Getting Back in the Game

M y story about having physical therapy starts with *not* having it. I watch people up and living life how it is meant to be lived, and I have the memory of being “normal,” running across a soccer field as free and far as my legs could carry me. Little did I know as I tore through the defensive line to make a goal that I would have to relearn how to walk.

My future, I happen to know, reaches beyond a bed, and the people and medical innovations that helped me realize my hope in the future combine in such complex ways that I can’t possibly explain here. However, the story I am about to tell—all in the present tense, as I remember seeing my world in those paramount moments of motivation—captures those critical moments in which hope formed. Hope and humor—mine, my mother’s, and that of all the physical therapists who helped me—are the indispensable ingredients of my success.

It’s 8:30 on Monday morning, early October 2004, 2 weeks after I wake up from a 2½-month coma. I’m propped up in the electric bed and totally helpless, unable to move my body, no muscle control whatsoever. The door to the hospital room swings open, and my physical therapist, accompanied by a nurse, rolls in this huge, gruesome-looking throne of horrors. I signal my mother for my alphabet board and pound out, “Not WHEELchair!” The weeklong musical question every day chimes enticingly: “Would you like to get in a chair?” Once committed, I can see myself at a desk doing schoolwork. What a great disappointment! It takes 4 people to lift me out of the bed and prop me in that huge contraption. I feel my heavy head flop to the left. Mom runs like the wind to fetch a couple of washcloths out of the linen closet and stuff them in the crook of my neck to help the headrest cradle my limp head. I can bear only half an hour of sitting upright before a splitting headache consumes me. But in those 30 minutes, I take a crucial first step toward freedom. I also realize that freedom rolls out of reach, and rehabilitation offers a way to retrieve it.

My memory flashes back to a green, windy, competitive soccer field over which I’d been running since kindergarten. The flash flickers and then fades. I must focus all of my energy on the present challenge. I have to learn how to walk. I realize that, before I walk, I must overcome various obstacles in my path. I must learn to sit up, make bridges, get on my hands and knees, crawl, kneel walk, and weight shift. The following morning my nurse finally finishes monitoring my vital signs, and I try to
get Mom’s attention. “Want wheelchair!!” I spell out. Relief overcomes her; she proudly
witnesses my ability to flip my initial perspective toward the chair. After much ado, we
set out to explore the world with new eyes.

From the ventilator ward, with the blessing of insurance, I move upward onto the
rehab floor. The next day, my physical therapist lays me down and fastens me into the
LiteGait* harness. We use this contrivance for standing and attempting to kick a soccer
ball into a goal. I work hard on the treadmill, trying to make my brain relearn how
to move my legs. My therapist gets a few people around to help. Everything from my
hips down needs help to move.

Later that day in the hallway, I see an outpatient girl walking independently with a
cane; of course, my heart swells as my therapist says with confidence, “You’re on your
way there. It might take some time, but I wouldn’t fret about it.”

I catch my mother’s fiery hair before she fuels hope by saying, “Come on, let’s work,
she’s got a lot of life to live.” Mom charges ahead with perseverance. Her belief in the
effects of physical therapy determines a good part of my success. She makes sure that
I maximize time on the LiteGait because she believes I have no time to lose—just like
a child’s window of opportunity to learn how to read.

“More, more, more,” I mouth in response. I am eager to walk, but I have to be able to
crawl and stand first, which is part of my physical therapy program. Using the LiteGait
jumps me ahead and works by living the goal of walking. Feeling the movements of
walking re-teaches different parts of my brain to walk. Walking on LiteGait is like
peeking at presents before the big day.

“Let’s get this show on the road,” the physical therapist assistant says as she looks at
my therapist, who smiles and looks down at me, again encouraging and confident.
My world fills with support from all sides. I thrive on applause, praise, support, and
encouragement. In time, I realize what I still have, and my personality still responds
to positive input. At first glance, life appears unreal, but that doesn’t necessarily hinder
us from living it as fully as we can.

I leave the hospital to live at home again, and a new, exciting transformation with its
ups, downs, flips, and all begins. What was once a quiet home at the end of a cul-de-
sac turns into Grand Central Station with therapists, specialists, teachers, and nurses
coming and going throughout the day and night. Despite this, I try hard to maintain
learning to walk as my main focus.

Both my occupational therapist and my physical therapist work with me on core
strengthening, the root of doing any movement from writing to dancing. My physical
therapist from Rehab Without Walls starts with practicing standing at the kitchen sink
with all hands—mine clutching the sink, and my therapist’s steadying me. The first time
at the sink, I need every kind of supportive technique; after a number of times, I am
able to steady myself with only the additional support of my therapist on my hips. After
more than a year, my balance improves to the point where I am independently stand-
ing, supporting myself with both my hands holding the sink. Today, I’m putting dishes
away while gripping the counter with one hand. I can dare to imagine myself in my
own kitchen, raising my own family someday. My mother and I notice another dramatic
improvement. I’m standing at the sink helping her with dishes and she wants me to move
over, so she nudges me! Not even with her hand, but her hip! Imagine that.

In September 2006, we are lucky enough to get the great opportunity to go to the
University of Washington every day for 4 weeks to work on the LiteGait. My beloved

* Mobility Research, PO Box 3141, Tempe, AZ 85280.
Patient’s P.O.V.

physical therapist from Rehab Without Walls, Vicki Stevens, meets with Dr Anne Shumway-Cook to get ideas about some proven beneficial exercises to do with me. Anne asks Vicki to have me brought in. They begin to think that I am a good subject for an experiment that would have me in a daily workout on the LiteGait for a full month at the hospital and for 5 months at home. But even with Anne and Vicki and Mom and Dad to assist, my walking on the LiteGait still needs one more person.

In walks [physical therapist] Dr Kristin Cernak, our missing link to success. I can imagine the conversation between her and Anne about me:

“Excuse me, Dr Shumway, is there anything you need assistance with… so that I might learn from you?” Kristin might propose.

Anne’s response as she lights up in amazement at the perfect timing: “You’ve come to the right place at the right time.”

“I will do anything you want,” and Kristin agrees enthusiastically.

Soon she finds herself squatting on the floor lifting my leg. Like it is meant to be, Kristin becomes part of the team, and we’re on.

I make a party out of meeting all the new, eager faces. I understand that moving my body in walking might help to retrain different parts of my brain to function somewhat “normally.” Within 2 weeks, other physical therapists at the university are noticing my rapid improvements and are saying that they are going to start using the LiteGait and the treadmill with their patients. I enjoy hearing how my progress is going to help others. I hope that other kids relearning to walk don’t have to rely on “lucking out.” The opportunity to walk using the LiteGait should be so much more available than just chance.

Relearning to walk is both painstakingly laborious and heart-wrenchingly exciting. In the long run, it all evens out, pretty much. Keeping hope and faith right nearby helps to sustain the strength so critically needed.

The journey doesn’t end yet. Soon after we got home from the hospital, my tough family bought a NuStep® machine, a recumbent cross-trainer. For a while, we called it “the walking machine” because it was going to strengthen my legs for walking. Then, after our time with the university, we bought a treadmill and a frame for our living room to continue, with the help of a physical therapist, the skills I learned in moving my ankles and legs in the walking position. Weight-shifting continues to be an obstacle. It’s still very difficult to bear even just some of my weight on just one leg while keeping my balance. Currently, we are going to a therapy clinic just for kids, mostly teens. We just bought a recumbent 3-wheel trike for riding in the park. I can use a walker, but I must walk very slowly to keep my balance, and I need someone right behind me to be there for losses of balance. We discovered a new gait trainer recently. It’s a walker with a lot of support. I’m able to walk at a respectable speed with no hands clutching me.

Mom helped me realize how important it is to harness the energy from our outrage at hearing pity. Having people in your day who are bright and full of happy looks and who push you hard, while at the same time keeping an encouraging smile on their faces, is crucial. Positive energy fuels hope, the way your friends rooting you on from the sidelines makes you run faster at a game. I have to hand a good chunk of credit over to my physical therapists, especially Vicki Stevens, for always passing the best assists, like my soccer teammates used to do for me on the field.

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