

Sunday, January 31, 2016 - Love Does New Things: Caregiving

Luke 10:30-37 CEB

Marysville United Methodist Church

Pastor Jenny Smith

Last year I walked into the bathroom at my Grandma's home and saw this taped to the mirror. "I understand my memory doesn't always work well but I can live by myself in my own home. I can walk, I can breathe, I can feed myself, I can swim, I can read, I can hear, I can see, I can love, and there is so much more to be thankful for." My mom had posted these words to remind my Grandma each morning who she was.

Many of you have in the past or are currently caring for an aging loved one. Or you will be in the future. Watching my mom care for her mom was my first glimpse at how difficult that task can be at times. I don't think my mom felt prepared to see her mother change so drastically. But she was willing. To call her everyday and remind her to take medicine. To give her a bath. Take her on a walk. Feed her. To be the hands and feet of Christ to her mother.

My friends, as we talk about caregiving today, that's all God asks us to do. We don't need to feel ready, **just willing.**

There are many ways we could talk about caregiving today, but focus is good, so here's what we can do. Let's talk about what it feels like to be a primary caregiver for a loved one, like a spouse or an aging parent. Some will apply to those raising young kids as well. But we'll focus in on those caring for someone who are later in life. We'll look at the story of the Good Samaritan for some guidance from Jesus and share some hope and help for those in the midst of caregiving. Then I'll end with a story about a great way to talk about these things now, instead of later.

Since I haven't walked this road before, I spent time with four people this week who have. I share with you their wisdom and grace today.

"We're grieving the change in our loved one + learning new skills at caregiving + taking care of our normal responsibilities + likely not caring for ourselves = a roller coaster"

"Some of us are not wired to be caregivers - but you may surprise yourself - God may give you strength you never thought you had."

"Some of us are long suffering and will care for someone at the cost of our other relationships."

"It's similar to being a parent with young kids to care for but one minute, the parent treats you like you're still a young child, and the next minute, you need to be taking the lead. It's really hard."

"A particularly painful reality is that the primary caregiver watches their loved one slowly deteriorate. Others don't see the day to day changes."

"My faith was challenged. "Why is God making her stay here? She's all alone. She just wants to go home and see her family."

"My mother kept trying to prepare me but I didn't want to talk about her dying."

Judy's story

It's overwhelming at times - the decision to move my mom 3 years ago into a facility. I was absolutely exhausted. I didn't even like her. So angry with her. I did things because it needed to be done. To

hold her and kiss her - that stopped - I was so frustrated. I felt trapped. The decision to move her was the most heart wrenching difficult thing I've ever done. You have to go through it to decide to move them into a facility. It's awful. It's hell. I came home and pounded on her bed, I'm so sorry, over and over. She begged to come home. "If you really loved me, you'd take me home."

Your parents want only you to take care of them. But it's alright for you to not have to be there. They will be cared for. I visit a couple hours a day about 4-5 times/week. I plays piano for folks. After she moved, I got to be daughter again and to advocate for her. I can kiss and hug and not feel resentful again. But it does still feel very limiting. Guilt is wrapped so much up in this. Don't do it alone. We brought mom's doctor into the whole thing. Understanding dementia helps you respond in a much better way.

Scripture connections

When I think about the story of the Good Samaritan, it's an invitation to be someone who notices the pain of others and responds. As we talk about caregiving today, let us consider a significant action of the Good Samaritan. He noticed, paused his agenda, provided direct care and then made sure the hurt man got the care he needed. The Good Samaritan didn't provide all the care himself. He may have not been the one most equipped to care for the man, but his compassion and resources saved the one who was hurting.

Kerry's story

My current caregiving role is not the one I had planned or even imagined. My plan was not God's plan. My plan was to care for my husband at home. Period. There was a crisis and suddenly my husband was moved out of our home and into a long term Alzheimers care facility. Needless to say, I was not prepared, emotionally, to have my husband move away. I not only missed him, I had tremendous guilt at not being able to keep him safe and keep him at home. It took months for me to come to terms with my guilt and grief.

What helped me the most was my faith. I prayed continually and saw God's grace in even the most unlikely places. I looked for, and found, the blessings. That was huge. I was able to put one foot in front of the other everyday. Going back to church and experiencing the love of my church family was also important.

Today, I am accepting, and adjusting, to a new normal. I realize the normal is ever changing. I have learned "how" to visit my husband. I have learned new ways of communicating with him. We have a life together even if he doesn't live with me. I am still his wife, his primary care giver, and advocate.

It has helped me to reach out to other residents, in fact, it gives me great joy. There are people who never have visitors, ever. I try to connect with them when I visit John. I participate in the activities for families and make an effort to get to know them. We're all in this together and we can help each other.

Encouragement from caregivers

- **Be an advocate** for loved one
- **Get educated** - knowledge of the disease helps so much in how you care for them
- **Build a support team** - you cannot do this alone - it's healing to talk to others about your experience and to hear theirs
- **God is with you**
 - It's okay to talk to God about how you really feel - "Really God? Just take them now! Don't let them suffer." Be honest with your God. God can handle it.
- **This journey can be an honor**
 - Try to remember what an honor it is to help them walk through the end of their life.

- An honor to care for loved one AND the hardest thing I've ever done
- We try to honor our loved ones throughout their life - have conversations along the way about end of life - then we can forgive ourselves if we feel like we haven't measured up
- "She saw me arrive and I got to see her leave."
- **Take care of yourself** - I heard this from every single person I talked to
 - CUP & PITCHER ILLUSTRATION – water pouring from pitcher into cup – we care for others from the overflow – but when we're disconnected from the things that fill us up, no wonder we're exhausted, frustrated and angry
 - Take care of yourself - it's not selfish - in fact, it's the only way you can care for someone else.
- **Have the hard conversations now**
 - Don't wait until you can't make the decision for yourself - choose a long term care option for yourself sooner, rather than later.

Conversation Project

Last fall, as we prepared for a family trip to Bend to see my parents for Thanksgiving, my parents mentioned they had something they wanted to talk to us about one of the evenings. So in our family schedule, we scheduled Monday night for about an hour after the kids went to bed for this secret conversation. The night came, and we put on jackets, grabbed blankets, drinks and gathered on my parent's back porch around a fire. For the next hour, Mom and Dad took turns reading from a packet of paper they had filled out. They'd heard about something called The Conversation Project. This effort is dedicated to helping people talk about their wishes for end-of-life care.

In the past, I would have avoided this conversation like the plague. Yes, I know my parents will die. But at this age, it's hasn't been something I was ready to even remotely consider. But I have to tell you, it was a holy evening out on that porch. I could just feel it. We were doing really important life work in that circle of my most dearly beloved people on the planet.

We got to say things to each other that some people never do when life takes someone quickly. There were some tears and mostly laughter. And it wasn't awkward nervous laughter that was trying to break the tension of the difficult conversation. It was laughter that said "Yup, that's how our brother would want to be celebrated after he dies. That'd be perfect!"

And my mom got a chance to tell all of us, "We've gotten good long term care coverage. We'll look at facilities that we might like. It's okay to have us live there, especially when it's hard to care for us. And I'm going to write myself a note for you to give me when I refuse - so that I can try to remind myself this is actually what I want for you all."

And at one point, I got to lean over to my mom, put my hand on her arm and say, "Mom, it will be so sad when you pass. But we'll be okay. We've got each other." I never would have thought there'd be space to say that at this point in our lives. A deep part of me already feels so much better because I got to say that now - we never know what and when life can change.

One of my brothers shared afterwards, "It reminded me just how much mom and dad have been an example of living a Christ filled life. Knowing that the end of their time here on earth is not the end of their lives and that talking about that would help us understand that even more. Also it led to a deeper connection that week during our vacation. When you talk about the end, you appreciate the journey that much more."

And my sister said it well: "I went into it apprehensively, not knowing exactly what would happen. (We tend to have lots of these talks in our family of two pastors!) But what ended up happening was

honest, real, sad and happy conversation. I feel better about dealing with my parents' death when it comes because we've talked about it together. It will feel like they're with me because I know we're doing what they want.”

Talking about end of life issues is hard. No matter how you feel about it. It's hard. And too many people are dying in a way they wouldn't choose, and too many of their loved ones are left feeling bereaved, guilty and uncertain.

Did you know...

- 90% of people say that talking with their loved one about end-of-life care is important. 27% have actually done so.
- 60% of people say that making sure their family is not burdened by tough decisions is “extremely important.” 56% have not communicated their end-of-life wishes.
- 82% of people say it's important to put their wishes in writing. 23% have actually done it.

It's time to transform our culture so we shift from not talking about dying to talking about it. It's time to share the way we want to live at the end of our lives. And it's time to communicate about the kind of care we want and don't want for ourselves. I believe that the place for this to begin is at the kitchen table—not in the intensive care unit—with the people we love, before it's too late. Together we can make these difficult conversations easier. We can make sure that our own wishes and those of our loved ones are expressed and respected.

Church, consider having this conversation with your family. Choose a time when you'll be together without little ones running around. Make it a special evening. Acknowledge it will be hard, but so worth it for all involved. Get all the resources you need at www.theconversationproject.org.

I came across this reflection this week: *Dying doesn't cause suffering. Resistance to dying does* (Ira Byock, MD). Entering into this season of life with someone is difficult. You're acknowledging your mortality and theirs. It invites you to do deep soul work with God as you come to a place of acceptance and peace about death being a natural and even beautiful thing.

As followers of Christ, we fully believe death is not the end, it's the beginning of the next beautiful thing. And we can either choose to resist it, push it down, avoid at all costs. Or we can open our arms, let down our guard, and fully enter into the pain and fear, trusting God is still present in the midst of it. And that our acts of care (noticed and unnoticed) are helping to usher someone into the arms of God. May God walk with us all through life's difficult and beautiful moments. Because that's what love does. Amen.