

**Breaking Barriers**  
**everybody belongs • everybody serves**

**Spring 2017 (Paid caregivers)**

**An Outward Shift in Focus**

**by Jenna C. Hoff**

Inglewood CRC, Edmonton AB

We certainly don't blend in as we enter our church on Sunday morning. With my husband pushing my wheelchair, I roll into the sanctuary, a communication device replacing my voice as I greet the church community that has wholeheartedly embraced my family through our unique journey.

Two young people bring up the end of our parade as they tromp along behind us, their heartfelt desire to resemble rock stars evident in their black clothing and wild hair. One sports a necklace he proudly made from a thick metal chain normally used to secure motorcycles.

We may not look like the other families in our church. I'm just glad we're here at all, not only because it took more choreography than a ballet between me, my morning caregiver, and my husband to get me and my equipment out the front door, but also because recently God put us together as a family.

Just a few months ago my husband and I became caregivers and legal guardians to a young man, aged 20; our home was approved as his new care home. His sister, now 17, joined our family seven years ago from the foster care system through the miracle of adoption. Both live with developmental delays and intellectual disability.

When we were asked if we would open our home to the young man, we were given just one day to decide. The request came at a time when my own disabilities were the greatest they had ever been, including adapting to a wheelchair. I was also adjusting to caregivers coming twice daily to help me. Yet we sensed in our hearts that God was calling us to welcome him as our newest family member.

Becoming a caregiver turned my focus outward from myself and my disabilities toward offering my abilities for the care and benefit of another.

I've been given the gift of loving with all my heart, which has broadened my understanding of the Father's unconditional love. I've learned acceptance, including their desire for rock star attire; after all, God accepts each of us as we are. I've learned to sacrifice, advocate, access needed resources, and dream bigger dreams.

I can truly say it has been one of the greatest blessings I've ever experienced to have these young people in my life.

## Themes

This issue—**Paid caregivers**. Many people with disabilities receive supports from others. Articles in this issue have been written by people who hire caregivers, provide care, or have a loved one who receives paid support.

Summer 2017—**Pastors with a disability**. Are you a pastor with a disability, or does your pastor have a disability? How has your church changed, or what changes has your church made, as a result of your pastor living with a disability? Please send us a note about it **by May 19**.

Fall 2017—**Learning from children with disabilities**. What have you learned from a child with a disability in your church? Or, do you have a favorite children's book about disability? Please send us a note (up to 400 words) **by August 25**.

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### **The Mutuality of Caregiving**

**by Mark Stephenson**

CRC Disability Concerns

Doug Rottman has had many caregivers in the 30-plus years since he became paralyzed in a water-skiing accident. When asked by acquaintances what the caregivers do for him, Doug usually replies, “They do for me what I can’t do for myself.” Through their assistance with transportation and more, Doug’s caregivers have helped him attain more independence, including working in various jobs.

Doug finds caregivers by advertising on a website, by word of mouth, and by advertising at local college campuses. He enjoys the energy that young people bring, and he likes training them because many are studying for jobs in the medical field.

Though helpful, having caregivers is complex. He must find good people, train them, and coordinate their schedules with what works best for him and his family. When his schedule changes, sometimes caregivers can be flexible with their time and sometimes not. Usually, his caregivers who are in college want to take off for breaks and summer. Many of them work with Doug only for a semester or a year. Doug’s roommate, Chad, also helps with some caregiving.

Vacations are different and sometimes require more from

a caregiver. The last two summers, Doug, his three children, and a caregiver traveled to Colorado. Although his caregivers are not officially working 24/7, compensation needs to be fair because they are unable to work elsewhere during that time.

Doug deeply appreciates all the people who have been helping him through the years. “It’s a relationship working with caregivers,” he says. “Sometimes they vent to me; other times I share with them. I need them to be helpful and sometimes I need them to work quickly, but I try to make it reasonably fun.”

The work caregivers do puts them in the middle of Doug’s life. “Despite ups and downs in my life or theirs, I still need their help.”

In some cases the relationships have grown close. Doug has attended the weddings of three of his caregivers and will go to another this summer. Several years ago, one of Doug’s roommates who helped Doug in exchange for room and board met Doug’s cousin. Now they are married.

“Having people who are dependable, reliable, and friendly increases my quality of life dramatically.”

### **'I Like it When...'**

*Alice's son lives in an adult foster care home. She wrote this letter imagining what her son would say to his caregivers if he could.*

Dear Caregiver,

Thank you for talking to me when you dress me in the morning. It makes me feel less uncomfortable about needing the help, and it makes me feel like you don't mind helping me.

Thank you for not sharing with everyone else how many times I wet my pants or had a bowel movement. After all, I don't know how many times you went to the bathroom today. Sometimes I don't smell really good. I am sorry about that and wish it could be different. It makes me feel good when you don't complain about it.

Thank you for feeding me my meals at the appropriate temperature. Yes, I will eat it even if it is not the right temperature, but only because the alternative is to go hungry. And while you are feeding me, I really appreciate your talking to me instead of the people you work with. I would like it if you told me about the movie you saw last

night or how much you like the weather outside. When you only talk to the people you are working with, it makes me feel like you forget that I am here. I really like it when you wipe my chin carefully with a napkin instead of scraping off my chin with a spoon. It hurts my chin and makes me feel like a baby.

When you talk to me before you touch me or my wheelchair, I feel less scared. Sometimes I get shoved around without even knowing where I am being pushed. I like some surprises, but mostly on my birthday.

Most of all, I like it when you ask me what I would like to do and try to figure out what my choice is. It makes me feel like I matter. Even though it is not easy to do, I try hard to communicate with you. Sometimes I smile when I am comfortable. Sometimes I fall asleep right away if you lay me down just right. These are the ways I let you know what I like. If I am frowning, crying, moaning, or yelling, it means something is wrong. I wish I could tell you what was wrong so that you don't get irritated with me so often, but I don't have that luxury.

—Reprinted from *Breaking Barriers*, Summer 2007

## **The Task of Paying Attention Daily**

**by Andrew Spidahl**

Hope Church (RCA), Holland MI

Now put my arm out to the side. Other arm. OK, now right arm...wait!" There's a pause, and I realize I've stopped breathing. "OK, start with my hand, and try moving it toward the window..."

I'm trying to help Randy put on a sweater, but after six minutes I'm starting to wonder if I'm helping at all. I'm discovering that each movement matters, each step must be explained. He's trying to help me, and although he was awake at 7:30, we're just now at 9:15 getting dressed. We'd still like to get in the chair, do hair, brush teeth, check email, and get breakfast—hopefully before noon.

Never have I had to pay closer attention to basic tasks than I do as a caregiver for Randy. The same routine that I thoughtlessly stumble through in 20–30 minutes each morning takes Randy and me two hours or more. Each movement is broken down into steps—motor off, lean the chair back, pull on right knee, hand on the chest—while extra-sensitive elbows and toes make certain moments and motions painstaking for both of us.



“Slow down.” “Pay attention.” “It’s not about you.”

These internal reminders just as easily could be spiritual mantras. Certainly there are times when we both need to step back and breathe. This work requires patience and sustained attention, and it’s tiring. But without trying it also lends reverence and care to simple, otherwise forgotten tasks such as washing your face or putting on socks.

Father Richard Rohr writes, “Paying attention to the task within the task, we begin to move from the first to the second half of our own lives.”

What is the task within the task of putting on socks? Quite simply, it’s care. We are performing the task of caring for Randy, together. This is the task that is hidden within all the other tasks, and revealed because we both have to pay so much attention to what we’re doing—we have to take so much care. How we pay attention to this task of caring for Randy is ultimately how we love ourselves, others, and the world. Are we feeble, distracted, clumsy, short, frustrated in these attempts? Yes. But I don’t think love is an end to which we succeed or fail; rather, love is a daily,

ordinary practice that begins with attention.

I will get better at the daily routine with practice, and Randy will have to coach me less and less, making room for more efficient, easy, and productive mornings. But these times of forced attention, sometimes frustrating, are gentle reminders of why we even do these tasks. It is a wonder just to be alive; it is our task to care for and love this life we have been given.

## **Receiving Care Leads to Serving**

**by Robyn Saylor**

Trinity Reformed Church, Grand Rapids MI

I was 35 when I left home, and for the next 14 years I was able on my own to do everything I needed. As I got older I became weaker and started falling because I couldn't rely on my legs due to cerebral palsy. I became panicky, screamed at people, and lost the emotional strength I had built up over the years. If I couldn't be independent, I told people, I did not want to live.

I had to stop fooling myself, and focus on transitioning to a different way of life that could be good for me.

There are two programs for someone like me needing paid

caregivers: self-determination, where the client fires, hires, and does all the paperwork; and case management, where a case manager gathers all your bank statements and provides the hours for you.

Before going with either of those, I tried a service that does household chores, but I encountered challenges. One night, my caregiver walked out on me and left me on the toilet all night. I can't do my own money management, and I feared a caregiver might take my money. I also knew folks who had been beaten by their caregivers.

Eventually I switched to a case management approach. I can stay in my own apartment with all the assistance I need. A case manager determines what kind of help I need and how many hours I'll need assistance. Caregivers give me a shower, get me out of bed, help me brush my teeth, help me into bed, etc. Because of them, I can be alone for long periods of time. They have assisted in acquiring adaptive equipment that helps me stand up, transfer onto a toilet, and other things.

Having the right assistance has improved my quality of life and helped me as God's servant in the community and in the world. Getting the necessary care improved my energy

so I could advocate better for others. I want people with disabilities to have opportunity to work—a goal worth fighting for, even in churches. I advocate for public transportation since it's harder for people to have a job if they don't have adequate transportation.

It's less expensive to provide home healthcare than putting people with disabilities in a nursing home. We need more home healthcare workers, but one problem is they get paid less than somebody working at McDonald's—another area needing advocacy.

I was 49 when I stopped being independent. At 58, I've learned that when your body, your circumstances, and everything you've relied on change, you must accept what you can't change and fight for what you can.

### **Editor's Note**

#### **The Gospel through Touch**

I'm thankful for the supervisory and administrative staff at the adult foster care home where our daughter lives, and I most appreciate and value the people who provide her daily care—dressing, bathing, toileting, feeding, and so on.

Although our daughter cannot speak, these caregivers have found ways to understand, as best they can, what she would like. The way they interact with her not only provides for her daily needs, but also communicates that she has value. In fact, you could say that loving touch communicates the Good News.

In his dissertation, Dr. D.O. Neil Cudney describes “a tactile declaration of the gospel” and cites 1 John 1:1, “What was from the beginning, what we have **heard**, what we have **seen** with our eyes, what we **looked at** and **touched** with our **hands** concerning the Word of Life...” (emphasis added).

The stories in this issue describe people giving and receiving care. When caregivers gently, lovingly, respectfully provide care, they proclaim the love of Jesus. Give thanks to God and say thanks to the men and women in your church and community who provide care in private homes, group homes, nursing homes, and in other settings. Pray that their care may be another way that God’s will is done on earth as it is in heaven.

—*Mark Stephenson*

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