



# SPEAKING OF CARE

## GIVING AND RECEIVING

This booklet is about the demanding and complicated relationship between caregivers and care-receivers, particularly when this connection occurs within the same household.

### SETTING THE STAGE

Hello. My name is Maggie. My husband, Ron, and I have been professionally and personally involved in both roles. Ron is a Lutheran pastor and has served as a chaplain in institutional ministry in both hospitals and nursing homes. I am a physical therapist with extensive nursing home rehabilitation and home health care experience. Ron and I were both widowed when we first met in a nursing home. He was the chaplain; I was the physical therapy supervisor. We were married in that same nursing home 16 years ago. We knew when we married we both had some health problems, which came more to the forefront as time has passed. Both our spouses had died very suddenly, and we thought we knew what people meant when they said, "live for today." These days we remind ourselves of that often. Ron has been diagnosed with Parkinson's disease for almost 16 years now, and I have congenital heart problems, as well as chronic back pain. My role is mostly that of the caregiver and Ron's role is that of the care-receiver.

We do, however, occasionally switch places.

What does all this mean? It means God made us complex and wonderful. We are versatile. We can both give care and receive it. God cares for us all the time, and He is always willing to listen to our complaints, concerns, anger, fears, or whatever other feelings or emotions we throw His way. Life really is a moment-by-moment scenario when grappling with health problems, whether those problems are short term or progressive.

This booklet is a team effort. We want to help you with the challenges you face and let you know you are not alone. God is always with you, and there are many others facing these or similar challenges too. Don't be ashamed of your feelings; they are real and meaningful. As adults we come to learn the age-old lesson we learned as children: "It is better to give than to receive." When we were young it seemed nothing was better than a gift. Later in our lives, though, we began to realize the true joy is in *giving*.

The roles of **caregiver** and **care-receiver** are loaded with personal feelings, struggles and, sometimes, even conflict.

As we honestly share our struggles with you, it is our hope you will receive strength and hope in knowing you are not alone. The important thing to keep front and center is remembering that God cares for *each* of us round the clock.

So let's explore this idea then. Is it better to *give* or to *receive*? There's a distinctive dynamic to each of these efforts. What follows below are our viewpoints—won from personal experience and observation.

## LEARNING HOW TO RECEIVE CARE—GRACIOUSLY *from Ron*

Let me begin by saying I do not receive care well. I have learned how to give, but I have not learned how to receive, especially when it comes to accepting *care*. Accepting someone's help on my behalf involves so much more than me simply telling them "thanks" for their assistance. Receiving care involves the *ego*. I don't want someone caring for me. I want to care for myself! Furthermore, receiving care seems to produce a sense of indebtedness that can be difficult to handle.

I remember the first time someone carried my plate at a buffet dinner, I felt embarrassed. I should be doing this was my thought. My ego was working against my better judgment. Thanks to the wonderful servers and friends who got me to the table without a mishap. Still, there was something inside me grumbling over this situation. "No, don't help me! Let me make my own mistakes!" declared the inner voice in response to the care given on my behalf. I needed to do more than say, "thank you." I needed to *show* my appreciation.

Do you see why it's necessary to learn how to receive someone else's care? When responding in a grateful—and graceful—manner to help offered, it becomes a powerful and positive event for the caregiver. Unfortunately, it's easy to neglect returning a warm, appreciative response to care delivered. It is never too late though to become a thankful care-receiver. And as a final point, don't be afraid to let people love you. Learning how to graciously receive might just prove tougher than learning how to give.

## GIVING AND RECEIVING CARE IS A DYNAMIC PROCESS OF GIVE AND TAKE *from Maggie*

Assisting a loved one whose needs require daily attention is not easy. He or she is fighting to make progress and needs our help. Gains made are often small and incremental, but they're gains nonetheless. Typically, victory doesn't mean a conclusive, once-and-for-all-time cure, but rather the forward advance that comes when two people are making something positive happen.

Still, change is hard. We want things to be like they were. The problem is they're not! When we have a really good day we can't help but hope things will return to what they used to be, or at least better than they have been. We start expecting the days that follow will be good days too. This can have its drawbacks if it causes us not to appreciate the moment and savor the good things taking place right now.

In our lives we all have many roles—child-wife-husband-mother-father-daughter-son—besides any professional roles we might have. Sometimes, we ask ourselves, "Who am I?" since our present role in our relationship with the person for whom we care has changed. It may have even reversed. Our new role may not be one we wanted but one we received by sheer circumstance. Through it all, it is important to keep our thoughts centered on God, who alone is unchanging.

## *from Ron*

In her career my wife is a physical therapist and has been for more than 40 years. She is also a mother, a grandmother, a sister, sister-in-law, aunt, and a good friend to many. In addition she often answers to "Dr. Mom." Family members, as well as many friends, seek her advice on health problems before *and after* they see their own doctor.

It is in her role of Dr. Mom we sometimes have our disagreements. I don't want to see Dr. Mom. I saw my doctor and physical therapist yesterday. Now, I just want a little love and sympathy from my wife.

Can she do it? Of course, she can, as long as she stays in her role as wife. That means I must stay in my role as husband.

I thank the Lord for my wonderful wife for sharing my responsibilities as husband, father, and grandfather. Reversing roles and responsibilities is not always easy, but often quite necessary.

## ANGER, LOSS OF CONTROL, AND TURNING IT OVER TO GOD *from Maggie*

Feeling angry with your situation? Feeling angry at what life has dealt you and your loved one? That's not uncommon. In fact, it's a feeling most caregivers and care-receivers regularly experience. Part of that anger probably comes from the loss of control in our lives—not that we ever really had control—but so it seemed.

God is always in control and when we “let go and let God,” as the saying goes, life is much easier. We spend so much time anticipating what will happen next that we forget to *participate* in what is happening now.

Recently, I was sitting outdoors in the country by a little lake watching a dragonfly. It was so beautiful—just a touch of blue in its wings. I noticed the dragonfly's wings were both iridescent and translucent. As I thought about it, I realized these are qualities I seek as a caregiver in my character.

Iridescent according to Webster's Dictionary means “a rainbow-like play of colors.” The rainbow for us as Christians is a reminder of God's promises and a symbol of hope. We need to be a reminder to others of God's promises and hope in our daily care-giving. God's promise for eternal life gives us hope to experience whatever we face in our daily life. As Jesus said, “... And surely I am with you always, to the very end of the age” (Matt.28:20b). Translucence is another quality we can model. According to the dictionary, it means “shining or glowing through” and the definition goes on to say, “as the translucent rays of the sun.” If we replace the word “sun” with “Son”—then, what a beautiful picture we have! Isn't that what we struggle to achieve in our daily lives—letting the Son shine through?

Next time you are feeling really angry or dejected over your care-giving situation, step back for a moment—*or longer*—and collect your thoughts. Pray for God's comforting grace. Then, when you're ready, try picturing the care you want to give your loved one as one serving another with God's Son shining through you!

*from Ron*

Why do I get so angry? Sadly, we take our anger out on the ones we love. The refrain of that old song keeps coming to mind: “You always hurt the one you love, the one you shouldn't hurt at all.” My caregiver works very hard to keep me active and independent. Why do I get angry with her? My disease isn't her fault.

At other times, I get angry with God. I believe He is powerful enough to handle my situation, but I still get angry with Him. Thankfully, He is always ready to show me love and forgiveness. I agree with Martin Luther when he said, “All sickness is of the devil. God sends no sickness into the world. It all comes through the devil.” That is why our constant prayer must be this: “Let Thy holy angel be with me, that the wicked Foe may have no power over me.”

Rather than be angry with God, we can begin by thanking Him for our caregivers and for all the sacrificial assistance they give. Then we can be sure to thank our caregivers for all their support and assistance. When we do, we will find something remarkable happening in our lives: our anger and disappointment will be replaced with thanksgiving.

## LOSS, REMINISCING, AND MOVING FORWARD

*from Maggie*

As we go through life, we often find ourselves making adjustments toward the future.

Making these changes can be a positive event. They can be sad, however, when old and cherished ways require significant modification or some things are shelved altogether. The necessary changes resulting from illness are often demanding and carry with them some unpleasant choices. We may have to give up prized things and replace them with things that aren't our preference.

Gone may be independence, both physical and mental. And it is not only the care-receiver who loses independence; it is also the caregiver. With many new responsibilities the caregiver's schedule is suddenly quite full. Giving up a home and moving to more accessible housing for the one receiving care might be necessary. One's identity even transforms as the roles of caregiver, nurse, or even, maid, become more prominent.

Have you ever thought that maybe it's time to reconsider your life, especially *your attitude* as you try to adjust to these changes? I often feel my responses are grumpy and short. I constantly apologize at the end of the day, and my prayers always include a hearty request for greater patience. God's grace gives us the opportunity to reconsider our approach and regroup daily. What a renewing gift is God's matchless forgiveness!

As we consider our attitude and approach, we can start with little things. God's grace and compassion for us is new every moment of every day. He always gives us the opportunity to do better than we did yesterday. His Spirit is ever ready to help us.

Undergoing change is hard. We might have to look hard for *moments* of joy in what used to be *entire days* of happiness. But those moments can still be just as rich and full of blessing. This is because there's an understanding that you're positively assisting another person's well being. And as you look for affirmative experiences, cherish the cheerful memories. Recalling those times and reminiscing together can expand the happy moments in surprising ways.

*from Ron*

As I get older I discover I talk more about the past than I do the present. Often I find myself telling the same stories over and over again and (*groan!*) the same jokes too.

Aristotle once said of the elderly around him: "They are continually talking of the past, because they enjoy remembering." He was talking about people who were aging—people like you and me.

For those of us who live long enough, the day comes when we realize our past is longer—*much longer*—than our future. Psychologists describe our habit of telling stories about the past as "reminiscences." Remembering past experiences and their significance gives new meaning to one's life. *Successful remembering* leads to what one person has described as a sense that everything that has occurred in life has "fit into place" and happened for a reason.

### **DRAWING STRENGTH FROM OTHERS** *from Maggie*

When you feel overwhelmed do you ever stop and look at what you have accomplished? Consider what you achieve in your daily struggles. Whether you realize it or not, other people can see this.

Recently, I was feeling overloaded and felt like I was failing. There was just too much to do. I called my best friend since childhood to talk and vent. She is my "safe harbor." She knows she doesn't have to fix things; she just needs to listen. She told me, after listening to my frustration, how very proud of me she was. She said, "Just look at what you've accomplished and what you do every day—not to mention all the complex relationships and difficulties you have to deal with." She told me that if she were in my situation she probably would have crawled under the bed a long time ago. Wow! That *really* made me feel good. I never even considered crawling under the bed! I must have been doing better than I thought.

If you don't have a safe harbor, try to find one. Ideally, this person will listen to your honest expression without feeling compelled to *fix* your situation. It could be a friend, family member, pastor, counselor, or even a physician. Having a trusted individual to *hear you out* without trying to remedy your life can be a great asset.

Support groups can be helpful too, and you'll probably know if you're ready for one. It can be very uplifting to talk with others and realize you're not the only one facing trying problems. Something to remember is that it could prove a little scary, as you just might get a glimpse of what could be ahead for you and your loved one. Remember, we don't know our future. Only God knows that and, therefore, we must trust Him. Nevertheless, you can learn a lot through group discussions by listening to what has worked for others.

## VOLUNTEERS—A CRITICAL LIAISON IN THE CARE EQUATION *from Ron*

Have you ever considered volunteering? The most important people in my ministry were my volunteers. The work they did was crucial. They saved the chapel precious cash by repairing hymnbooks and doing other tasks at no charge. But it was in their ministry that they excelled. Reading Scripture, singing hymns, and leading devotions—these were the things they did best.

Some of my volunteers were also caregivers at home. They cared for aging parents, spouses, children, or other family members or friends. They did that round the clock. What prompted them to become volunteers too?

To this question, there were a variety of answers. Some volunteered to get away from their *own* pain and sorrow. Others volunteered to recapture some much-needed meaning in their lives. Still others said it was a way to give back to their community. Whatever the reason, volunteers deserve our frequent thanks and admiration for going above and beyond the call of duty.

You can find volunteers almost anywhere doing just about anything. I have seen volunteers who tutored, and some who wrote letters for the elderly. I know a homebound lady who became a telephone contact for children in her neighborhood. Others perform small repair jobs or serve as readers to individuals who are visually impaired.

One Sunday in my parish a woman told me her husband had recently suffered a heart attack and was also showing early signs of Alzheimer's disease. Her request was simple: "Pastor, if I could just find someone who would sit with my husband an hour each morning. Then I could take a break and read the morning paper. It would be so helpful." We found a volunteer from the congregation to take this task.

"A volunteer is a person who can see what others cannot see, who can feel what most do not feel. Often, such gifted persons do not think of themselves as volunteers, but as citizens in the fullest sense; partners in civilization," according to former President George Bush. It's amazing how helping another person through volunteering benefits the giver as much—perhaps sometimes even *more*—than the receiver.

## TRUE OPTIMISM COMES FROM RELYING ON GOD *from Maggie*

We were driving to church on Easter Sunday and passed a Goodwill store. I looked twice at the lit sign in the front window. One of the *os* in Goodwill was not lit, so the sign read, "Godwill."

This might sound silly, but for me this sign was an affirmation that God heard my prayers from the night before. I always struggle with control; I worry about what comes next and leaving my life in God's capable hands. I know this is a struggle for most people. It is the basis for much of the philosophy of Alcoholics Anonymous and the well-known "Serenity Prayer."

As the Psalmist says in Psalm 143:10a, "Teach me to do Your will for You are my God. ..." God does teach us, especially when we try to take control. This usually ends up in a disaster or leaves us feeling totally overwhelmed. Then, we cry out to God in desperation, "I don't know what to do! Tell me, show me!" The verse goes on to say, "... may Your good Spirit lead me on level ground" (Psalm 143:10b). The path we walk is far from level. However, if we are in good condition—meaning if we are *close to God*—we can take the hills without exhaustion and descend the valleys confident in His promises to us.

While we should be realistic in our approach to challenges, God's grace and His love for us should make us boldly optimistic as well. God will help us approach our decisions with the realistic optimism His Word provides. We need to be patient, listen, and practice trusting His will because, like the sign says, *God will!*

*from Ron*

After the storm comes the rainbow. It is a sign of God's love, but most of all it is a sign of God's promise of hope. How wonderful it is after the storm: the sky brightens, the air is fresh, and we see God's multicolored rainbow in the sky above us.

Many of us know something about storms. They can rise quickly, often with no warning. That is the way it is with storms in our lives too. They tear through our world and then they are gone, leaving us with a mess to clean up. Life's storms can leave us in disarray, bringing with them pain, despair, loneliness, fear, and an overwhelming sense of hopelessness.

How does one find renewed hope after such storms? For the Christian, hope is not just some pie-in-the-sky ideal. Since the Christian's hope is anchored in the death and resurrection of Jesus Christ, it is a *living* hope. It is not a frail or perishable expectation based on a whim. It is based on the certainty of God's Word, attested to by numerous eyewitnesses, and recorded for our benefit.

The Christian's hope knows that when there appears to be *no* hope whatsoever—there *is* hope—a way through the anguish and disaster he or she is battling. In God's Word, we possess many faithful promises for our future. Though we may live in seemingly impossible circumstances where nothing is going right, there is still the living and eternal hope we have in our faithful and living Lord.

## **THERE'S JOY IN SERVING** *from Maggie*

Do you get frustrated attempting tasks you think you should be able to do but can't quite achieve anymore? Do you find yourself getting the job done but dissatisfied that it takes six times longer than it used to? This may be the time to ask someone for help or consider hiring an individual to assist you.

While as a caregiver you may have these feelings, ponder for a moment how many more times the care-receiver struggles with this situation.

While some of us may seem to have abundant talents, there are others who probably feel their skills and capabilities are limited at best. According to Psalm 139, David acknowledges the unique creatures we are: "I praise You because I am fearfully and wonderfully made; Your works are wonderful, I know that full well" (Psalm 139:14). We are unique and one of a kind in God's eyes. You have a special place in God's Kingdom. We need to remember our special-ness and the fact that each one of us is individually crafted by God. Both the caregiver and receiver are part of God's grand design. Though the one receiving care may not always show us how much we mean to them or even seem grateful for our care, the caregiver should try not to be burdened by this response. After all, this response—or lack of one—is unfortunately not unlike that which God's creation—believers included—show Him on a daily basis. How often do we forget to praise Him and thank Him?

Maybe it's time to remind ourselves how grateful we should be for the opportunity to be serving one of His children. Maybe it's time we ask God to help us show that feeling of special-ness in our care giving.

By putting Jesus first and concentrating on our relationship with our Savior, we can find joy and peace through Him in the service we render. "Peace I leave with you, my peace I give unto you: not as the world giveth, give I unto you. Let not your heart be troubled, neither let it be afraid" (John 14:27).

Joy *does* come from giving!



## CAN SUFFERINGS PRODUCE JOY? *from Ron*

As I was growing up, one of the acronyms for **JOY** was **J**esus – first; **O**thers – second; **Y**ou – third. As a child this memory device seemed to make perfectly good sense. Believing that Jesus was my Lord and Savior, He was first in my life. Helping others came in second and I, logically, was third. It just made sense.

As we get older somehow things get confused. We now try to spell **JOY** as **YOJ**, **JYO**, or **YJO**. We have lost our **JOY** because we no longer put Jesus first in our life. As adult Christians we are told to be joyful in our sufferings. “*Rejoice in our sufferings*”? I don’t think it can be done. You want me to find joy in my pain?

Can anyone really avoid suffering? No, it is part of the human nature inherited from Adam after the fall of man into sin. Yesterday, I had a new car; today I am no longer able to drive. Yesterday, I walked about freely drinking a soda; today, I need a cane and I am drinking a laxative. Yesterday, I had a job; today, I can no longer work.

Suffering, oddly enough, can have some beneficial outcomes. It can rouse us; it can awaken us from our lethargy and point us to the suffering Savior. The writer of Hebrews said it best: “Let us fix our eyes on Jesus, the author and perfecter of our faith, who for the joy set before Him, endured the cross, scorning its shame, and sat down at the right hand of the throne of God” (Hebrews 12:2).

Jesus found **JOY** in His sufferings because He was fulfilling the plan of His Father. Can *anything* we go through even begin to touch on the immense suffering, agony, and grief He carried for us when He went to the cross with our sins? Whatever battles we fight over the evils of this world should lead us to greater blessings, if we face these sufferings in Christ and in the power of His resurrection.

Can I find **JOY** in my sufferings? *Absolutely!* I’m laying down my sorrow and pain for the **JOY** of the Lord.

## DEMANDING CIRCUMSTANCES SHOULDN’T DETER OUR CELEBRATION *from Maggie*

Sometimes I get the nagging feeling something will always go wrong. It bothers me when I feel this way. I want to be positive and thankful in all things. My youngest daughter began teaching me how to do this when she was a small child. No matter what happened, she would always say, “just be glad” and apply “the cup-half-full” philosophy to the situation. She still helps me stay on track by reminding me to be consistently thankful even when I get stuck in the negative.

If we really look, there is always something to celebrate and be thankful for. We need to appreciate what we have instead of being frustrated about what we want or don’t have. We do well to remember the words of the apostle Paul: “Be joyful always; pray continually; give thanks in all circumstances, for this is God’s will for you in Christ Jesus” (1 Thessalonians 5:16-18).

*from Ron*

Celebrate? It’s usually easy to celebrate the big things of life. It’s those insignificant things, however, where celebration is tough. We can be thankful for successful hip surgery, yet forget to be thankful for the wheelchair we used all week for mobility. Can we celebrate an evening sunset? Can we celebrate a pain-free day? Can we celebrate the work of others who make our lives easier by the selfless things they do for us?

### Celebrate LIFE

Our life is a gift from God; He alone has given us life. “For You created my inmost being; You knit me together in my mother’s womb” (Psalm 139:13). God is our Creator and our Sustainer. He gives us all we need for this body and life.

### Celebrate LOVE

“Dear Friends, let us love one another, for love comes from God. Everyone who loves has been born of God and knows God. Whoever does not love does not know God, because God is love” (1 John 4:7-8). Our love is two-dimensional. First, it is God’s love reaching down to touch us; second, it is us reaching out in love to touch someone else.

### Celebrate LAUGHTER

In Psalm 126, God’s people are returning to their homeland after a period of exile in a foreign country. “Our mouths were filled with laughter, our tongues with songs of joy. Then it was said among the nations, ‘The Lord has done great things for them.’ The Lord has done great things for us, and we are filled with joy” (Psalm 126:2-3).

The joyful spirit of those returning exiles prompted their neighbors to say, “The Lord has done great things for them.” Is our attitude a joyful witness to our faith? Can people see our joy? Can they hear our laughter, and do they give glory to God for all He has done for us?

Celebrate all that God has done for you!

## CAREGIVING AND RECEIVING—TWO OPPORTUNITIES TO SHARE GOD’S LOVE

### *Ron’s closing*

Amen means simply, “it is true.” We hear it and know the hymn is over. We hear the amen and know the sermon has ended.

Someday God will close out my life with an amen. The last note of my life will be sung. The final word of my sermon will be spoken. And I will know that *everything* God has promised has come true. If I can trust God at the finish line, why can’t I trust Him for the race leading up to it? If the truth of God is to be revealed at the end of time, why can’t I believe it today?

Reflect on some of God’s magnificent promises:

(Jesus says) “... And surely I am with you always, to the very end of the age” (Matthew 28:20b)

(Jesus says) “I will not leave you as orphans; I will come to you” (John 14:18)

(The LORD says) “When you pass through the waters I will be with you” (Isaiah 43:2a)

(The LORD says) “... I will not forget you” (Isaiah 49:15b)

“and (we) are justified freely by His grace through the redemption that came in Christ Jesus” (Romans 3:24)

Be assured of this, our Lord has been with us in every difficult situation. For a real eye opener to God’s grace and love for us, read Revelations 21:1-6.

These days there are many helpful resources available to both caregivers and care-receivers. Consult your network of friends. Visit with your pastor. Find out what’s available through area health agencies. Spend an afternoon at your local library. And, of course, if you have Internet access, get online and start surfing!

The giving and receiving of care obviously go hand in hand. Though both aspects of life have their demands and difficulties, each can best be managed and understood when considered in the light of God’s love for us. His Son Jesus’ ministry on earth was one of ultimate caregiving—both in the life He lived and in the death He died—each on our behalf. Yet, there were people who served *Him* as well—His earthly parents, His disciples, His friends—and these individuals fulfilled important roles in His life.

It is important to remember that whether we’re giving or receiving care, it is God whom we ultimately serve. He is the One who deserves our praise—whether offered as a caregiver or as a care-receiver.



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