thrive

Living Well with Limb Loss

ISSUE #19

Sibling SUPPORT

Brothers & Sisters of Amputees

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ISSUE #19

FEATURES

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DEPARTMENTS

WELCOME

> ***"There is always one moment in childhood when the door opens and lets the future in."***
>
> – Deepak Chopra

thrive founder and publisher, Jeff Tiessen

Brothers and sisters. I have one of each. They became a younger brother and sister of an amputee sibling – me – when they were quite young, seven and five respectively. Their worlds, like mine, changed forever on one sunny winter's afternoon in February.

It was the 1970s. I was 11. Our parents were young, our mom still in her twenties. Obviously, no Facebook Groups for support, no Google, and not even a booklet or manual on "how to raise a child with an amputation"… or two in my case. Friends, family, church, teachers and community were the resources my parents turned to… and The War Amps. All, very fine resources in fact, which stand up as such still today.

But lost in this circle of care was sibling support. Not necessarily forgotten, it just wasn't really a thing then. So, what about siblings? What about the impact of a brother's limb loss on mine? Research says… as you'll read in this issue, it can be very impactful for some, both positively and negatively.

From my perspective, I know this for sure: being a young amputee resulting from a well-known accident in a small town comes with dubious celebrity. People know who you are. And often, when townsfolk met my siblings at the corner store, or the arena or soccer field, time and again they'd first ask: "How is your brother doing?" Not so much, "How are you doing?" I often wonder how that impacted my brother and sister?

Jeff Tiessen, *publisher*
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ABOUT THE PUBLISHER: Disability Today Publishing Group, a disability community leader for over 25 years, is known for its quality publications, and compelling editorial. The publisher of *Alignment* for Orthotics Prosthetics Canada, and a host of in-house magazine and book titles, the media firm is led by Jeff Tiessen, an amputee of 45 years. Tiessen, a three-time Paralympian, award-winning journalist and Canadian Disability Hall of Fame inductee, is a respected advocate within the amputee community, the prosthetic profession, and other healthcare fields as well.

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No Thank You!

And Other Foreign Phrases

By Kimberley B.

I love words.

Three in particular have considerable power, and depending on the situation and who says them, they can have profound effects on the person on the receiving end of them.

Even when they're interspersed with other words, you still get the basic underlying intent. What are these magic words you ask?

"No thank you."

"Would you like some more cake?" "No, thank you."
"How about some tea?" "No, thanks, I'm fine."
"Can I get that for you?" "No, thank you, I've got it."

See how succinct and decisive they are? So, why is it that some people can't accept those words when they come from someone with a disability?

TRUE STORY: One night, after an improv class, my buddy Dan and I were loading our wheelchairs into his car when a young couple walked past us to their own vehicle. We could hear the young lady telling the young man in a slightly urgent voice to go over and help us. Taking her advice, he walked over and the conversation went like this...

Friendly Stranger (FS): "Can I give you a hand?" Me (still in improv mode), "No thanks, we've got four already."

FS: "Uummm, are you sure?" Dan, giggling uncontrollably at the speed of my wit manages to spit out, "No, really, we've got it."

The Friendly Stranger is no longer smiling. He's standing there looking back and forth between us and his girlfriend and after a second or two of uncomfortable silence (for him) he gets visibly agitated and walks away.

We finish loading our chairs and ourselves. As we were driving away, the young couple pulled up beside us and the girlfriend blurts out: "We were just trying to help, you didn't have to be such assholes."

Dan and I, still in improv mode, pass it off as anal "crabs" (currently regarded as able-bodied) without a sense of humour.

A few months later another incident: I'm halfway up an escalator, holding on to the railings, when someone grabs me and tips me backward. I barely keep my grip and look behind me to see a man holding my chair telling me, "It's okay, I've got you."

The top lip is coming fast and I know he's going to try and lift my back wheels up and tip me out so I say, "Let go of my chair please." He says again, "No, it's okay, I've got you."

Now I KNOW it's going to be bad so I start shouting at him: "Let go of me!" The man finally realizes I mean it and lets go, dropping me one step before the top lip. I regain my control and just barely make it off safely.

And most recently: I'd just finished grocery shopping and had everything loaded. I stood up, propped myself against the bumper and was lifting my chair into the back of my truck when along comes this well-dressed woman who says, "Let me help you with that."

With the situation completely under control, I smiled at her, said "No thanks, I've got it" and then turned back to finish loading my chair. Well, the next thing I know I'm off balance, desperately trying to stay upright, having a tug of war over my chair with this woman whose assistance I had just politely declined.

"It's okay," she said with a fierce look of determination on her face. "I don't mind." She was completely oblivious to the fact that she was forcing her will on me. "Well, I do mind," I said.

I regained my balance, got my chair in my truck, looked at the woman and said loudly and firmly, "I said NO!" She walked away in a huff. Seconds later she pulled up behind me and said: "I was just trying to help, you b@#%$" and drove away.

It made me wonder… why did these people get angry at my refusal of their "help"? And why did they feel they had the right to chastise ME for THEIR bad behaviour?

I think there's still a segment of society that has no intention of letting go of their outdated notions of people with disabilities being helpless and not able to speak for ourselves either.

It's disrespectful to force "help" on anyone. But they don't see that. They see me as not being properly grateful for their intrusion.

And based on my own experiences, it would seem that some people actually think we're not allowed to use the word "NO".

The reality of this is chilling. Granted, the first incident was verbal but the others had a very real potential for physical injury. In my case, the "help" was simply aggravating – in the end there was no damage done – but many other people aren't that lucky. I know of instances where individuals were seriously injured by the actions of intrusive strangers. A dear friend died as the result of one.

I realize that I'm more independent than some, and I understand that those who need help are quite thankful for the well-intentioned assistance of strangers who OFFER and then wait for acceptance before they impose themselves on us.

We all can use a little help sometimes, and to those strangers, I say "thank you" on behalf of those whose lives you've made a little easier.

To those who think my right to say "No" is at their discretion, I say this: "When I say 'No thanks, I've got it,' I mean it. But thanks for asking."

AGREE OR DISAGREE? *The way in which we as amputees respond to offers of assistance, with respect to our limb loss, is very much a matter of personal choice. Whether you agree or disagree with Kimberley B.'s perspective, it is just that – her opinion. Does your take on this subject differ? Let us know. We'll share your viewpoint with readers in our next issue of* thrive magazine. *Email us at jeff@thrivemag.ca. Visit Kimberley at http://unlimbited.com.*

FIT to FIT

Reebok recently announced its first-ever adaptive footwear collection: Reebok Fit to Fit. Designed specifically for athletes and everyday consumers with physical challenges, the Reebok Fit to Fit collection provides functional footwear that enhance everyday life for those with disabilities.

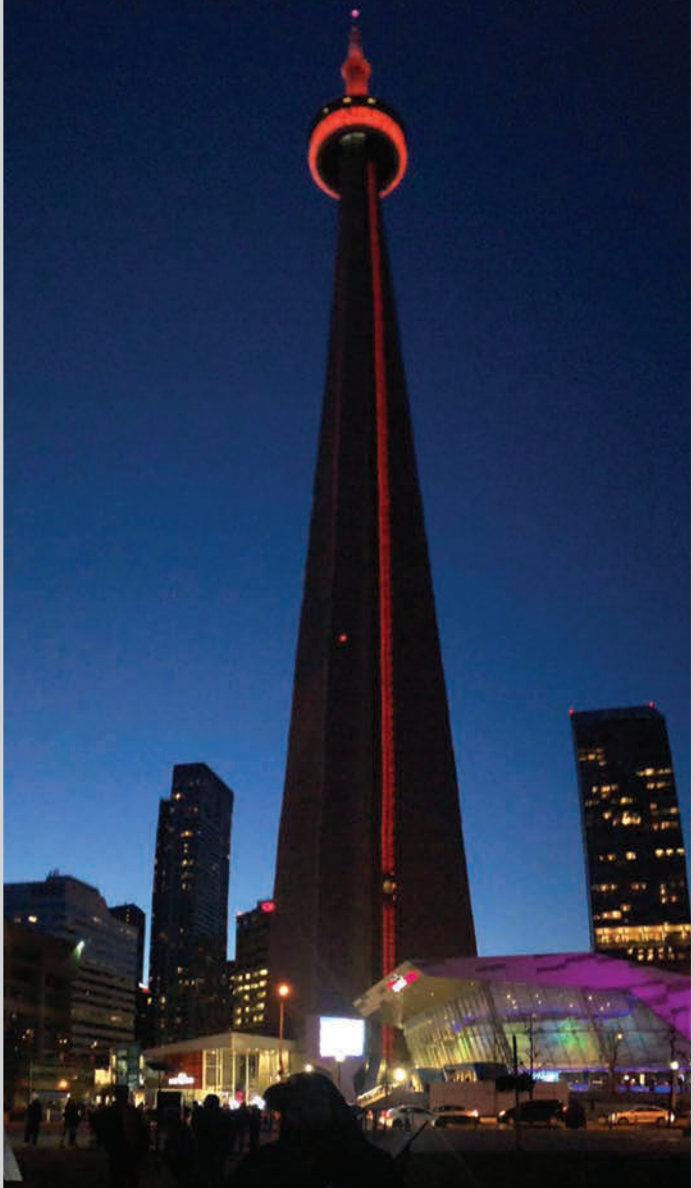
"We're proud to introduce our first official adaptive collection to help those with disabilities thrive — from sports and fitness to everyday life," said Todd Krinsky, a senior vice president at Reebok Design Group. Each featuring a zipper on the medial side allowing for better fit and lockdown, the Nanoflex Parafit is meant specifically for workouts and activity, whereas the Club MEMT Parafit offers a lifestyle option with removable sock liner for custom fitting. The collection is available at Reebok.com and Zappos.com.

FOOD FOR *Thought*

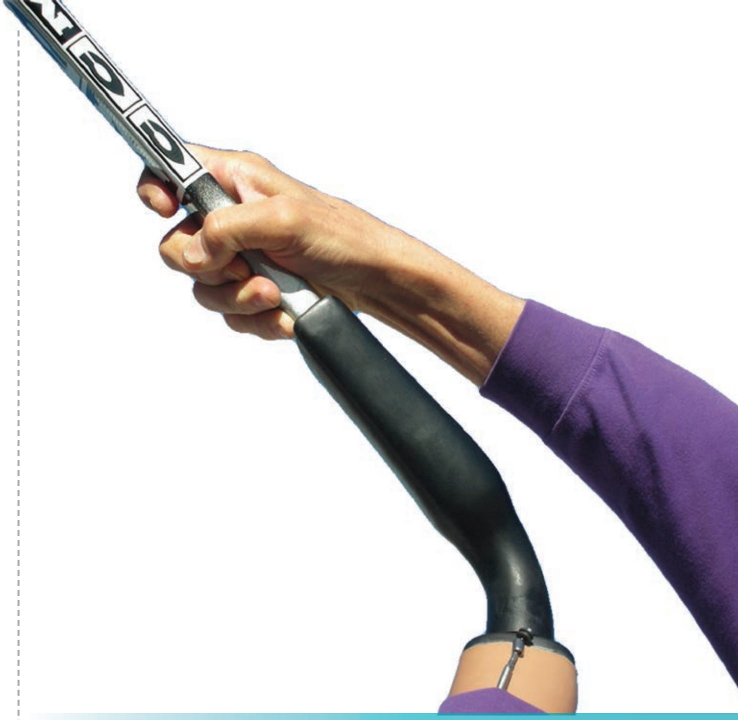
The newest Gerber baby melts hearts with her joyful giggle and loves to snuggle. She is also the first Gerber baby with a limb difference, as baby Isa Slish from Oklahoma was born missing part of her right leg. The seven-month-old was announced as the winner of the 2022 Gerber Photo Search on the TODAY Show, surprising her parents, Meredith and John, live on the air.

Isa was born without a femur and a fibula in her right leg. "While the world around us seeks to embrace individuality and uniqueness, we hope that awareness for limb differences will lead to greater inclusion for children like Isa," Meredith said.

LIMB LOSS AWARENESS MONTH



Recognizing Limb Loss Awareness month in April, Toronto's CN Tower was lit-up orange thanks to the advocacy efforts of the Amputee Coalition of Toronto. Check out other great limb loss awareness initiatives and messages from across Canada in April at #limblossawareness.



HOCKEY HAND

A new high-performance prosthetic device for playing hockey, Fillauer's Power Play is designed for "top-of-the-stick" handling control. The all-polymer construction provides for agile stick and puck control and powerful shots. The energy-storing design performs much like the human forearm and wrist. It flexes and rebounds for shots and will bend away under load to prevent injury. It can be modified to provide the level of flexibility and power that the player demands.

Stay In Touch

Sign up for Naked Prosthetics' quarterly newsletter to stay up-to-date on the latest advancements in partial hand prosthetics: www.npdevices.com/stay-in-touch; #NakedProsthetics; #ItsAllAboutFunction.

JUST ADD WATER

Ossur has tested and refined select components to make sure they stand up to the elements, whether it's fresh, salt, or chlorinated water.

Cheetah Reaches New Heights

Andrea Lanfri has proven that for him, anything is possible! Congratulations Andrea for reaching the summit of Mt. Everest at 8,849 metres above sea level. Andrea is the first athlete with multiple amputations to reach Everest's summit. Not only that, on his adventure he ran the world's highest mile at 5,190m on Ossur's Cheetah Xtreme blades in just nine minutes, 48 seconds. #livewithoutlimits.

Putting Accessibility on the Map

Saskatchewan Paralympian Lisa Franks is helping expand the Trans Canada Trail map for people with disabilities. More than 35 nature trails have now been mapped for accessibility Canada-wide.

The Trans Canada Trail introduced its Accessibility Mapping Program in 2021 alongside AccessNow, an app which shares accessibility information about parks, trails and buildings. Trail users and mappers send in information about the trails and people can gauge how accessible they are for their own use. Moose Jaw's Franks, an accomplished Paralympic wheelchair basketball player and wheelchair racer, mapped the Saskatchewan additions of the 2022 expansion.

Franks said she loved the outdoors as a child but when she started using a wheelchair at 14 years old, she didn't know how to keep doing outdoor activities. "A lot of people don't know where we can go with a mobility device," she said on CBC's Saskatchewan Weekend.

Information about the trails is uploaded by new mappers and riders, who note points on the trail which deter some mobility device users. One situation was reported where a barrier at an access point meant to block motorized vehicles from entering the trail inadvertently stopped a mapper's wheelchair, which couldn't fit through the access point. In this case, it was fixed.

Franks's most interesting obstacles were horses. "They were licking my head," she laughed. "They were most interested in my mobility device — I was on an adapted mountain bike at the time — but they're more familiar with it now."

Peer Mentors Wanted

University of B.C. is seeking Canadian amputees to mentor others through its SMART Program. Online training provided (4-6 hrs). Supporting others (5-10 hrs/week) for a six-week commitment. Hourly compensation provided. Requirements: unilateral BK or AK, must be two-years post-amputation, age 50+, prosthesis wearer, good communication skills. If interested, email noah.tregobov@ubc.ca.

Respect YOUR SKIN

The experts from ALPS South's R&D team have created a first-of-its-kind silicone liner that is 100% skin-friendly and hypoallergenic, without any chemical additives. The absence of chemical additives is the difference in ALPS liners, for a soft and delicate product for firm limb grip, and easy to clean. Discover more about Silicone Pro at https://easyliner.com. Plus, ALPS South has created a tool kit to help lower extremity amputees choose the ideal liner. Take the quiz at www.easyliner.com/en/choose-your-liner/ or download the App.

One LUCKY FIN at a Time

Animated movie character Nemo is known to many for his “lucky fin”, and how being made a little differently didn’t stop him from accomplishing anything he set out to do. In 2010, a mom of a three-year-old girl named Ryan began making limb difference awareness bracelets in celebration of her daughter and all individuals with a limb difference. Over 20,000 awareness bracelets later, sent to supporters worldwide, her Lucky Fin love continues to spread daily.

Founder Molly Stapelman created the nonprofit Lucky Fin Project to raise awareness and celebrate children and individuals born with symbrachydactyly or other limb differences (upper, lower, congenital, and amputee). With a support network for parents across the U.S. and around the world, links to medical information and resources on limb differences are sourced and shared. To join, visit www.luckyfinproject.org.

BONJOUR ACCESSIBILITY

The new “Québec for All” brochure, its 5th edition, features more content for people with disabilities and their friends and families planning a visit to Québec. Each regional section presents accessible or partially accessible establishments according to categories defined as follows: parks and outdoor activities, culture and heritage, flavours and traditions, sports and recreation, and accommodations. The online edition offers an interactive format. Click on an establishment to view the Kéroul sheet and obtain more details on the site’s accessibility. Order a free copy of the guide by calling (514) 252-3104.

TUNE IN and GET COSI

Physical therapist and amputee specialist Cosi Belloso is the host of Cosi Talks, a live weekly show where she hosts special guests and answers questions about limb loss. The Cosi Talks Facebook page is intended to provide education, information, and empowerment to the limb loss community. Learn more at www.cositalks.com. Send your questions!

PRODUCT CATALOG

#makinglivesbetter

Overcoming the Mental and Physical Challenges of Limb Loss.

Massimo's Story.

My name is Massimo and I'm on the Italian National Paralympics Para Rafting team. When I was 9, I was diagnosed with osteosarcoma on my left heel. Although we treated it with chemotherapy, it had metastasized to both lungs. A month later, it was decided that the limb had to be amputated immediately. This was a difficult period for me. I always wore long pants after the amputation because I didn't want anyone to see my prosthesis and start asking questions. Then, between ages 16 and 26, I began to ask myself if I wanted to spend my life living in the dark.

Once I recognized that I had nothing to hide, I decided to challenge myself and start running. I soon realized that this could be a turning point. **Now, I could truly take control of my life.** In 2018, I found myself winning both the 60 meter indoor and the 200 meter indoor in the Italian championship. That was the same year I was contacted by the Italian Rafting Federation, who told me they were looking for athletes to form a team for the Paralympics. I have never held back, so I said let's give it a try.

Sports have always been a fundamental part of my life. It's what saved me. Sports give me something to try to accomplish every day and improve on. The only thing that makes me different from anybody else is my prosthesis, but nothing else because fundamentally, I don't feel different from anyone else. I am so lucky to have a partner who has always supported me and my whole family, who have kept me motivated to keep going. I'm also grateful to ALPS for helping me carry out my plans since their liners and other products help me keep the skin of my residual limb in perfect shape. When I get home and remove the prosthesis, I find no irritation or inflammation, so I know these are top-of-the-line products.

MASSIMO'S GO-TO PRODUCTS

- ✓ Eco Liner
- ✓ Flex Sleeve (SFX)
- ✓ Antioxidant Cream
- ✓ Superior Performance Sleeve
- ✓ Vacuum Integrated Pump (VIP)

ALPS

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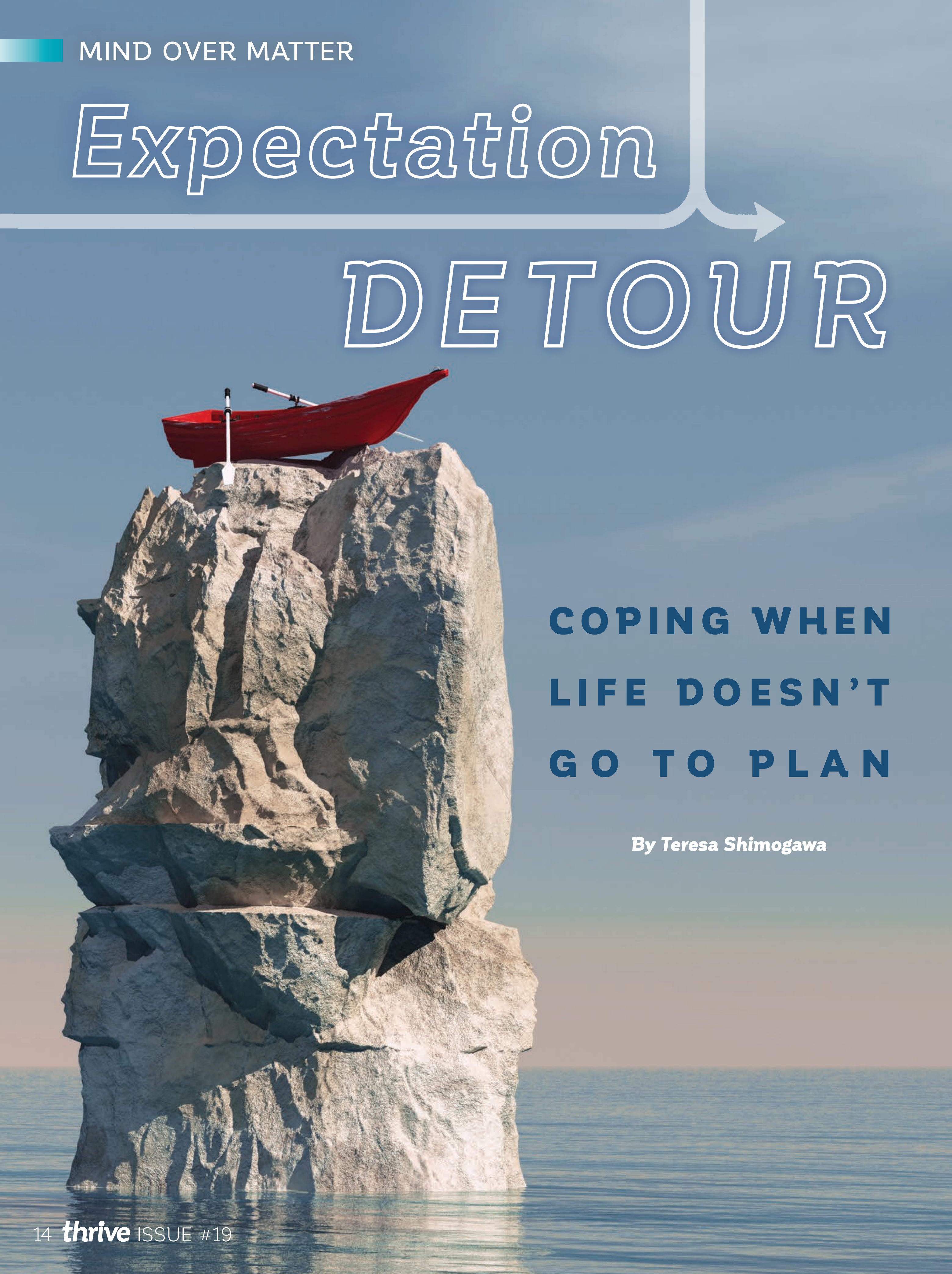
MIND OVER MATTER

Expectation DETOUR



COPING WHEN LIFE DOESN'T GO TO PLAN

By Teresa Shimogawa

“WHAT WILL MESS YOU UP MOST IN LIFE IS THE PICTURE IN YOUR HEAD OF HOW IT IS SUPPOSED TO BE.” *~ Unknown*

I expected to get into college. I expected to have a career after a lot of hard work, and that one day I’d meet a nice man and we would get married. We would buy a house together and start a family. We’d have babies and go on vacations and grow old together.

I expected that one day I’d take care of him until he took his last breath, and then I’d join a travel group with other retired women. My adult children would come over for dinner, and we’d take a family vacation with the grandchildren every year. That’s how it all played out in my mind.

I had a linear view of life. You go to point A, B, C, and so on. You do what you’re supposed to do, and you work hard. It was very simple with these expectations. Follow the recipe and then eat your dessert.

SPOILER ALERT: Life was that simple until the universe pulled the rug out from beneath my feet.

It was an ordinary school day when my life fell apart. These sort of things usually happen on ordinary days.

My husband and I were both teachers, and we woke up before the sun rose to begin our assembly line of breakfast and lunch preparations. Afterward we’d wrangle children and get them dressed and ready for departure, which was basically like herding cats. Then, he dropped them off at their respective places. I picked everyone up after school.

In between all of that we worked and went to meetings and ran errands and bathed children and cooked dinner and tended to all the usual moving parts of domestic life.

Except on that ordinary day, none of it happened.

On April 27, 2016 I woke up and found my husband dying on the living room floor. Out of left field, in an instant, the life I expected was gone.

I never considered the possibility of becoming a thirty-four-year-old widow with a one-year-old who I was still nursing, a three-year-old barely talking in sentences, and a six-year-old only two months away from his kindergarten graduation.

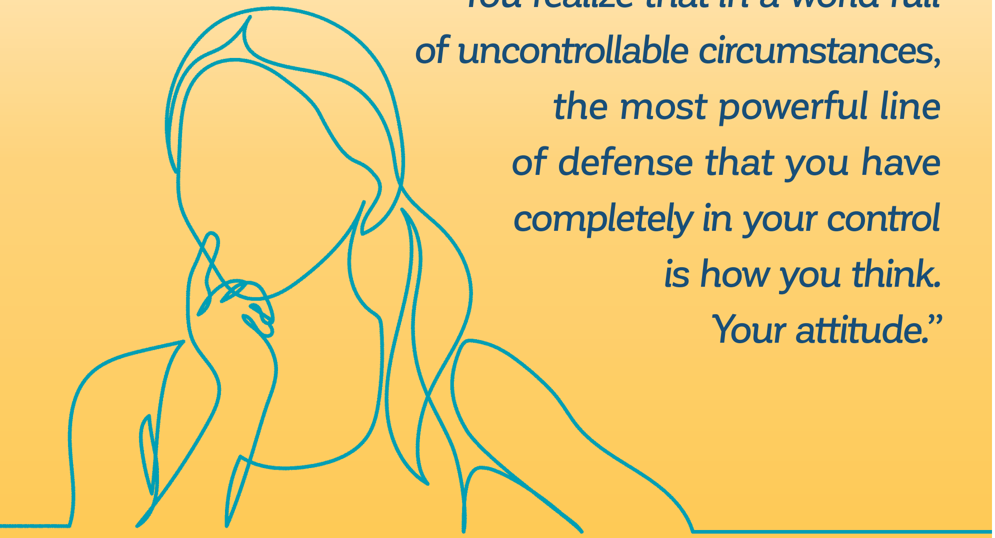
I was thrust into an alternate reality of gnarled, tangled grief, and it was in this new place that I had the painful realization that the life I knew, the one that was familiar and most comfortable to me, was over.

My husband and I planned each of our children down to the day. We even had number four, the one who would never be, scheduled in the calendar.

But now I was a single mother. A widow.

It’s kind of embarrassing to admit, but during this time I wasn’t only mourning the loss of my husband. Sure, I missed him so much that I couldn’t eat. I couldn’t sleep. I lived my days in exile, not knowing where I belonged. The tediousness of my new life as a single mother wore me down to the bones. The loneliness that festered inside of me created a painful hollowness that felt hopeless; the unfairness of this cosmic roll of the dice made me want to give up more times than I would like to admit.

But there was something else I was grieving: the loss of the life that I expected to live. My dashed expectations. The trajectory of my life that was forever altered, now



> *"You realize that in a world full of uncontrollable circumstances, the most powerful line of defense that you have completely in your control is how you think. Your attitude."*

headed in an unknown direction that felt like it would surely kill me.

We expect our lives to materialize the way we envision them in our hopes and dreams. When life doesn't go as planned, it can be difficult to reconcile the disappointment of our new reality. Resistance is the first defense. We don't want to believe or accept the change.

This wasn't the life I chose. I deserved something better, I thought. "This" seemed so patently unfair. Why me? I clung to those thoughts and let them bury me deeper and deeper into the abyss.

My expectations were never real. They were nothing more than thoughts in my head. Assumptions. Desires. Never guarantees.

It was always like that, but for me it had been on a micro level. Micro-disappointment, like not getting the job I thought I wanted. A relationship that ended. Losing a bid on a house. I never prepared myself for real disappointment in life. Earth-shattering disappointment that makes your world crumble and introduces you to your new constant companion: pain.

I remember how mad my husband used to get when I'd be surfing Facebook, bemoaning that so-and-so got a new car, or how in love a couple seemed to be, and why can't we go to Hawaii like so-and-so?

"Everyone puts their best life on Facebook," Kenneth told me. "It doesn't mean anything."

"No," I insisted, shaking my head. "So-and-so and so-and-so are madly in love. Look at how passionate they are with each other. Why don't we hold hands like that?"

"We have three kids under five," he said, rolling his eyes.

I wish Kenneth lived long enough to know that the so-and-so's got divorced. He would have told me "I told you so." And for once, I would have gladly told him he was right.

It's memories like those that I like to lean into. Life can't be as horrible or as wonderful as it appears in my head. There has to be middle ground.

When I'm feeling an extreme of any emotion, I have to remind myself of this. It's just thoughts in my head. Sandcastles built out of feelings, and sandcastles get washed away when the tide rises and brings in a new day. It's not a matter of being a good or a bad thing. It just is.

My expectations have been a thing that I've had to live with my entire life. I've always had high expectations for myself. Failure was not supposed to be a thing. As a widow, I found myself floundering in a new reality where I felt like I was constantly failing. Legitimately not capable of doing what I once could.

I wasn't the same mother to my children. This new me had less time and patience. She was more tired and overworked and in pain. I had to learn to live with the limitations of my new life. Nothing I could do was enough. I wasn't enough. Those are all very toxic feelings to carry around when you are already drowning in grief.

But there is only so much time you can spend falling deeper into your pit of despair. One day you realize that you are no longer falling and have in fact reached the bottom. There you are, alone with your despair, so sick of yourself that you can't even handle your own negative thoughts anymore. You can't take one more second of it.

This is your moment to get up and wash yourself off and start over.

When the despair stops roaring in your ears and you have a moment of quiet, you can begin to think objectively about your life. Your new life.

I realized what was wrong with me. My problem, I decided, came from my expectations. They were the root cause of my despair.

I expected a long life with my husband, even though he was always a mortal being who was never promised to be mine forever. I expected a lot of things, except for the only thing that was true about life: We are only guaranteed today. Yesterday is over. Tomorrow is unknown.

I knew I wanted to live as best as I could. I wanted a fulfilling life that was hopeful, joyful, and meaningful.

I'd have to change my expectations if I wanted all of that. It was impossible to get rid of the expectations completely. I'm only human. Besides, expectations do serve a purpose. They've helped me in life. They've also hurt me.

The middle ground, I decided, was finding "flexible expectations." I couldn't be rigid in my thinking. I wanted to have standards and goals, but I needed to have wiggle room for the inevitableness of life not going as planned.

I had to become more resilient and strategic about my setbacks. I needed to have long-term perspective and not feel like individual moments in my life were the be-all, end-all. I needed to be less attached to a prescribed way to live.

You realize that in a world full of uncontrollable circumstances, the most powerful line of defense that you have completely in your control is how you think.

Your attitude.

Your perspective. Is that glass half-full or half-empty? You decide.

How you think is your resilience. Your ability to get back up and dust yourself off. The way that you know life is worth living, not only during the moments of joy, but also during the challenges and pain and heartbreak, and this is the reason you persevere.

Maybe my expectations never betrayed me after all. Maybe it was actually supposed to be one of my greatest teachers in life.

Around a year after my husband died, I sat down and made a list of "good" and "bad" from the past year. It had gone by in such a blur that I felt like I needed to go back over the details. I anticipated a pity party as I recalled all of the terribleness.

The bad: my husband died. Single.

The good: new friendships, a loving community who showed up for us when we needed them, saw an old friend for the first time in eleven years, more productive than ever with my writing, my kids were happy and adjusted little people, we had a nice roof over our heads, I loved my job that didn't feel like a job, we were healthy.

It was very telling. We tend to focus on the negative. My mind wanted to go back to the dark moments of the past year. But after re-reading the list, it was clear that the year wasn't all bad. There were many bright spots in the hardest year of my life.

Mooji said, "Feelings are just visitors. Let them come and go."

I try to always remember that.

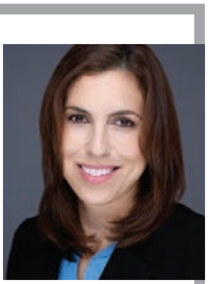
It's okay to feel terrible. You aren't broken for feeling that way. You just can't let yourself get attached to the feelings. None of it reflects who you are, nor are they any indication of what your future looks like. They are merely the temporary visitors.

When the feelings visit me, I acknowledge the pain. Hunker down. Maybe clear my schedule. Lower my expectations of productivity. Give myself permission to rest while I let the thoughts pass. Then I move on. It's not that you ever forget the pain, but moving on is a way to compartmentalize it so it does not destroy you.

Eighteen months later, I'm a different person than who I was before my husband died. It's not the life that I initially chose, but in many ways I am living a more intentional life with a lot more choice. There is some degree of excitement in what I call my "renaissance." There are no rules. You just live as authentically as you can, with what you have, doing the best you can, and that's it. No secrets.

Everything that you need to persevere is already inside of you, and this truth is liberating.

ABOUT THE AUTHOR:



Teresa Shimogawa is a human being trying to do good things in the world. She is a teacher, storyteller, and currently studying to be a Shin Buddhist minister's assistant. She writes at www.houseofteresa.com.

This article was published at www.tinybuddha.com. For daily wisdom, join the Tiny Buddha list at www.tinybuddha.com. You can also follow Tiny Buddha on Facebook, Twitter and Instagram.

Ask Aristotle

You have questions. You asked about kids and limb loss. With the help of Aristotle Domingo, the founder of the Amputee Coalition of Toronto, and his peer network, we have answers.

Q. I was just informed that my child is going to lose a limb. What should I expect?

A. Whether a child is born with a limb difference, or it is acquired, it is a life change for everyone including you as parents, your child's siblings, other family members and friends. You'll likely experience a roller coaster of emotions – grief, guilt, anger and worry about the impact on your child.

These are normal feelings and it is okay to feel them. Acknowledging them as you feel them may help you adjust to the changes. It takes time and each person is unique, but your child needs you. Don't dismiss your feelings. Self-care is important for you. Talk honestly about your feelings with a trusted family member or a friend, and talk to other parents whose child has experienced limb loss too.

Q. My child is being bullied at school for having a limb difference. What can I do?

A. Anyone can be bullied at any time in their life, but children are most vulnerable to this behaviour and its consequences: anxiety, depression, low self-esteem and other mental health issues. You're likely feeling angry, overwhelmed, sad, helpless and frustrated. Recognize the issue and address it. Be proactive. Here are some suggestions on ways to help your child:

1. Listen to your child's experience calmly and take it seriously. Reassure them that it is not their fault that they are being bullied and they do not deserve to be bullied because of their limb difference.

2. Work on some simple strategies with your child to give them an opportunity to resolve the bullying themselves, such as walking away from the situation. Build your child's confidence by inspiring them with positive roles models like para-athletes, celebrities, community leaders like Terry Fox, and even fictional characters who have a limb difference.

3. Assure them that you will take appropriate actions including meeting with their teachers, and the bully's parents, to address the issue. Follow-up on that promise.

4. Encourage your child to spend time with other children who positively impact them… joining clubs, groups or sports teams is great for encouraging personal strength, confidence and friendships.

5. Seek professional support from your medical team including a psychologist for your child if the bullying has affected them deeply.

Q. My child was born with a limb difference. How do I share the news with others?

A. Parents-to-be sometimes share that they are expecting a child with a limb difference with family members and close friends right away. Some decide to share the news with others after the child is born. There is no right or wrong way to do this. It's up to your comfort level and personal decision when to share the news.

What's more important is being an advocate for your child and discussing your child's uniqueness with others. Some parents feel that it is not necessary to draw attention while others want to discuss it to enhance inclusivity, acceptance and educate others. Remember, it is not unusual for strangers to stare, point, ask questions or offer unsolicited advice. You'll hear comments that can be intrusive, inappropriate and sometimes offensive.

Generally, people are not being deliberately hurtful. It's a good idea to decide on your approach early to help your child, family and friends, and others, understand how you want to talk about it.

Q. I've just experienced limb loss. How do I explain that to my child?

A. In addition to your experience of loss and grief, expect your child to ask about your experience. They may ask questions like, "Why did this happen?"; "Does it hurt?"; "Will this happen to me?"

Remember that they have curious minds and it's their way of dealing with this change. Put them at ease with answers that are logical for the child to understand. For example, you can say, "No… it will not happen to you too." It's not a time to deflect with "I didn't eat my vegetables growing up." Alleviate fears by providing information that your child will understand and is appropriate for their age.

Q. My child will not stop talking about my limb loss to other kids on the playground. What should I do?

A. Kids don't always understand the scope of a parent or an adult experiencing limb loss. For some kids, they may share until they feel they have shared it enough. It's best to speak to your child about boundaries and what should and shouldn't be shared about your experience with others.

Encourage them to share in safe spaces with other family members where they can "talk it out" as much as they need to. They are also dealing with emotions attached to your experience. Search out groups that offer children of parents with limb loss the space to interact with one another, to connect with others who understand what they are experiencing. But if the problem persists, seek guidance from your medical team. Your child may be experiencing other anxieties and fears about your limb loss that is causing this behaviour.

More solutions for living well at www.amputeecoalitiontoronto.ca.

ABOUT THE AUTHOR:

Aristotle Domingo's journey to amputation began when his mom found him passed out, unresponsive. What ensued was 15 years of struggle. He had his left leg amputated below the knee in 2017, and his right in 2019 changing his life for the better. The athlete, actor and advocate is the founder of the Amputee Coalition of Toronto, and recipient of ParaSport® Ontario's 2020 Ambassador of the Year Award.

FEATURE

SIBLING SUPPORT

Giving Voice to Brothers and Sisters of Amputees

By Max Warfield

> **In the family car, tired, hungry and bored siblings clash noisily in the back seat. From the living room, a young brother complains that he does not get as much attention and compares himself to a fifth wheel. A teen sister groans about having way too much responsibility, exclaiming that she's too young to be the glue that holds the family together.**

At breakfast, parents fraught with family fighting and pressing schedules treat aggression as normal. Communication is tense and unproductive. Stress shortens fuses and each day is a powder keg. The family includes a child amputee, but what about his or her sibling(s)? What are their roles in this family dynamic? What about the impact on them?

When a child is born missing a limb or undergoes amputation due to an accident or medical cause the entire family is affected, including siblings. Having a brother or sister who is living with a disability can be challenging at times for children and teens.

Studies show that being a sibling of a youth with a disability can have both positive and negative effects. These effects are contingent on interrelated factors such as gender, culture, disability type, peer relationships, family size, family functioning and connectedness, and the emotional availability of parents. Even simple things, like consistent household routines, are linked to positive outcomes.

While most siblings are well-adjusted, they may be subject to increased risk of negative externalizing and internalizing behaviours, like anxiety, depression, guilt, and lower social competence.

It has been consistently reported that sisters of children and youth with a disability are especially vulnerable to the emotional demands of the family. They also take on a more parental role compared to brothers, and account for a higher incidence of emotional problems among non-disabled siblings.

Guidance for siblings of youth with disabilities can be found in peer support groups which offer knowledge about their siblings' experience and work to cultivate an understanding of their own role in the family. Family support groups are reportedly the most effective type of program in helping siblings, particularly when used alongside peer support groups.

Ability Online has been hiding in plain sight for decades as a safe place for siblings of those with a disability to meet new friends who share similar struggles.

"Some siblings are put into a role of caregiver very early," tells Michelle McClure, Ability Online's executive director.

RESEARCH SAYS… “The majority of 12-15 year-old-siblings of youth with disabilities felt their responsibilities were too much.”

“It’s ‘take your brother with you!’” says McClure. “And then you might see jealousy or resentment surfacing in different ways. They can become angry with their amputee sibling because they get more attention from their parents; not necessarily ‘better’ attention – but with doctor’s appointments, surgeries, follow-ups and so on. With those priorities, brothers and sisters can feel left out.”

Ability Online has earned the rare claim: “We’ve been running an online support community for 32 years!” The organization provides an innovative model of support for vulnerable youth and young adults with disabilities. The goal: reducing social isolation and increasing inclusion. “Our supportive and safe online community fosters positive attitudes and builds self-esteem which contributes to emotional health and wellness,” explains McClure. She adds, “Ability Online has always held a special interest for siblings; always included them.”

As a well-liked social outlet, some kids enjoy the platform so much they insist that their family wait to celebrate their birthday until their Ability Online friends can join in. McClure knows that making the sibling of someone with a disability feel included requires intent and effort from the parent. Keeping everyone healthy and happy is always the goal, but the sibling’s feelings can become lost by the equally overwhelmed parent.

“The sibling may act out,” McClure shares. “We have seen that over the years. But they are just needing to have their own identity and the ability to live their life their way. Looking after their sibling can be all-consuming.”

The answer? Well, not clear-cut but McClure emphasizes that it’s about respecting and encouraging differences. “It’s about family dynamics; some parents lean a lot on a sibling in the caregiver role. Some have the wisdom to let kids be kids.”

There is an economic factor to this as well. Where there is a family that is well-situated to hire help to give balance, so is there a less well-off family that can’t afford the support. One can afford different therapies; another can not afford a community caregiver. The level of challenge also depends on the extent of the disability.

Without intervention and help, some families can head toward trouble as all involved feel overwhelmed. If a caregiver does not schedule some time for his or her own needs, it becomes unhealthy. Self-care is paramount – one cannot give to others if they do not take care of themselves first. Family members may seem lost at home or school. A child might begin to question what is fair and what is within their control, fueling more stress. A sibling that is

RESEARCH SAYS… “Siblings may also feel guilt about being ‘normal’ and others report feeling stressed when parents expect them to treat their sibling with a disability ‘normally’.”

struggling may exhibit signs, like decreased concentration, apathy, perfectionism, along with hints of feelings of guilt, anger, numbness, sadness and helplessness.

In addition to counseling, the peer-to-peer programs available, including McClure's Ability Online, are effective. McClure's program started out as an online community for kids with a disability, so they would be able to connect with each other and not be alone with their challenges. It expanded to include siblings, and also to support parents.

"Everybody needs support in that whole dynamic," she says. "Providing much needed support is really important, whether that is just a distraction from life so that you can laugh with people that get you, or it's a shoulder to cry on. Parents talking to parents, kids talking to kids, sharing experiences."

As McClure observes, "if parents say something is good for you, it can sound like nagging, but if a friend tells you — you are more inclined to listen. Even the siblings, they can talk about loving their sibling but not loving the situation at times, and not being afraid to say that out loud!"

For decades, kids meeting other kids in the same shoes has encouraged youngsters. Don Meyer, from the state of Washington, understands this. He has written many children's books to this end, including *The Sibling Slam Book*, and introduced "Sibshops" in the early 1980s. He felt there were no play-based support models available to siblings. Today, Sibshops meet all over the world, including Canada. The organization describes these meet-ups as "pedal-to-the-metal events where kids meet other siblings, talk about the good and not-so-good parts of having a "sib" with special needs, play some great games, learn something about the services their brother or sister receives, and have fun.

Sibshops offer get-togethers in a safe environment of kids on parallel paths. Siblings can openly share their joys and challenges, and even brainstorm new ways to handle different situations. The kids talk, listen, and make new friends. Parents appreciate how the service is geared just for siblings, providing a nice balance for the family.

The charity NowWhat Support Services in Ancaster, Ont., offers SibShops. In Ottawa, Able2 offers a therapeutic Siblings Group for children and teens. "Our Sibling Group runs every week, divided into four age groups up to seventeen," tells Heather Lacey, executive director of Able2.

"The facilitators who run our Sibling Group have clinical backgrounds," says Lacey. "It has a clinically therapeutic premise because it can be hard to be a sibling. Care usually takes up a lot of time. Many don't understand disability. Here, siblings talk with each other about what it's like for them. They talk about their feelings all the while being educated about disabilities. We want to reduce the stress in the family and help individuals build better relationships." NowWhat surveys show that over 80% of participants experience a difference, and come back year after year.

While the kids are playing and learning, the parents are commiserating, having coffee, sharing issues, problems and pet peeves while offering solutions learned from experience. "All families have good intentions, but some realize that goals can seem out of reach without professional help," says Lacey.

"A family without a disability is stressful enough," she says.

RESEARCH SAYS... "The typically developing sibling may experience 'disability by association' and negative experiences such as increased responsibility, less attention from parents, and feelings that their family is different."

RESEARCH SAYS...

"As adults, siblings of a sister or brother with a disability were found to have higher tolerance of people, more compassion towards others, an awareness of the impact of prejudice, and stronger bonds with their families."

Helpful Resources: www.youth.society.uvic.ca to access Siblings of Youth with Disability www.siblingsupport.org (Sibshops).

FAMILY TIES

Tips to Help Parents Address Issues Siblings Face

Source: War Amps of Canada

- Be open with brothers and sisters about the amputation. Explain the amputation in simple terms appropriate for the age of the child.
- Young children have vivid imaginations and sometimes think they have done something to cause the amputation, fear the same thing may happen to them, or are simply worried about the sibling with the amputation. Provide plenty of reassurance early on that everything is okay and make sure they understand the amputation.
- Encourage siblings to share their concerns and ask questions. By being open with a brother or a sister, parents pass on their positive attitude towards living with an amputation.
- Sometimes, because of doctor appointments and prosthetic fittings, you spend more time with the child amputee. Set aside some "special time" alone with other siblings to share an activity they enjoy.
- Treat the child amputee and his/her siblings equally by dividing chores according to age and ability. Firstly, siblings will see that no favouritism or special allowances are being made towards the amputee child. Secondly, it gives the amputee child more confidence as they take on and accomplish tasks like their brothers and sisters.

"A disability is an extra layer of responsibility that can feel overwhelming. Many siblings feel left out and that they are not getting the level of attention they need while the focus is on someone else. They need an outlet."

There are many family relationship skills that can be worked on to become proficient. "Good, productive communication — creating a family that opens up to each other while fielding questions are encouraged," Lacey advises. "Being accepting of emotions rather than suppressing them is so important. So is being reassured how hard it is for parents to meet everyone's needs at the same time, and how to avoid favouritism."

There are not a lot of sibling groups around. And youth face many mental health challenges. "The last couple of years has had such an impact on kids, leaving them questioning the uncertainty of school and their environment," Lacey says. "However, I feel the pandemic opened a new door. Zoom has its faults but also its advantages. Meetings were easier to attend. Parents didn't have to search for babysitters, and we had attendees from outside of Ottawa. Sibling support groups are ripe for enhancement and expansion."

ABOUT THE AUTHOR:

Max Warfield was born in Ridgefield, Connecticut, now making his home on the southern shores of Lake Ontario. A correspondent for the *Lockport Union Sun & Journal* and the *Niagara Gazette*, Warfield has also written and published several novels.

thrive
Living Well with Limb Loss
ISSUE #19
Sibling SUPPORT
Brothers & Sisters of Amputees
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Residual Limb Reminders
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The Skinny on SKIN CARE

Disorders, Contributors and Healthy Reminders

Contributions from Rick Riley, Certified Prosthetist, and Limbs 4 Life Inc.

Whether you are a new amputee or have lived with limb loss for years, skin care is always important. With the summer season upon us, skin care and hygiene become even higher priorities.

All amputees have a basic dilemma. No matter how well-fitting our prosthesis may be, our residual limbs don't stay the same size, especially with changes in activity levels and fluctuating temperatures inside and outside our sockets.

Residual limbs swell, shrink, get pimples, muscle cramps, calluses, blisters, and any other malady that afflicts normal human skin. But the skin of the residual limb is rarely normal. Scar tissue, skin grafts, and skin folds are often lifelong companions. Then, to compound matters, we house this skin in a warm, moist, and dark environment all day. And to add insult to injury, we subject these appendages to pressures that they were never designed to withstand. This is the life of the residual limb.

Our skin is our first line of defense against the invasion of infection and disease. It is comprised of several layers and is constantly regenerating. It has sweat glands and hair follicles which can be sites of irritation.

In your prosthesis, your limb is confined in an airless socket, where heat accumulates and perspiration is trapped, creating a potential jungle for bacterial or fungal growth. To try to prevent skin conditions that compromise the use of your prosthesis, appropriate skin care should be an essential part of your daily regimen.

Whether you're involved in high levels of exercise and activity, or more casual forms of active living, the importance of skin care and stump hygiene to get you to the finish line is the same.

COMMON SKIN DISORDERS

- General irritation/rashes and abrasions.
- Contact dermatitis… allergies to cleaning agents, skin products or prosthetic materials.
- Cysts... resulting from constant rubbing which may start as small bumps or nodules.
- Adherent scar tissue... slow wound healing or repeated skin breakdown can be more susceptible to breakdown.
- Folliculitis... bacterial infection/inflammation at the base of the hair follicle.
- Oedema/skin swelling... many amputees experience fluctuations in limb volume which can mean wearing compressive garments when not wearing their prosthesis.
- Ulcers... resulting from bacterial infection or poor circulation.

SKIN DISORDER CONTRIBUTORS

- Direct trauma/pressure
- Friction
- Altered fit
- Heat and perspiration (amputees have reduced skin surface area to dissipate body heat and tend to generate increased body temperature with most activities since more energy is required, leading to increased perspiration).
- Diabetes (reduced or altered nerve sensitivity and circulation to the extremities make diabetics more vulnerable to skin disorders).

SKIN CARE REMINDERS

- Daily cleansing of the residual limb using a mild, non-perfumed soap, preferably at the end of the day (the heat of a shower can make your limb swell and damp skin in a socket may be more prone to irritation).
- Include a good rinse to remove soapy residues (another potential skin irritant).
- Follow this by drying the skin thoroughly with a clean, soft towel.
- While moisturizing is not always a familiar concept to men, for amputees it is essential to keep the skin supple and in good condition.
- Use a non-perfumed product and apply at night after you've removed your limb for the day.
- Keep well-hydrated with plenty of non-caffeinated fluids (water is best!) if you're not on a fluid restriction.

SPECIAL CONSIDERATIONS FOR DIABETICS

- Dry, cracked and itchy skin can be an entry point for skin 'bugs' and subsequent infection.
- When blood sugar levels are high the body loses fluid and becomes dehydrated, leading to dry skin.
- For those on dialysis or fluid restrictions, your skin is likely to be even more dry, requiring additional moisturizing throughout the day.
- Diabetics are likely to have altered temperature perception and should avoid excessively hot baths/showers.

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SOCK AND SOCKET CARE

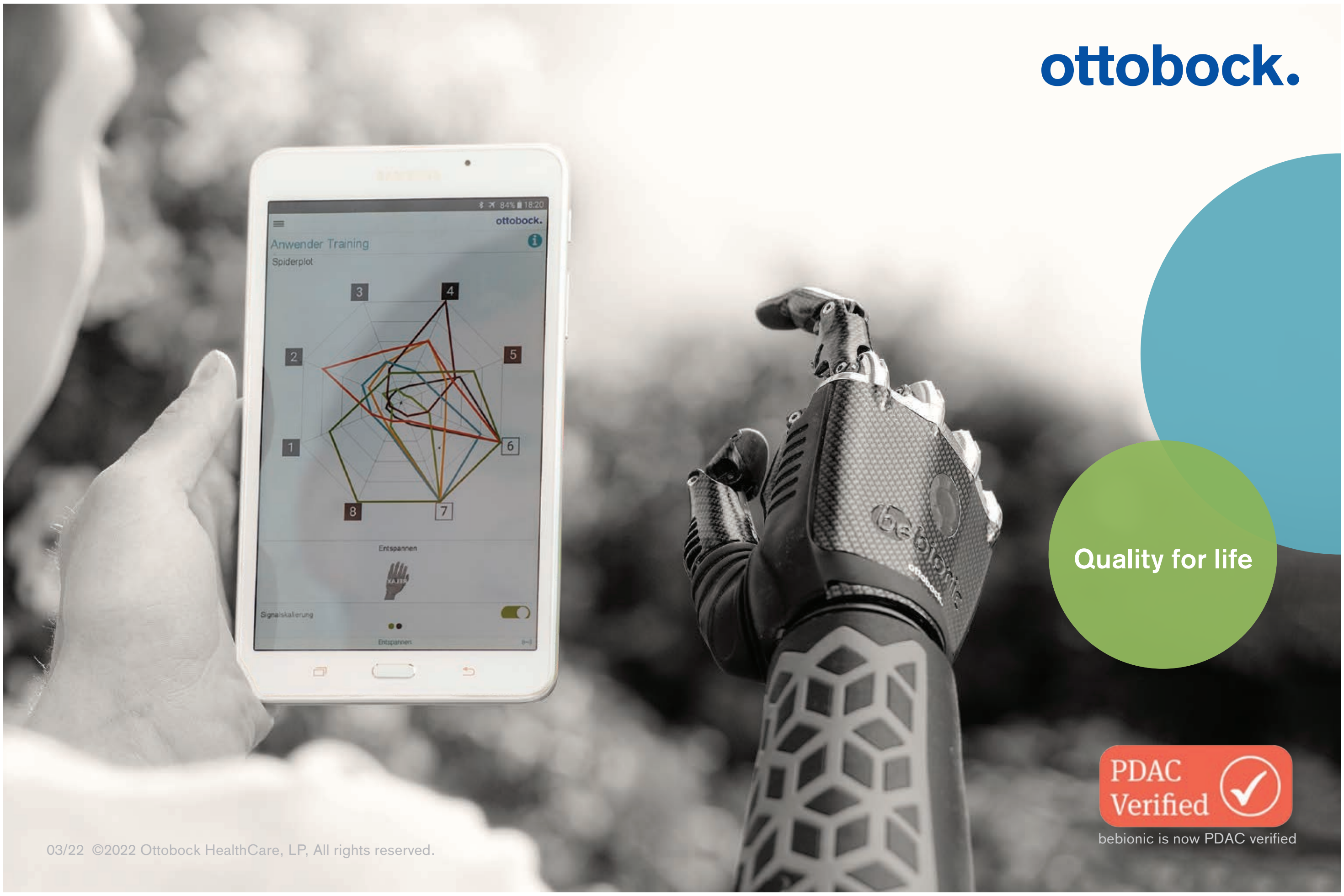
- Newer socks wick away perspiration more effectively, but more importantly it is essential to change your socks regularly, even moreso during the warmer months.
- Carry a face cloth or chamois to dry the limb thoroughly before re-donning.
- Carry spare socks in your handbag, backpack, glovebox.
- Wear dry socks as much as possible.
- Use mild soap to wash socks/nylon sheaths and rinse thoroughly.
- Remember to clean the liner and socket after removal at night (this part of the hygiene regimen is commonly missed!).
- Some prosthetic liners and products require particular attention. If unsure, check with your prosthetist about which skin products and cleaning agents should be used. It is even more important not to leave residues on the skin with a lot of these products.
- If excessive perspiration is a problem with a prosthetic liner, sometimes an antiperspirant is recommended.

OTHER REMINDERS

- Check your skin daily before and after using your prosthesis (a quick check is better than a major skin breakdown).
- Skin grafts often have very little sensation and require a few extra checks.
- Shaving is not recommended... it increases the risk of irritating the base of the hair follicles and ingrown hairs.
- If your prosthesis doesn't fit well, or with the impact of years of use, there is potential to develop thickened skin or callous which is more susceptible to breakdown.
- If skin breakdown begins, scar tissue will always be more fragile and more susceptible to breakdown than uncompromised skin.
- Early wound management is a must… especially in the diabetic group. Seek professional advice if you have a wound that isn't healing within 2-3 days.
- Signs of infection include redness, swelling, warmth, pain, drainage or discharge and may be accompanied by a rise in body temperature and blood sugar levels. If you develop a skin problem, it is recommended to seek a prosthetic review or doctor's assessment ASAP.
- Where possible, stay off the prosthesis until the problem area has healed.
- All this is to say, good skin care and a well-fitting prosthesis should keep your skin healthy.

References: Skin Problems in the Amputee Clinic: Dudek N et al, American Journal of Physical Medicine & Rehabilitation, vol. 85(5): 424-429. Prosthetic skin care: ACA in cooperation with the US Army Amputee Patient Care Program. The War Amps. Canadian and American Diabetic Associations.

NEXT ISSUE: PROVEN PRODUCTS AND DAILY HACKS FOR RESIDUAL LIMB CARE.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Virtual Rehab

By Lise Diebel, Hamilton Health Sciences
Photos: Josh Carey, Hamilton Health Sciences

Rec Therapists and Reality Games Make Re-learning Fun for Amputees

Lyndyl Smith isn't the sporty type. "My favourite pastimes are reading, calligraphy and spending time with friends," says the 21-year-old university student and Hamilton Health Sciences (HHS) client.

Yet, just a few weeks after undergoing an amputation below her right knee, Smith found herself blocking soccer balls and snowboarding down a mountain as part of the amputee rehabilitation program at HHS's Regional Rehabilitation Centre.

Snowboarding, soccer, and even parachuting are among the virtual reality (VR) activities offered to patients as part of a six-week amputee rehabilitation program. Patients visit the hospital for daily programming that includes seeing physiotherapists and physiotherapy assistants, occupational therapists and occupational therapy assistants, and receiving counselling services. These professionals help patients who have recently had a limb amputated adjust to new ways of managing daily living activities.

The VR activities help patients improve skills like balance, range of motion and mobility. Programming is led by the hospital's recreation therapists in partnership with occupational therapists.

Patients stand in front of a green screen wall. A camera projects their image onto a large screen and into one of the virtual reality games. They are completely immersed in the digital experience and become part of the game itself.

"Virtual reality made rehab really fun," says Smith, who was so inspired by her experience at the Regional Rehabilitation Centre that she abandoned her plans to study accounting at university and enrolled in the University of Waterloo's therapeutic recreation program instead.

Hamilton Health Sciences (HHS) patient Lyndyl Smith demonstrates her soccer goaltending skills with a virtual reality game. Smith took part in a six-week amputee rehabilitation program at HHS that includes virtual reality activities like soccer, skiing and even parachuting to help patients and clients improve balance, range of motion and mobility.

Recreation therapists use recreation, leisure and play as part of a patient or client's rehabilitation. "My experiences at the Regional Rehabilitation Centre pushed me towards this career," says Smith, of Oakville, who is finishing her third year of the four-year program.

Smith was born with underdeveloped feet, which made walking extremely challenging. Her right leg was weaker and experienced more pain than the left. So, at age 19, she opted to have it amputated below the knee, understanding that a prosthetic limb would make walking easier and less painful.

The surgery took place in 2018. She recovered at home, and in the spring of the following year Smith took part in the six-week amputee rehabilitation program for day patients. "It's offered in a group format," she explains, adding that her fellow group members were all seniors. Despite the age difference she found it easy to connect with the other participants, finding commonality in the virtual reality experience. "Programming was very interactive and a lot of fun," she shares.

No one in her group had tried VR before. "I didn't grow up playing video games," tells Smith, adding that some group members caught on very quickly. "It really was a lot of fun doing VR as a group. Some people would get quite competitive, in fact."

The amputee rehabilitation program has offered VR for about six years and is currently in the process of upgrading the technology, thanks to a donation from a former patient's family. The program's interdisciplinary team includes a physician, recreation therapists, physiotherapists, occupational therapists, a social worker, prosthetic and orthotic technicians, nurses, a pharmacist and a dietitian.

Depending on medical needs, patients with recent amputations are referred to an in-patient or medical day patient rehab program, where services include getting fitted for a prosthetic limb and learning to use it. Both in-patient and day patients can take part in VR programming as part of their rehabilitation.

Patients are assessed to see how they're managing with their new prosthesis, says Kathie Elstone, a recreation therapist with the program. "We start out simple, to assess such things as a person's ability to balance, reach for objects and shift their weight. These are important skills for day-to-day life."

Easier VR activities include playing the drums, and a game where patients reach for eggs that transform into birds when touched. From there, patients can choose to try more challenging VR experiences, like sports. With soccer, patients play goalie where skill sets include balance, reaching, bending and stretching. This game also helps with reflexes with the ball moving toward them at varying speeds.

Parachuting is another more advanced VR activity. It encourages multi-tasking, as patients concentrate on keeping their chute straight while at the same time avoiding virtual obstacles in the sky like birds and storm clouds. "You get so immersed in the activity that you don't even realize how much it's helping to improve your mobility," says Smith.

Lyndyl Smith's experience at the HHS Regional Rehabilitation Centre inspired her to study therapeutic recreation at university.

Recreation therapist Kathie Elstone demonstrates the downhill skiing option for patients who use virtual reality as part of their rehabilitation exercises.

All VR games encourage some level of multi-tasking, by keeping participants' minds on both the game and their movement. "When patients first get their prosthesis, they're very focused on it, and how they're walking with it," says Elstone, adding that the vast majority of patients in the program have lower limb amputations. "In real life, they need to be able to multitask. The VR games help with this because patients must focus on an activity while also being mindful about what's happening with their prosthesis."

Patients can also continue to enjoy favourite pastimes through VR games. "Someone who loves music may really enjoy the drumming," says Elstone. "And if a patient played a sport before their amputation, VR can help them explore what that sport might look like for them now, and how they can play in the community."

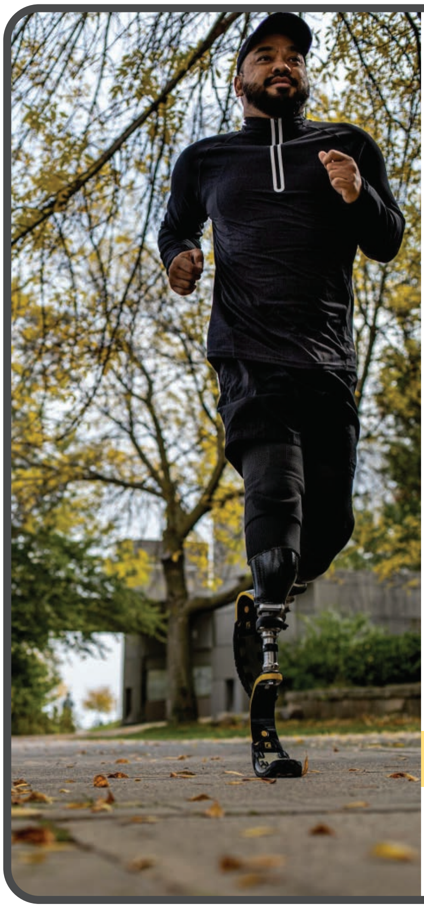
Having an amputation is a huge life change that can cause feelings of loss, depression and anxiety in some patients. "As you can imagine, someone who has gone through an amputation is going through a very difficult time in their life," says Elstone. "The VR experience can help people work through this. We have the element of fun in our therapy. We can show patients that life goes on after an amputation, and they can continue to do activities that they enjoy."

Smith agrees. "The virtual reality that we did — me and the people in my program — would bring out the competitive side in us. But you're also practicing your skills," she says. "Being here in virtual reality, you focus on the activity itself. It's a good way of doing activities without realizing that you're working on independence."

> *"We have the element of fun in our therapy. We can show patients that life goes on after an amputation, and they can continue to do activities that they enjoy."*

Originally published on HamiltonHealthSciences.ca


SOCKET SOCKS



Beat the Heat ….. on the Right Feet

Ottobock's X3 lets you shower, swim or work in damp conditions. The electronic knee joint is waterproof and corrosion-resistant.

While amputees excel in all activities of summer – swimming, fishing, boating, or simply enjoying the cool breezes by the pool or lake – a call to your prosthetist at the season's start is a good idea. There are some things to keep in mind with respect to the health of your prosthesis.

The iconic features of summer – hot temperatures, water and sand – can easily become destructive to your prosthetic device, requiring attentive care and forethought.

Whether it's a refreshing dip after working in a hot garden or being social with friends and cocktails in the shallow end, a pool might be calling. Even while choosing the simplest solution of swimming without a prosthesis – sunbathing, like showering, requires a plan. More warmth means more sweat and swelling and that might aggravate your residual limb. Some find relief with antiperspirants, cold showers, or a planned stay in an air-conditioned room before slipping on their prosthesis when swelling is problematic.

It is the season to change "stump socks" more often and remember to bring extras when traveling. In the heat, your skin will need more scrutiny for any breakdowns. When going to a pool or lake that you've never been to before, research the layout as much as possible; make yourself familiar with where and how you will swim, keeping in mind long-distance hopping is unsafe on slippery concrete or on hot sand.

High temperatures can also turn your car into an oven, deceptively warping and melting your valuables. Covering your poolside prosthesis with a towel will protect it from direct sun and playful splashes.

For shallow applications, some amputees choose a waterproofing cover for their device. If you own a back-up limb of relatively simple construction, it might be the better choice to get wet. The central trait of a shower, swim or dive leg, is water tolerance. Non-specialty limbs will rust or degrade after water submersion. While some prostheses are water-resistant, not all are waterproof, and overconfidence can become an expensive mistake. There is a difference between your limb getting caught in the rain or a splash from a hose and it being fully immersed in water.

If an unplanned dunk occurs, there might be immediate damage to moving parts; so it's important to disassemble (where possible), rinse and thoroughly dry any device, particularly after exposure to salt water or chlorine. Water can get behind the socket liner and result in the device detaching from your residual limb.

Sand is an abrasive, one that grates and damages moving parts, so thorough cleaning is a must after the beach.

Prostheses and crutches may fill with water, and become heavy, which may present a test of balance. Many do not float and can be lost to the depths.

Advancements in specialty limbs continue to evolve, giving water-sport enthusiasts more options. These typically have fewer moving parts and more aeration for drainage, along with buoyancy design. Enthusiasts can equip themselves for powerful swimming or for agility on water skis with components designed to be completely submerged in water for long periods. They are constructed with perfect seals and utilize nylon and stainless steel to prevent corrosion.

New knee and ankle joints offer improved water-resistance and longer performance while under water. Being in water means walking on slippery surfaces, requiring a sole that will not slip, an issue solved with high grip patterns and material. Legs designed for diving are designed with neutral buoyancy and flow.

Ask your prosthetist about a water-resistant or waterproof prosthesis that's right for you.

Ottobock's Aqualine system provides multiple options for below- and above-knee amputees in the pool, shower, or at the beach.

Ossur's waterproof Balance Foot S provides the stability, security and safety that K2 users demand, while elevating the K2 experience to the next level.

RHEO Knee is an advanced prosthetic device from Ossur. Not waterproof, it is weather and splash resistant.

NEXT STEPS

Returning from Rehab

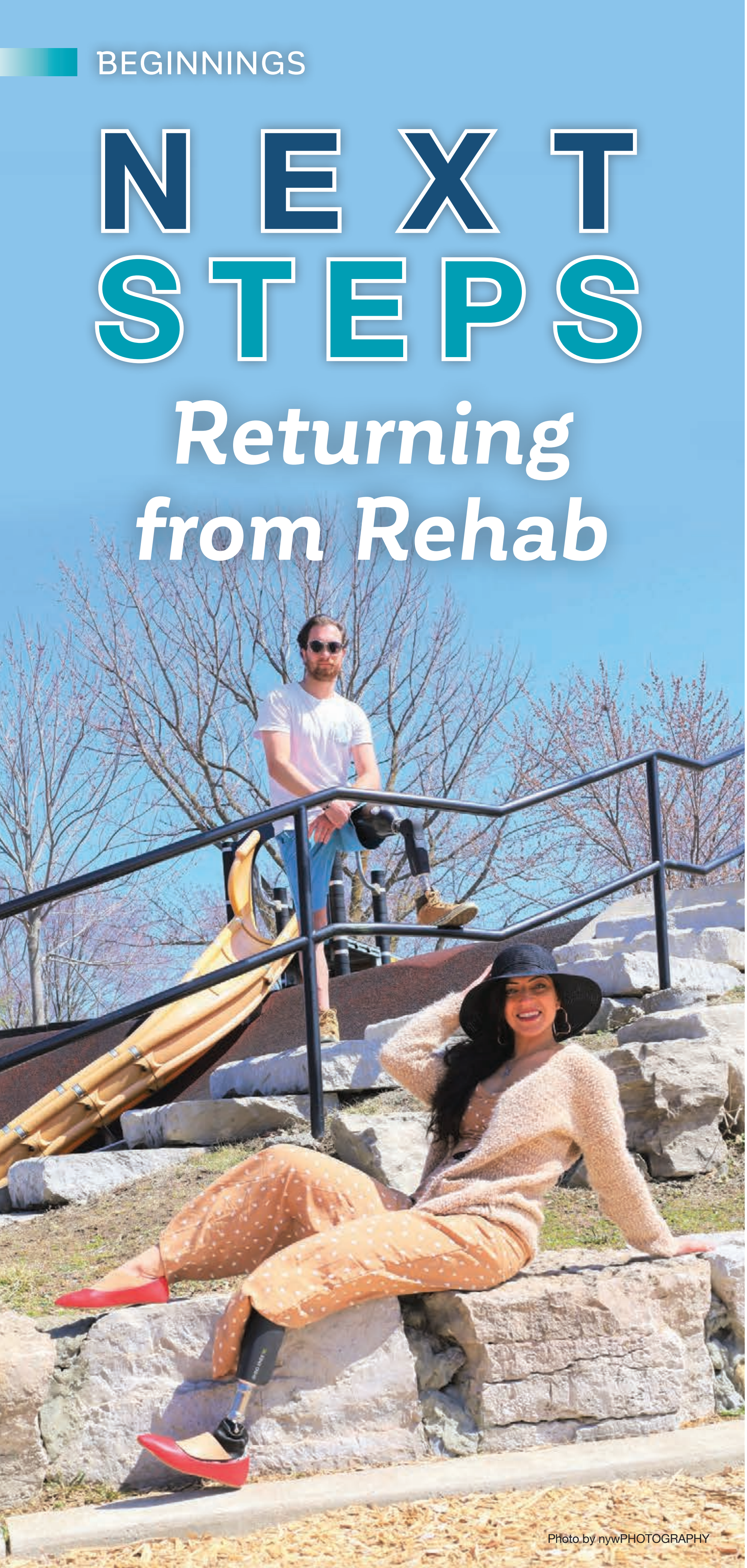


Photo by nywPHOTOGRAPHY

By Rouzalin Hakim
and Mathew Levinson

A four-part series from two new amputees on their journey from the familiarity of rehabilitation to the unknowns of home. Rouzalin and Mathew share their fears and challenges – both physically and emotionally – and their progress as well, as they meet the tasks and trials associated with learning to live with limb loss.

Rouzalin and Mathew:

When you first come home to your family, friends, and surroundings you're enveloped by buzzing distractions. But as things start to quiet down you're left to settle into your new life as an amputee. Meeting and managing the daily challenges and obstacles that were at first so daunting is a huge step. But then comes a new dilemma that never really crossed your mind until it suddenly does – now what?

You're comfortable navigating your own home on a prosthesis or with a wheelchair, but what's next? The pressure of going back to work begins to mount. The lack of motivation to step outside of your comfort zone is a problem, or conversely, feeling so motivated that your body can't keep up. It's all about finding balance… pushing yourself to try new things or get back to the things you love while remembering that your body and mind still need time to heal.

> “Being the only amputee in a fitness facility can prove difficult and uncomfortable… but taking the steps to face that head on brings me pride. Having a health and fitness goal keeps me focused and motivated.”

Rouzalin:

First, there was the initial rush and excitement of finally coming home. Once the dust started to settle so to speak, and I had a moment to reflect, I wondered: “Where do I start?”

This journey is so different for each and every one of us. Yes, we are a very caring and empathetic community that shares an indescribable bond as amputees, but how do we know where we stand on the spectrum of physical and emotional measures? What is ‘expected’ or ‘validated’ in these times? How do you go from knowing who you are and what you are capable of, to not even knowing how to manage your day-to-day routines?

I, unfortunately, do not have the answer and I’m not sure a definitive one even exists – I’m just here to share the very beginnings of my journey in hopes that it will help others along the way.

Personally, I was struggling to accept that this is my new life. Not every day was the same struggle. In the beginning, the days had no measurement or consistency. They unraveled as they pleased, and I was on the reactive side. Some days were light, and I had enough energy and happiness to go about my day just like I used to. I would go to work, see friends, run errands, even go to the gym and be proud of whatever I was able to do with my day.

Then there are the ‘other’ days, the heavy days, the days where your energy is just not there and your will to push through is exhausted. On those days it was hard to find the motivation to continue even with minimal tasks. I gave in at times because I didn’t really have the strength or will to fight. But mostly, I still pushed myself and I did the best I could to show myself compassion and acceptance. Life was not linear before my amputation, so I don’t expect it to be that way now. I try to remind myself of that.

As a new amputee I find that there are so many variables that run through your mind with each new thing. Everything is foreign at first and can be extremely overwhelming. I’m coping with assistive devices (crutches, a walker and a wheelchair), phantom pain, sourcing energy, adjusting to my prosthesis, and figuring out my capabilities.

For me, peoples’ reactions are what make me feel the most insecure and vulnerable. Not everyone reacts negatively, but just differently. Sometimes I catch people staring for too long, totally unaware of how uncomfortable it makes me feel. Sometimes people move a ridiculous distance away from me in the aisles of grocery stores, for the good intention of giving me safe space. Not the most comforting feeling for me. I have older neighbours helping me now when I used to be the one helping them. I am beyond grateful, but it highlights the major shift in my life. “Will I ever be capable of repaying them, or shovel snow from my car independently and confidently again?”

Luckily, time is on my side. As time goes on, I’m getting the hang of things – becoming more comfortable and adapting. I remember being told about the resiliency and adaptability of amputees. That didn’t really resonate with me initially. I needed firsthand experiences to confirm it.

Outpatient rehab and follow-up sessions go a long way. Physio helps with balance, coordination and strength. Hitting small milestones brings self-reassurance. An important milestone for me was getting my second socket. It fits so much better, bringing with it a ton of relief and hope. The locking valve is now towards the back of the socket which gives it a more discreet look. Padding on the 'seat' has relieved skin irritation. The new socket gave me a great deal of confidence to test my comfort zone little by little. Heavy days became more infrequent. My purpose and drive became more recognizable.

I returned to work virtually, and part-time. I expanded my support system, and joined a gym with a personal coach. Fitness has always been a huge passion of mine and feeling like it was compromised due to my accident played a huge toll on my mindset. Finding my way back to the weights provided a sense of accomplishment and courage.

I choose to go to the gym only on days that I feel energized and safe enough. I removed the expectation and pressure of going on days I didn't.

Being the only amputee in a fitness facility can prove difficult and uncomfortable both physically and emotionally at times, but taking the steps to face that head on brings me pride. Having a health and fitness goal keeps me focused and motivated.

Spreading out my resource of energy is a vital learning curve that I'm still experimenting with. I was always a very on-the-go person, so having to plan for events and tasks is very foreign to me. But, in the eight months since my injury I am improving my energy, outlook, comfort level and enthusiasm. I suppose this is part of acceptance, a stage I never believed I'd reach.

I know this comes to us at different times and in waves. If you haven't reached yours yet, don't give up or try to rush it. It comes organically, not according to any prescribed timeline. Trust in yourself.

Roz's Tips:

- For lower limb amputees, silk socks for your prosthetic foot help with shoe changing.
- A prosthetic foot that is one size smaller than your sound one helps with shoes too.
- Clean your liner before you shower so it's clean and dry when you're done.
- Bring entertainment (book or magazine) to your prosthetic appointments.
- Include Massage Therapy (if possible) in your recovery process; it's amazing!
- Stay in contact with friends from rehab – no one gets us the way we do.
- Speak to fellow outpatients and share experiences.
- Optimize the upcoming seasons – find joy in every one.

Mathew:

> "It's important for your mental recovery to know that you can still do the things you loved before; it just might look a little different."

After a busy first few weeks getting settled at home, things started to quiet down. I was still on two crutches, but able to move around my house relatively well. As an avid sports enthusiast before my amputation, I was eager to get back into the activities I loved. And when I say sports, I don't just mean one or two, I mean all of them. Football, basketball, golf, baseball, hockey – you name it – sports were an integral part of my life.

That said, it was really difficult to take that next step back to sports while I was still so reliant on crutches and aids for balance. I think for anyone going through a life-changing event – it's important to get back into the things you loved before however you can, whether it's sports, music, art, writing or gaming. It's important for your mental recovery to know that you can still do the things you loved before; it just might look a little different.

One morning I made my way downstairs for a workout, but before I even touched the weights I was distracted by the row of putters and golf balls my dad and brother use to practice every day. I needed to try it. At the time I was using two crutches to get around, but I had been easing myself into using just one. I decided to ditch the crutches all together and just grab my putter. I figured I could use it like a cane, right? So, I did. I hobbled over to set some golf balls up about 10 feet from the practice hole. My aim wasn't great, but it just felt so good to have a little glimpse into what was possible.

I had done some research and followed a few people on social media who played the sports I used to with a lower limb amputation like mine – that gave me an immense amount of hope that one day, with practice, resilience, and determination, I would too.

Physiotherapy sessions have been extremely helpful in taking that next step, and the work I did there was so important in my recovery both physically and mentally. With every session I felt

more confident in my balance, and comfortable on my prosthesis – while getting physically stronger at the same time.

Sometimes you feel too tired to drag yourself out of bed in the morning and make it to those sessions (whether they're at home or not) but they are beyond worth it at the end of the day. The more comfortable I got with my prosthetic leg, the more eager I was to push my limits – safely, of course. So, one day I decided to try playing some basketball.

I had worked on a few basketball exercises with my occupational therapist – simple dribble drills and changing directions. I felt like I was in middle-school gym class again. In a weird way it was muscle memory, with one less muscle and one new one. I was training my mind and leg to adjust and adapt. I went to the court and tried a few shots. I started with a few misses, but found my range pretty quickly. I even tried dribbling under my prosthetic leg – it was like when you first learn to dribble through your legs as a kid, lifting your leg high up over the ball with every bounce. But just like when I was a kid, I knew I would get better with time. It felt awesome.

It wasn't all fun and games though. I was eager to try all the sports and activities I loved but they didn't always go as planned. After playing basketball I was so exhausted on the walk back from the court, to the point of a few muscle spasms in my residual limb along the way. Massaging my limb helped a bit, but I still needed a long nap when I got home.

It was a bit of a reality check that I still don't have the energy I used to, and I probably won't for a while. I also fell for the first time, while playing disc golf with a friend. I wasn't hurt, but it was a scary moment where suddenly you're on the ground and don't know how you got there. And again, like a kid, I got up, dusted myself off, and kept pushing forward. With every fall, and every misstep, I believe that I'm bouncing back stronger.

All in all, my advice to anyone going through adversity is to get back to doing the things that make you happiest – in whatever capacity you can. Through your recovery, look for inspiration in other people who have gone out and accomplished amazing things, because with the right mindset you can too.

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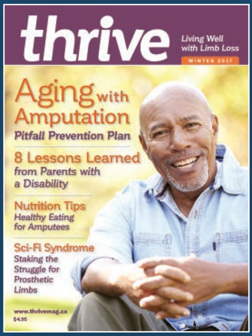

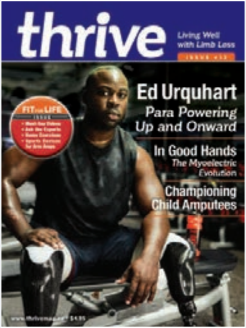

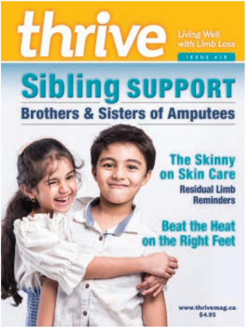

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Marleigh (left) and Rachel

CAMP CANDOU

Where Bonds for Amputee Youth are Built to Last

By Jennifer Rodriguez

As a first-time overnight camper, 12-year-old Marleigh Vickery-McDonald came to Camp Maple Leaf not knowing what to expect exactly from her five summer nights at a brand-new camp.

Marleigh had intended to come to Camp Candou, an integrated Camp Maple Leaf offering for kids with limb loss and limb differences. It was 2021 and the pandemic ensued, limiting registrants for the "amp camp." Not deterred, Marleigh instead joined LPO (Little People Ontario) at their camp for children of short stature. "She was welcomed with open arms," says Camp Maple Leaf Director April Young with a smile.

Yet ironically, arriving as the only camper with a congenital limb difference, Marleigh meets her camp counsellor Rachel Quilty, otherwise known as "Pascal", who shares the exact same limb difference as Marleigh… both missing their left hands.

Camp Maple Leaf, a charitable organization founded in 1955, is located on Jacob's Island in Ontario's Kawarthas. The organization offers week-long camp sessions for children with unique life challenges and integrated camps for kids who need help with specific life challenges.

April has a life challenge story of her own, one that led her to become a camp director. She was a patient at Sick Kids Hospital as a child. Her cystic fibrosis meant constant visits and tests

Photos courtesy Camp Maple Leaf

for her respiratory illness. At the same time April was a camper, sometimes away for weeks at a time at sleepover camps.

With a lot of experience in camping and camp counselling, particularly with kids with cancer, April acquired a significant amount of knowledge from youth with unique medical needs. When she got the opportunity to design a charitable camp on an island, April described it as a "camp director's dream".

She emphasizes, and embodies, spirit in everything she designs. From camps serving children from military families, to camps for kids who are grieving a loss, to camps for those with various disabilities, they all are offered for specific reasons and invite campers' siblings to join in. April highlights the importance of friendship in each camp, with the phrase "friendships that follow you home" as one of her "Six Goals in Six Days". Each camp is a place where kids are able to help each other navigate through relatable challenges.

With exceptional populations as her customers, April collaborates with medical experts on specific challenges that campers like Marleigh and Rachel face. "I'd like to have as many campers as we have experts," she says, speaking to her vast network of support. For Camp Candou, she sourced advice from seasoned amputees and prosthetic clinic practitioners, as well as the Amputee Coalition in the U.S. which suggested that air conditioning in the cabins would allow prosthetic devices and residual limbs to cool down when campers went to bed at the end of the day. The Amputee Coalition also hosts a camp for children with limb differences, sharing ideas with April and other camp organizers freely.

For Rachel, being a camper for as long as she can remember and becoming a camp counsellor at age of 15, the 23-year-old is

quite accomplished in both her camp world and her professional life. That confidence carried over easily into her relationship with Marleigh.

Rachel has a wide range of interests, from artwork and outdoor activities to her work experience as a Communications Specialist and a Lifeguard and Swimming Instructor. All throughout her time given to her 9-5 job she still remained dedicated to camping on weekends, something rooted in camping road trips with her family as a child.

Marleigh described meeting Rachel as “a perfect welcoming”. She says Rachel was so calming, loving and like a safe place for her. They bonded immediately over a necklace that Marleigh was wearing, which happened to come from an out-of-town café that seemed like only the two of them would know about. Not only a coincidence, the necklace was an instant connection that brought them together. Taking on new challenges together, and consistently encouraging one another, they quickly grew a strong camper-counsellor relationship.

One of the first things that Rachel observed about Marleigh was that she did not wear a prosthesis. When Rachel opened up her suitcase full of prosthetic devices, Marleigh was mesmerized. It was a new world of knowledge for her, especially when she saw Rachel’s NEXO device and her HoneyComb prosthesis. As soon as she could, she introduced Rachel to her family to share her “prosthetic closet” with them too and point out the particular prosthesis that she wanted.

With her bond with Rachel in hand, Marleigh began to confidently volunteer in the camp plays, and singing and comedy shows. Aside from sharing the same disability, April describes them both as “bubbly girls” who helped one another gain confidence throughout any activity.

Rachel learned the importance of teamwork through some of her own challenges at camp. When it was time to achieve her Level D in Canoeing, which required her to solo run canoes, she struggled. She was unable to paddle using any other stroke besides forward. To help Rachel achieve her Level D, her team members rallied around her. With help from the maintenance staff, together they crafted a paddle that worked for Rachel by connecting it to an adapter on her left arm. Rachel had her own special paddle. It was a process getting to that final version but she says the Duct

Camp Director April Young

Tape and Gorilla Glue and welding on early versions was worth every step along the way to get to the final product. She received her Level D and bronze medal.

One of the first challenges that Marleigh and Rachel took on together was learning archery. Marleigh was quick to let Rachel know that she didn't need any help, determined to figure it out on her own. Rachel countered by expressing her own need for help. Both needing to participate with just their right hands, they worked it out as a team of two. "If there was anything that was the biggest help from Marleigh," Rachel reports, "it was her determination and resilience."

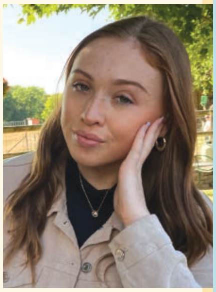
In the words of both Marleigh and Rachel, Camp Maple Leaf is a home away from home. "There is no place like it," Rachel explains. "It's a place where you can learn the 'nitty-gritties' of life, and share them with each other." Marleigh agrees, and adds that it is "somewhere where you feel that sense of belonging."

Camp Candou, the camp designed for amputees like Marleigh and Rachel, is a place made for those with their disabilities to come together, but not solely focus on their disability. As Rachel says, "it is the reason why you are in the camp, but there is additional support, like your siblings, and an environment where you can be yourself and take on challenges with people who will help you figure it out."

Rachel and Marleigh remind us that once you are at one of Camp Maple Leaf's camps, you are not identified by your disability. Instead, individuals are identified for little, fun things, like Rachel being known as the "open-toe shoe" girl which she and Marleigh share as an inside joke. And Marleigh, she's known for her fun-loving nature in performances.

With a passion for performing and taking on her own roles, Marleigh is looking forward to a chance to teach others, and more acting opportunities, and returning to Camp Candou as a camp counsellor like Rachel one day. And for her, her new friend Rachel will always be known as Pascal, holding her camp name just as close to her as Camp Maple Leaf.

ABOUT THE AUTHOR:



A graduate of Media and Communication Studies from Brock University, Jennifer loves storytelling and developing valuable content. She grew up learning about prosthetics and orthotics from her father, a certified orthotist and prosthetic technician. She's watched her mother master various insurance industry roles for over 20 years. With two very hard-working parents, her main goal is to follow their footsteps.

ROOTED IN SPORT

As with most things with roots, the Amputee Coalition of British Columbia has some intersecting twists and turns.

Its incarnation was a by-product of the 1976 Olympiad for the Disabled in Ontario. Born out of this event was the Canadian Amputee Sports Association (CASA). Several keen volunteers rounded up more keen volunteers and provincial chapters began popping up. That's what happened in B.C.

B.C.'s Madeleine Anderson *(pictured above)* **was asked if she would get a B.C. group organized and registered. It took some time, primarily due to the fact that Madeleine moved to Alberta for five years.**

In 1982, the B.C. Division of CASA was formed. Over the years, CASA-BC members felt that the association needed to be more inclusive. After all, not all amputees can, or want to, play sports.

In early 2008, a few amputees who gathered as a support group hosted by GF Strong Rehabilitation Centre in Vancouver arrived at the same conclusion: many amputees, especially recent ones, were not being well served. No information or support in their time of need. Families, spouses, and parents needed some assistance too.

Enter the Amputee Coalition of B.C. By this time, CASA-BC was all but non-existent. The new mission took root and the organization's name officially changed to ACBC.

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