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The Iowa Review

Volume 44
Issue 3 *Winter 2014/15*

Article 41

2014

Proprioception

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Recommended Citation

Drew, Jennifer Alise. "Proprioception." *The Iowa Review* 44.3 (2014): 154-167. Web.
Available at: <https://doi.org/10.17077/0021-065X.7544>

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Proprioception

It has happened in little ways since he was born: a twisting and fluttering of the hands, waving of the feet, mouth working into and out of a lopsided, stretched-out *O*. Excitement also animates his lungs, as though his breath has a life of its own. I hear these minute gasps coming from the backseat of the car and look in the mirror to see him bouncing around, his gaze upcast, his face an occasional smile. When he was an infant it was hardly noticeable, but now, as we inch toward his third birthday, it has become something at which people stare. Even if no one stared, even when it is just the two of us, and though it's been happening for some time, watching him do it is painful. When he flaps and kicks and gulps at the dinner table, we try to bring him back to us, hold his hands on the table and tell him to calm his body. Often we give in to books and puzzles and the iPad, which sometimes focuses him and sometimes just makes him crazy, especially if it's Bert and Ernie and off he goes, dancing away. Would you try to feed a person who was doing aerobics? Sometimes we have no choice, and sometimes, like last week, when he unintentionally sucked a mouthful of unchewed pasta down his throat, it ends a meal.

Though I know I'm not supposed to, I've long thought of these episodes as "spaz attacks." The term stuck with me after I read it last year in a young adult disability novel in which characters with cerebral palsy refer to themselves as *spazzos*, appropriating perhaps permanently a word our culture has done its best to redefine.

The *Oxford English Dictionary* dates the first use of *spaz* to 1957, when it was used in Indiana by the *Hammond Times* newspaper: "Jewelers, furriers, and furniture dealers go through similar merchandising tortures whenever Wall Street spazzes."

spaz, *v.*

slang (orig. *U.S.*). Often considered *offensive*.

intr. To lose physical or emotional control, usually as the result of an intense emotional experience; to act in a bizarre or uncharacteristic way. Freq. with *out*. Also in extended use.

Merriam-Webster's *Collegiate Dictionary, Eleventh Edition*, puts it at 1965:

spaz., *n.*

slang: one who is inept: KLUTZ

Spaz, of course, is short for *spastic*, which has been around for centuries. Webster's traces the etymology—Latin *spasticus*, from Greek *spastikos* (“drawing in”)—to the year 1753, and Oxford agrees:

spastic, *adj.* and *n.*

A. *adj.* 1. a. *Pathol.* Of the nature of a spasm or sudden contraction; characterized or affected by spasmodic symptoms or movements.

b. *spec.* in names of special ailments. *spastic paralysis*, a condition in which some muscles undergo tonic spasm (sometimes resulting in abnormal posture) and resist passive displacement, so that voluntary movement of the part affected is difficult and poorly co-ordinated.

2. Performing involuntary contractile movements.

3. a. Affected with spastic paralysis.

b. In weakened use: uncoordinated, incompetent; foolish, stupid. *slang.*

B. *n.* a. A person with spastic paralysis.

b. In weakened use, esp. contemptuously: one who is uncoordinated or incompetent; a fool. Cf. SPAZ *n.* *slang.*

A spaz attack, Google will tell you, “is when someone is physically out of control and just freaking out.” Yahoo message boards, ever helpful, add this: “With some people it’s having too much sugar and caffeine, and to others it may be a seizure.” Urban Dictionary says it’s “a sudden freaking over an event or situation that 99.9% of normal people would consider to be uneventful.” Or: “a gesture where you fling yourself wildly, shaking from head to foot. Can come on randomly or be planned. A spaz attack is the greatest of all comebacks. Very fun in a chemistry lesson.”

Other things you learn from Google: Tiger Woods reportedly used the word in 2006 (“as soon as I got on the green I was a spaz”), causing an uproar in Great Britain but little reaction in the U.S. There’s an interesting post about this by Benjamin Zimmer on Language Log, an online compendium hosted by the University of Pennsylvania. According to

Zimmer, the BBC conducted a survey of offensive terms and found that in Britain, *spastic* is the second-most offensive term for disabled people, after *retard*, and as an insult overall, it is “slightly less offensive than *twat* and *piss off*, and slightly more offensive than *slag* and *shit*.” Zimmer links this extraordinary sensitivity to Joey Deacon, a man with cerebral palsy, who, in 1981, the last year of his life, appeared on the children’s television show *Blue Peter* and became much beloved. Other reports suggest that televising a man who spoke unintelligibly and spazzed out in his wheelchair only gave new barbs to children the world over.

If, for the British, *spaz* and *spastic* remain connected to the neuromuscular disability they describe, in America, Zimmer writes, *spaz* has “long lost any resonance it might have had with the epithet *spastic*.” He cites several sources credited with the divergence, including the *Oxford English Dictionary*, which cites an excerpt from Pauline Kael’s 1965 book *I Lost It at the Movies*: “The term that American teen-agers now use as the opposite of ‘tough’ is ‘spaz.’ A spaz is a person who is courteous to teachers, plans for a career...and believes in official values. A spaz is something like what adults still call a square.” But according to a 1958 Caltech graduate who recorded the term in 1956, it also meant the opposite of square: “A person lacking in the common social skills & virtues. See TWITCH.” By 1978, *spaz* had been reincarnated on *Saturday Night Live* as Chaz the Spaz (played by Steve Martin) in a sketch called “The Nerds,” and the following year, there was *Meatballs*, featuring a character named Spaz.

But is *spaz* really so divorced from its origins in America? What this says to me is that we have taken the discomfiting idea of brain damage and a body’s uncontrollable limbs and drawn it out to its logical conclusion—more palatable thus anesthetized—to mean an incompetent or uncoordinated or uncool person. After all, it is only in the last four decades that people with disabilities gained equal rights under the law.

A few months ago, my husband and friends and I were at a stand-up show on Sunset Boulevard, and one of the headliners, an older gent, did a very funny routine about his membership with Alcoholics Anonymous of Beverly Hills. Then he segued with a joke: “Let me ask you,” he said, “why do kids with Down syndrome always have the same haircut?” The audience began to snicker. “Do they all go to the same stylist who tells them, ‘Yes, a bowl cut really is best?’” Big laughs. I don’t like to be *lame* (another easily commutable way of saying *square*), but I found myself choking up. I was still smoking cigarettes then, so I went outside and sucked one down. All I could think about was my son’s classmate, a beautiful, jovial two-year-old who has Down syndrome, and the fact

that he too has a bowl cut, and how his dad would have reacted had he been in the room.

So perhaps we can't take a joke when it applies to us, or maybe it's really only funny—rather, fair—when it originates with the person to whom it applies. But I think I know what Lenny Bruce would say about that. I'm referring to his famous bit on the N-word, and how he said that if President Kennedy would only go on television and use it over and over, it would have no more power than *thank-you* and *good night*. ("Well, I was just trying to make a point, and that is that it's the suppression of the word that gives it the power, the violence, the viciousness.") I've always loved that bit, and in its light, perhaps *spaz* has been reclaimed—perhaps even become, in a culty sort of way, beloved—in America. Unlike the N-word, *retard* has not attained forbidden status. Some people still find it acceptable to ridicule the disabled in stand-up comedy, I suppose because there are no angry Down syndrome audience members to deter it. To my mind, there isn't much that is funny about people with a genetic disorder whose haircuts look alike because their faces look alike because of their genetic disorder; but then I'm a special-needs mother, and I can begin to see how special-needs parents look alike too, so recognized by our lack of humor.

Among the many print references to *spastic* that Oxford lists, here are a few I find poignant:

- 1896 *Pediatrics* II. 194 The staggering, uncertain gait of the spastic, often with knees striking or actually crossed, with knees flexed and heels raised, is well known.
- 1937 P. M. GIRARD *Home Treatm. Spastic Paralysis* i. 10 As a spastic child later learns to walk, a typical "scissors gait" is frequently observed.
- 1937 E. R. CARLSON in P. M. Girard *Home Treatment Spastic Paralysis* p. xix, Through repeated exercises...the spastic gradually acquires muscular coordination.
- 1977 *Whitaker's Almanack* 26 (*advt.*) Jonathan has been severely spastic since birth, and is unable to walk unsupported. He also has difficulty with speaking and writing.

All of them can describe my son.

And here I arrive at a central difficulty, which is defining his place as a person with a toehold in the world of special needs. I feel compelled to do this for my son's sake as much as for you, the reader. My son, to

whom my husband and I affectionately refer as “the boy,” has cerebral palsy, a term I am rarely prepared to explain to someone who doesn’t know what it means. You can say it’s a congenital disorder, but this is somewhat inaccurate, because in the boy’s case, the injury occurred long before birth, when a blood clot formed in the placenta at twenty-six weeks and for a time caused hypoxia to his brain. Congenital, as a word, sounds so much like syphilis. You can say it’s a neurological impairment, which might translate as “retarded.” You can say that *cerebral* refers to the cerebellum, and *palsy* refers to movement, so you see, it is a problem with movement originating in the brain. Specifically, cerebral palsy is caused by damage to the parts of the brain that control movement, or motor function. As a disorder, it is nonprogressive, meaning the damage that occurred was a one-time deal; it will never go away, though some of the concomitant impairments can be overcome. But it’s hard to create an accurate picture short of bringing him along, and even then, people see what they see.

I often describe the boy in terms of who he is: smart, witty, bright, resilient, charming. He wears hip glasses, and he happens to be a beautiful child, which is a step ahead in itself. He is nearly three years old, and if looked at by that measure, he is far from the typical child his age: he is not yet walking or talking, though he crawls and uses American Sign Language. He may walk with crutches, or he may end up in a wheelchair. I think talking will be hard for him, but he will learn to do it, though he may be for some or many years hard to understand. Because of his diagnosis, he is at risk for developing contractures, scoliosis, cardiovascular and pulmonary complications, and early-onset osteoarthritis. But even so, he is far from the worst CP you’ll ever see. I used to describe him as “special-needs lite,” because we are nowhere near the difficult end of the spectrum. He can, for instance, sit and hold up his head and use his hands and he is healthy and affectionate and focused and not at all violent. It is imperative to say how lucky we are.

Accidents of Nature is a young adult novel published in 2006 by Harriet McBryde Johnson, and its cover is raked with garish words: *spazzo, cripp, freak, stigma, outcast, walkie-talkie*. Next to *cripp* is *power*; below *ghastly* is *everyone’s a winner*. The book showed up in a search for “cerebral palsy” in my library’s online catalog, which returned twenty-five results, most of them books I am never in the mood to read—*Handling the Young Child with Cerebral Palsy at Home*, fourth edition, or *Yoga for the Special Child*, or *The Brain That Changes Itself: Stories of Personal Triumph from the Frontiers of Brain Science*—the last of which I actually bought, but have not opened.

I clicked on *Accidents of Nature* because I read this excerpt describing it, and after that, I went and got it off the shelf:

I'm in the middle of a full-blown spaz attack, and I don't care. I don't care at all. At home I always try to act normal, and spaz attacks definitely aren't normal. Here, people understand.

The book takes place over ten days at a summer camp for disabled teens in North Carolina. It is 1970, twenty years before the Americans with Disabilities Act and five years before the Education for All Handicapped Children Act—a time when “crippled” people were mostly confined to separate homes and schools. Johnson's account is fictional; however, the jacket copy states that the author went to a “cross-disability summer camp until age seventeen,” and for this reason and more, I see much of her in the fast-talking girl who becomes the narrator's catalyst and friend.

The excerpted passage follows a scene in which the campers are playing horseshoes. Our narrator, Jean, who has cerebral palsy, watches as a “walkie-talkie, MR girl” named Margie aces the game (“walkie-talkie” because that was the nickname campers gave to people who could do just that, and “MR” is for “mentally retarded,” which until recently was still a legal diagnosis under the *Diagnostic and Statistical Manual of Mental Disorders*):

Margie takes her position. On the floor beside her feet there are four horseshoes.... *Clang*. A ringer! Cheers rise up. I go spastic: all four limbs jerk wild and free, and from my mouth comes a wild, free squeal.

...Then comes the third. *Clang!* We're in a frenzy.... The fourth lands. Another perfect toss. There are no horseshoes left.

I'm in the middle of a full-blown spaz attack, and I don't care. I don't care at all. At home I always try to act normal, and spaz attacks definitely aren't normal. Here, people understand. They know a spaz attack signals that I'm excited. They're excited too, so they squeal with me; some even spaz on purpose, if you can call that spazzing, and fool around making CP joy-sounds. Sue cuts them a look to make them stop copying me, but I like it.

I stay semispastic through lunch. Three times I choke on my food. I don't even try to calm down until rest period.

I cannot tell you how often I have thought back to this description. It more or less encapsulates my son's behavior, which no doctor or therapist has been able to explain so succinctly, and gets at the essence of why we read: there are very few people who can tell certain stories, and until the boy is old enough to describe this feeling to me himself, if he ever wants to do so, I suspect this is the closest I will get to understanding his experience.

Back when the movements were just becoming worrisome, ignorance kept us from connecting them in any real way to the boy's brain, or even to his diagnosis. Because they seemed to happen mostly when he was sitting—in the car, in the high chair, in shopping carts—we thought perhaps he was not in a well-supported position and his proprioception was off: once he slid out of alignment, his body could not locate itself in space. This was a subject of much debate among his therapists, and we bought and tried various positioning cushions. But because the movements could also signal some new degenerative development in the brain, his therapists urged us to seek an expert's opinion, so we made an appointment with the chief neurologist at a cerebral palsy research center at a prominent area hospital.

The boy was diagnosed with cerebral palsy when he was eighteen months old. The most evident type of CP he has is spastic diplegia, which means that the spasticity or muscle stiffness is primarily in his legs. But most people with CP are affected by a mixture of types, and, as the chief neurologist, or, as I call her, the expert, explained, the boy also has extrapyramidal or dyskinetic CP, which would explain the writhing or dancelike movements of his extremities and the difficulty he has with speech and balance. The expert suggested that we see another prominent neurologist who runs a pediatric movement disorders clinic, and said we might also try behavioral therapy to help him learn how to control the episodes. She had no word for what the episodes are called.

A week or two later, we met with our regular neurologist, mostly because I wanted to see if he could get our insurance to pay for the expert's suggestions. Our neuro had just seen the expert at a conference on epilepsy and supposedly conferred about our case (a prospect that makes me unendingly curious), but he said he disagreed with her, and persisted in calling the episodes "stereotypies." But that's not really

the point. The point was his relaxed ease, which he's always had, about the boy's future—my boy, who was sitting in a little-kid chair, with his serious face, happily ripping examination-table paper into careful little shreds and sprinkling them on the floor. (He must have known what I was thinking.) The neuro said I needn't worry about the so-called "stereotypies," which are not related to CP at all, because "when he gets older, around the time he starts first grade, he'll realize that this behavior isn't normal and other kids are staring, and he'll figure out a way to control it."

There are many things that are disturbing about this advice, and *Accidents of Nature* captures them all. The narrator's story is more or less that of a "Crip" hiding in a "Norm's" clothing. Jean, who is seventeen and uses a wheelchair, is accustomed to being the only disabled person in her small town and surely learned to control her spaz attacks in a manner similar to that prescribed by our neurologist. She is provincial and Southern-proper: nicely tan, with blonde hair and blue eyes that she is proud of. Her new friend and soon-to-be catalyst, Sara, also uses a wheelchair, but her diagnosis goes unnamed. Sara, the daughter of two professors whom she says descend from the "landed class," doesn't bother to shave her legs, and that is only the edge of things. Her torso "collapses like an accordion" and leaves her head hovering somewhere above her knees. She wears long, baggy skirts and big glasses and braids her hair. Nothing about Sara fits in; in fact she spends most of the book flouting the system, upsetting the camp authorities, and questioning every assumption she thinks they have about people with disabilities. Sara goes too far every time she opens her mouth, whereas Jean never goes far enough.

One of their early conversations goes like this, after Jean, in her halting CP pitch, asks Sara if she too goes to "nor-mal school":

"Not yet. I've been in Crip school, but at the end of this past school year, my teacher told my mother she can't teach me anymore, so I'm out. The public schools don't take Crips, so I'm going to a private school. An all-white private school, no less....

"This private school is taking me because my mother has a friend on the faculty.... But Crip school is great because we're all crippled—it's truly bizarre—and there's only one Republican in the class!"

My parents voted for Nixon in the last election and for Goldwater before that. But that's none of her business.

"Maybe you can give me some lessons on how to be a Crip in Norm school. I'll have to start figuring that out, I guess."

Jean replies, "I don't think of my-self as crip-pled. I'm like eve-ry-one else."

To which Sara says, "Aw, come on. You're a Crip. Otherwise you wouldn't be in Crip Camp. Say it loud, 'I'm crippled and proud!'"

The statement starts Jean off on her second spaz attack of the day, and she can't reply.

The truth is sometimes hard to look at without its various guises, its plastic covers; that's why most of us instinctively either stare at or look away from an obviously disabled person. It is difficult to merely *see*, and perhaps Johnson lets her readers in too close for their own comfort. It goes without saying, I suppose, that this kind of shorthand—*crip*, *norm*, *spazzo*, *walkie-talkie*, language that disregards the proper names we use to both protect the subject from insult and keep everyone else from some measure of the truth—can be offensive to some people. I have noticed in a few small-minded reviews that other people have found *Accidents of Nature* to be unreadable. You can't see the words *crip*, *spazzo*, and *walkie-talkie* without knowing what they are. Look at the book's very title. Hypoxia to the brain, missing or extra or truncated bits of DNA—these things are not supposed to happen in nature, but they do.

Politically or medically correct terms, on the other hand, tend to distance us from what they actually describe. We say *brain injured* instead of *brain damaged*; we say *involved* to connote the extent of a disability, to stand in for details like *he can't keep his tongue in his mouth*; we reject *disability* for *differently abled*. We say *non-ambulatory* and *nonverbal* instead of *he's not yet walking or talking*, and in the case of my son, to use these terms is to skirt reality. *Ambulate* means to move from place to place, so saying that the boy is non-ambulatory doesn't tell you that while he can't yet walk, he can crawl like the devil and use a walker with a lot of assistance. Nonverbal doesn't say anything about sign language or proficiency with a "talker" or communication device, and it could also mean "minimal use of language," so why would I employ this term to describe my son, who can say "go" and "yeah" and "mama" and "da"

with his voice and who has, with ASL, the comparative vocabulary of a four-year-old?

Plumbing the depths of *spaz attack*, I look for medical terms to put in its place. It has been months since we saw the expert, so I am surprised to learn that the boy's new possible diagnosis has been the clue all along. Dyskinetic cerebral palsy, Wikipedia tells me, is divided into two subtypes: choreoathetoid and dystonic. Choreoathetotic CP is "characterized by involuntary movements most predominantly found in the face and extremities." So should the movements be called dyskinesias? Perhaps. But dyskinesia, as a neurological disorder, is associated more with Parkinson's than CP. *Choreo* leads to *chorea*, which is simply classified as one of a group of dyskinesias, and is lent more commonly to Huntington's disease. One quickly gets lost in the labyrinth of terminology. What I like about Wikipedia's definition is the description of the movements, which "appear to flow from one muscle to the next" and which "occur on their own, without conscious effort." This rings true. *Chorea* makes me think of *choreograph*, as it should, since it comes from the Greek *khoreia*, "dancing in unison," or *khoros*, "chorus." I like this, on the one hand, because it actually means what it says: the hands and legs are dancing more or less in chorus, as are the breath and mouth, which allows for a measure of beauty where most people see none. On the other hand, as a word, *chorea* is pure puff; it expresses none of the discomfort, none of the aching, none of the facts.

So perhaps I choose *spaz attack* because naming something as it is releases some of its hold over you, the medical patina, and also makes it more pointed, more bright—it becomes something you can hold in your hand, something that is, more or less, yours.

Part of why I am drawn to *Accidents of Nature* is because it's about our worst-case scenario: here are two girls in wheelchairs, girls who have full lives and are pretty far from miserable. This comes home in the book's epilogue, which is a letter written by Sara J. Buchanan to Willie, a boy who shows up throughout the book as Sara's erstwhile sidekick, a "hideous guy" who is unexplainedly disfigured, whom Jean never manages to look in the face.

I know I am not, as a reader, supposed to view fiction through the lens of an author's life, but I don't think Johnson intended us to ignore the numerous parallels here between Sara's and her own life: after all, she called the book a historical novel, and the facts of her biography are public knowledge. Johnson, who passed away in 2008, was a lawyer and disability rights advocate who suffered from a degenerative neu-

romuscular disease, the details of which, her sister told the *New York Times*, Johnson preferred not to know. Sometime in the 1990s, Johnson appeared on an NBC talk show protesting telethons, particularly Jerry Lewis's. In the epilogue, Sara too has become a lawyer, roaming "the Norm world almost as if [she] belong[s] in it," appearing on television to protest telethons and Jerry Lewis—this skinny woman whose ribcage is planted on her lap, gladly navigating cobblestone streets from her wheelchair, as Johnson did.

In 2003, Johnson published an article in the *New York Times Magazine* after taking on philosopher Peter Singer for his views on the morality of euthanizing "severely disabled infants." The chronicle of her interactions with Singer is lengthy and touching. At one point, she describes asking Singer to arrange her trip to Princeton, including requesting that her meal for the dinner to which she's been invited be pureed. A few weeks after I read that piece, I stumbled across an interview with Johnson on *Ouch!*, a British disability blog, and learned that her favorite food was oysters.

Johnson's central argument in her discussion with Singer is that people like herself are not "worse off" and that, if her lack of abilities seem to the "Norm" world a pity or a shame or any of the various things we say about people who cannot do all the things we do, she is still capable and deserving of life. Nowhere is this point made so vividly in *Accidents of Nature* as at the end of Sara's letter to Willie:

You have your nerve, asking about my love life....
Well, FYI, my love life is rich and varied. I love old city streets—there's nothing like bumping over slate sidewalks and brick streets in a rickety vintage E&J. I love soul food and my TV remote control. Stuff like that....
I love "pure and chaste from afar," just like the Sand Hills Community Youth Chorale always said we should.
And I love you, dear hideous comrade of ancient struggles. As I hope you've always known.

It is hard to put a finger on why exactly the epilogue has such cumulative power, particularly as, the first time I read it, I missed it, and I suppose most readers will if they don't look further into Johnson's life. Part of what makes the book bearable is the fact that it is a novel, and therefore allows the reader to separate from it slightly—allows, anyway, for the possibility of suspended disbelief. But Johnson pulls a late trick in the last pages, in which she seems to say, no, now that you've accepted

my story, I'll tell you that it was all true, and here's how I've ended up: yes, alone, and yes, crippled, but also with a career and friends and as much longing as any of us might accumulate in a life—that it's possible to see the beauty first, before you see the chasteness or the chair. My affection for Johnson stems from this viewpoint. Her writing allows me to step inside this world that the boy, my husband, and I now inhabit, a world to which only the boy will ever actually belong. I want, as much as I am able, and as much as I know it will one day annoy him, to be able to relate.

Every night around twelve, the boy and I sit in the rocking chair. Sometimes my husband and I argue about this, because he says I have needlessly woken our boy by changing a diaper that might not need to be changed, but I have come to like the twenty extra minutes I get to hold him in my lap. He used to sleep through it until we started making him wear leg immobilizers to bed. They are soft and cast-like and run from the tops of his thighs to his ankles, and they close with Velcro, with two additional Velcro straps to keep them tight, so they make an awful noise when you take them off, which you have to do in order to remove a diaper. It took months, but he got used to them, as children can more or less get used to anything, and now he sometimes asks to put them on.

After the immobilizers, we introduced hard plastic orthotics, which we call his boots, that reach up his calf and keep his feet flexed at ninety degrees. He has worn these since we had Botox injected into his legs. Between the immobilizers and the boots, he gets twelve hours of stretching that we would never be able to incorporate into his day, and it should make a big difference in the effectiveness of the Botox—the idea being that while the medial hamstrings and soleus (lower calf) muscles are deadened, we can stretch them past what they would normally tolerate, so that when the Botox wears off, his muscles are a bit more lengthened.

While we sit together, I often think of Emily Rapp, whose book, *Still Point of the Turning World*, sits unopened on my bedside table. Emily Rapp who, along with her late son, Ronan, has become part of my daily consciousness. Ronan was close to the boy's age, not yet three, when he died from Tay-Sachs, a hereditary disorder that is always fatal; the later photos of him on Emily's blog still bring me to my knees. As parents, we want our children not to suffer, and this means one thing to the parent of a child with special needs and quite another to the parent of a dying child. One detail that was acutely painful to me

about Emily's experience parenting Ronan was that he too underwent physical therapy. On her blog, *Our Little Seal*, she wrote about Ronan's therapist's weekly notes, which listed what they had done each day; in one note, the therapist mentions helping Ronan locate his body in space. Proprioception. The boy and I expend so much energy trying to best his diagnosis, but Ronan's was unrelenting, and any progress against it could only be palliative, and too short. There is a clawing desperation to Emily's early writing that I recognize in other special-needs mothers I know, mothers with whom I imagine Emily would have gladly traded places. I think of Robert Hass: "Longing, we say, because desire is full / of endless distances."

It took me a long time to read Emily's blog when it first came to light, so I procrastinated by checking her memoir out of the library, a disability memoir, as it turns out, about growing up with a prosthetic leg; she was born with a genetic defect that they treated then with gradual amputation and prostheses. The scenes I remember most vividly from the book are of Emily as a child, lying awake at night in a full-body cast each time she had a new amputation to remove a little bit more of her left leg—nights containing an untold number of private miseries.

Along with the nighttime bracing, the boy attends hours of physical, occupational, speech, and feeding therapy each week, bolstered by more of this work at home. He has, since the age of nine months, not known any other kind of life. There is a scene that touches on this in *Accidents of Nature*, in which the two girls discuss their early years of physical therapy. Sara was able to crawl as a child but never had the strength to stand; she seems to have always known that she would live in a wheelchair. She tells Jean about her physical therapist, a German woman her mother called the Bitch of Buchenwald, and that she was relieved when the decision was made to let life have its way with her legs.

Jean, who at seven was able to walk using a gait trainer and leg braces, is shaken by Sara's story, and thinks, "Can a wheelchair be a choice, and not a failure?" In a later scene, when the friends are making fun of the song "You'll Never Walk Alone," she wonders if "walking is something you can mock. Not walking as an ordinary means of getting around, but Walking as a big dramatic idea."

When the boy's physical therapist sold the idea of the night bracing to me, I knew that in essence she was saying it was either this or a wheelchair. There have been many studies about the ineffectiveness of Botox without concurrent and prolonged stretching; once we decided to do the Botox, there wasn't really any choice about the rest of it. Sometimes I

give the boy a night off, and he goes back to sleeping the way he likes, in that tummy crouch he never embraced as an infant, with his butt in the air. I know he would sleep a lot better without the bracing, and sleep is already a challenge, but I also know that this is one of the things we have to endure—it is specifically one of the things he will have to endure, likely until he is finished growing. I don't want to fail him, but I also don't want him to remember a childhood of being pushed too hard. I have to decide for him now, between wheelchair and walking. Later, I tell myself, he can make the choice.

But somewhere in here, you wonder: How much is too much? Are thirty hours a week of early-intervention school and therapies and drive time to and from too much? Is physical therapy four afternoons a week too much? Is the nighttime torture too much? All this, for a child who has many years of brain plasticity ahead of him?

Tonight, as I put the immobilizers back on, he begins to wake up, and then he starts to cry, and I wince, knowing my husband will hear from the next room. I will sit with you in the rocking chair until you fall asleep, I say. The same chair in which my parents rocked my siblings and me. He's tall now, and with immovable parts, he can no longer rest his head on my shoulder the way he wants to. He's too big and stiff, so I have to sit him sideways, his new giant body, his legs like boards across my lap.

He leans against me and I tell him, you are three feet tall and you are almost three years old, and when you were born, did you know, you weighed three pounds and fifteen ounces? There is magic in triplicates, and there is magic in him. Yeah, he says, in his round little voice. He says yeah to everything. He drinks some water, and I listen to it go down his throat toward his belly; when he's finished, he gives me the cup and lifts his arms and waits. I pick him up and stand, leaving the comfort of the chair so I can hug him, and he tucks his arms beneath mine. The hard plastic toes of his boots knock against my legs. We stay like that for a while.