

Breaking Barriers

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Spring 2016 (Adjusting to acquired disability)

Yearning, Treasuring, Hoping

by Eric Groot-Nibbelink

Bethel CRC pastor, London ON

On March 16, 2014, every parent's nightmare phone call came to our home when a police officer informed us that our 25-year-old daughter, Jenica, had been in a horrific car accident and flown to hospital. She had sustained several life-threatening injuries including severe head trauma. What followed was a mix of agonizing fear, raw lament, and confounding hope. After weeks in a critical care trauma unit, months in various stages of a coma, and six months in hospital, Jenica was well enough to be released and cared for in our home. The physical, emotional, and spiritual toll on us as parents, sisters, family, and friends cannot be captured in a few sentences—a reality true even now, almost two years later.

Having completed bachelor's and master's degrees in English, Jenica was working as an intern with the Kuyper Center, a CRC campus ministry. She was set to attend Calvin Theological Seminary with a presidential scholarship in September 2014 and was involved with both youth and

music ministry in her home church. Through her love of others, infectious joy, and enthusiastic relish of life, she was delightfully enjoyed and loved by the people around her.

However, with the accident, almost everything changed in Jenica's life, except the shared love and joy of those around her. Since her release from hospital, Jenica's vigorous schedule is dominated five days a week by therapy consisting of physiotherapy, voice therapy, speech/cognitive therapy, hand therapy, various medical appointments, and training in the latest assistive technology.

Given the extent of her injuries and the initial prognosis, Jenica has amazed doctors, nurses, therapists, and essentially everyone with whom she comes into contact. In fact, many have described her recovery as "miraculous," no matter the worldview of the person assessing it. Jenica's tenacity and persistence combined with her gracious and positive attitude have benefited her greatly and testified to others of God's grace and presence.

Moving forward, many daily physical challenges and confusing emotional and spiritual struggles remain. We are filled with amazement at God's mercies in helping Jenica to recover and progress as she has, and simultaneously we encounter moments of deep sadness with her and for her as she travels this new and indeterminate road. We yearn

for what was. We treasure what is present. We wonder about what might have been. We find hope in signs of new, God-given possibilities and potential. Each day we carry our new understanding of the uncertainties of life and travel a well-worn path of reaching for the words of the poet in Psalm 130, “I wait for the Lord, my whole being waits and in his word I put my hope.”

For Jenica’s perspective, see “Still Seeing God Anew” on page 4.

Themes

Spring 2016—Adjusting to Acquired Disability. Some people have lived with disability since birth or early childhood, but others acquire a disability later in life. We hope this issue will help readers understand the grief and the life lessons that disability can bring so that they can respond with empathy to those living an acquired disability and to their loved ones.

Summer 2016—Living with Seizures. About two percent of adults have a seizure sometime in their lifetime. About one third of these people experience more than one. Do you or a loved one live with seizures, or did live with seizures for a period of your life? Please send us a note describing your experience **by May 20.**

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Still Seeing God Anew

by Jenica Groot-Nibbelink

Bethel CRC, London ON

After preaching a sermon entitled “Seeing God Anew” on March 16, 2014, I was involved in a serious car accident and spent nearly six months in hospital. Though I do not understand why my accident happened, I have been enabled to see God anew since the accident. God has been incredibly faithful to me in my recovery. Though the journey is long and difficult, I continue to make gains. I have also met so many people who have been able to partner with me in beautiful ways as I work hard to achieve my recovery goals.

While in hospital, I listened frequently to what I called my resurrection song, “After the Storm” by Mumford & Sons. This song speaks of an individual looking up “after the storm” and then yearning for “a time, you’ll see, with no more tears/And love will not break your heart, but dismiss your fears/Get over your hill and see what you find there/With grace in your heart and flowers in your hair.” This particular song highlights the necessity of living as a people of grace with a love for beauty.

The book of Colossians also speaks of living as people of grace. In Colossians 4:6, Paul advises, “Let your conversation be always full of grace...that you may know

how to answer everyone.” Though written thousands of years ago, I find this verse to be apt today. So here are some tips for interacting with people who have experienced an acquired brain injury (ABI) or traumatic brain injury (TBI).

1. Suggest a quieter location if in a noisy place. People with ABI/TBI are often very sensitive to noise.
2. Be patient. People with an ABI/TBI may need time to think and respond.
3. Allow for rest periods. Fatigue is a common trait in people who have ABI/TBI.
4. Treat them as you did before their injury, unless told otherwise by family members, friends, or therapists. Sometimes, all that is required is to slow down the rate of your speech.
5. Be gracious. People who have had a brain injury may get easily agitated or upset. Depending on the case, people with ABI/TBI may not respond in socially acceptable ways.

Note: for additional tips from Jenica for interacting with someone who has an acquired disability, see the editor’s note on page 16.

When Disability Suddenly Strikes

by Julie E. Yonker

River Rock CRC, Rockford MI

When my husband Jeff suffered a spinal cord injury from a bicycle accident shortly after moving to Belgium, our world turned upside down. Suddenly, we were coping with a traumatic injury in a country where we did not speak the languages nor understand the socialized medical system. Our daughters were adjusting to a new school and a paraplegic dad in hospitals for ten months. Suddenly, I was not only a wife and mother, but also a patient advocate, counseling psychologist, nurse, physical and occupational therapist, wheelchair mechanic, home and car repairer, financial and insurance liaison, and more.

The sudden disability of paraplegia forced us to reevaluate many assumptions and ideals we had as a married couple. We had to grieve many losses such as our active lifestyle, plans for an active retirement, financial future, corporate career identity expectations for Jeff, and the loss of half of Jeff's functioning body.

As I look back on this "sudden" arrival of disability in our lives, I realize God had been preparing me for this "sudden" event for many years. As an adolescent, I volunteered in hospital emergency departments, which allowed me to make Jeff's extensive hospital stays easier and enhanced my role as patient advocate. In college, I was an athletic trainer, which prepared me to understand and assist Jeff and his physical therapists. Sadly, I knew how to grieve, because my mom died five years previously.

If I could decide, I would not have planned on disability entering our family's lives. Disability has complicated and robbed our lives of many things. However, disability has also provided the opportunity to undertake roles and challenges that have enriched our own lives and the lives of others. For example, through our testimony during Jeff's accident recovery, several people who witnessed our reliance on God became Christians. In my role as a professor at Calvin College, students who know my story often share with me their story of suffering. Although our suffering stories are different, suffering is common to each story. This common denominator allows me to provide a sympathetic ear and wise counsel to help them navigate their life journeys.

Our entire family has ministered to others in ways that would not have been possible if disability didn't suddenly enter our lives. God redeemed our disability in order to allow our family to be agents of renewal in the lives of others.

Choosing to Bless God's Name

by Jeff Yonker

River Rock CRC, Rockford MI

I was 15 years into a rewarding career in Finance with Procter & Gamble. We were comfortably living in Western

Europe, and I travelled frequently to interesting countries such as Kazakhstan, Uzbekistan, Romania and Bulgaria.

One weekend, my wife Julie and I were out for a casual bicycle ride in the Belgian countryside. We were nearly home when the front tire of my bicycle caught a crack in the road. I was thrown from my bicycle, with my back hitting a stone wall next to the road, damaging my spinal cord and rendering me a paraplegic. In just an instant, almost everything about my life and my family's life changed for the worse.

In addition to my damaged spinal cord, the accident caused many other injuries and complications. I spent two months in a Belgian hospital not equipped to handle my injuries. When I had recovered enough to travel, I was transported to a spinal cord rehab hospital in Switzerland. The Swiss hospital had to "repair" some mistakes the Belgian hospital made, and I needed seven months in Switzerland to recover and learn how to take care of myself as a paraplegic.

During those nine months, I had many difficult days, wondering if I would ever be able to function in a wheelchair independently. But God was with me the whole time. My family placed dots on a map of the world to show where people were praying for me. As the map hung on the wall behind my bed, it reminded me of God's presence around the world and gave me an opportunity to

witness to curious nurses and other healthcare workers, most of whom had no relationship with Jesus Christ.

Despite my long and difficult recovery, and challenges I still face today some 16 years after the accident, I am comforted by the lyrics of the song “Blessed Be Your Name.” Like the lyrics say, at times I felt like I was in the “wilderness,” the “darkness,” or on “the road marked with suffering.” God gave me a lot of great things in my life, but the song’s paraphrase of Job 1:21 reminds me that God can give and take away here on earth. Because I have the promise of eternal life with him, where all pain and suffering will be in the past, my heart will still choose to say, “Lord, blessed be your name.”

Prayer that Overcomes Limits

by Linda (Visscher) Roorda

North Spencer Baptist Church, Spencer NY

All of his life my husband Ed had to struggle with limited vision, being classified legally blind from infancy on. He struggled in the classroom, not being able to see the board, often refusing to ask for help. Nor could he do all he longed to do. At 6-foot-7, he couldn’t play football or basketball. He could swim like a pro, but wasn’t allowed on the team for fear he’d hurt himself or others by straying from his lane.

Yet, he had accomplished so much with so little for so many years! He could milk cows, climb silos, drive tractor and do all the field work except plant corn, and that was only because he couldn't see where the last row left off. With his limitations, he knew to be extra cautious and it always paid off.

The day came that Ed's sight was completely gone. He went through a difficult transition and grieving process, as most people do with a serious loss. None of us knew how best to handle the change. It was a learn-as-you-go process until we found professional guidance specifically for the blind. And then, his old self rose up to meet the challenges, determined to do whatever he could to face whatever came his way—with a catch.

For 27 years we burned wood to heat our house, but with complete loss of his sight Ed could no longer use a chainsaw or an axe to split wood. As he stacked firewood one day without any remaining fragments of light and color to guide him, the rows kept collapsing. He simply could not get the pieces of wood to fit together well enough to stay upright in neat rows. In utter frustration, he sat down and put his head in his hands, feeling like a complete failure. It seemed that even this last bit of enjoyment in stacking firewood was being taken from him, too.

Except, while sitting there, he decided to pray and ask God for help in this seemingly simple, but now very challenging task. He prayed that God would guide each piece of wood he picked up so it would fit and the rows wouldn't fall down, so that he could stack the wood himself without having to ask for more help. As he stood up and once again picked up the firewood, he soon realized that every piece he stacked fit. Actually, they fit perfectly! When he was done, his rows stood straight and tall without collapsing!

And then he began hearing comments from neighbors who marveled at how great his stacked firewood looked. By a man who couldn't see, no less! As Ed told anyone who commented, "It wasn't me; it was God." It was only after he prayed each time before he picked up the first piece of wood that he was able to manage this seemingly impossible task. But, if he forgot and just delved right in to stacking, the wood invariably collapsed—until he sat down and had a little talk with God.

Aphasia: Source of Frustration

by Reg Laws

Ebenezer Reformed Church, Mississauga, ON

"I am not drunk! I have aphasia!" (Yes, I've been asked about having had too much to drink.) In December 2011, while in the hospital following surgery for a new

pacemaker/defibrillator, I had a stroke that left me with weakness on the right side of my body. I could not speak.

With time, speech therapy, and practice, things are coming together, but speech is still a chore, especially grammar and putting words together. My brain is so overworked sometimes that just trying to think of what word goes next and what makes sense is hard for me.

According to the National Aphasia Association, aphasia is an impairment of language, affecting the production or comprehension of speech and the ability to read or write. Aphasia is due to injury to the brain, most commonly from a stroke. Brain injuries resulting in aphasia may also arise from head trauma, from brain tumors, or from infections.

Feelings not included in the textbook definition that describe what I often find myself thinking about aphasia include:

- Stress
- Alone
- Frustration
- Anger
- Hopelessness
- Grief
- Loss of self-esteem
- Emotional complications
- Short attention span
- Give me time, please!

All choices are hard; I change my mind so many times at a restaurant that I still don't get what I want! Social settings are hard because I am always on guard, trying to anticipate what is coming next or what I should be saying. I miss out on conversations because I can't listen fast enough. In fact, I don't do anything fast anymore! Even math and numbers, which used to be second nature to me, are a challenge.

But I am comforted by Christ's presence, and his peace keeps me from feeling overcome with bitterness or anger.

A Good Attitude Helps Others

by Molli Brunsting

South Grandville CRC, Grandville MI

October 11, 2013, began as an ordinary day for my husband and me. We planned to go out for breakfast and then spend the weekend at our river house up north. Suddenly I had a tremendous pain on the right side of my back. I thought I had a kidney stone, so I sat down a few minutes. When I tried to get up, I could not walk.

I went by ambulance to the hospital where I had probably 20 tests that were inconclusive. When I was discharged a week later, I still could not lift up my right leg or walk. The nerve roots going to the right lower quadrant of my body

were severely and permanently damaged. Through inpatient physical therapy I learned to use a static walker to move very short distances. I have to drag my right leg by moving it from my waist.

Several months later I was diagnosed with transverse myelitis, which strikes one person in a million in the United States every year. Of these, about a third completely recover, a third recover with some impairments, and a third never recover. There is no known cause or cure.

Although I am considered in the last third, many people are praying for my complete recovery. Our God is a God of miracles. I have to use a wheelchair most of the time, but can function pretty well. I can dress myself, do housework, and cook. I continue to work part time at my church.

Though I cannot walk, my biggest inconvenience is that I cannot drive. I do have wonderful friends, family, and a husband who get me where I have to go. I am thankful that I know that God is always with me and has kept me from depression over the losses I have experienced.

A good attitude will not heal me but it makes it easier for people to be around me! Forty-three years ago, I had my left leg amputated below the knee but always felt I could do pretty much everything I wanted. Now, transverse myelitis has changed my life in so many ways.

I know that I would not be able to live in my home by myself. I do not know what lies ahead, but I am comforted in knowing that whatever changes need to be made, God will be there with me.

ALS Brings Traumatic Change

by Jim Curry

Drayton Reformed Church, Drayton ON

In rural Ontario my wife Annette and I raised three beautiful children, who as adults have provided us with seven grandchildren.

In spring 2014, after 21 years of working for the local municipal council, my voice was failing me. At that time I was diagnosed with myasthenia gravis, a speech impediment, and in December 2014 I went to London Health Science Hospital in London ON for a series of tests. The diagnosis then was changed to Bulbar ALS (amyotrophic lateral sclerosis, or Lou Gehrig's Disease), a dramatic and traumatic turnaround. I was given two to five years to live.

I am getting weaker and have lost a lot of weight. Since October I take nourishment by receiving liquid through a feeding tube. It's a challenge to maintain weight. I cannot talk or swallow. I have a speaking machine, a cough assist, and suction equipment.

There was a five-kilometer walk last summer to raise money for ALS. I completed it, but this year I will have to use a wheelchair to complete it because my strength has diminished.

On Christmas night I had pneumonia and was in the hospital for eight days while receiving strong antibiotics. I was very weak getting out of the hospital, and it took many days to gain my strength back. My arms are much weaker and balance is a challenge. Falling is a source of pain.

I continue to serve as chairman of Drayton Reformed Church's Disability Committee. Our group of four has been active for several years in making our church comfortable and safe for all. We are in compliance with the Accessibility for Ontarians with Disabilities Act (AODA) and are following its mandate.

We have lots of support from our family, the five guys in my life group, our church, and our community. We are blessed.

I do not know what the future holds, but I will trust in God, who knows the future, to call me home.

Editor's Note

"Help Me Understand . . ."

Jenica Groot-Nibbelink's article (p. 1) had ten tips for interacting with people with Acquired Brain Injury. Five of those ten could apply to interacting with people with any kind of acquired disability, so I "stole" them for this note. Jenica wrote:

- Every case is different. Find out about the person, the way the disability came into their life, and the recovery that has already taken place.
- Be inquisitive. Ask the person questions. Show them you care.
- Understand that rehabilitation can be a full-time job, consuming a person's day and energy.
- Treat the individual as their age dictates. Allow them to ask for help when needed.
- Above all, treat individuals with respect.

We make assumptions easily about people who have acquired a disability perhaps out of fear of our own mortality, intimidation in the face of someone whose life changed dramatically, shock at how much someone has lost, or pity that keeps the person and their disability at arm's length. Whatever the reason, we can behave in unhelpful ways, and have a tendency to want to "fix" people.

So Jenica does not suggest we give advice. Instead, she encourages us in various ways to listen. We can be most

helpful and loving when we make this simple request, then close our mouths and open our ears: “Help me understand . . . ”

—Mark Stephenson

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