

Accompanying Disability

Caretaking, Family, and Faith

Topher Endress
with
John Endress

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“Topher Endress alternates his down-to-earth and theological reflections on accompanying people with disabilities in supportive relationships with chapters written by one of those persons, his father, John, who describes his own adjustment to quadriplegia caused by a hiking accident. This book highlights both the grittiness and sublime and can be read by anyone.”

—**BILL GAVENTA**, Founder and Director Emeritus,
Institute on Theology and Disability,
and author of *Disability and Spirituality:
Recovering Wholeness*

“Endress offers a deeply moving and theologically rich reflection on the intersections of disability, caregiving, and faith. Through poignant storytelling and thoughtful analysis, *Accompanying Disability* challenges us to reimagine the sacred roles of accompaniment and care, revealing God’s presence in the complexities of everyday life. This is essential reading for anyone seeking a nuanced and compassionate exploration of caregiving as both a spiritual and transformative act.”

—**JOHN SWINTON**, Professor in Practical Theology and
Pastoral Care, University of Aberdeen

“*Accompanying Disability* is a beautiful and honest collaborative theological project between a theologian and his disabled father. Accompaniment theology offers a new way of doing disability theology that honors first-person disability narratives and accompanying theological reflections on caregiving.”

—**DEVAN STAHL**, Associate Professor of Religion, Baylor University

“Intrepidly joining his father on his difficult journey from avid hiker to quadriplegic, minister and theologian Topher Endress invites us to think anew about accompaniment and disability theology *from the perspective of the caregiver*. A powerful testimony to how to give care and keep company with those in need.”

—**BONNIE J. MILLER-MCLEMORE**, author of *Follow Your Bliss
and Other Lies about Calling* and E. Rhodes and
Leona B. Carpenter Chair and Professor Emerita of Religion,
Psychology, and Culture, Vanderbilt University

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Introduction

Close your eyes and picture a disability. What do you see? Perhaps the symbol of accessibility, the near-ubiquitous white stick figure sitting in a wheelchair? Or maybe you are picturing a set of hearing aids, a crutch, or a ramp. Maybe you are seeing a person you know, with their specific disability highlighted.

Ask a group of people to picture “disabilities,” and you will likely get back a different answer for every single person. Despite how concrete and material the experience often is, disabilities are a pretty tough concept to define. People with disabilities, even those with the same diagnoses or labels, are often so different and distinctive in how they experience the world that coming up with a solid definition that fits everyone’s reality is an impossible task. And that isn’t even considering the radically different types of disability; after all, what is it that knits together a man with cerebral palsy using a powered wheelchair and a woman with significant cognitive disabilities, or a veteran with post-traumatic stress disorder and a Deaf child?¹

Sometimes categorizations of disability are legal. Sometimes they are medical. Schools make use of set criteria to decide who gets certain services, like extra time for tests or in-class

notetakers. Disabled people are eligible for certain legal and economic aids but are restricted from many others. Drawing a line to say who is in and who is out is important in those cases. It is a very blurry line, in most instances. “What is a disability?” is an important, challenging question; the deeper question, though, is “Who gets to define a disability?”

Disabilities are inherently more complex than we ever tend to acknowledge, at least in public spaces. It’s far easier to turn disabilities into the object of our pitying gazes, or the subject of our scientific research, and far harder to say with any credibility that there is pride to be had in disabilities alongside the pain. Naming a particular set of genes that produce a series of uncommon phenotypes takes scientific effort, but it is ultimately easy. Naming the ways we are irreversibly changed by the presence of disability, whether it is our own life or someone else’s, is a much less straightforward task. But that’s what I want to do. I want to explore how disabilities are normal and natural, yet shock our systems and break apart our expectations of the world. I want to see the pain and the reality of disabilities that hurt while holding space for disabilities that make the world more fun, more loving, more whole. I want to acknowledge that a disability is a *thing*, but it also shows the *absence* of a thing in our society. I want to ask these big questions and figure out what we do because of them.

In many cases, to be disabled is to be different—and worse off as a result. Fortunately, thanks to countless self-advocates and allies, there has been an emerging shift in this pattern of thinking. “Disability” is rapidly becoming a term that is less loaded with prejudice and more focused on naming what supports and accommodations someone may need to be fully part of their community. There is much more to be done, of course, but good things are happening.

Sadly, often these good things are happening in spite of the church, rather than because of it. Historically, the church has always been a pretty mixed bag when it comes to disabilities—sometimes doing wonderful work to support and care for people, sometimes doing really terrible things in the name of

God. Disabled people have been subject to ostracism, pity, and even torture at the hands of Christians, even as disabled people have found solace, love, and welcome at other times. Theology can be used for good or harm. Helpful theology is a blessing, leading to better care and a deeper relationship to faith. Bad theology, which connects disabilities and mental illness to a lack of faith, sin, or demons, is a curse many still live under.

Disability theology is the conceptual work being done to try to understand disability issues from multiple angles, seeking to be responsive to the lived experience of people while focusing on the “big picture” stuff like “What makes a person a person?” and “How is God active in the world?” Disability theology asks questions about God’s providence, or what it means to find healing, or why things like genetic divergences exist. But beyond the big, philosophical stuff, the day-to-day experience of disability is no less important to theology. Disability theology is the work of trying to navigate the church’s role in the world, God’s action in the world, and human diversity, all while holding together these strands of specific personal experiences alongside historic philosophy and theology. It is, safe to say, a tough—and wonderful—field. Thinking theologically about disabilities offers us a way to engage real problems in the world and offer real answers. But that work is hard. How do you maintain a claim that there is an order to the world when a man becomes a quadriplegic? How do you look a parent in the eye and tell them you believe in a God who is good even when they find out their child has a disability that is likely to lead to an early death?

One of the main tenets of disability theology is that the people who actually experience disabilities ought to be the people most responsible for leading the conversations. That is not always the case, of course. For one, a lot of historic theology was written by nondisabled people, and it wouldn’t be fair or wise to throw out thousands of years of their work. And second, disability is not located only in the lives of disabled persons themselves.

Those of us who care for disabled people in our lives have a different, but no less important, experience. We inhabit a

particular role that is related to, but not identical to, the experience of being disabled. Disability theology helps us see the overlaps, and differences, in those experiences. There are of course disabled caregivers, too, but in this book, I am focused on a story of caregiving itself.

This book has several important functions, I hope. First, it widens who we imagine is capable of doing theology. One does not need to study theology at a world-class university, writing with constant reference to old dead men, to be a theologian. Theology is worked out among us as the people of God. There is certainly a role for the writings of old dead men to play, and much of it is quite good, even, but I hope you can find your own voice as a theologian with something to offer the world, formal degrees or not. Disability theology is helpful in naming that life experience is a form of theology, and it allows us all the freedom to see our own stories as powerful narratives that expose God's work in the world.

Second, this book advocates for a new division to emerge in this field: accompaniment theology. The field of disability theology is a small but important intersection that addresses the lived experience of some one billion humans across the globe. Often, the field is a churning sea of disabled voices, parents and caregivers, and interested folks who aren't totally sure why this burns as a passion within them. For a number of years, I fell into that last category—a minister who cared about students with disabilities. Then, suddenly, I transitioned overnight into the second, when my own father suffered a debilitating fall and became a quadriplegic.² Learning from disabled theologians, scholars, and faithful Christians has been integral to my own faith journey, and I hope to provide a shift in focus from lumping together anything to do with disability and instead offer a more nuanced division between the theological insights and experiences of disability and the insights and theology of accompaniment and caregiving.

Disability and accompanying disability are not the same experience, but the work each uncovers is universally useful to the church and to those whose lives are shaped by disability—theirs

or a loved one's. To be disabled is to be in a particular set of relations with the world and the people around you, so naturally those who are on the other side of those relationships have a critical part to play. Acknowledging that these experiences are different, but intimately connected, allows all of us to learn from one another more richly and powerfully, exposing the ways that God is at work in our lives, in the lives of those around us, and in the wider world too. My hope is that by carving out clear space for those of us who experience caregiving, we can open even more space concurrently for disabled voices to have their own dedicated platform, making that much more clear the ways God is moving among us all in particular ways.

With more clarity about what life looks like for those who support, love, and care for disabled people, we can begin to see the theology that is written by so many different experiences. It might be easy to say that God is at work in a given situation, but it is much harder to say how without exploring the challenges and joys of being disabled. Likewise, when we divide out the experience of caregiving, naming it as a particular site where God is present, we can see the overlaps and differences more clearly. Caregivers and disabled people need one another, and need to know that their experiences are deeply worthwhile to the wider church.

In this vein, I believe sharing my father's story next to my own theological reflections opens a particular and important distinction in the field. If disabilities are rooted in experience, it does no favors to combine the firsthand experience of disabled people with the secondhand experience of those who care for them. The field of disability theology is growing and being reshaped as more and more people begin to see the importance of the work, which means more and more disabled voices are being taken as serious sites of theological generation. Rather than simply supplanting the nondisabled voices in the field, what we need is a new term, a new category that more accurately describes the work that God has set before us. I deem this "theologies of accompaniment."

Too often, being a caregiver means being focused on someone

else at the expense of being cared for yourself. Maybe you feel like your own story has been lost in favor of someone else's needs. Maybe you are feeling empty, not cared for in the ways you need and unable to give any more. I hope this book is in some sense a practical help for those who are struggling to provide adequate care to someone they love.

Caregiving is hard. It is often thankless. Regularly, people get burnt out and can't find anyone else to cover them, so they continue to work without breaks even to the detriment of those they serve. If that is you, I'm sorry that I can't offer you any material respite. I won't be showing up at your house to cook, clean, or do laundry while you take a nap. But maybe knowing another person's story, seeing what struggles and joys someone else has experienced, and knowing that you are not alone in navigating this world will be a small help to you. It is good to know that we are not alone.

This book is for any number of people. Pastors who want insight into lives that look different from their own, so they can provide better care. Disabled people who are interested in hearing how the people around them might be experiencing their role as caregivers. And most especially, accompanists themselves, looking to see their lives reflected in these pages.

God is at work in all of our stories and lives, no matter how burnt out or burdensome you feel.

1

Narrative

Telling a Story

I attend conferences on theology.

My dad attends conferences on land reclamation. Well, he did.

At the time when we—my father and I—began writing this book, I was a PhD student in between stints as a congregational minister. As a young, fledgling academic in a pre-COVID world, with a relatively small number of publications to my name, I was always keen to attend conference after conference. Partly, I needed to be rubbing as many elbows as I possibly could—jobs in academia don't exactly grow on trees, and it isn't lost on me that the number of folks self-categorizing as “religious,” while still a vast majority of the planet, is shrinking. So any opportunity to network, whether it was in Dublin, Ireland, or Dublin, Ohio, always felt like an investment in my potential career. Every presentation was another line on the CV, which would hopefully one day impress someone enough to consider me for an interview.

I'm not sure it was ever really working. But, hey, most conferences come with free lunch, at least.

My dad, on the other hand, was at the very tail end of a long career. One day, on a visit home just after yet another conference on theology, I walked into his room and caught him on a call with some group, referred to by some long acronym whose true name I wouldn't even hazard a guess at. After, he mentioned he was unlikely to join any more of their meetings, as he thought he had nothing more to offer them in terms of expertise, acquired through years of driving the back roads of the state, traipsing through farms and wild hills, and making hand-drawn survey maps in an era just before Google Earth. Having spent a few decades as one of the very few credible voices able to speak across the aisle to two major institutions of our area—coal mining companies and the government—meant that he was a sought-after expert. Very rarely did he need to attend a conference just to pad a résumé; he may, however, have attended a few simply for the food.

Growing up, whenever I'd walk into his office, built into a corner of our basement, I'd find him on his computer poring over spreadsheets, at his light table making quick marks on massive maps of the countryside, or on the phone with some high-up at a local coal company, soliciting more work projects for his one-man consulting business. It would be common for my mom to have to yell down the enclosed staircase at least twice, often more, to remind him to come up and eat dinner with us. It wasn't familial negligence; it was what was necessary to keep things running. Certainly, he was there for our recitals, plays, tennis matches, homework help, and some general hang-out time, but the price of being flexible enough to be involved in our lives was that "work time" became default. When he wasn't actively taking time off to do something, he was hard at work.

Postdisability, when I walked into his bedroom, a new space built on to the first floor to accommodate his physical needs after his accident, it was far more likely that he'd be lying around and listening to some Bob Dylan, or maybe Emmylou Harris or Todd Snider. Or, if it was between Halloween and January, he might be watching the movie *Bad Santa* for the umpteenth time. The rest of the family has no idea why he developed such

a strong affinity for that movie in particular, but frankly a great deal about my dad defied explanation. Whether it was music or movies, his default time became something different. Finding him at work, then, was an odd sight, even if once familiar.

Writing about a person after they have died is a particular project. It is difficult, but considerably easier than writing about someone who is present. It gives you freedom to say what you want, since they can't really object. But that freedom begets honesty, and honesty makes writing all that much harder. This book was initially a project between the two of us—a caregiver with a background in disability theology and an actually disabled man. One at the beginning of a career, the other at the end. Only some of it was ever completed together, though. The more I wrote, particularly after his death, the bigger the challenge became: What if I wrote something he would have disagreed with? What if I wrote something too personal that he wouldn't have wanted shared? Who gets to decide those things, and what is right?

Everything is a question of ethics. Or at least, I think it is. But then, that's what I study: ethics, disabilities, and theology.

My dad's field, land reclamation, is the process of "resetting" the land (and soil and vegetation and animal life) after it's been used by humans. Primarily, he worked for coal companies, a common enough employer in southern Indiana in the 1980s and '90s, acting as the middleman between companies that wanted to spend as little money as possible and a series of often-contradictory government regulations that rarely considered feasibility or cost in their demands. He was of the opinion that lofty bureaucratic idealism was never going to lead to a healthy treatment of the land, just as unrestricted use without demand for restoration would lead to ruined environments. As such, he had a lot to say about the problems of a government that regulated issues beyond its understanding. It could be assumed, given that his work naturally served to hold coal companies' feet to the fire by enforcing said regulations, that he also said a great deal about corporate interests through his actions.

In fact, at one point in his life, he testified in a federal case

against his own employer, causing them to spend millions on cleanup projects. However, in doing so, he exposed a series of regulations that made essentially no practical sense when it came to caring for the environment. From what I've heard, it was a point of pride for him, knowing that he refused to compromise his principles in order to assuage either side of the suit.

I like to think that I carry some of that principled pragmatism in me.

Much to the chagrin of my father, I vacillate between buzzing my hair into something appropriate for office work and growing it long like a Gen X slacker, temporally displaced but still clinging to my flannel, unkempt beard, and strange love of early 1990s alt-rock. It is likely that I'll be in my running shorts (the *short* running shorts, the kind that require a brief liner in order to not be obscene) and on my way out for a short seven-miler. I tend to let my hobbies dictate what I wear to the office, which means that I have absolutely written sermons in spandex and peer-edited journal articles dressed like Shannon Hoon. But hey, I have great legs, so I don't see the problem with the running gear, and Blind Melon was awesome, so I don't see a problem with the disaffected postrock look, either.

These are, of course, the things that I would say about myself.

If you had asked my dad about who he is, he'd likely have led with something about being a husband, a father, or a newly minted grandfather. He may have mentioned his love of the outdoors, especially the Great Smoky Mountains. He may have mentioned that he was born and raised in Evansville, Indiana, and that apart from his years attaining two degrees at Purdue University, he continued to live in his hometown for his entire life.

He likely would have skipped some of the other aspects, like being someone who impressively ran his own business during a volatile era for coal companies and being athletically competitive with himself to the point of injury many times throughout his life.

You would, assuming you had a conversation of any real length, determine for yourself that he was a kind and good-

natured fellow, someone who would be polite to strangers as a baseline but could be quickly persuaded into quick-witted banter. You might pick up a sarcastic streak, although one that lacked the bite of someone who was actually rude. You'd certainly note a level of confidence and intelligence, though he would never be one to show off.

I don't know when in your conversation he would have mentioned the 500-pound elephant in the room. Or rather, the 500-pound wheelchair he used for mobility. Maybe it would have been acknowledged if he had needed to take a pressure break, mentioning that he was going to move his chair in a way rarely seen in public. Or, if he had a muscle spasm and needed to be repositioned in order to access his controls again. Maybe, if you were interacting closely, he'd have accidentally run over your toe when you weren't paying enough attention to his trajectory and your environment. He would apologize, of course, but if it was your own fault he wouldn't have felt too beat-up about it.

I watched him go from an energetic, surprisingly fit man of a certain age to a man who used an electric wheelchair, controlled by sensors placed in a half-halo around his head. Before his accident, he cycled. He played basketball. He hiked. He played tennis. He was the kind of dad who would learn whatever sports his children picked up, just so he could help us practice (and, I think, because he enjoyed being a good athlete and because he loved being a part of his children's lives, which should go without saying, but often can't).

The stories that follow are not a work of loss. This is a work of life. And as anyone tasked with caregiving knows, life includes loss. His life included loss before his accident, and it included loss after his accident. In some ways, his accident itself was a loss, though in other ways it wasn't.

Or perhaps that's what I want to be true. Maybe I want his life to be somehow unchanged across the chasm that was becoming a quadriplegic. I don't want his life to be marked by a disability. I know this seems like a devaluation of the entire concept, which seems odd given my commitment to people with disabilities. For whatever reason, making disability into

something big, all-shaping, and totally changing one's life seems like a simple way to pit the disability against the life of the disabled person. That is something that seems quite easy to do in our society, fixating on something we deem a "problem" and ignoring the actual person behind the label we've thrown on top.

When I come home and my dad is working on this conference call, just like when, as a child, I used to run down the stairs and across the concrete floor and into the closet where we had a spare refrigerator to grab some sugar-laden syrupy soft drink and I'd see him across the open unfinished basement, staring into his maps, I see a man who lives consistently over time. And when I come home to see him lying in his specialty hospital bed, I see a man who has changed far beyond the expected order. How do I understand this man, my father? How does it work to be a minister and a son, or a theologian in the house of the people who taught you to use a toilet, or a disability scholar pushing the chair of a disabled man who is at once so much more and never less? How can I know who he was, and is, and will be, and therefore who I am?

I may never know. But if I shine a light on different aspects of our shared lives together, if I shine light onto our *time*, our *economy*, our *history*, our *spaces*, our *performances*, maybe I'll find something true about John Endress. Something that is true about the work God calls us into. Something true about what it means to accompany.

Accompaniment cannot be distilled to these five themes, but through them we can see something begin to take shape. Namely, that whatever lens we use to explain our life, and the life of those we care for, there is a Spirit moving within it, knitting together these different perspectives into one cohesive life. Each person's story is complex, of course, but more importantly it is sacred. That means that trying to explain someone's life is an act of describing our own theology; there is something at stake in trying to determine a theology of accompaniment, a theology contextualized by caregiving and navigating the overlaps and boundaries of disparate lives which are bound together—the authenticity of the claims we make about God.

FINDING AN ABLED PLACE IN DISABLED SPACES

At disability conferences, the most common question is “What brings you here?” That really means “Which acceptable narrative describes you?” It has become the price of entry into these communities; give us your story, justify your presence here, and we will accept you as “belonging.” There is often a real sense of distrust from the outset, primarily because so much of the world is openly hostile to folks with disabilities. Eugenics is alive and well in our world, but that’s a discussion for later. Most people, and families, with disabilities have endured countless acts of aggression, from needing to prove one’s haplessness in order to receive aid such as Individualized Education Programs (IEPs) or veterans’ benefits to being openly excluded from civil or human rights like marriage, housing, or earning a living wage. In such an ableist world, most people simply can’t be trusted, so in order to participate in disability conferences, they need to be able to prove their own credentials. Us able-bodied people, particularly white men, have yet to prove that we are regularly worthy of that trust, so in order to be accepted we must give something up, we must locate ourselves in the wider narrative in some public fashion, typically around the first coffee break.

The acceptable narratives are limited in scope, but shift depending on context. There’s the very common “parent of a child with disabilities.” When I walk around, most people probably assume I have a child or maybe a sibling with some sort of significant disability. Maybe they assume I have a parent who has some sort of degenerative disability like Alzheimer’s or dementia, but as a man I’m way less likely to be encouraged or mandated to become their caregiver, so I doubt that’s an assumption any make.

As a caregiver, you have a narrative. Sometimes, it is a lot less “standard” than what other people want it to be. It is easier to understand someone if you can put them into a box, but caregiving is too wide, diverse, and complex for that to be truly helpful. You might be caring for a child with significant

intellectual delays, an adult child with addiction struggles, an aging parent, a spouse who has had an accident, or any number of situations; even if the general story can be told, it doesn't mean people will actually grasp what your life looks like. It is OK to be frustrated by people who think they can understand your life based on a single story, trope, or label.

In theological contexts, another common narrative is “religious leader just now realizing disabilities are, like, a *thing*.” Our religious training institutions have long shied away from teaching about disabilities in any meaningful way, and while that's a fairly bold and far-reaching attack, I stand by it because our religious institutions have been very up-front about their own oversights in this field. It is incredibly common to talk with a minister who can't name more than three people with disabilities in their congregation. Bear in mind, the national average is over one in every four people, so any congregation with more than a dozen or so worshipers likely contains more than three disabled people.¹ Ministers, chaplains, and other religious leaders have no more proven themselves faithfully safe than the politicians who make life miserable for disabled folk, especially when one considers the damage of theologies that prioritize faith healings or link ill health to lack of belief or outright sin. I regularly meet ministers who boldly proclaim that “we don't have any disabled people here” as if it was some sort of valid excuse for ignoring support needs, rather than a condemnation of how oblivious they themselves are as people.

All too rare in many “disabled spaces” are, surprisingly, actual people with a disability / disabled people. I name both terms because labels are political, and these seemingly similar titles are used in very different ways. “Person with a disability,” which uses “person first” language, names that the person in question is just that—a person. The disability doesn't define them, it's just one aspect of who they are. In some sense, that's helpful because it reminds us that disabled people are also doctors and professors and janitors and bowling alley enthusiasts and accordion players and fans of *Parks and Rec* and hopeful and fearful and happy and sad and all the other things that make up being a person. Conversely, “disabled person” reminds us that to erase

the disability is to erase the person. You can't be *you* if you stop "having" autism. The child with Down syndrome would be a completely different child without that third copy of their twenty-first chromosome, just as I wouldn't be *me* if I weren't white, straight, or male. "Disabled person" challenges us to not see disability as something inherently negative or something to be purposefully ignored.

I don't fit neatly into these accepted categories of disability conference attendee. My story began in earnest when I was a university student serving as a youth group leader for high school students. As a young guy, eager to invite others into the world of faith I had rediscovered during my own high school days, I was quick to say yes to pretty much anything that would welcome more kids into our community. I was happy to be the awkwardly old guy chatting with loner kids sitting on the fringes of the student section of high school basketball games, even as I was front and center of our university student section on other nights (often noticeable on TV due to my bright gold spray-painted jorts and pink hair). I was happy to meet students for lunch, sitting on the floor against lockers, even as my classmates were taking afternoon naps in the quad on sunny days (or, far more common in northern Indiana, napping on the student union couches on cold, windy days). I wanted these kids to experience the revelations I had, so when a student decided he wanted not only to come along to our weekly gatherings but also to join us for our weeklong summer camps, I was quick to welcome him in.

I did not suspect that the student, whom I will call Barry, would pose much of a challenge to integrate with the group, although he had some support needs of which I was frankly ignorant. Barry has several diagnoses of various disabilities, each one intersecting with the others in ways that only made sense in his own body and in his own experience; another student with the same named disabilities would have been entirely different. When I needed help guiding Barry through our group discussions, or when I wasn't sure how to help Barry engage with other students, my efforts to find appropriate supports fell on similarly ignorant ears. The adults in my life, particularly those

in charge of the overall ministry I worked with, those whom I trusted to help me navigate the world of disability support, knew only platitudes and general advice. Only two, a couple who were willing to welcome Barry into their own lives, to learn about him *from* him, were able to help. For their witness and example, I am continually grateful.

But as for the majority of ministry guides and theological texts? Mostly bullshit. That's why I started to really dig in and study disability theology. That's when it became obvious that God "placed disabilities on my heart," which is a phrase I say when I'm speaking to Baptists. The disappointment in the available literature led me to seminary, and eventually to my PhD focus.

But this long story doesn't really work when meeting people at disability conferences. It doesn't fit any of the accepted narratives. Still, it's what I claim, even if it takes more explanation than just saying, "My dad is disabled."

Your story might not be very straightforward either. Being a caregiver can look radically different, person to person, and that isn't always easily seen or accepted. You might not even call yourself a caregiver right now, even if you provide love, support, and regular care for someone. That's OK, too. You know the facts of your own life better than anyone, label or not. Like the term "disability," "caregiver" is also blurry. There are some specific legal definitions, of course, that impact taxes and particular rights, but I want to suggest that plenty of caregivers operate well outside of those boundaries. What we need, therefore, is a better language for what God is doing in our lives, a theology of caregiving that can support us, guide us, and challenge us.

WHO OWNS A STORY?

The conference was originally supposed to be held in Durham, North Carolina. Sadly, upon viewing the grounds of Duke Divinity School, it was determined that the Summer Institute on Theology and Disability could not be hosted on such an

inaccessible campus. While the school was open to hosting, including making available campus rooms for attendees, it just didn't seem reasonable to ask participants who required mobility support to endure a constant stream of unfriendly architecture and design all week. Rather than being on Duke's campus, with its beautiful English Gothic stone facades and impressive chapel, we were relocated to downtown Raleigh.

I have nothing against Raleigh; it was a nice place to visit and a lovely little city. But a downtown setting for an international conference offers some challenges in terms of accessibility, too. Namely, it was expensive as hell and a lot of the sidewalks were in a sad state, given the amount of use they got each day.

As a student, or more accurately, as a young person who was poor enough to be pitied by the conference director yet dependable enough to have shown up to volunteer at this same conference several times, I was tasked on the first day with stuffing info sheets into folders and handing out name badges. The institute draws a reasonable amount of new faces each year. Still, there are only so many people working in the intersection of theology and disabilities, so a good chunk of us insist on coming along annually. It is a place where people just *get it*, and you don't have to explain the absolute basics to someone who has never once considered "disability" as a meaningful category. That shared language allows conversations to settle in quickly, where there is some implicit trust that the person you are talking with has already learned to more or less straddle the ever-shifting line between acknowledging disabilities and not fixating on them.

As the registration period died down and attendees made their way to hotels or happy hours, Bill, the director, came over to where I was fitting unused folders back into storage boxes to introduce a lone straggler—a middle-aged, though youthful, man called Shane. He was an Australian theologian who flew to North Carolina from across the world just to offer a keynote on his recent book. His tousled blond hair and casual demeanor immediately brought the words "surfer dude" to my mind, although the motorized wheelchair likely meant that surfing wasn't the most accessible activity for him.

Bill thought I might help this jet-lagged theologian navigate the city in advance of that evening's program. When most people went to rooms to change, nap, or grab a quick bite, Shane knew he was probably better off exploring the area and looking for barrier-free paths between the buildings we'd be using that week. Fair enough. I've seen enough massive gaps in sidewalks and poorly signaled construction projects that even I, as a very mobile man, can grasp how challenging it must be to get around in many cities.

We decided to try our luck and headed the four blocks to the church where we had been invited for an optional evening prayer before the conference's opening session. As we began making our way through the strangely doughnut-shaped lobby of the hotel, Shane zipped ahead of me, as if my own feet were some sort of disability that he in his chair had overcome. Noticing quickly that I, unaccustomed to someone using a wheelchair moving so much more quickly than my father, was effectively left in his dust, Shane paused and turned back with a quizzical gleam in his deep-set eyes.

"Sorry," I answered, perhaps overeager to avoid any social faux pas in front of a major professor at the start of an important conference. "I'm not used to chairs being driven that fast!"

He cocked his head slightly and asked the obvious follow-up: "Oh, do you work with quads?" Meaning: Why would you be familiar at all with wheelchairs? How did you earn your place at the disability table?

NEWS REPORT: JOHN

Hiker Evacuated after Smoky Mountain Fall

GATLINBURG, Tenn. (Oct. 10, 2010)—An Indiana man who was injured while hiking on a remote trail in Great Smoky Mountains National Park on Sunday afternoon was rescued by a team from the park.

Park Ranger Brad Griest was responding to a call about a distressed hiker when he was told about the badly injured hiker farther up the Alum Cave Trail. The second hiker, identified as John Endress, 55, had reportedly fallen and suffered possible head or spinal injury.

Hiking to where the man had fallen took Griest about 45 minutes.

The man said that he could not feel his body below his neck. Griest supported him with a cervical collar, gave him oxygen, and then monitored his vital signs until a 13-person litter crew arrived. The man was then strapped to a rigid backboard atop the litter and evacuated down the Alum Cave Trail. The crew had to maneuver the litter on steep ground, cross several creeks, and use rope belays. The injured hiker was accompanied by his son, who assisted in the evacuation.

The litter team reached the trailhead at 10 p.m., where they were met by a Gatlinburg Fire Department ambulance. Endress was taken to Sugarlands Visitor Center and then flown by Lifestar helicopter to the University of Tennessee Medical Center at Knoxville, the Level 1 trauma center closest to the park.

I was the hiker who informed Brad of the man who had fallen, after my first-ever trail run.

After my dad fell and I heard a deep, strange groan like I had never heard before, I knew something was wrong. We had been moving at a good clip, maybe 3.5 mph going downhill, our left sides against a glistening rock wall and our right sides open to the tops of trees growing on the steep mountainside. His foot hit a rock, or a root, or something, and he fell. His hands went out to brace himself, but fell impotent against the wet rock, the slick face offering no friction as he hit the ground at full force. I think there was another root where his neck landed; I really can't be sure.

I made sure, several times, in fact, to command him not to move his head (although he had already rolled onto his back nearly instantly). It was deeply ingrained in me that when someone falls, you don't let them move their head or neck. I'm not actually sure where that was instilled in me to begin with, to be honest. But it was the very first thing I thought of.

We were at a bend with a great view, maybe two miles up from a fairly popular trailhead. We had been hiking all day. We covered about twenty miles before the accident, and that meant at one point we were probably deep into a mountain trail some seven or eight miles from the nearest frequented spot. Even if we had run into someone else back where we had come from, what would they have done? But we weren't in those remote spots anymore. We were in a section of nature that by sheer luck had become a common tourist location. And that meant people.

Not many. Just one family, in fact. Two parents, a child. Young. Maybe eight? I was always bad with ages. Unfortunately, this was a family visiting Tennessee from Japan, and they spoke limited English. The little girl came up to us and offered a Band-Aid. Very sweet.

I was able to communicate reasonably effectively that under no circumstance should his head be moved, and then I left. I left my father, who had fallen and seemed to have done serious damage to himself, possibly a brain injury or who knows what, lying in the woods on the side of a mountain with a Japanese tourist family to keep him safe. And I ran.

I had never really run in the woods before. I didn't do cross-country in high school. I did tennis, and our running was usually sprints, nothing longer than a mile (and that was only when we were in trouble for goofing off). I really started running more in college. I tried to become a runner in high school, but it just didn't stick. My tennis coach gave me a running log-book as a senior gift, though, because she noticed that I seemed to earnestly try to break into the habit. And that book stuck. I kept it for years, through several moves, well after I switched all my running data to the panoptic apps that track my heart rate and cadence and VO_2 max.

As I raced down that mountain, I had two thoughts: “Do not fall, you are not helping him if you get hurt too. Mom would kill you if you died trying to get help for Dad,” and “I’ll have to look this route up later to put it in that book.”

I don’t always like the way my mind works.

For a long time, I would periodically google “when are you a real runner” as if some magic formula would tell me how many miles to run a week, how fast I needed to be, or how much my shoes would need to cost in order to credibly say, “I’m a runner.” It felt like after years of trying to be something I knew I wasn’t, I was really just acting. I’m not a real runner, I am just some weird tennis player who is doing cardio.

The first time I felt like a runner, I was on the final hour of an all-nighter of college. In my first year, on a crisp but reasonable October night, I sat in a twenty-four-hour computer lab drinking Monster Energy and eating Cap’n Crunch, filling in my biology lab notebook with all the missing data that I had collected but never adequately recorded. At 5:30 a.m., I finished. I didn’t want to risk sleeping past the deadline at 8, so I went to my dorm, tried to change silently to not wake my roommate, and went for a run.

At night, after the bars have closed and the silence of rural Indiana finally falls on campus, there is a sense of peace and calm. School is all about doing doing doing, achieving and researching and growing and never standing still. But not at 5:45 in the morning.

By the time I turned the corner from Northwestern to State Street, students were lining up for the bars, eager to parlay their pregameing of OJ and vodka into Purdue’s famed Breakfast Club, in which students dress in Halloween costumes and hit the bars on game days starting at 7 a.m. It’s raucous, but fun. Very college. But before the laughter and shouts of the crowds, as I rounded the back side of the intramural fields and watched the sun come up, I felt like a runner. I felt powerful. Connected to the ground, feeling all the intricacies of the path as it wove side to side and up and down, an undulating river that beckoned me to explore it. There was peace. And promise. And challenge.

For the first time in my life, I was a runner.

The second time I felt that feeling, I was barreling down the trail past Alum Cave and Inspiration Point, wearing hiking boots and frantically checking for a phone signal. Every root, every rock, every blind bend, I felt it all and noticed it, even anticipated the bumps and cracks, because I couldn't afford to trip and fall like my dad had.

Claiming that Brad reached him forty-five minutes later, as per the news report, is a bit of a stretch. First, it took me about ten minutes to convince him that he should abandon his other distress call. Someone on the same trail, apparently, had fallen ill, and two emergency mountain rescue responders were headed to help. But I happened to catch Brad as they were loading up in the parking lot. Had I been slower, they might have gone up past me, down a fork that I missed, out of sight and unknown, never to make it to my dad. But I made it there as they were adjusting their packs, the trunk of their SUV still open.

"How did you know we needed you? Did someone manage to get a signal and call for help?"

"Yeah, we got a call about someone falling ill; they think it's a diabetic issue."

"What are you talking about? There's a man who had a fall on the trail and has possible head and neck injuries!"

"No, we have a call about someone falling ill."

"And I'm telling you, one of you is going to come with me instead."

Brad was wonderful. But at multiple points I did offer to carry his pack for him, as I thought it would speed us along. He generally kept about a 2 mph pace. In his defense, he needed to conserve energy, plus he was carrying an extra fifty pounds of gear. In spite of what I wanted at that moment, which was to charge up the mountain as fast as possible, he was well aware that the approach that offered the best chance at survival was one that was slow, methodical, and conservative. And in my defense, I knew I had left my injured father on the side of a mountain with little to no supervision, so I don't think my desire to rush was too unjustified.

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