

CARING FOR YOUR AGING LOVED ONES
by Monica and Bill Dodds

Respect Life

If you're a family caregiver, we thank you for what you do. In the middle of all your daily concerns and duties, it may never have occurred to you that *caregiving is pro-life*. But it is. Your compassion, dedication, and hard work are testimonies to the value of human life.

For more than fifteen years we've been writing about, and working with, family caregivers. We've discovered that, yes, there is a spiritual component to the vocation of caregiving but there are also the nitty-gritty details. We've learned that while every situation is unique (whether, for example, you're helping your spouse, your parent, or your child with special needs), there are common, basic issues for both the caregiver and the care-receiver.

Here are some of those issues and points to consider in addressing them.

*From a Caregiver's Point of View:
A Better Understanding of What You're Going Through*

Anger

The stress of caregiving can unleash a torrent of unexpected emotions and bring challenges that often have no clear solutions.

At times, anger can be a dominant feeling for many reasons that would be easier to identify and understand if you and your loved one weren't already so drained, both physically and emotionally. You might be mad at your parent for getting old or your spouse for resisting you when you try to help. Mad at healthcare professionals who don't seem to understand that this is *your* loved one and that makes all the difference in the world.

- Remember your loved one isn't necessarily mad at you. You may simply be the target because you're there or because you make him or her face all those fears head on.
- Try to find some time for yourself. Look for a support group or good friend where you can "dump" some of that anger.

- Forgive yourself. Go back and apologize. Don't let guilt over that anger eat you up. You can start over again.

Guilt

Guilt can goad us into being better people but all too frequently for a family caregiver that guilt alarm never stops ringing. It helps to realize that no matter what you do—no matter how much or how little—you are likely to feel guilty. The truth is, even after a care-receiver dies, the guilt can live on. "I should have . . ." "I shouldn't have . . ." "Why did I . . . ?" "Why didn't I . . . ?"

- Remember that you're not perfect. Not a perfect spouse. Not a perfect parent. Not a perfect son or daughter. Not perfect at work or home or anywhere else. You will never be a perfect caregiver. Never.
- Know that you can set limits. As your loved one's health continues to fail, he or she is going to need more and more attention, but that doesn't mean you'll be able to continue to match that need. Permit yourself to say, "I can't do that." Sooner is better than later. Don't wait for a crisis to arise before getting supplemental help.
- Keep in mind that no matter how much you do for your loved one, his or her health is going to deteriorate. Your loved one is going to die. And it's not your fault.

Exhaustion

Exhaustion is more than just being tired. It's being tired for weeks, being tired for months. At the same time, exhaustion can bring on a sense of helplessness and even hopelessness.

- Don't deny the problem. Admit that being exhausted isn't good for you personally or for you as a caregiver. An exhausted caregiver can't be a good caregiver.
- Give yourself a tiny break. A minute or two. Go into the bathroom, shut the door and wash your face with cool water. Or walk out onto the porch by yourself

and take a few deep breaths. Taking a day off may seem impossible, but you can take a one-minute break. And you can build on that.

- Get help. Ask family members to assist. Look into respite care. Even a few hours once a week can help a lot. Consider joining a caregivers' support group. Many caregivers find it extremely beneficial. In some cases care for your parent is offered while you attend the group.
- Remember, it's better—and easier—to prevent exhaustion than to reach that point and have to come back from it. You're not being selfish if you take breaks, get some exercise, eat right, get your sleep, and ask for help. If you take care of yourself, you can continue to provide the first-rate, loving, compassionate care you want your loved one to have.

Respite Care

Human beings weren't created to work nonstop seven days a week, fifty-two weeks a year, or to be responsible for someone else twenty-four hours a day. Our bodies and our minds simply can't maintain that grueling schedule. But in many ways, that's exactly what many primary caregivers try to do. And it's not good for them or for the people in their care.

“*Respite care*” means a break for someone who is taking care of an ill person, a rest for the person primarily responsible for the well-being of another. No matter what the particular circumstances may be, the basic truth is the same: A primary caregiver needs to take breaks or soon will burn out, soon will be unable to take care of anyone, including himself or herself.

- Admit that caregiving is a complicated experience. It's physically and emotionally draining. Respite care doesn't mean a week off every six months or a free weekend every few months (although those types of breaks are also very helpful and healthy). It is several hours, perhaps once or twice a week, away from the situation with someone else assuming the role of caregiver.
- Realize it can be hard for you, a primary caregiver, to allow someone else to do your job, even for a short while. Then, too, others—including family members—may not understand why you need to get away. And the person in your care may not understand either.

Don't be surprised if you do feel guilty when you're taking a break. If you blame yourself because you need to get away for a time. If you feel bad because in some ways you might not want to go back.

- Remember respite care will help you be a better caregiver. Taking that short step back from the immediate situation will help you see it better. It will give you a moment to catch your breath.

- Remember, too, that the break is for you. Don't fill the time running errands for the person in your care, going grocery shopping, getting the car fixed, and so on. Do something for you.
- To find someone to help you with respite care, check with the local Catholic social service agency, ask at the parish or contact a local program. (See “Eldercare Locator” in *Resources* for a way to learn about all elder services in your locality.) Ask for help from family members, fellow parishioners, friends, neighbors, the community, and social service professionals. Many people would like to help but don't know what you need. Let them know specifically what they can do.

From a Care-Receiver's Point of View: A Better Understanding of What Your Loved One is Experiencing

Independence, Control and Self-Determination

Your loved one values his or her independence and many decisions you and he or she make revolve around this key concept. As you make decisions, it's helpful if you keep in mind these guidelines:

- Encourage and allow independence. Don't take over tasks or make decisions your loved one can still handle. Whenever possible, let your loved one be in control. Giving up control, or having it snatched from us, can make us angry and frightened. What you may see as a mere detail can be monumental to your loved one.
- Remember each of us has a God-given right to self-determination. We were created to make choices. We were given free will. This means that your loved one has the right to decide what activities to do each day. That's fine, but at some point your loved one's ability to make safe decisions may begin to fail. Your aging family member or spouse may begin to choose what is dangerous or unhealthy or may lapse into self-neglect. That's not a valid excuse for you to decide on your own that your loved one is “incompetent” and to take over *all* decision making for him or her. Limit your control to those areas where your help or intervention is needed.

Losses and Grief

Quite often, what your loved one is feeling is a tremendous sense of loss -- in so many areas. The process of aging or dealing with a terminal condition is a process of letting go bit by bit. It's losing many things and being forced to accept the fact that many of them, if not most, will never be replaced. As a caregiver, you are helping your loved one cope with a succession of losses.

- Remember that some losses are permanent. Among the most difficult is the death of an adult child. Usually the biggest loss of all is the death of a spouse. To grieve after the death of a loved one doesn't mean experienc-

ing a single emotion. Grief involves a host of feelings. It's commonly accepted there's a "cycle of grief."

- Realize that as your loved one ages (or health deteriorates), he or she becomes unable to perform the everyday tasks that person used to love and may feel a part of his or her identity is being lost. For example, your mother or wife is no longer the "super housekeeper" with a spotless home. Her yard is no longer the prettiest one on the block. She can no longer bring her famous scalloped potatoes to family gatherings. And if she isn't that great housekeeper, gardener or cook, what is she? Who is she?
- Keep in mind that, with the absolute best of intentions, you may seem to be taking over. Being downright pushy, is what it feels like to your loved one.

Changes in Roles

A role reversal (an adult child assuming some of the duties of an aging parent) or an assumption of new roles (taking over responsibilities formerly handled by one's spouse) is rarely an easy transition.

- Go slowly. Be gentle. Don't suddenly charge in and take control. Start with small things. If at all possible, let your loved one still play a part. Maybe your mother or wife can't host Thanksgiving dinner but can still make her mouth-watering cranberry sauce for it. Maybe your father or husband can't go crawling around under the car but can accompany you when you "both take it in" to a 30-minute oil-change shop.
- Be alert to the emotional undercurrents in your changing relationship. Your loved one is experiencing losses and understandably feels frightened. You've lost something too. As he or she grows older or sicker and loses more abilities, you're losing the person who once comforted you.

"I don't want to be a burden"

Care-receivers are often concerned about "being a burden." Your loved one might bring up the subject when you're feeling angry, upset or frustrated. Typically, the immediate answer is "No, you're not!" Typically, the immediate feeling is guilt.

- Admit that what you're doing *is* hard. Remember this situation will not last forever. Fortunately, and unfortunately, it will end. Meanwhile, look for outside support. Try to avoid becoming so overloaded that your loved one *does* seem like a burden.
- Realize that your loved one may need to be reassured more than once. Yes, you told him or her last week but you need to say it again.

- See if there's some small part of a bigger task your loved one can do to feel like he or she is helping out at least a little bit. Better still, see if there is something he can do for you, even if it's a token gesture to say "thanks"—setting the table or folding the laundry, for example.
- Sit down with your loved one during a calm time and talk about the idea of him or her being a burden. Let your parent or spouse know that providing care is something you want to do. Yes, there are hectic moments, but you see taking care of him or her as a privilege. It's a way of saying "thank you" for all he or she has done for you. You can also point out that you view your love one's accepting your help as a gift from him or her to you.

Spirituality: A Better Understanding of Your Vocation

God alone knows all the particular circumstances—the feelings and emotions, the life experiences and personality quirks, the baggage and hot-buttons—that can make taking care of another person hard work.

And knowing all that, God has chosen you to play a central role in providing that care. Just as from the cross Jesus asked St. John—the patron saint of caregivers—to take care of his Blessed Mother, God asks you to help take care of someone else He deeply loves. But that doesn't mean providing care is simple or easy.

One of the hallmarks of Catholic spirituality is that throughout our lives each of us is personally called by God to use a particular talent, to meet a particular need. For you, now, that vocation is taking care of loved one.

Caught up in the very many everyday details and demands of caregiving, it's easy to overlook the spiritual side of what you have been asked—called—to do and what you are doing. What you're doing is a prayer, and the path you and your loved one are taking is a pilgrimage.

It is the Father calling his beloved child home. It is the Father asking you to help his son or daughter along these final stages of that journey.

It is his Son whom you are tending. It is the Son who has told us whatever we do for those in need we do for him.

And it is the Spirit who is with you right now. It is the Spirit who will never leave you. Even during those times when it seems he has gone away and taken his gifts—wisdom, courage, knowledge and the rest—he is still present.

God the Father, the Son, and the Holy Spirit, will richly bless you and your loved one in this life, and in the life to come.

Monica and Bill Dodds are the founders of the Friends of St. John the Caregiver (www.fsjc.org). Monica is the author of A Catholic Guide to Caring for Your Aging Parent (Loyola Press) from which this material was taken.

Program Models

How Your Parish Can Help Caregivers

Any parish beginning a ministry to caregivers would be wise to keep three basic points in mind:

First, parish members who are caregivers may not identify themselves with that term because they truly don't see themselves as that. Rather, he is "only" doing all the cooking, cleaning and laundry – helping out more around the house – since his wife's surgery. Or she is "only" lining up Meals on Wheels and other services for her dad who lives in another part of the country. Or they are "only" the legal guardians and primary support for an adult child or a sibling with Down syndrome.

What this means is that when the parish announces a new service or program for caregivers, the caregivers themselves may not realize it applies to them and that it's being offered to help them.

Second, because caregivers have extremely busy schedules and little or no energy to spare, it can be difficult for them to attend a meeting or other event, even one designed just for them.

And third, because caregiving is very personal and no caregiver is in it for the glory, the caregivers in a parish may be uncomfortable with any form of public recognition. (Such as asking "All caregivers now stand up to receive a special blessing" at the end of Sunday Mass. Instead, offer the blessing without asking them to publicly identify themselves.)

With those points in mind, here are some suggestions for starting or enhancing a ministry to caregivers in your parish:

- Remember family caregivers in the prayers of the faithful at Mass and the parish bulletin when praying for those who are sick. ("For the members of our parish who are sick, for their families and for those who take care of them: John Jones, Maria Romero . . .").
- Talk about caregivers in homilies and thank them for their example of Christian service and love.
- Include educational and resource information on a regular basis in Sunday bulletins and in material sent home to families through the school.
- Provide printed material in the back of the church, and material and links on the parish's Web site.
- Mark the second Sunday in November as "Family Caregivers Sunday" (November is National Family Caregivers Month). Celebrate December 27th as the feast of St. John the Apostle, Evangelist . . . and Caregiver. Include family caregiving in Respect Life Month material.
- Get and read a copy of the United States Conference of Catholic Bishops' "Blessings of Age." Purchase copies and make them available for parishioners.
- Survey the parish to identify the needs of the caregivers in your community.
- Collect and distribute information from the local Area Agency on Aging, diocesan programs, the Internet, and other sources.
- Start a caregiver support group.
- Establish a system and train volunteers to provide respite care for caregivers. (Even an hour or two a week can be a tremendous help.)
- Instruct extraordinary ministers of the Eucharist making visits to the homebound to also offer assistance and encouragement to family caregivers.

- Host a "Caregivers Day" to honor your families' caregivers with an event that recognizes their contributions, offers them information to help them in their tasks, and gives them an opportunity to meet and pray with fellow caregivers. Include respite care as part of the event for those who need it but don't be disappointed if attendance is low. (Remember Point 2!)
- Get parish groups—such as the Respect Life Committee, Knights of Columbus and Catholic Daughters of the Americas—interested in finding ways to help.
- Sponsor educational presentations for pastoral ministers and parish staff to increase their awareness of a caregiver's roles and needs.
- Set up a prayer chain so that fellow parishioners can remember the needs of caregivers in their prayers.
- At a communal Anointing of the Sick, ask the community to also pray for family caregivers.
- Offer support to parish staff and school faculty members who are family caregivers.

How Your Diocese Can Help Caregivers

- Encourage parishes to promote care for family caregivers and spotlight parish programs that are working well and can be duplicated.
- Provide material and links on the Web site.
- Include information in diocesan publications.
- Mark the second Sunday in November as "Family Caregivers Sunday" (November is National Family Caregivers Month) and December 27th as the feast of St. John the Apostle, Evangelist . . . and Caregiver. Include family caregiving in Respect Life Month material.
- Encourage hospital chaplains and extraordinary ministers of the Eucharist who visit the sick and homebound to offer assistance and encouragement to family caregivers.
- Sponsor retreats and educational workshops for family caregivers.
- Offer support to staff members who are family caregivers.

Resources

Blessings of Age, Statement of the U.S. Catholic Bishops, USCCB, Washington, D.C., 1999.

A Catholic Guide to Caring for Your Aging Parent, Monica Dodds. Loyola Press, Chicago, 2006.

Resources available from the Friends of St. John the Caregiver: (P.O. Box 320, Mountlake Terrace, WA 98043; 425-744-8016; MonicaDodds@YourAgingParent.com.)

"The Little Book of Caregiver Prayers" (booklet)
"The Basics of Catholic Caregiving" (pamphlet)
St. John the Caregiver holy card with caregiver prayer
Friends of St. John the Caregiver informational pamphlet

Diocesan or Parish Packet: 10 copies of all items

Internet Resources

Programs of the Friends of St. John the Caregiver

www.YourAgingParent.com
Spirituality, information and resources for caregivers.

www.CatholicCaregivers.com
Training and educational material for parishes and dioceses, including monthly bulletin briefs and fliers, and Prayers of Intercession.

Friends of St. John the Caregiver
www.fsjc.org
Membership organization offering spiritual support for those who give care, those who receive care, and those who assist others giving care.

Other

Administration on Aging
Elders and Families
www.aoa.gov/eldfam/eldfam.asp

Catholic Charities USA
catholiccharitiesusa.org

Eldercare Locator
A public service of the U.S. Administration on Aging. The Eldercare Locator connects older Americans and their caregivers with information on senior services available on the federal, state and local levels for any ZIP code in the United States.
www.eldercare.gov
1-800-677-1116

Pontifical Council for Health Pastoral Care
www.healthpastoral.org

United States Conference of Catholic Bishops
www.usccb.org/prolife