—is very helpful.

Don– Caregiver for his wife

I recognized that my coping skills were shot – I couldn't do it anymore. My doctor had suggested medication before and I refused – I thought I could/should be able to do it all on my own. I brought it up to my doctor and went on an anti-depressant. People are ashamed to admit that they need medication but CAREGIVING IS TOUGH WORK. It has helped me.

Terry– Caregiver for her husband

The wonderful helpers that came to our home.

Dorothy– Caregiver for her husband

We recognized how miserable Michael was toward the end. Death was a relief for him and this helps us to cope with losing him. We had always hoped that we wouldn't have to leave him behind – that he would die before us.

George and Inga- Caregivers for their son

All of our wonderful memories, all of the fun we had together over the years.

Dorothy– Caregiver for her husband

Taking a caregiver class or going to a caregiver support group helps you to cope.

Ellen– Caregiver for her husband

It made me feel good to do something special for Michael. He loved to eat – right up until near the end. I would get out a cookbook and let him pick out something he wanted for dinner. Making it and seeing him enjoy it made me feel good. The experience made him feel good too – despite his disabilities, he was contributing to the family unit.

Annie—Caregiver for her brother

You've Got to Be Kidding

Finding Humor during Challenging Times

By Laura Zimmermann, MA, RNC, CMSRN

"What? Laugh at a time like this? You've got to be kidding." As a caregiver both at work and at home, I thought it was just too serious to find humor caring for my ill loved one and all the people in the hospital. Watching people I loved deteriorate and suffer certainly was not a laughing matter.

But, just when I least expected it, a joke or humorous moment would come from my loved one or someone I was caring for in the hospital. For instance, a single woman with pancreatic cancer in my care had developed a severe gastrointestinal issue that required keeping a bedpan or commode close at hand. The commodes we had were very small and when I brought one in to see if it would be OK, she said, "It's better than this thing!", throwing the bedpan.

One day, I answered her call bell and found her sitting on the commode. "I can't get out," she cried. I began to assist her and the two of us ended up in bed together. She was partially on top of me, and we just looked at each other and began to laugh. As we started calming down and moving out of each other's way, she stated, "Boy, I haven't had that much fun in bed in a long time." She laughed so hard the rest of the day and every day we were together. People like her gave me the courage to giggle behind the seriousness of all the stuff.

The familiar reflex "You've got to be kidding" provides a clue for how we can survive the anxiety and chaos created by life's challenges. As caregivers, we are at high risk of becoming sick ourselves, and humor can help relieve and release our stress. If our loved one is included, we both are likely to reap the rewards of laughter.

The Health Benefits of Humor

"A clown is like an aspirin, only he works twice as fast." Groucho Marx.

Norman Cousins drew attention to the health benefits of humor in his books *Anatomy of Illness and Head First: The Biology of Hope*. His debilitating disease left him in almost constant pain. He discovered that watching comedy films and laughing helped him sleep pain-free for two hours longer. His books and testimonial to the power of laughter drew the attention and curiosity of the medical community. Researchers wanted to know how this happened and began to study the effects of humor. Scientists have since discovered that laughter relaxes the body and eases muscle tension, reduces problems with

- ☐ **Make peace** – In every experience, positive or negative, there is a need to let go of what **was**. Until you do, you can't appreciate what **is**. Life has changed in ways you may never have expected or planned. Your loved one is no longer able to do things that s/he used to do. You are engaged in tasks you never imagined you would – or could – do. Accept this new reality and open your heart to the strengths, relationships and experiences that it brings.

☐ **Forgive yourself** – No one is perfect. We all stumble and make mistakes from time to time. Recognize any hurt you may have caused and vow to do what you can to make it right. Forgive yourself does not mean that you are no longer responsible for your

"If you want others to be happy, practice compassion. If you want to be happy, practice compassion."
Dalai Lama

Of course, you want to be sensitive to when humor is appropriate. As professional comedians know, timing is everything. For instance, when you or someone you love is first diagnosed with a serious illness neither of you may be ready for humor. Instead, there might be a need for crying and sorting out changes and questions. How did this happen? What does this mean? What do we do?

Another key to introducing humor into caregiving is to make sure to use the “connecting” type of humor. You’ll know you’re doing this when the laughing comes naturally, is contagious and energizing, and involves and embraces others.

Here are some tips for making sure your humor is connecting and not offensive.

- Use humor after another person initiates humor.
- Aim the joke at yourself.
- Poke fun of the situation rather than at another person or group.

Do a brief humor inquiry: Has your loved one given you any clues that indicate they are receptive to humor? Does she attempt to share humor with anyone? Is he able to perceive and understand humor? Does she prefer a certain comedy artist, comedy show, or comic strip?

Tips on Creating Comedy

Find one humorous thing a day and begin to collect them in a scrapbook. I use one and it has been a therapeutic tool for me to take a five-minute fun break and look through the pages and see what I collected over the years. You might even be amazed at what you thought was funny last month. Looking at it today, you might ask yourself, “What was I thinking?”

- Build a humor library and video/DVD collection at your home.
- Read the comics first. You can register to receive your own custom-made comic strip via e-mail at www.mycomicspage.com
- Hang around with or call a “laugh” buddy.
- Create a “fun first aid kit.” Collect toys, squirt guns, bubbles, tongue twisters; whatever makes you feel playful and ready to laugh. Involve your loved one in building the kit or have your own special one.
- Make time for “play time/silly time” with the fun kit or any other activities that bring out the funny side in you.
- Join a laughter club. (Do a web search for “laughter club” to find one near you)

Do this smiling meditation.

Morning and Evening Smiling Meditation Exercise

Find a comfortable place to sit with your head and back supported. Close your eyes, take a deep breath, called a “signal breath,” and shift your focus onto your breathing. After a few breaths, begin to form a smile. Just start with a gradual smile, making it bigger and bigger until your teeth show. Breathe comfortably, continuing to hold this toothy smile for a minute or two while visualizing pleasant scenes.

“Sometimes your joy is the source of your smile, but sometimes your smile can be the source of your joy.”—Thich Nhat Hanh

A sense of humor helps us manage the stress of caregiving, providing a moment to disengage from the suffering while still remaining sensitive. Laughter brings us into the moment, and that is a moment of joy, love, and hope. There is something wonderful about sharing a laugh with another person. It always makes you feel better.

10 Tips for Family Caregivers

- 1.** Caregiving is a job and respite is your earned right. **Reward yourself** with respite breaks often.
- 2.** **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
- 3.** When people offer to help, **accept the offer** and suggest specific things that they can do.
- 4.** **Educate yourself** about your loved one's condition and how to communicate effectively with doctors.
- 5.** There's a difference between caring and doing. **Be open** to new technologies and ideas that promote your loved one's independence.
- 6.** **Trust your instincts.** Most the time, they'll lead you in the right direction.
- 7.** Caregivers often do a lot of lifting, pushing and pulling. **Be good to your back.**
- 8.** Grieve for your losses, and then allow yourself to **dream new dreams.**
- 9.** **Seek support** from other caregivers. There is great strength in knowing you are not alone.
- 10.** **Stand up for your rights** as a caregiver and a citizen.

What do you know now that you wish you had known when you started?

I wish I had known that it is important to keep involved with your own activities. This makes you a better caregiver and allows you to pick up the pieces of your life when caregiving ends.

Ellen– Caregiver for her husband

I wish I had known that Mother would get used to the atmosphere at the facility – that it would come to feel like home to her. Recently, when we returned to the nursing home after going on an outing with the residents, my mother said to me, “I’m glad to be home”. This gave me such peace – I knew the decision to have her move there was a good one.

Renny– Caregiver for her mother

I wish I had known not to be afraid to ask for help.

Dorothy– Caregiver for her husband

I wish I had known that it is important to get away and do something “normal” on a regular basis. The first time using respite is so hard – you feel very guilty – but it is essential to being able to keep going.

Terry– Caregiver for her husband

Realizing that dementia gets worse over time and at the end of the tunnel my husband will die was sad, but also helpful. It put things into perspective and helped me to cherish every moment more.

Ellen– Caregiver for her husband

I wish I had known about the support group meetings - they really helped me.

Dorothy– Caregiver for her husband

I wish I had known about this very useful book: “My Stroke of Insight: A Brain Scientist’s Personal Journey” by Jill Bolte Taylor. It provides great information on how our brains function and how this functioning is impacted by a stroke. It also gives insight into how a person who has experienced a stroke experiences life and how caregivers can cope with this new reality.

Terry– Caregiver for her husband

I wish I had known this useful tip: Keep a notebook in your loved one’s room where you write down a bit about each visit. What you talked about, where you went, what you did together. Leave it with your loved one. My mom reads her notebook over and over – this helps her to recall our visit despite her memory deficit. It also helps to pass the time between our visits – it keeps us connected.

Renny– Caregiver for her mother

The Spiritual Rewards of Caregiving

by Sheryl Karas M.A.

In the past several weeks I have had the unusual privilege of working with caregivers who have found great joy and meaning in their caregiving experience. One person told me that he thinks he was brought back from the brink of death himself a few years ago in order to provide the loving support his wife now needs with Alzheimer's Disease. He believes with all his heart that God meant for him to do this work and it gives him great strength, determination and courage.

Another caregiver described to me how it was to care for a deeply beloved parent. She said, "I've become more sensitive to my own mortality and to what matters in the end. Truly loving someone, being aware of beauty and keeping the senses alive helps you appreciate each breath. Some people get that from studying Zen or reading books, I learned it from taking care of my mother."

Another caregiver echoed this very thought the following day. She said that her spiritual practice is to be present to every moment. Her mother, having lost her memory and ability to plan for the future, actually lives that way. It gives her great pleasure to assist her mom in having the most enjoyable present moments that she can.

All of these caregivers were profoundly touched by their caregiving experiences. That doesn't mean, of course, that they never felt tired or resentful or overwhelmed. If that was true I never would have met them. Yet each of them was able to see their caregiving within a meaningful framework that made all the difference.

You can endure the most horrifying situations if you can find a greater meaning. A well-known concentration camp survivor, Victor Frankl, actually wrote several books and developed an entire field of psychotherapy based on the theory that the search for meaning is the primary human motivation. He strongly believed that while we may not be able to change our biological, hereditary and environmental realities, we always have the ability to choose how we will think about our situations and how we wish to respond.

Recent studies point to the importance of recognizing and acknowledging the important role caregivers play in the lives of their loved ones. People who can find greater meaning and reward in their caregiving experiences have fewer health problems and feel less stress. Rewards include feeling like they made a difference in someone's life, renewed appreciation for one's own competence and ability to handle a difficult situation, the gift of being able to truly show the depth of one's love and caring, and increased self-respect. Families that shared caregiving responsibilities felt closer bonds of kinship, greater tolerance for other people's problems, more empathy for each other's needs, and less fear about the aging and dying process.

At the start of each New Year we traditionally review the previous one and make resolutions for how we want to proceed. This is also a great time to appreciate yourself for the important job you are doing as a caregiver and to renew your commitment for the coming year. Ask yourself these questions:

What am I proud of as a family caregiver?

How have I made a difference in my loved one's life?

What is my deepest motivation as a family caregiver?

What will help me achieve the ends that I seek?

And, what will I do this year to support and acknowledge myself for the great job I am doing?

Help is Available

Information and Assistance: This is a service that is easily accessed through the staff at the Senior Resource Center or Social Services. Individuals are provided with current, accurate and comprehensive information about public and private resources and opportunities available in their community. Staff will help problem solve and link caregivers with available services.

Support Groups: A safe place where caregivers can talk about their own needs, frustrations and concerns. Groups may be disease-specific or applicable to any caregiver. They are free of charge and, depending on the particular group, often led by professionally-trained facilitators.

In-Home Help: This service is designed to relieve you of responsibility for some of the daily tasks of caregiving. Housekeeping assistance, laundry, meal preparation, personal care assistance, transportation and medication monitoring are some examples. In-Home Help can be provided by family, neighbors, friends or a hired provider.

Respite: Respite is a period of time when the stress and responsibility of caregiving is temporarily transferred to a trained provider or another trusted person so caregivers may enjoy time away with “peace of mind.” Caregiver Respite can be provided in your own home, at adult day care, or in a care facility by professionally-trained staff, volunteers, family or friends.

Lending Library: A collection of resources – books, pamphlets and videos – that offer education and support to caregivers in their daily lives. Visit the Cornucopia Room for Caregivers at the Senior Center anytime Monday—Friday, 8:00 a.m.—4:30 p.m. Your local library may also have a collection of caregiving resources.

Classes and workshops: Offered to assist caregivers in fulfilling their responsibilities, making decisions and solving problems that impact the health and well-being of themselves and the one for whom they provide care.



Make peace – In every experience, positive or negative, there is a need to let go of what **was**. Until you do, you can't appreciate what **is**. Life has changed in ways you may never have expected or planned. Your loved one is no longer able to do things that s/he used to do. You are engaged in tasks you never imagined you would – or could – do. Accept this new reality and open your heart to the strengths, relationships and experiences that it brings.

Helpful Websites: **Forgive yourself** – No one is perfect. We all stumble and make mistakes from time to time. National Family Caregivers Association: www.thefamilycaregiver.org
Family Caregiving 101: www.familycaregiving101.org Today's Caregiver Magazine / Caregiver.com: www.caregiver.com or 800-829-2734 Wisconsin Family Caregiver Alliance: www.uwex.edu/ces/flp/caregiving National Alliance for Caregiving: www.caregiving.org AARP: www.aarp.org/families/caregiving Alzheimer's Association of Greater Wisconsin: www.alz.org/gwwi Caregiving.com: www.caregiving.com National Alliance for Caregiving: www.caregiving.org Caring for the Caregiver: www.wisconsincaregiver.org

Find the Door County Resource Guide for Senior Citizens, People with Disabilities and Their Caregivers at www.doorcounty.gov under “Quick Links”

Useful Books and Videos / DVDs:

Alzheimer's: Inside Looking Out – DVD on the experience of individuals with early-stage dementia **Bathing Without a Battle** – DVD featuring bathing techniques for individuals with dementia **Complaints of a Dutiful Daughter** – DVD documentary of one woman's care for her mother with Alzheimer's **Daily Comforts for Caregivers** by Pat Samples **Dementia Caregivers Share Their Stories – A Support Group in a Book** by Lynda Markut and Anatole Crane **Dementia with Dignity** – DVD on making care for people with dementia dignified and person-centered **Dying Well: Peace and Possibilities at the End of Life** by Ira Byock, MD **Elder Care: A Six Step Guide to Balancing Work and Family** by John Paul Marosy **Elder Rage or Take My Father...Please! How to Survive Caring for Aging Parents** by Jacqueline

Marcell **How to Go on Living When Someone You Love Dies** by Therese Rando **Learning to Sit in Silence: A Journal of Caretaking** by Elaine Marcus Starkman **Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease** by Joanne Koenig Coste **Losing LouAnn** by Clinton Erb **Pressure Points: Alzheimer's and Anger** by the Duke Family Support Program at Duke University **Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill** by Cappy

Capossela and Sheila Warnock **Taking Care of Parents Who Didn't Take Care of You: Making Peace with Aging Parents** by Eleanor Cade **The Caregiver Helpbook: Powerful Tools for Caregiving** by Vicki L Schmall, Marilyn Cleland, and

Marilynn Sturdevant **The Complete Bedside Companion: A No-Nonsense Guide to Caring for the Seriously Ill** by Rodger McFarlane and Philip Bashe

The Fearless Caregiver: How to Get the Best Care for Your Loved One and Still Have a Life of Your Own by Gary Barg **The 36-Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life** by Nancy Mace and Peter Rabins **What if it's not Alzheimer's : A Caregiver's Guide to Dementia** by John Q. Trojanowski, MD, Lisa Radin and Gary Radin **When a Family Member Has Dementia: Steps to Becoming a Resilient Caregiver** by Susan

McCurry **We Need to Talk: Family Conversations with Older Drivers** by AARP and The Hartford **Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's**

Disease and Related Illnesses by Anne Robinson, Beth Spencer, Laurie White and Eastern Michigan University

All the books and videos / DVDs listed, as well as many more, can be borrowed from the Cornucopia Room for Caregivers at the Door County Senior Resource Center.

For information and assistance getting connected with the services you need, call or visit the:



Make peace – In every experience, positive or negative, there is a need to let go of what **was**. Until you do, you can't appreciate what **is**. Life has changed in ways you may never have expected or planned. Your loved one is no longer able to do things that s/he used to do. You are engaged in tasks you never imagined you would – or could – do. Accept this new reality and open your heart to the strengths, relationships and experi

Disaster Preparedness for Caregivers

By Christy Wisniewski

We should all have a plan in place when a crisis arises. Caregivers must also plan for the special needs of their loved one when preparing for disaster. A person with dementia may not be able to respond safely to situations, and may not react to stress in a calm manner. The following tips can help guide caregivers as they plan for themselves and the care of their loved one.

Be calm and comforting

- A person with dementia will respond to your tone. Remain calm, patient, and flexible. · Be aware of emotions, which are often communicated through the person's behavior. Ask, "Are you feeling frightened?" Offer your hand or a hug.
- A person with Alzheimer's shouldn't be left alone, or left with a stranger. A person who doesn't understand Alzheimer's disease and its effects, or who doesn't know you or the person, won't understand how to respond to a difficult situation.

Create a safe environment

- As much as possible, try to maintain daily routines.
- Use simple sentences to indicate the need to stay where you are. Divert attention to a new topic. For example, "I know you want to go home. For now, we need to stay here. Let's see if we can get some lunch."
- Try to spend extra time with the person to help him or her adjust to the new environment. · Limit news media exposure to the disaster. · As appropriate, inform people around you that the person has memory loss.

Occupy your loved one

Portable DVD player (including power cord and/or extra batteries) and movies
Soothing music or audio books Favorite possession Games, puzzles, books, photo albums Arts and crafts materials

Take care of yourself

- Keep an emergency kit at home and in your car filled with items that will meet all your needs.
- Ensure proper nutrition and hydration.
- Maintain at least ½ a tank of gas in your car.
- Develop a support network and feel capable of asking them for help.

In addition to a Disaster Preparedness kit, a caregiver should be prepared to instruct another in the care of their loved one. The following page can be completed by the caregiver and added to the disaster preparedness kit:

Substitute Caregiver Information

What You Should Know About (name): _____

What he/she likes to be called _____ Past/present interests _____

Normal daily habits and routines _____ What upsets him/her? _____

Sleep routine _____ What calms or soothes him/her? _____

Eating and drinking routine _____

Contact Information:

Primary Emergency Contact Person (name): _____

(landline) _____ (cell phone) _____ (e-mail) _____

Secondary Emergency Contact (name): _____

(landline) _____ (cell phone) _____ (e-mail) _____ Out _____

of Town Contact (name): _____

(landline) _____ (cell phone) _____ (e-mail) _____

Health Information:

Physician(s): _____ Phone number(s) _____

Pharmacy: _____ Phone number _____

Health Conditions: _____

Medications (list the following for each one: name, strength/frequency/taken for/ prescribed by)

Special Needs:

List areas where special assistance may be needed (e.g., diet, mobility, toileting, eating, etc.)

- ▪ 湊.....

Other Important Information:

Tips:

Persons with dementia may require additional assistance and consideration during a disaster situation. Here are hints for helping to maintain a stable and comforting environment and for responding to agitated behaviors:

Try to reduce excess stimulation in the environment. Validate the person's emotions. Be prepared to repeat information, choices, and directions. Talk with the person in a positive way. Reassure the person that you are there to provide assistance. Speak clearly and calmly, and at a moderate speed. Do not physically force the person to do something. Other