

Caregiving (Part 1): The Need

Tim: We hear so much about the care industry. We hear a lot about healthcare. There's a lot of debate about what's the best kind of health care, and the term *caregiving* is thrown around a lot. What is caregiving? When we think of that, I think of—as my parents age—taking care of my parents. What do I need to do to help provide for them in their later years? But as you think about caregiving, how does that term strike you?

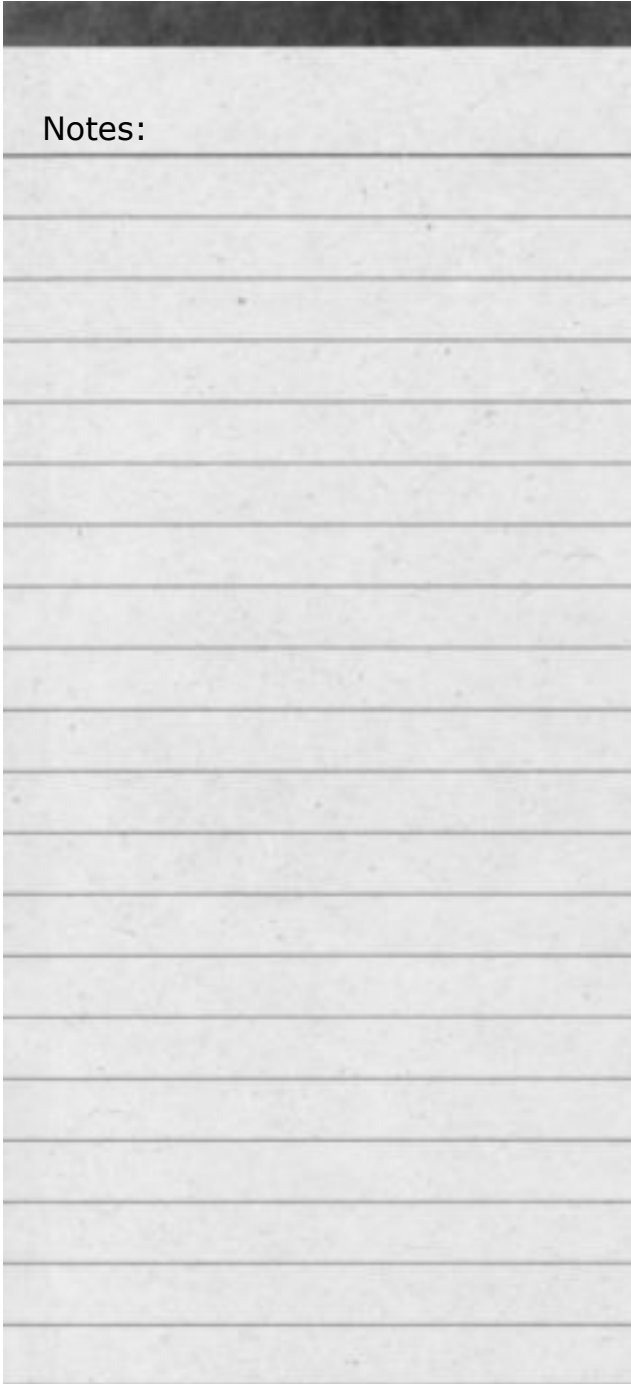
Roy, you've been a pastor for 48 years, and you currently work with church ministries here at RBC. You've also taken care of a spouse with a terminal illness.

And Shelly, you're an author. You've written two books on caregiving, and you speak about this at caregiving conferences. You know, what does this term mean as we hear it thrown around? Is it thrown around too much today? Do we make too much of it?

Roy: I think, after 48 years in the ministry, it's getting larger and larger—the definition, the boundaries of it. I'm thinking of a church in Cleveland where somebody said, “You need to make a call on this home.” When I got there, there was this child that was brain damaged, and this mother was devoted to this child. And I thought how does she do it? Just exhausting. Different situations that show the boundaries expanding way beyond aging parents or caring for the terminally ill. It's a huge topic.

Shelly: And I was just called down to do a conference—actually not, it wasn't a conference, it was a caregiver's support group

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just last week. I thought it was going to be a few parents who were just getting together. It was actually a church that's starting a caregivers' support group. I think this is more and more an indication of a growing need in our society; and statistics bear that out as well. That, in 1990, the ratio was one caregiver for every eleven people available to provide care. That statistic is now shrinking to one in four by 2050.

Tim: One in four?

Shelly: One in four.

Tim: One in eleven to one in four.

Shelly: From one in eleven to one in four. And then on the other side of that the need is increasing, will increase by 85 percent by 2050.

Tim: That's huge.

Roy: One of the most encouraging things that happened to me in the last year is a church in our city that asked me to come and talk about caregiving from my background, and 20 people showed up willing to be caregivers for this large congregation. Not just the staff. These are laypeople that want to give their heart to people that need somebody to love them.

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Tim: So you're talking—you're both referring to movement in the church.

Shelly: Absolutely.

Tim: The church seeing that this is a really desperate and growing need, not just among the people of God but in our whole society.

Shelly: Absolutely.

Tim: So how do we define caregiving? If you're going to put a definition on it, how would you . . .

Roy: Somebody in the network, in my personal family network, that obviously needs—because of physical, emotional needs—someone to step in and care for them.

Shelly: Right. For someone who's incapacitated in some way or another. And there are formal caregivers; there are informal caregivers. But the vast majority of caregivers in our nation today are those who are just family members and loved ones who are stepping in and providing care as spouses, as daughters, as sons, as sons-in-law, and that's why I think you're seeing a response from the church. You're finding a great response within the family of God because most of us who are doing it are doing it in

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the trenches.

Tim: Now there's all different levels of care; though the way you just described that you're talking about a whole spectrum. Paint the spectrum for me. How big is that?

Shelly: Oh, it's enormous.

Roy: Yeah. This church that I went to I gave them scenarios in writing. (They were sitting around tables like we are.) And how would you respond to such-and-such a situation? Some were simpler needs, you know, a guy out of a job—he needs somebody to care for him. But when I got to terminally ill, they wanted to shift that up to the pastoral level. They weren't quite sure they could handle that.

Tim: A little scary.

Roy: Scary, absolutely.

Shelly: You know we have increasing diagnoses of autism. Parents struggling with those kinds of things. We have increasing diagnoses of Alzheimer's at younger and younger ages. Those are some of the things that are really impacting on an escalating level. But we also have, you know, when you talk about brain injury, my son had a closed-head injury at the age of 19. We have people who are struggling with cancers as impacted you. A huge broad

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spectrum. The group that I met with last week—we had women who were terminal with cancer themselves who are caring for spouses with dementia, mothers who are caring for children.

Tim: It spans the generations doesn't it?

Shelly: Absolutely.

Tim: So it's not just an aging problem. That's a huge increase in our society, but it really does span all ages and generations.

Shelly: Absolutely.

Tim: So when we think, if we were to focus on decisions that you made, you were caring for elderly parents. You cared for your husband's father and you cared for your parents and you cared for a wife with a terminal illness; as you think of all that, you made decisions to take care of them in your home. I know there are a lot of people out there that go, "Ah, I could never do that." How do you wrestle with that, because I think the term "honoring parents" comes in here. How do you wrestle with making that kind of a decision?

Roy: For me it was on the journey: hospital, you know, this whole chemotherapy, radiation, and my wife reaching a place where she's got to get constant 24-hour care. And she just said, "I'd love to be at home. I want to be around the family. I know

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where I'm going.”

Tim: Didn't want to be stuck in a hospital?

Roy: Yeah. “I want to have friends and family visit, talk to them during the days.” And I said, “We're going do it.”

Tim: And then—but now that's a huge request.

Roy: Yeah it is.

Tim: Because that means a lot of changes at home.

Roy: And I was pastoring a church, and I probably didn't realize the physical and emotional pull on me. I would do it over again, because she was worthy of it, but . . .

Tim: There's the honor, isn't it?

Roy: Yeah. . . . But I'll tell you, it was quite a challenge. If I didn't have support, I never would have made it.

Shelly: Dan and I had discussed this issue early on before we were even married. He had had grandparents in his home. I'd had grandparents in my home, and we knew that this would be something that we would make available to parents if it was something that came up as an option.

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Tim: Before you were married, you talked about this?

Shelly: We did.

Tim: Wow!

Roy: That's rare.

Tim: Yeah, I never would have thought about talking with my spouse about how are we going to take care of her folks or my folks. I was just trying to figure out about us at that point.

Shelly: We did. Actually my grandmother had had dementia at the time. We called it hardening of the arteries and so did his grandmother, and so we looked at the possibilities of those kinds of things being inevitabilities in our family and just said, you know, "How do you feel about it?" And he said—and his father also had limited means and resources and so . . . I just said, "If that is an option that needs to be pursued, I'm fine with it." And he said he was fine with it. So we discussed it before we were even married.

Tim: So how do you walk through making that decision to say, "I'm going to bring a family member into our home," because that changes everything, doesn't it?

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Shelly: Everything.

Tim: So how did you walk through that?

Roy: I think with Maxine, it was—well, we had just one son, David, 16, living in the home. He had to understand that Mother's going to be—when you take your breakfast around that table, she's going to be 10 feet away in a hospital bed and struggling. And of course he couldn't envision that at 16.

I couldn't envision at 48 what that was going to be, but he knew, you know, this is what we're going to do for Mother. We had a son and daughter-in-law that lived a mile away. They were there every day.

Tim: So you had conversations with your son, who was living in the home at the time, as well as your adult children about the changes this was going to bring into your lives.

Roy: Yep, they were involved in the decision.

Shelly: I think that's very wise and very important to involve your children in those decision-making processes.

Tim: Because you're making the choice, but it's impacting . . .

Roy: It's affecting them.

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Shelly: It impacts the entire feel of the home, the culture of the home, the accessibility of the home. It will impact their social life. It will impact the way that home will feel after your loved one dies.

Roy: Yeah, the home begins to feel like a nursing home, you know—medicine, nurses coming in.

Shelly: Yes.

Tim: So my guess is there were things that you expected to experience, and then there were things that you didn't expect. Share with me a little bit: What are the things you did expect? What didn't you expect? And where did God meet you there?

Roy: I didn't expect—you know, her cancer went from lung to breast to a brain tumor—and I didn't realize that a brain tumor, where this was located, would affect her speech so that she could not respond. I had to make a list. And all she could do was point to it to say that's what I need. And then there were seizures; and that's a frightening thing to see somebody have a seizure.

Shelly: It's so difficult to be able to predict the physical chipping away that we often don't know.

Roy: You know, the doctor's telling me about a tongue depressor and all. I was scared.

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Shelly: Because we feel responsibility for the wellness. We take that on for ourselves, and we just . . . we grieve for every loss that comes. And so that's very difficult.

Tim: What about expectations that you had going into making those decisions?

Shelly: For making the decisions? Boy, the decisions . . . I didn't know how to navigate the mental health system; and when Norman came to live with us, it was at an era of time when Christians weren't supposed to really have mental illness.

Tim: Not supposed to struggle with that.

Shelly: No, and certainly not retired missionaries. And so people kind of looked at us when we talked about drugs for mental health and the mental health system and mental health hospitals. They didn't know how to engage us in conversation or support us in that, and I became kind of vocal. I became Norman's vocal advocate—a little bit of a militant.

Tim: But you could speak up at least and give him a voice that he didn't have.

Shelly: I wanted to give him a voice for that because he was a dear man of God, and this was not a sign of weakness in him.

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This was a sign of physical illness—as though he had cancer, as though he had kidney disease, and so it was important for me. I felt, in some way, inform people that he needed to be supported in this.

Tim: You talk very passionately about that.

Shelly: I do.

Tim: Because that means a lot, doesn't it, for both of you.

Shelly: It does. In the circles that I was in at that time, people didn't really truly understand. And I had to not become angry about that myself.

Tim: That's a temptation, isn't it?

Shelly: It is a temptation.

Tim: So in the midst of struggling with this, my guess is there were joys as well as part of the struggle. The struggle wouldn't go away, but my guess is there were—what were some of the joys you experienced in the caregiving opportunities you had?

Roy: The joys for me, you know, were times to visit with my first wife in these dying days and to see the body of Christ become real Christians.

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Tim: What do you mean by that, Roy?

Roy: I mean, you're supposed to visit the sick and, you know, and they were there at the door. They were there with meals. You know, David and I were supposed to cook all these meals. Is my daughter-in-law supposed to come every night and bring supper? And so all of a sudden they're being the church. They're being Christlike. And she probably had a stack of 300 cards, and to read the personal notes of what they thought of her. What a joy to read them. We saved every one of them.

Tim: I bet.

Roy: Yep.

Tim: Joys for you.

Shelly: Well, the gift of time, and with that comes, in some regards, reconciliation. You have that: You get the gift of reconciliation, because you get to know different layers of your loved one's story if you're willing to pursue that. What I found in caregiving: When I first came to know Norman, his mental illness made him a bit different from most people. He had excessive compulsive behavior, and he had severe social anxiety. But those five years that we had with him gave me an opportunity to find out things about his stories, personal story—things that had

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brought him to certain places in his life. And so I came to know him in a totally different way. And so that was just . . . there was a reconciliation and a closeness that came even though there were ways that I couldn't communicate with him.

Tim: You're talking about building a deeper relationship even in the process of caregiving.

Shelly: Yes.

Tim: Because isn't that where compassion really comes from?

Shelly: Absolutely.

Tim: To have a heart for another person, to walk with them in their story, to understand that you really can meet them where they're struggling, to provide for them health wise, provide for them mental health wise. That's really the point.

Shelly: And it is, I really believe, the most Christlike thing we ever do, because there is no earthly payback for this. Our loved ones are dying or, in many cases, they're unable—if they're handicapped—or physically unable to communicate with us, or mentally ill. There's no earthly return on this. It's just the pouring out of ourselves.

Roy: One of the things I saw: I did some interim churches, so I'm

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in and out, and this is one where I was in and out for one year. And Gloria and I, my present wife, had this absolutely precious woman. Well, first visit we made with her—she lived alone—she shared with us, “my greatest joy in life is my fellowship with God the Father, God the Son, and God the Holy Spirit”. And we said, “Boy, that’s a first.” I don’t think I’ve ever—I didn’t expect that one. And this was down close to Toledo, and she was in the Toledo hospital; and this was after I had left, and I found out that she died alone, and I was so sad. It is awful for someone who’s as precious as that, that there was nobody at their bedside when they breathed their last. Caregivers are there when people are fearful of dying and wondering about the unknown, and to die alone is terrible.

Tim: And that’s part of honoring who a person is, isn’t it? To honor their weight and worth and made in God’s image that we care for them in their days when they can’t care for themselves.

Roy: Yep.

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