# 

Living Well with Limb Loss

ISS<u>UE</u> #18

# Aging with Amputation

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# $C \cap N \top E N \top S$ issue#18

### FEATURES



Starting Together Rouzalin Hakim and Mathew Levinson are sharing their journey as new amputees.

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Aging with Amputation Planning for Prevention of Pitfalls.

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### WELCOME

### "Enjoy the little things. One day you may look back and realize they were the big things."

- Robert Brault

My niece is graduating from high school this spring. It's yearbook time and the graduating class



thrive founder and publisher, Jeff Tiessen

has been asked to submit their "departing words"... a whimsical or philosophical or prophetic personal quote for the back pages of the book.

My niece, a resourceful one, turned to her older cousins, uncles and aunts and grandparents to mine for her message. Her question to us to ponder essentially hovered around what is to say: "What do you know now that you didn't know in Grade 12?" - a message from our grown-up selves to our adolescence. We need not be poets my niece assured, and we could draw from other people's wisdom.

It's a great assignment as we move into 2022. Timely. Reflection always is. In our grown-up world today, bombarded with pandemic projections and protocols, do we afford ourselves time to reflect? Time to be grateful for what is good in our life? Appreciation for the paths we've travelled, as amputees, or our spouses, parents, children and practitioners.

In a world of worry and media-perpetuated breaking bad news, can we lean on the small stuff? The good stuff. Looking back, my advice to me as a teenager just learning how to be a new double-arm amputee might be as simple as this: "It's going to be okay."

That is not going to make the back pages of my niece's yearbook... but maybe Baltasar Gracian's message might: "Ability develops and reveals itself increasingly with every new assignment."

Jeff Tiessen, publisher jeff@thrivemag.ca

> **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 43 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.

# thrive Living Well with Limb Loss

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### **READERS WRITE**

# SENIOR SAVVY

Three years ago, at 72, my husband became a 2-BK amputee. He was a retired music teacher. Not particularly athletic, we as retired seniors had a lifestyle that included leisurely walking, driving, going on cruises and going out to dinner. We did not participate in sports, weren't hikers or climbers.



I say this because as much as we like the content of your magazine, we do wish for more articles about average seniors who are amputees. We admire and are inspired by young, fit, active amputees, but it would make for a more realistic publication with articles for and about retirees who are amputees. All the best, Molly and Bob

Editor's Note: Thank you for the reminder. We definitely took your advice to heart in putting this issue together and moving forward in 2022. Hope there's more relevant content for you to enjoy in this issue.

### NEW BEGINNINGS

My name is Rouzalin and I've been reading thrive magazine for the past few months. As a new AK amputee, I've found it extremely helpful and insightful in several ways. Reading thrive opened my eyes to a whole new world of possibilities that comes with being an amputee. I reached out to Aristotle Domingo who was on the cover of thrive in 2018. I organized a Q&A with him to share his insights with a group of amputees before my discharge date.

I've been writing about my own personal experiences, the trials and tribulations of being new to the game. While it's been super inspirational to speak to seasoned amputees, I think it would be a great idea to get the perspective of a newly-amputated individual. Having just gone through a major life change, things like phantom pain, limb mourning, PTSD, my first prosthesis, and various physical and emotional changes are fresh in my mind. I think I can guide other new amputees. I'd love to put together an article for thrive

from the POV of a newbie.

Editor's Note: We thought Rouzalin's idea is a good one for new amputees. Starting with Kind Regards, Rouzalin Hakim this issue, she and Mathew Levinson, also a new amputee, will share some of their thoughts and experiences in a four-part series beginning with Returning Home from Rehab. We introduce them to you in a feature story as well.



Aristolle Domingo



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Kayla Crnecki





### TAKE NOTE

# **PASSING OF WINTER**

A prosthetic-tailed dolphin named Winter that starred in the "Dolphin Tale" movies died recently at its Florida aquarium despite life-saving efforts to treat a gastrointestinal abnormality.

The 16-year-old female bottlenose dolphin died while being prepared for a procedure at the Clearwater Marine Aquarium where the famous marine mammal has long resided. Veterinarian Dr. Shelly Marquardt said the aquarium worked with specialists and marine mammal experts from around the country but the dolphin, which was in critical condition and declining, died while being held by caregivers.

Winter was two months old when her tail became entangled in a crab trap near Cape Canaveral, which forced its amputation. "Dolphin Tale," which was released in 2011, chronicled Winter's recovery and the unprecedented, lengthy effort to fit her with a prosthetic tail. The film, starring Harry Connick Jr., Ashley Judd, Kris Kristofferson, Morgan Freeman and Nathan Gamble, was largely shot at the Clearwater aquarium. "Many were inspired by her resiliency, including so many on their own health journey," the aquarium statement said.



CRITTER

EMENTAR

# **Adventures of Roxy**



Physical therapist Hillary Sussman has worked with many clients with disabilities in her 23-year-career. With that experience and some inspiration from her dog Roxy, who has undergone four surgeries, she's helping kids with disabilities gain more confidence around their physical limitations.

Sussman's first book – *Roxy and Maliboo, It's Okay to Be Different* – is a story about two lovable dogs with unique features that teach important lessons of limb difference awareness and acceptance. In her newest book, *Roxy and Tully, Words* 

*Matter*, Roxy raises awareness about prosthetic devices, how to handle bullying, the importance of word choices, and how they impact others. She plans additional books in the Adventures of Roxy series where Roxy learns something new in each one, makes new friends, and teaches life lessons as she faces new challenges. Learn more at www.adventuresofroxy.com.

8 thrive ISSUE #18

# Escaping Poverty, Pirates and the Pandemic at Sea

### By Chris Williams

Dustin Reynolds says he has pulled off a feat very few people in the world have accomplished — and doing it without an arm and a leg. The 43-year-old double amputee claims he circumnavigated the globe after setting sail more than seven years ago, ending his journey in Hawaii in late 2021.

The Ocean Cruising Club, although not a formal certifying agency, is a membership association for sailors and said it documented Reynolds's endeavour, even providing him financial help throughout his journey.

Reynolds lost his arm and leg in a motorcycle crash in Hawaii in 2008. He said the subsequent healthcare bills left him cash-strapped, and unable to restart his business. He was left with his commercial carpet cleaning van and fishing boat which he sold to buy a \$12,000 yacht and fulfill his idea of sailing around the world after reading about it on the internet. "I've never actually sailed before," he told FOX Television. "So, I started researching boats and how to sail."

He left from Kona, Hawaii, in 2014, an odyssey that took him to 36 countries including Tonga, Fiji, Australia, Indonesia and the Galapagos Islands, with his longest stay being 10 months in Bali. He documented his journey on his Instagram page and blog. Reynolds said he encountered storms on his journey, both literally and figuratively. The Covid-19 pandemic hit while he was docked in the U.S. Virgin Islands. He then sailed to Rhode Island to wait out the hurricane season before resuming his journey, taking him through the Panama Canal and back to Hawaii.

And then there were pirates. Reynolds said he encountered them sailing around the Solomon Islands. They hopped on his boat from their own. He scared them off by threatening to shoot them. "I didn't really have a gun on the boat but they didn't know that."

Through it all, Reynolds said his trip taught him a few lessons. "I've learned to ask for help," he said. "I was able to start trusting that things would work out and people would be there for me." He encourages others to also take a leap of faith.





# FITNESS APP FOR AMPUTEES

Designed specifically for lower limb amputees, this free app helps you achieve optimal outcomes with your prosthesis. The "Fitness for Amputees" app from Ottobock was developed by therapists and includes three modules: Strength and Endurance, Coordination and Balance, and Stretch and Relax. Each module includes multiple exercises that can be completed at different levels of difficulty, depending on your ability. The app allows you to set personal goals, track your progress, and even incorporate your own audio playlist into your program! It can be downloaded for iOS or Android devices at iTunes and Google Play.

# Legs 4 Africa

With Canadian operations, Legs 4 Africa is helping people walk again in sub-Saharan Africa. Through re-purposing prosthetic legs that would otherwise end up in landfills, and facilitating amputee-led community groups, Legs 4 Africa is giving thousands of people the ultimate leg-up every year.

In many parts of the world, prosthetic legs cannot be reused or recycled. This means that every year thousands of legs end up in landfills. By working with limb centres, manufacturers and the general public, the organization is trying to prevent this from happening in order to benefit others in need. Legs 4 Africa collects legs from individual donors and prosthetic clinics across the United Kingdom, France, Canada. Australia and the U.S. and since 2014 has saved over 10,000 legs from landfill. To learn more visit www.legs4africa.org.



# FIRST TO FLY IN ZERO-GRAVITY

New space firm, Mission Astro Access, is challenging the perception that space travel is only for those who meet specific physical criteria, and has sent its first disabled crew on a zero-gravity flight.

"It was magical," says Sina Bahram of his first experience of weightlessness. "I've wanted





to do this since I was four years old, but the underlying assumption was 'that's totally impossible'." The blind computer scientist from North Carolina was one of 12 ambassadors with disabilities selected to experience a zero-gravity flight while conducting experiments looking at inclusive space travel.

"It can benefit the entire aerospace community," Bahram says, explaining that adjustments made for people with disabilities makes everyone's lives easier.

In October, the Mission Astro Access crew travelled to Long Beach, California, and boarded a Boeing 727 for a parabolic flight. Sometimes referred to as the Vomit Comet, the plane flies in large arcs. As the plane tips over the arc it goes into free-fall creating weightlessness for about 20 seconds.

Ambassador Mary Cooper always dreamed of space travel but thought it to be impossible for her. The aerospace engineering and computer science student at Stanford University was born with fibular hemimelia, where part or all of the leg bone is missing. Cooper had her left leg amputated below the

knee as a baby and uses a prosthesis. "It's one of my favourite things about me now," she says.

Each crew member worked on specific experiments in line with their disability to see how the industry could move forward, inclusively. Cooper's experiment gave her permission to cartwheel. She wanted to prove she could station keep – manoeuvre around the cabin safely – with and without her prosthetic leg.

Mission Astro Access isn't alone in this space race. The European Space Agency called for six para-astronauts this year as well. Mission Astro Access' 12 ambassadors will now also "rethink life on earth" and encourage greater inclusivity within the science, technology, engineering, and mathematics (STEM) sectors.



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# Calling all Inventors!

### Blue Heart Hero's Kitchen Announces Accessibility Contest!

Blue Heart Hero (developers of the CURVD mug) invites all designers, engineers and enthusiasts to share their designs for a 3D printable assistive device that makes kitchens more accessible. It can be an attachment to open the fridge door, or maybe something that helps someone with a visual impairment cut vegetables, or a solution that helps those in impoverished countries.

Xometry, the leading platform for on-demand manufacturing, is proud to serve as a lead sponsor of Blue Heart Hero's Kitchen

Accessibility contest to leverage technologies like 3D printing to make items that help people with disabilities in the kitchen. Entries are FREE. The submission deadline is March 27, 2022. Full details are available at www.bluehearthero. com/design-contests-1.



### BIONIC KID COMIC

Teenage brothers Zachary and Christo joined forces to create a special comic titled *The Bionic Kid* with the goal of raising money to give another kid like Zachary the chance to get a fully-funded prosthesis.

When Zachary was younger, he received a prosthesis with the help of Limbitless Solutions, a U.S.-based nonprofit organization that specializes in free prosthetic devices for children. So far, the duo has released two issues and have raised \$11,000.

*The Bionic Kid* comic is a product of love for all involved. Lead authors Christo and Zachary submitted their scripts to Dr. Albert Manero, Matt Dombrowski and Victor Davila at the University of Central Florida (UCF). They, along with UCF art student Kirk Macy, are making this dream come true! For more, visit www.thebionickid.com.





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### POINT OF VIEW



Olay's new lid was made for people with disabilities. Too bad you can't find it in stores. High-profile companies like P&G, Lego and Nike are launching inclusive designs. But does inclusive design matter if the release is exclusive?

Skin-care giant Olay recently released a face-cream lid ostensibly designed to be "accessible for all." the latest iteration of consumer goods positioned to serve people with disabilities. Olay announced its limited-edition lid prototype developed for "consumers with a wide range of conditions, from dexterity issues and limb differences, to chronic issues causing joint pain and vision impairments," with fanfare. To publicize the new packaging, it launched an ad campaign including video and a lush multi-page advertisement in the Sunday print edition of The New York Times.

The easy-open lid includes four features: a winged cap, extra gripraised lid, a high-contrast product label, and Braille text for "face cream." It is designed to fit on four creams in Olay's popular Regenerist line, and is available exclusively on the Olay website — not on store shelves.

Upon closer inspection, it's clear this launch is more of a PR [public relations] tactic than a genuine effort to make more accessible products — and Olay is far from the only brand to take that route. Inclusive design is not typically acknowledged as the marketing campaign that it often is. It is difficult to find a product created through an inclusive design process that has succeeded beyond its hype.

Adaptations to existing products and new flexible features



# NOT Available in Stores

By Liz Jackson and Jaipreet Virdi

are increasingly being launched by the largest corporations in the world. Nike, Unilever, and Procter & Gamble are among the companies that have launched "accessible" or "inclusive" products seemingly "for all." Yet, important elements of these launches have consistently faltered.

According to the campaign, Olay's design team incorporated insights from consumers "with a wide range of conditions" and met with external experts — including disabled journalist Madison Lawson — as well as team members with personal experiences to inform the making of the lid.

Despite this seemingly comprehensive outreach, consumers with disabilities have responded with skepticism. Emily Johnson, a tech and social media journalist, said in an interview that "most 'accessible' products aren't about disabled consumers at all." Rather, they're a public relations strategy, used to retain the loyalty — and praise of non-disabled consumers, and frequently fail to consider disabled consumers as an audience in brand messaging.

For example, the Braille text is limited to Olay's cap. Only a fraction of legally blind people actually know how to read Braille, and there are other, potentially more useful ways to convey information. "I could scan the barcode with my phone and get much more specific information than 'face cream,'" said Elizabeth Hare, a scientist who is blind, works on accessibility and uses screen-reading software. As with Braille, however, it can be tricky for many blind and low-vision people to locate a QR code or barcode, which shows the challenge of claiming the universality of this or any other accessibility feature.

It is interesting that Olay chose to print "face cream" in Braille, given what another Procter & Gamble subsidiary, Herbal Essences, did in 2018. They chose to differentiate shampoo and conditioner bottles with raised stripes and dots after learning from a focus group how few people know Braille today. Olay's use of Braille reads as an empty gesture; as Johnson notes, "labeling different products with the same label and no details in Braille is useless."

What does Braille communicate if it's not actually informative? Perhaps that Olay's winged lid fails to effectively symbolize disability, so it incorporates Braille as a way to visually demonstrate its commitment to inclusion.

Olay's brand line, "open for all," is typical of how disability-centric designs are pitched and sold to the public. The moniker "for all" does two things: first, it signals an alignment of the brand with the virtues of inclusive design. "For all" has become shorthand for the inclusive design mantra "solve for one, extend to many." Second, it inspires consumers, who have learned to associate the language of "for all" with corporate diversity and inclusion narratives.

It is disingenuous to claim an accessible product is "for all" when its distribution channels are less accessible than those for the mainstream product. And yet, inclusively designed objects tend to get released as limited editions through select channels — like Olay's, only available on its website and not on store shelves.

First published by Fast Company. The full article can be found at www. fastcompany.com. Liz Jackson is a disabled advocate, designer, and a founding member of The Disabled List, an advocacy collective that engages with disability as a critical design practice. Jaipreet Virdi is a disability historian, scholar, activist, and assistant professor at the University of Delaware. She is the author of Hearing Happiness: Deafness Cures in History.

# Impressed to the Max

By Kimberley Barreda



There are a lot of fitness products out there these days, and if you've noticed, many brands are jumping on the adaptive train. That's a really good thing.

One of those companies is Detroit-based MaxPro Fitness. The product, MaxPro SmartConnect portable gym is one of the most accessible workout systems I have ever seen, or used.

I first came across them at the Consumer Electronics Show in 2020, during Media Days, a pre-show opportunity to visit with companies before the show opens to the public. It's one of my favourite shows to attend as media, as it's highly accessible and packed with intentionally and accidentally accessible technology of all types. And "accessibility" is an actual product category, so there's a lot to see.

Being a lifelong double aboveknee amputee and wheelchair user, being able to live independently and hopefully well is my goal. My product searches always come from that point of view. Can I reach it and use it from my chair? Is it heavy? Can it enhance someone's (disabled) life in other ways? How much does it cost? Do I have room for it?

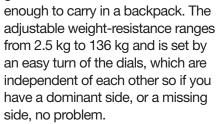
I was in one of the many healthtech halls when I saw a man at one of the booths putting his feet on a machine on the floor and start pulling on some handles.

His stance seemed to be about as wide as my front casters which is the kind of thing a wheelchair user notices, like the tiniest speck of broken glass on the sidewalk. So, I went over to see what it was. I pushed my way through the crowd of TV cameras to the front and got my first close-up look at it and instantly noticed how accessible it was.

When their presentation was over and the cameras moved on to the next big thing, I stuck around and asked if I could try to wheel up onto it as it seemed to be the perfect size, and disabled people struggle with fitness options. The gentleman who I originally saw using it – inventor Nezar Akeel – said yes, and so I did, and my casters fit on it perfectly.

I spent the next few minutes doing my best impression of a knowledgeable weightlifting routine (I learned it from my Arnold Schwarzenneger bodybuilding book) while the others in the booth asked if they could film on their phones. A conversation ensued about the size of the market – our market – which then turned to the health and fitness needs of the community, a very important distinction that they've embraced not only with welcoming users with disabilities to their brand, but actively seeking out users with various disabilities for feedback and incorporating it into their company.

So, what exactly is the MaxPro SmartConnect? It's a portable, foldable, full-body cable workout system that weighs around five kilograms and is small



The weight is digital, so there is no danger of dropping a heavy weight onto yourself or the floor, or tipping yourself over. Gentle cable return mechanisms prevent snap back of the handles, which are just one of the multiple attachments that include handles. wrist/ ankle cuffs, quad loops and a wide (padded) bar. The portability feature is supported with straps, corner protectors and quality ratchets which make it easy to attach the MaxPro to just about anything that will support the stress of the workout - trees, posts, deck rails, and doorframes for example.

For newcomers to fitness, Max-Pro has an EXTENSIVE video collection of workouts in its app, which also allows you to track your own achievements and progress. The company's exercise professionals also work with a number of disabled users to develop specific plans and programs for us, based on varying disabilities and needs. The fact that



it's highly configurable makes this the ultimate family product, as virtually anyone can use it.

Need a higher angle? No problem, the wall mount lets you position it easily at the most convenient height for a wheelchair, therapy table, a bench, or while standing or even seated on the floor or a bed. Company and end-user support is phenomenal, with regular motivational emails and workout regimens. The price? It's \$849 USD and backed up by a 60-day satisfaction guarantee. For more info, visit maxprofitness.com. And since I first tried it I got myself one of course. And the company has won an award for the product and welcomed Mark Cuban as a partner thanks to Nezar's successful presentation on TV's Shark Tank... during which the product's accessibility was duly noted.

Kimberley Barreda is an influencer, networker, writer, reviewer, promoter, and consultant specializing in lifestyle, sports, marketing and event planning related to the disability community. She gets to plan parties, go to cool events, and give stuff away. She's also a web developer, volunteer, and every now and then still does a bit of modeling.

Point of View features the opinions of its authors and not necessarily those of thrive magazine or its publisher Disability Today Publishing Group, Inc. Content is published as opinion editorial.



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### MIND OVER MATTER



# **REST** is the Best Protective Gear

**By Kelly Ramsdell** 

### "The time to relax is when you don't have time for it."

~Sydney J. Harris

No matter what airline you fly, there are safety instructions at the start of every flight that the flight crew goes over with everyone on the plane.

The important ones are also listed on a card in the seat pocket in front of you. Besides letting you know where the exits are, there is always some version of the following statement: "In the event of a change in cabin pressure, oxygen masks will automatically drop from the ceiling. Put your own oxygen mask on before helping others."

Most times, there's no further explanation about this particular safety procedure. I suppose that if there was, it would sound a bit dark. Something along the lines of "there's no use you starting to help someone else, and failing, and then both of you passing out."

The phrase "put your own oxygen mask on first" is so commonplace that people use it in other contexts. Medical personnel and counselors say it to caregivers when they mean to remind them to take care of themselves; some bosses say it to their harried employees who are in the process of burning out.

On the one hand, it's similar to the advice given by the Six-Fingered Man, Count Rugen, to Prince Humperdinck in the movie The Princess Bride. "Get some rest. If you haven't got your health, you haven't got anything." It's a way of advocating basic self-care by maintaining one's own health.

On the other hand, it can sound puzzling or even contrary to what we believe. What's so bad about putting the needs of others first? Isn't it selfish of us to prioritize ourselves when other people need us to care for them? How can we rest when there is so much to be done?

I used to scoff at the idea of putting my own oxygen mask on first, but I learned the hard way to pay attention to this particular platitude.

A little more about me, so you know where I'm coming from: I have rheumatoid arthritis (RA) and fibromyalgia. I came down with RA almost twenty years ago, when I was a single mom taking care of my two young daughters, working a full-time job as an attorney, taking care of my own house and yard, cooking, cleaning, and doing EVERYTHING.

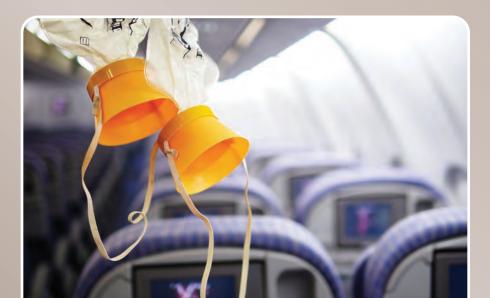
I rarely asked for help, and on the one occasion that I asked my mom to watch the kids for a weekend so I could get a break, she turned me down. Her message, and the one I had already internalized, was that mothers don't get to rest.

I put my kids first, my job second, the house third, and to be honest, I am not sure if I was even on the list of my top five priorities. In the end, I paid for it with my longterm health. After my diagnosis with RA in 2002, I ended up on long-term disability (because I was fortunate to have good disability coverage at work). It's been nearly twenty years, and I still can't commit to a "regular job" outside of my home because (a) stress causes my conditions to flare and (b) even if I can show up for a day or week, there's no guarantee I can do it longer than that without my symptoms acting up.

The link between stress and the onset of RA is fairly well-documented, and I had stress of all sorts back then. Also, and I tell you this to make it clear: I ignored myself.

I ignored my health, my need for sleep, my mounting stress levels. To the extent that I thought of myself and my own needs, my self-talk was a nonstop negative inner critic, constantly telling me what I was doing wrong. It quickly shut down any thoughts that I deserved a break or any assistance.

In the context of my own life, "putting my own oxygen mask on first" might have been permission to ask for some help, or hire some







help. It might have looked like reducing how many hours I was working. It might have looked like me putting myself in bed at a decent hour every night instead of burning the midnight oil to do client work, sew Halloween costumes, and clean the house. It most certainly would have looked like getting more rest. Since I did none of those things, it is little wonder that my health took a beating until I was forced to slow down and rest.

These days, I know to listen to my body when it sends out a warning. To take a rest the first time I notice things starting to act up, because if I don't, a flare is certain to follow. I schedule recovery days for the day after travel, or the day after an infusion treatment.

Over the years, I've arrived at an analogy that I prefer to the oxygen mask one. It has to do with firefighters. As I think about things, I picture two firefighters who go about things in very different ways. The first of these two firefighters sees your house on fire and runs toward it in his T-shirt and shorts. He grabs a garden hose lying nearby and gets close to the house to get the water from that garden hose to reach the flames. If the flames explode or the wall falls down, he will be injured, or killed, and others will have to rush in to rescue him. His garden hose might be helping, but only a little. He has to back away after only a few minutes and the house continues to burn.

The second firefighter grabs her helmet and respirator. She puts on her flame-retardant suit and her boots and gloves. It takes her longer to get to the house, but she is fully prepared to take the high-pressure hose and use it, and can hang in there and work until the flames are out.

If your house was on fire, which firefighter would you be? The one who rushes in without thinking or taking care of themselves, or the one who takes the time to ensure that she is protected and prepared?

Our natural instinct is to rush in and help, to do all we can right away. But sometimes, it is better to take just a bit of time away from that burning house so that we can take care of ourselves and our bodies — our own equipment — so that we can hang in there and be of assistance much longer.

It is not selfish of you to take time to preserve or improve your physical and mental health. Under either the oxygen mask or the firefighter analogy, it's using the proper equipment for you to be able to continue to do all the things that need to be done to take care of the others who depend on you.

Of course you want to do the best you can under whatever circumstances you face. Taking care of yourself, taking breaks, asking for help: all of those things will allow you to hang in there a bit longer, and do the job a bit better. You deserve nothing less.

### ABOUT THE AUTHOR:

Kelly Ramsdell is the founder and CEO of Actually-I-Can, Inc., which helps women and



those who identify as non-binary to reclaim and redesign their lives with aligned ease. She has written two ebooks – *12 Tips to Help You Sleep* and *Lower Your Anxiety* – to help people through trying times. Order them at www.actually-i-can.com.

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By Max Warfield and Jeff Tiessen

Rouzalin Hakim and Mathew Levinson unexpectedly found each other in the same strange place at the same time. Strangers themselves, they have forged a friendship, sharing the same journey as new amputees. But while their paths overlap, they diverge at the same time.

# Mathew Levinson

St. John's Rehab at Sunnybrook Hospital in Toronto over the last six months presented a stark new realm of reality for Mathew Levinson. Yet, even at this early stage of his rehabilitation, he carries a desire to share his insights from this experience because he believes it will help others.

The 28-year-old from North York sustained an above-knee left leg amputation in July of 2021 – an incident involving a train in Banff, Alberta. He was born and raised in Toronto and returned home to start his rehabilitation. Levinson hopes to spare new amputees difficult lessons in a strange world never considered beforehand. He tried to be a source of encouragement at the hospital and discovered a like-minded patient there named Rouzalin Hakim. He was comforted to learn that she was keeping a journal chronicling her experiences — just like he had been doing. Together, they agreed that they should share their thoughts as a means of informing new amputees what they might expect in this place of unknowns. "We have very different perspectives on the whole thing," he says.

Before his injury, Levinson worked as a copywriter for an advertising firm. He's always enjoyed all sports and things active. He loves snowboarding, hockey, basketball and golf; anything that creates a challenge for him to surmount. It is this upbeat mindset, he acknowledges, that has helped pull him through the past several months and impress the St. John's staff with his "positivity".

"I feel fortunate that my accident didn't leave me in worse shape," he tells. "It could have been even more serious." He has channeled this attitude into learning to walk more guickly than expected and earning confidence from those around him that his approach is authentic. "I was in Calgary for a few months before the accident. After losing my leg I moved back home and re-situated myself here in Toronto with my parents. I am fortunate to have such a great support system behind me when I need it."

Levinson has always been

# Rouzalin Hakim

A fear of stairs isn't something that Rouzalin Hakim ever imagined she'd experience. A self-described "go-getter" and "adventure seeker" there was nothing that this workaholic and fitness fanatic could imagine that she couldn't overcome. She questions that belief right now but knows it's still in her to lean on.

Not many months ago her feet were firmly planted. She knew exactly who she was. But her recent amputation has left her searching to describe herself and find her identity again. "All those things that I felt proud of, and safe in, and looked forward to, have been altered," Hakim shares. "It's really hard to plan ahead right now. There are a lot of fears."

Hakim was born in Egypt and moved to the U.S. when she was five years old. Spending most of her youth in New Jersey she moved to Toronto with her family at 17. A stint in Australia for a couple of adult years notwithstanding, Toronto is home for the 35-year-old. Her father had worked in the U.S. prior to the move and recognized that, being Christian, North America offered more opportunity for his two daughters.

After high school, one of his daughters followed an academic path earning her a PhD. The other, Rouzalin, jumped into the work world right away. "I'm a Jillof-all-trades," she laughs. "I'm very versatile but it seems that this type of work has followed me wherever I've gone. It's one of those skills which you have or you don't." Today Hakim works for an information technology dispatch firm. Hakim lost her left leg above the knee in a single vehicle accident. Travelling home at night from her gym in Oakville her motorcycle hit debris on the road. It was a highway off-ramp that she had navigated hundreds of times. She collided with the median. "I was an experienced conscientious rider," she offers, "but motorcycle versus median. Median wins." That was late August, 2021.

Sunnybrook Hospital would be her destination that night and St. John's to follow that... eight weeks in total. She had never heard of either place. She describes her two weeks at Sunnybrook as a time of shock, confusion, disbelief, and guilt, which she stills carries with her. "I had a lot of trouble believing that this happened to me. I didn't know much about the circumstances of the accident at the time except that I caused this myself. It was all on me. My motorcycle and my leg were gone. I find it hard to forgive myself."

Hakim understands that amputation takes a unique and personal path for everyone. "That's what life is; life is



different for everyone," she acknowledges. "I've found that it's okay to struggle as much as I need to right now. As long as it's not consuming me. I am owning it and it's very personal. But it's just one part in a long life to come. The physical and mental changes are hard and scary, but I know I'm not alone. I'm just unique."

She is grateful for so many different perspectives and outlooks that others have shared with her that have been so helpful. "But stairs are terrifying, maybe my greatest fear," she says. She articulates that fear, as it relates to everything she knew about herself having changed. "You don't recognize your emotions, or your body. You just don't know how to do things right now. Even going outside. Running small errands can be difficult to do myself, and scary. The fear of not knowing who you are right now. That's most paralyzing."

an independent sort, but now his role of being the self-sufficient helper has flipped. "It's huge how my family is there for me. It felt awkward at first, but I knew the help was essential. They have a Maltipoo named Brady that has been great, too. The dog hangs out with me and has been good company."

The hardest aspect for him so far has been the long period in the hospital: long days and nights where he felt stuck and confined. "I can be an impatient guy and it was hard. Like now, I will be eager to go; I'll get downstairs and realize I forgot something upstairs! Then it takes another five minutes up the steps and another five minutes back down. However, giving up or skipping things is not an option. It's important to put your head down, take a deep breath, learn from things. It can be frustrating. It is exhausting. But I try to stay positive and do things the right way even though it all takes much longer now."

From last summer to now, Levinson has traveled the hard journey those who survive trauma endure. Grieving was intense. "A head wound was part of my injuries, so I do not remember the accident," he shares. "This leaves me conflicted, as I want to know, but I don't want to know. I think it has helped in a way."

Phantom limb pain has also been minimal for him. "I have been fortunate with phantom pain; I have phantom sensation, like right now I feel a limb is there, but it's just pins and needles, like it's asleep."

Somehow it comes naturally — but not easily right now — for him to see the bright side of things. It is a skill he works hard at and nurtures, he admits.

But Hakim, as she always has, finds joy in life as she lives it. "Having my sister by my side... she's my one-woman-army. Working out. Friends." And she's trying to appreciate small achievements. "I've always set very high standards for myself, so it's hard to appreciate how well I'm doing right now on this new journey. At times it just doesn't feel very accomplished. But, I'm comparing myself to my pre-accident self. Yes, I'm back to work, but only part-time. I'm back to the gym, but only three days a week. At first though, I didn't think I was ever going back to the gym. I'm so proud of myself and I know I have to resist seeing the things I can't do before

seeing things I can do right now."

To do that she's taking this recovery time to give time to her hobbies. She's journaling, painting, reading, cooking and colouring. "I want to get into more drawing and baking." Hiking and bicycling are targets too. "I'm missing my morning jog. I love running. I love anything outdoors." And so is wearing heels again.

There are also some needs that need addressing. "I need some modifications in my home. Sturdier railings. Modifications to the bathroom and the steps to get into my house are difficult. Another thing I didn't ever anticipate was financial stress. One of the most stressful things coming out of rehab is money.

"When together, I forget that there's a difference between us... especially because I walk faster than he does."

### "I believe in trying not to dwell on what was, but to look forward to what is going to be."

"One thing that has helped me physically is having a positive mental outlook. No matter what happens... a fall or set back... you have to believe you will keep moving forward. It's about learning to not get frustrated with yourself and coming to terms with how everything takes longer. It is a learning process. So much of this [rehabilitation] is mental."

Levinson just recently moved from "test" leg to "final" leg. "I'm excited to see what I can do now," he says brightly before conceding, "I do have worries. If anything, I am too cautious when I walk. I have a fear of falling — for right now. That will improve eventually, I'm sure." He prides himself on "catching on to things quickly". Learning new skills in prosthetic care has been, "Not bad, but trying to remember to do all of these little things throughout the day leaves me way more tired at night. It requires more energy, and I don't always have that energy."

Getting the hang of things will come for him, as will more defined long-term goals. That is on the shelf for the moment. "For now, I'm taking it slow. It's winter. The big goal I like to picture in my mind is playing a round of golf with my brother and my dad. Come summer, we're going to play!"

That pleasant image is buoyed by other positive facets of his

situation. "I am fortunate that I can drive, since my right leg is fine. My career will be good, too. I can return to what I was doing when I am healthy again."

Levinson is also thankful for the staff at St. John's and has met supportive Torontonian amputees as well. "Todd Domingo [*thrive magazine's* Ask Aristotle] visited with me and was great. We talked sports mostly. But I also spoke to him about how I want to share my journey with *thrive* readers. I've found the biggest thing about all of this is that most of it is the mental approach for me... even more than the physical. I believe in trying not to dwell on what was, but to look forward to what is going to be."



Your bills don't stop. They're waiting for you on the outside but I couldn't go back to work."

She knows she needs to reconnect with the outside world too. "I've been afraid to leave my home at times," she admits. Rehab prepared me physically to get back out in the world but I found it [rehab] to be very impersonal. It was a struggle to find the psychological help I needed.... finding someone who could relate to my questions."

But she also admits she was resistant to peer visits during her recovery. "Everyone around me was a stranger and I didn't want another one," she shares. Hakim has yet to share the news of her injury with some of the closest members of her family. While hard for most to understand such a secret, Hakim explains it in this way: "I was the strongest, not just in my family but in any group I was part of. My sister used to come to me for everything. Same with my mother. We've never had such a trauma in our family. I was the go-to for the family. I just can't let my mother see me like this yet. Not yet."

Yet, a budding new relationship is helping with her struggle to open up. "I'm working hard to not question the relationship. It's very different this time around. I'm appreciating that someone else is finding beauty in me when I'm wrestling with it. We can be very silly together. We joke about date nights at the grocery store. When together, I forget that there's a difference between us... especially because I walk faster than he does. I'm starting to feel less insecure. I'm starting to appreciate going out for a walk again. I have insight into where I'm going, just right now it's not that easy." FEATURE

Titie

# AGING

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with Amputation

### PLANNING FOR PREVENTION OF PITFALLS

By Max Warfield

Canada's population is becoming older. It's a fact. A statistic cited by the Ontario Minister Responsible for Senior Affairs projects that Canadians 65 years old or more will double by 2036. Although not often vocalized, the dynamic merits of seniors are valued for many reasons, people creatively using their wisdom and tenacity daily, elegantly demonstrating to the younger generation that the inevitability of a lonely decline is a misconception.

Aging is not an illness. We all could use a helpful hand now and then, and for Canadian seniors, there are a wealth of organizations offering answers to life's challenges. The problem is that a high percentage do not take advantage of them.

Dr. Barbara Liu is the executive director of the Regional Geriatric Program of Ontario in Toronto, which supports a network of providers in twenty-six hospitals with evaluation, education and research. "We give older people a strong voice, becoming their advocate," Dr. Liu describes. "We look at the whole person – homelife, their housing situation, social interaction, jobs in the family, etc., all of which become the broader determinants of health.

"Seniors may look similar," Liu goes on to say, "characterized broadly with grey hair and stooping posture, but they are far from homogeneous. They are more diverse than young people, with more varied physical challenges. To face these, we like to view the many health professionals as a team. A doctor, nurse, physiotherapist, occupational therapist, prosthetist, social worker, pharmacist and others can contribute collaboratively to a senior's care, utilizing their own particular expertise. In between visits, the goal is to sustain gains made towards overall well-being."

While all age groups need to be vigilant in daily life, seniors must put more planning into their routines. It seems as we age, risks increase in complexity. Perils intensify. Hazards such as falls, the ever fragility of self-esteem, and ordeals of navigating the healthcare system while suffering chronic conditions require more effort.

These matters can be even more compel-

ling for amputees. Issues overlap and can aggravate each other. Good emotional and physical health can be attained, but a simplistic formula for success is hindered by the variety of lifestyles, health histories, and family relations. If a senior merely focuses on avoiding falls and becomes fiercely educated on safety, an advantage is gained over a statistically devastating health hazard. It is a hard fact that seniors must pay particular attention to this threat due to age-specific factors:



diminishing agility and eyesight, bones becoming more brittle, and typically an abundance of prescribed medications. Statistics show that certain workplaces and sports are more likely to lend to a ruinous fall, but elderly persons lead the pack for susceptibility due to carrying multiple risk factors. However, according to a Registered Nurse Association of Ontario publication on clinical best practices, many falls are preventable and predictable.

To avert a series of undesirable and compounding consequences after a spill, results that can include financial ramifications, a senior should engage the medical community pre-emptively to protect continued good health and independence.

Your medical team can help in several ways. They will evaluate side effects from medications, highlighting possible drowsiness, disorientation or dizziness. They will also offer warnings about ailments such as arthritis, diabetes, dementia, or depression, all of which may initiate a fall.

In addition to monitoring possible impacts of one's own personal health profile, focusing on the home is important. It is common practice for an occupational therapist, or other healthcare professional, to visit an amputee's house (especially a senior's), using their



stairs are noted as dangers to be avoided. Furniture needs to be an appropriate height, especially the bed.

Amputees should also make strategic decisions on where to place their prosthetic device for the night. Space to turn around and navigate should be kept in mind, such as providing adequately wide aisle ways. The more lighting and hand rails added, the safer, with



experience to evaluate specific hazards. On inspection, pets underfoot, loose carpet edges, throw rugs, slippery floor wax, misplaced cords, clutter and loose tread on

grab bars and rubber mats suggested for bathrooms, perhaps the most dangerous room with slippery floors and cloudy steam. Many of our living arrangements can find us alone often, so keeping a telephone nearby and accessible for emeraencies is recommended. Knowing your physical limits is advised, such as not trying to carry

something so bulky or heavy that it is beyond your abilities.

Outside, proper lighting is vital, as is avoiding cracked sidewalks and protruding roots, while handrails near steps should be used by habit. Weather should be respected, as ice and high winds may easily knock one down. Good practices such as not rushing to answer the door or "running" to the phone are wise.

"Widen your steps and shorten your stride," suggests Janet Campbell of West Park Hospital in Toronto, a physiotherapist who works with amputees, repeating these fundamental hazards and adding more. "Bend a little bit. Take the time to put on good winter shoes. Walk with a friend. Another good idea is to take part in the free twelve-week Falls Prevention and Mobility Exercise group that meets in community centres."

All of us have almost tripped, promoting a giggle of embarrassment, but the threat is real and to be considered seriously. Your medical team is there to support you, including your prosthetist, whose unending job is to help his or her patients find good balance. "Maintaining and maximizing what you presently have is so important," describes prosthetist Karen Littman of Hamilton Health Sciences. "My patients are diverse, aging in their own unique way. Some display physical abilities into later years that exceed others. Skin issues become common in older people so we make adjustments, fitting a softer interface, or perhaps a gel sock."

"Some seniors find what was normal is now intolerable," tells Marty Robinson, prosthetist with PBO Group. "We will modify the prosthetic design and make it softer and lighter. Aging clients deal with atrophy and feeling more boney, so we add shock and sheer reduction to the liner. Some seniors become attached to 'what works', holding on to older equipment, missing out on new materials. If we think it will mean improvement, we try to persuade them by arranging a trial with the new componentry. Ease of donning becomes more important later in life, as grip strength declines and less complicated devices are more appealing."

Although over 400 risk factors for falls have been identified by researchers, becoming fearful of falls to the point of inaction is dangerous as well. Weighing risks of personal freedom and exercise is important, as a sedentary lifestyle is unhealthy also. "Too much sitting is not healthy," Dr. Liu insists as one of her tenets. "Some may still pursue sports, while others cannot and find new activities that agree with them."

"A thirty-minute workout fit into an entire day of sitting does not undo all of that inactivity," reminds Littman.

Staying active can also mean socially active, another important ingredient to happiness that should be sought by seniors. There are a great number of senior-oriented groups one could join across the country. Website searches give results based on interest, many that are found nearby. There are also many opportunities for a senior to volunteer, helping not only that organization but themselves, enriched by the feeling of being needed.

"Some view their prosthesis as a second chance, even later in life," relates Robinson. "Volunteering is great; the patient sees results of their involvement, making them realize how they can still make important contributions. Organizations really value their time, and self-esteem is important."

Perhaps as frequent as falls, depression is prevalent among seniors. Although common, it can not be dismissed as just a normal part of aging. Disregarded mental illness may lead to diminished function, substance abuse, increased mortality and can slow the healing process. It may arise without warning or family history. Members of your healthcare team appreciate that geriatric health is a specialty, as seniors must manage changing relationships with family and friends, may be thrown into a new living situation, all while dealing with a changing body and altered chemistries. Ironically, some downward trends mentally may be solved by fixing a basic issue like transportation or companionship.

Your prosthetist will not diagnose a mental issue, leaving it to professionals in that field, but the healthcare team would like to see treatment sought earlier and more often, as mental maladies are shown to improve with treatment, and an early diagnosis produces optimal management.

Other potential triggers of depression include life shifts such as the loss of a loved one or changes in environment; as well as long-term illnesses, dementia, poor diet, alcohol use and side-effects of medication. Signs include feeling blue for two straight weeks, unusual



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fatigue, trouble sleeping, lack of concentration, confusion, change in appetite, memory loss, feelings of worthlessness, unexplained aches, changes in personal or home appearance, and having trouble with numbers. Statistics show that stigmas holding sufferers back from seeking treatment need to be overcome for better mental health results.

Amputee seniors find success when they listen to their healthcare team and their specialized recommendations. It's very important to exercise regularly and not to sit for long periods of time. Happiness can be

found when the effort is made to get out and pursue a hobby and attend social groups. The variety of challenges for a senior seems daunting and the number of warning signs incalculable. Yet, the choices of solutions are even greater. And seniors can have their healthcare team standing behind them. There are plenty of smiling seniors with amputations serving as excellent role models for us all.

### **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.





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**HEALTH & FITNESS** 





**Courtesy of the Ottobock Wellness Library** 

What is wellness? It's really about balancing the different parts of your life that allow you to live to your fullest potential. It's about achieving positive changes in many areas of your life... physical, emotional, environmental, social, intellectual, and occupational... and getting back to the activities you love, whether that is golf, Pilates, or just living a healthy lifestyle.

Have you heard of Pilates, but not exactly sure what it is? Ottobock asked three Pilates experts to share their professional expertise and tips when considering an adaptive Pilates experience. Pronounced pee la teas, Pilates is named after the German physical fitness specialist Joseph Pilates (1880-1967). Pilates created a system of exercises using special equipment designed to improve strength, flexibility and posture. In fact, Pilates was devised as a form of adaptive exercise for people injured by accidents or the effects of the First World War to find wavs to help them restore their mobility and health.

Pilates cleverly devised exercise apparatus out of their hospital beds, using the frame and springs to create routines to address their needs. Many of the modern exercises used today came from the rehabilitation setting.

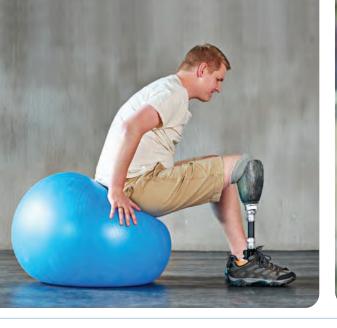
#### **PILATES TODAY**

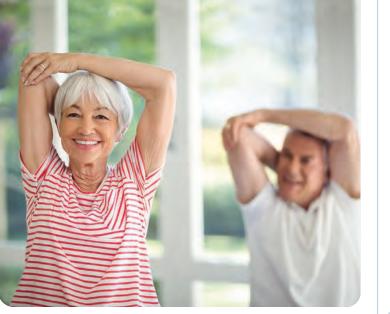
Today, Pilates is done in a studio with an instructor, privately, or in a small group class. It is an exercise that is highly adaptable to meet the needs of almost any level of fitness. Pilates makes use of springloaded equipment designed to support the body while providing a challenge to the muscles. It also increases body awareness through feedback delivered from the equipment and springs. The majority of the work is done from a prone (lying down) or seated position. There is some call for standing or arm bearing, but it is easily modified. Pilates is generally focused on improving posture, alignment, breath, and use of the body.

#### IS PILATES RIGHT FOR YOU?

Pilates is a great choice for someone who wants to learn how to use their body well, to correct the misalignments, strains and painful patterns that keep us from enjoying our bodies fully. Pilates can also help us achieve vitality, strength and flexibility to do more in our daily lives with greater ease and enjoyment. Many people living with limb loss or mobility challenges find that Pilates enables them to reconnect with their body as a whole on a physical and mental level.







#### SELECTING A PILATES INSTRUCTOR

*Visit.* Schedule a time to meet with an owner, or an upper-level instructor, to discuss your needs and goals. This gives you an opportunity to get a tour, meet other instructors, and see if the studio is a good feel/fit for your needs.

*Training.* Start with reading the instructor's bio. If you can't find it on the studio's website ask for it to be sent to you prior to your visit. How comprehensive was their training? A reputable training program is a course with at least 600 hours of study and teaching. Extensive training can be well over 900 hours with 250 hours of teaching prior to certification.

Ask if he or she has been certified on all the equipment, or just one or two pieces? Pilates is a very expansive system and makes use of several different pieces of equipment, each with its own strengths. If the instructor has experience with only one or two, they will be unable to provide you with a varied, adaptable experience. They should have a Reformer, Cadillac, Wunda Chair, Mat, and Barrels, and be qualified and experienced teaching them all.

In addition to initial training, find a studio that is committed to

ongoing instructor education and inquire about the instructor's recent Continuing Ed course. A reputable instructor will be registered and certified with the Pilates Method Alliance (PMA).

Chemistry. When you meet with your potential instructor, do they take the time to talk with you and learn about your expectations, needs, and concerns? Pilates is a wonderfully adaptive system which can easily accommodate almost any situation. The best lessons are when the instructor really applies what you want and need and helps you find the exercises that serve you best. Each lesson should be crafted to address YOU, and should be as unique as you are! Can they adapt if something isn't working for you? Do they work with you to have a successful experience? If you're getting the feeling that you're being expected to conform to a standard set of rules and exercises, this instructor may not be for you.

Even the best instructor may not be the one for you if there just isn't any chemistry. Can he or she really relate to you and give you instruction you understand, or do you find yourself scratching your head and wondering if you're doing it right? A good instructor is clear, concise, and knows how to explain things so you get it.

*Empathy.* Does the instructor have experience with injury, trauma, or limb loss – either personal experience or with a client? Having an ability to empathize with a client's limb loss is important. Does their personality make you comfortable? If you're going to be working closely with someone, you may as well like them, right? It'll make the lesson that much more enjoyable.

*Equipment.* Does the studio have access to a variety of equipment? In particular, a Cadillac is a table-like piece of equipment that is extremely versatile for people with limb loss. Full studios have Reformers, Chairs, Cadillac, High Barrel, Small Barrels, Tower Stations and a variety of props at hand.

Amenities. Does the studio have accessible bathrooms? Private changing rooms? Identify the areas that are must-haves for you and ask to see those things on your tour.

As always, consult your physician or healthcare professional prior to beginning any fitness regimen.

### PRACTITIONER PROFILE

# **RECREATION** *Therapy*

By Amanda Parent, R/TRO, CTRS and Kimberly J. Lopez, Ph.D.

MORE TO IT THAN FUN AND GAMES

The therapeutic recreation profession is often misunderstood and its role, as an important member of your healthcare team, is often underestimated. Contrary to popular belief, "there is more to it than just fun and games." Together with patients and clients, a Recreation Therapist develops recreation and leisure goals and plans to support a client's goals for physical activity and independence. Recreation Therapists understand of course, that a prosthesis can be integral to day-to-day activities and maintaining independence.

Through supporting new transitions to past or existing activities, or accommodating new ones, ultimately, Recreation Therapists aim to utilize leisure to support life-balance and overall well-being which are unique to each individual.

### What is a Recreation Therapist?

A Recreation Therapist (RT) is a professional who has studied in the field of therapeutic recreation (TR), and is now a practitioner. TR is a process that utilizes functional intervention, education and participation in recreation to help amputees, among many others, acquire the skills, knowledge and confidence needed to enjoy leisure activities as independently as possible.

### What Role Does an RT have on Your Clinical Team?

Adding value to any clinical team, an RT's principles and process can complement healthcare team discussions by sharing their assessments, and contributing to the rehab and life skills training plans... not just after injury but at any point during your life. An RT focuses on what a client CAN do and what they WANT to do.

Together, RTs and clients determine current activity interests, abilities, needs and barriers to a meaningful leisure lifestyle in order



to set goals. And then an RT looks to recreation and leisure activities and programs that will best help to meet those goals. An RT can also advocate for you, and make introductions and develop relationships with activity leaders in your community for you too.

For example, where a client has a goal of improving strength and balance, an RT might utilize meaningful activities for the use of a new prosthesis in a practical situation. The RT might observe that client taking a city bus to her or his favourite coffee shop. Or, maybe at a community swimming program where the RT can gain insight into a client's ability to utilize the facility, what barriers are faced, and what would be the best plan to manage the environment with a prosthetic device. The RT's work includes sports too. Like Keli Cristofaro's work. As an RT at St. Joseph's Care Group in Thunder Bay, Cristofaro provides a great example of how her clinical team worked together to help a young hockey player get back into the game after a below-knee amputation.

Cristofaro worked with a physiotherapist to help their client develop balance and strength for walking with his new prosthetic leg. With this achieved, the next step was skating, starting first with her young client practicing using his prosthesis while roller-blading up and down the hospital halls. Next was to go to the local ice rink where he skated for the first time since his injury. While skating, the team quickly noticed how the prosthesis would lose suspension once their client worked

"The therapeutic recreation profession is often misunderstood and its role, as a contributing member of your healthcare team, is often underestimated."



up a sweat. The team worked together to find solutions and after some trial and error, they fashioned a garter system for the leg to keep it secure while he was skating and perspiring. Their client went on to join an amputee hockey team that competed in Canada and the United States.

Not only can an RT provide adaptations to enable amputees to continue to participate in meaningful leisure activities, they can also provide parasport resources, community leisure education and other community supports.

Cristofaro says that she has worked with a lot of clients who experience anxiety about how others in their community will react to the appearance of their prosthesis. When facilitating community outings with her clients, she often provides education on how to deal with stigma and how to manage these attitudinal barriers. For example, when some school-age kids were staring at her client's prosthetic leg, Cristofaro encouraged him to talk to them about his prosthesis and show off his "transformer leg". "It's about helping my client feel confident going into the community and relating to others unfamiliar with a prosthesis," she shares.

For an amputee, the prosthetic device is important, and what can make the most impact is how the device contributes to quality of life. In the same light, leisure interests often shape how we identify ourselves (eg. runner, artist, baseball player, musician, movie-goer, etc.) and contribute to our world. With appropriate support – from RTs, prosthetists, and other members of the clinical healthcare team – we are able to engage his or her leisure identities, which can have much meaning in our lives.



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### PEER SUPPORT

You have questions. You asked about winter weight gain, isolation, inactivity and the blues. With the help of Aristotle Domingo, the founder of the Amputee Coalition of Toronto, and his peer network, we have answers.

### **Q.** I tend to gain weight over the colder months. What do you recommend?

A. This is not specific to the limb loss community. Many people gain a bit of weight during the winter months - with holiday festivities and less access to outdoor activities, we are all bound to gain weight. Giving yourself, without guilt, that bit of freedom is allowed in my books. Regaining control and concentrating on eating well is the key, however. Focus not on New Year's resolutions; instead, focus on getting back to your healthy eating habits. If you are starting a journey to healthy eating, start a journal. There are many digital apps that can help you if you are tech savvy. Eat healthy with lean proteins, Omega-3 fatty acids, and seasonal fruits and berries to replace sugar cravings. Check with a dietician or a doctor about good foods for healthy eating and weight loss.

### **Q.** What is SAD and is it real?

**A.** SAD, or Seasonal Affective Disorder, is very real. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) this is a type of depression experienced during the fall and winter months in countries where there is less sunlight during the day. It tends to dissipate in the spring. SAD is triggered by the season – hence its name - and has been described as feeling sadness or having a depressed mood, loss of interest in activities, loss of energy, and sleep interruption or not feeling rested even with a full night's sleep. It is best to talk to a medical professional about SAD. In addition to what I talk about below in creating a self-care routine, there are some tools you can use like sunlamps and meditation techniques to address symptoms of SAD. Speak with a medical professional before you self-diagnose.

### Q. Long, dark days and cold temperatures don't motivate me to do anything. I am on the couch watching TV not being productive and feeling isolated. Any tips to get out of this rut?

**A.** Stick to a daily self-care routine. Create a schedule for your self-care routine from waking up to going to bed at night. For example, set your alarm to wake up at the same time every morning. Do morning yoga or stretch for 10-15 minutes before



getting dressed for the day. Make your coffee or your morning drink and maybe watch some light morning TV for 20-30 minutes. Get inspired by the recipes or crafts and DIY projects they feature. Commit to turning the TV off at the end of the show and move on to something else. Grab a book or a magazine and settle into your reading spot. Avoid reading in your bedroom. It's not time to head back to bed. Set a timer for 30 minutes to an hour of reading.

Stick to a lunch schedule every day. Make a plan for the afternoon or evening, maybe tidying up, or doing the dishes or the laundry. Maybe call a friend or neighbour. Since we are not seeing a lot of each other in person, hearing a friendly voice or seeing them on a video call can brighten your day.

Go outside, weather permitting, for some fresh air and sunlight. A short 15-20 walk will do wonders for your physical and mental health. Maybe go to the grocery store to buy ingredients for that dish you saw on TV earlier that you'd like to make for dinner. After dinner, schedule some more TV time or watch a movie, or read some more of your book. Set a time for bed, the same time each night. No distractions... lights out.

Another key to a daily self-care routine is having enough free time for things you want to tackle that day or for other things that come up unexpectedly. A routine provides focus of tasks so that you do not get into an unproductive lull or a rut.

### **Q.** I was able to go for longer walks in the warmer months. What can I do indoors to stay active?

**A.** Walking outside in the winter may not always be suitable, especially if your lower limb loss is new. You may still be dealing with a new prosthesis and uneasy balance. Add slippery sidewalks and wet roads and that's a fall waiting to happen. Here are a few exercises and resources you can do at home:

1. If you live in a condominium or apartment, take your walks in the hallways. If you are good with stairs, walk up and down the steps between floors. It's never a bad idea to have someone watch you or assist you when you are first attempting these exercises. Check the availability, and pandemic protocols, of your condo gym, city recreation centre, or a local gym.

2. Check out these easy "At Home" workouts with everyday things around your home: www.amputee coalitiontoronto.ca/blog-post/how-to-keep-up-with-your-rehab-while-physical-distancing.

3. Light chores around the house can be turned into a mini workout as well. Folding clothes or putting dishes away uses arm muscles, for example. For an extra abdominal or core challenge, do them standing up if you can. Lean on the kitchen counter for support but engage your core as you do the lifting or the folding of clothes.

### **Q.** I get sad, angry or depressed whenever I reflect on my limb loss. What can I do so I don't get into that space in my head?

A. Self-reflection is a good exercise if it allows you to venture out of the feeling of sadness, anger, or depression. But self-reflection in a negative way can have the opposite effect. Speak to your medical team about seeking support for mental health to help you through what you are feeling. Mental health is an important part of your physical recovery. You cannot do physical tasks if you are not mentally prepared for them, and that is especially true while doing physical rehabilitation.

More solutions for an active lifestyle at www.amputeecoalitiontoronto.ca.

### ABOUT THE AUTHOR:

Para-athlete Aristotle Domingo

is the founder of the Amputee Coalition of Toronto. He is a double below-knee amputee and an avid runner who also competes



in men's seated field events – shot put, discus and javelin. He also plays sitting volleyball and took home the gold at the Niagara Penguins Sitting Volleyball Classic in 2019. He also plays golf and is a member of PGA of Canada's Diversity and Inclusion Task Force.

### PARENTAL GUIDANCE



## When a Parent or Grandparent Loses a Limb

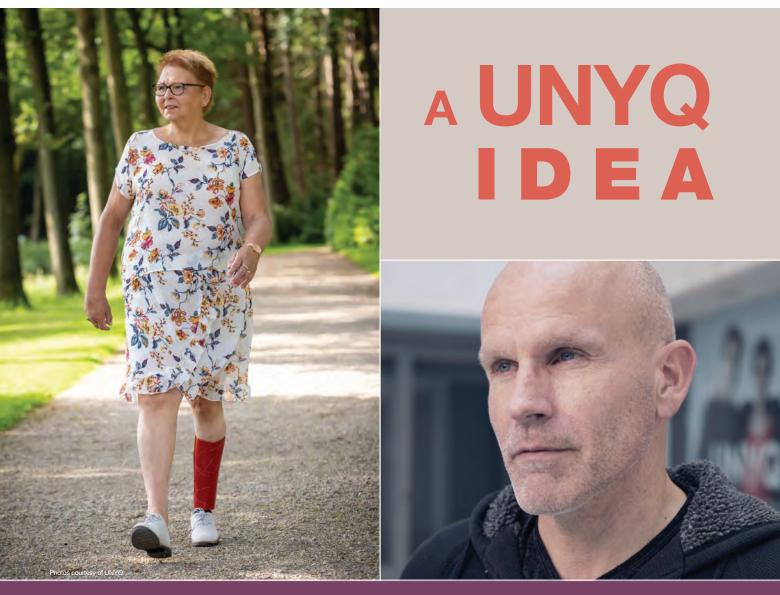
### by Pat Isenberg, Amputee Coalition Outreach Education Coordinator

- Be prepared to assist the child with an answer that is appropriate for his or her age and developmental level.
- Pain is scary to children. Talk about different types of pain in terms the child can understand. (Remember the time you burned your finger? Or, the time you fell off your bike?) Remind your child that eventually pain gets better.
- Avoid giving children too much information, such as details about a complicated disease process or the amputation surgery.
- Can this happen to me? Alleviate fears by giving information that kids can understand. Remember that your explanations need to be planned to avoid creating additional fears or anxiety.
- Is this my fault? Younger children are egocentric; when things happen, they feel responsible. Make certain children know that they did not do anything to make this happen.
- Limb loss is not a punishment. However, if it's the result of an accident, you may want to talk about safety issues at an appropriate time.
- Children will not "catch" this. Hugging and touching are still safe and very important parts of healing for the entire family.

- The parent is still a mommy or daddy, or grandparent, regardless of the limb difference. Talk about what is important – daddy can still read a bedtime story; mommy will still brush your hair.
- You may want to discuss things that may be different. Mom may have to learn a new way to bake chocolate chip cookies; dad may not be able to walk the dog for a few weeks (or months).
- Call upon the child's natural desire to help. You can be mommy's right hand until she learns to use the new one.
- Explain the new words: prosthesis, limb, residual limb, prosthetist. Make a game out of spelling or pronunciation of these words.
- Avoid adverse reactions. Explain differences in advance to prepare the child. Show pictures of other people with limb loss to desensitize the child.
- Focus on the similarities, but prepare for the differences. Have your child talk or write about his or her feelings, or express themselves through a drawing.
- Children are curious. Remove the mystery from the prosthesis by asking your prosthetist to explain the components used.
- If possible, have your child talk with other children whose parents have lost a limb.

Excerpt from Limb Loss Education & Awareness Program, © 2001 Amputee Coalition. For more helpful resources on living with limb loss visit www.amputee-coalition.org.

### INDUSTRY PROFILE



### THE PASSION AND PRIDE OF EYTHOR BENDER

## "I think it's important to show what you really are. I really want to be free and feel comfortable. When you are hiding something, you're not free." – a UNYQer

Founded on the mission to tear down the walls of stigma that accompanies amputation, a San Francisco-headquartered company enlisted 3-D printing technology to promote personalized design and fashion for prosthesis wearers. With its production team in Spain, with its own printing plant, the industry-leading company is global. That company is UNYQ.

UNYQ creates prosthetic covers for upper and lower limb amputees, customized products made in mass quantities. Its products are, at the same time, aesthetically beautiful and practical and functional, produced with an intent to help heal and reflect individuality. In other words, UNYQ is about body image. *Thrive* publisher Jeff Tiessen had the opportunity to chat with co-founder Eythor Bender from his home in Spain about the company, its customers and the man behind the mission. **thrive:** In reading other interviews about UNYQ, it's clear that your product is about more than the plastic that your designs are printed on so to speak.

Eythor: Absolutely. The product changes conversations. It's about confidence. We consider the product to be a fashion item. Prosthetic function is important of course, and there are companies producing very good prosthetic devices. We're not about getting people to walk or run. We look more to body image as our mission. The conversation changes from being about what happened to you, to who you are. So, it's about using 3-D printing and imaging technology to create a product around the person and who they want to be.

thrive: How did the product idea come about?

Eythor: My co-founder was Manuel Bosa Hernandez. He's an amputee and came up with the idea of focusing on body image and prosthetic covers. But he was too early. The technology was still underdeveloped and too expensive. In 2014 we teamed up to form UNYQ. That was the pivot point when the technology became less expensive and we secured the IP. Both Manuel and myself worked for Össur previously. We knew that although many were walking again, sometimes something was still missing. Some still hide from being an amputee. The ability to be more expressive with our product seems to help people with their identity and image of themselves.

thrive: How much influence do consumers have on the product?

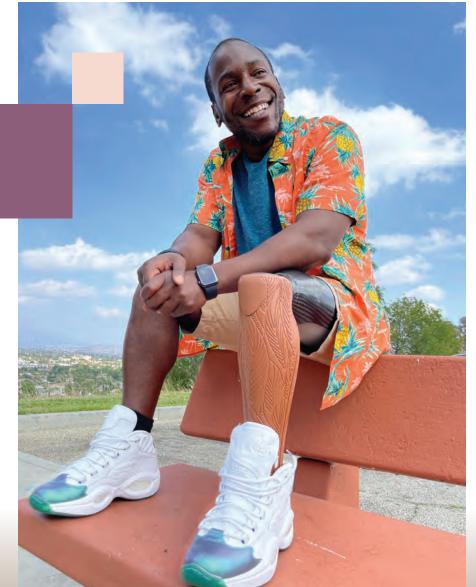
**Eythor:** UNYQ is all about the community. We not only launched a product but we launched a forum for the amputee community to talk about fashion and technology and how it impacts them. We rely heavily on UNYQers to influence our product. We get feedback for future designs. Through social media we connect with them around the world. It's something we take very seriously.

**thrive:** For amputees who want one... how do they get a UNYQ cover?

**Eythor:** We work with over 450 clinics around the world. We have a clinic locator. We have an on-boarding system through an app where your measurements and photos are







uploaded and where you select your design. The app leads you through the whole process. Pick your design. Pick your colour. The combination of colours and designs creates quite a few options. Every year we're introducing new designs. Anyone can download the app for free. Three to four weeks later your product is shipped.

**thrive:** Let's talk about you for a moment. What was your path to UNYQ?

**Eythor:** I am not an amputee but don't hold that against me. My background in prosthetics comes from my work with Össur. I think I was employee number 35. I was head of marketing and sales, working to expand the company globally. My 13 years with Össur was a wonderful journey. I then ran two companies involved in exo bionics – exo skeleton technology – and from there, in 2014, I started my own company which is UNYQ.

thrive: You went from very sophisticated technology to something that might be considered more simplistic.

**Eythor:** The product itself is simple but the technology behind it that people don't see is quite sophisticated. It's a new generation of technology creating custom products for the user... and doing it on a mass scale. Bionic technology is fascinating but unaffordable for many. And that frustrates me. It's almost like teasing the amputee community.

What I learned in prosthetics and in my exo skeleton work is that as much as these products can help you walk again, you have to want to wear it. And that's where body image becomes so important. Our product encourages people to use their prosthetic devices. I like to take things to the next level and it doesn't have to just be the next





level of technology. It can be the next level of how we look at things.

thrive: We've seen that as much as there is a push for new technologies, there also can be resistance within the industry. How have you been received as the "new kid on the block"?

**Eythor:** Change is difficult. It's exciting to introduce new technologies but it always comes with challenges, especially in the medical field. Reimbursement presents a roadblock, but so do people's perceptions. We've found that once people see the product, and feel it, they're impressed and resistance is overcome quite quickly. It's the experience, which is much better than just seeing the product in pictures.

**thrive:** At the end of the day, what constitutes a good day at work for you?

**Eythor:** Spending time with our customers. Getting feedback, hearing their feelings. Learning how we can improve. Last year we launched a new category of covers, with some new materials, and we got very positive feedback on how we've improved things. That's where I get my most joy. Much better than the paperwork!







## Returning from Rehab

By Rouzalin Hakim and Mathew Levinson

As new amputees, one of the biggest fears we've faced – both physically and emotionally – on our journey so far is leaving the safe space that is rehab. Not only going out into the real world that isn't fully accessible but even going home – because home isn't what it used to be. What was once the most familiar place in our lives is now filled with new challenges and experiences around every corner. While it was incredibly daunting at first, a new mindset and attitude has given us the ability to adapt. We're learning that you can make home feel like home again... maybe even learning a few things about our new lives as new amputees along the way.

ЗE

### Rouzalin

I had been home twice before my final discharge. My outlook had changed a lot from those visits. In the days leading up to my first home visit, I was extremely excited to leave rehab. I was looking forward to sitting on my couch, watching my TV, drinking my wine, enjoying my home – just desperate to go back to my world.

This excitement was only partially fulfilled because I was going home to an empty townhouse – without any assistance or my prosthetic leg or even a wheelchair. I only had my crutches. My fears were amplified as soon as I entered my house, as immediate as the first step, literally. But I took them as lightly as possible knowing that this was not going to be the norm for me. I must say though, this was as uncomfortable as I have ever been in my own home!

And it brought on new worries and fears. What will my future look like? I've lived alone for so long that I wouldn't know how to make other arrangements work. Even if I were to ask my sister to move in with me temporarily, what would it be like to rely on someone in my own home? How much is too much to ask without feeling like a burden?

As my first weekend went on, I noticed my emotions scattering. Have I lost so much of my independence that I can't even navigate safely in my own house? These fears came and went. It was hard to grasp it all. I felt like a complete stranger in my home. I felt so lost and overwhelmed that I couldn't bring myself to face the outside world. I never missed rehab as much as I did right then. I returned to rehab not a moment too soon.

A few weeks passed. I continued to go to physio and was getting slightly accustomed to my new leg. My doctor and prosthetist agreed on a discharge date of November 4, 2021. That reality hit hard.

Yes, I was physically prepared at that point, but knowing what I knew

"Today I wore my leg even longer. Then I vacuumed which I've been waiting to do all by myself for awhile. I'm actually proud. I've also gotten back to meal prep."

from my home visits I just didn't feel ready. That I was going to be alone scared me. I was going from being surrounded by people going through the same thing as me to being the only amputee around. The daily "comforts" of rehab would be gone.

Being out in the real world frightened me too. The stares because I was different now. I didn't share the severity of my accident with many people which meant my support would be limited. That was okay to me... I was already uncomfortable with the little help I did get.

Prior to this accident, I had been a very active person. I loved the gym, hiking, running, biking, and my biggest passion was getting on my motorcycle. I was the "go-to" girl in both my professional and personal life. I took pride in everything I did. And now everything I loved to do would be more difficult or seemingly impossible.

Discharge Day. The big day. Freedom. Release into a whole new world. The next milestone of my recovery. So, why did it feel like the scariest and loneliest day of all? I can't quite describe the feeling I had. A deep-down knowledge of needing others. I had never needed anyone to do anything for me.

I arrived home overwhelmed again with a flood of emotions. This time though, I had my new leg. My small home felt so big. Everything seemed just out of reach. The stairway seemed endless. It was a hot mess. For the first few days I was bombarded with visits from strangers – my new OT (occupational therapist), medical deliveries, nurses, a PSW and case managers. My sister was there the entire time. I couldn't be more grateful, but that gratitude came with guilt. I did my absolute best to do everything on my own, but it was just too much. Standing to cook for myself, which I had been looking forward to so badly in rehab, proved to be exhausting. Going upstairs to bed took forever. Showering was terrifying. Mornings were a struggle. Deciding when to put on my prosthesis, on my own now, felt very unnatural.

I'm happy to share, and as cliché as it sounds, it did get easier. I slowly adapted and became more efficient. For example, I sorted out a schedule. planning nurse, PSW, and OT visits to my house. I'd request the PSW in the morning to assist with showering. Then I would request my nurse shortly after to check my wounds and help with my prosthesis. Then homecare to help with (but not do) my meal preps and things around the house (for sure LAUNDRY). And then I would ask my sister or a friend to come by in the evening just to help with whatever was left or simply for a visit.

It didn't work out perfectly every day, but I gained some control back which meant so much to me. It gave me time to focus on my emotions which seemed to be all over the map. That was my main concern. A lot of people will tell you that it's just as important as physical recovery. For me, I think it was more. I remind myself that every emotion I go through, any time, any day, is justified. I'm still going through good moments and bad ones every day, but I remind myself that I've been through a lot and it's okay to feel how I feel right then and there.

### Here's to leave you with some tips I've already learned. Hope they help with your recovery too! Roz's Top 12 Tip List you might say.

- **1.** Plan out when and where to leave your prosthesis.
- **2.** Cook more than one meal at a time.
- 3. Shower with assistance for safety.
- Place household necessities (socks, meds, water bottles) thoughtfully.
- Leave extra chargers in different rooms/levels of your house.
- 6. Take advantage of energetic days.
- 7. Give yourself extra time or you will be late.
- 8. Clean up as you go; things can get messy fast.
- 9. Grab extras from the grocery store so you don't run out.
- **10.** Do your outpatient rehab right away; it's so beneficial.
- **11.** Try to accomplish one small task every day. It can boost your mood.
- **12.** Try your best to be true to you!

### Mathew

After being in the hospital and rehab for over three months, I had been anticipating my discharge date for weeks. It didn't scare me. It excited me more than anything.

I felt ready – to me going home meant getting back to doing the things I loved, with the people I loved. Life would look a little different, but I was up for whatever challenges I might face if it meant being home. I couldn't wait to face them head on.

Before my amputation I was the type of person who liked to be on the go – moving around, always up to something, never still. With the severity of my injuries, I was limited to the confines of a hospital bed for weeks, and that really motivated me to view my departure from rehab with a positive outlook. Going home to me meant being my old self again. Playing sports, playing music, sleeping in my own bed, having dinners with the family and goofing around with friends who couldn't visit while I was at rehab.

I was fortunate, and grateful, to be surrounded by such an unbelievable support system to go home to. I was living alone before my injury but planned to move back in with my parents and siblings after my discharge. It gave me the reassurance that there was always someone around to pick me up when I fell, or better yet make sure that I didn't. When the day came to move home I said my bittersweet good"Today was freaking amazing. It may have been the best day of my life. I didn't do anything extraordinarily different than usual. I just spent time at home - finally with my family."

byes to the friends I had made at rehab but was excited to say hello to the friends at home who had been with me in spirit this whole time.

Home. I faced my first challenge right away - the small half-step to the door. I smiled, mostly at the expense of my dad and brother who were nervously standing on either side of me to make sure I didn't wipe-out. I stepped up. It wasn't graceful, but I made it unscathed. I knew that the more I did it, the better I would get at it. It was my introduction to my new life at home as an amputee. Nothing was going to be as easy as it once was. I was sure though that with enough practice and patience I could do it. I spent the first weekend home just spending time with family. It was the best weekend of my life.

After that first weekend I began getting more familiar with my once-familiar house. I started to pick up little tricks and habits to make getting around easier. Rather than carrying a full set of crutches up and down the stairs to each floor, I found a second set of old crutches that I kept in my bedroom while my main set stayed on the main floor. That way I could just focus on the task at hand – not tumbling down the stairs.

Another helpful trick I quickly learned was the beauty of a backpack to carry my belongings around the house and between floors. I was still on two crutches at this point, which made holding objects in my hands difficult. The backpack carried everything I needed for the day from my phone charger to socks for my limb and even my pills. It saved me scrambling around the house to find something I needed.

Moving home from rehab is a learning process; it takes time and patience. But your home is also the perfect place to practice overcoming similar obstacles you'll face in the real world. Whether it's carrving things around the house, so you can one day carry groceries around the store, or getting up a small step into the house which isn't dissimilar to stepping up onto a curb on the sidewalk, everything you do at home is practice for your new life as an amputee. It gets frustrating at times, but above all it's about being patient with yourself... and be open and willing to accept help: whether it's from a crutch, a backpack, a friend or a loved one.

## MARK LUDBROOK



A five-time Paralympian, Mark "Luddy" Ludbrook is one of very few Canadians to win medals in both the Summer and Winter Paralympic Games. He won silver and bronze as a para-swimmer in his first Games in 1984, in New York. Fourteen years later, at the 1998 Winter Paralympics in Nagano, Japan, Luddy took bronze in the Super-G as a para-alpine skier. He also competed at the 1988 Games in Seoul and the 1992 Games in Barcelona and on the slopes in 2002 in Salt Lake City where he was honoured as the Team Canada Flag Bearer for the Opening Ceremony.

Always sporting his fun-loving personality, Luddy made a big splash in the Paralympic community when he was spotlighted as a *Toronto Sun* Sunshine Boy before his last summer games. Born in Port Colborne, Ont., raised in Stouffville and considered a Whistler local, Luddy now lives in Australia, still competing in marathons and masters events.

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#### **07. Duck Max Reusable Tie Straps**

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### **09. Reliefband® Sport**

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### Wayzn Smart Pet Door

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### **06. Hot Bento Lunchbox**

Easily enjoy a hot meal in 10-15 minutes, anywhere. Hot Bento is a battery powered device that stores your meal until ready to eat. \$99.99 at https://hotbento.us.

#### **08.** Avokadio

Avokadio is a breath analysis product. It can quickly and easily read ketone levels, ammonia, and other biomarkers in your breath. \$199.00 per year. https://www.avokad.io.

### **10. Vespera Smart Telescope**

Astronomy made accessible with this smart device that works with a smartphone or tablet, from anywhere. \$1499.00 at https://vaonis.com/vespera.

#### 01. Dignity Lift

to and up from the toilet

independently, easily and

safely, reducing bathroom

falls. \$999.00 to \$1499.00

https://dignitylifts.com.

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The world's first fidget computer mouse. A tactile, silicone-bodied wireless computer mouse with

pliable nubs to help you

hedgehoghealth.com.

focus. \$39.99 from https://

**02. Hoglet Mouse** 

### 03. Lili Lamp

The Lili lamp produces almost imperceptible light flashes, which corrects the "mirror effect" helping dyslexic people read more easily. €349.00 at https:// www.liliforlife.com.

#### 04. On2Cook

Microwave / induction combination cooks quickly while retaining maximum nutritive value along with color, texture & structure of your food. \$549.00 at https://on2cook.com/.

WINTER 2021

### FINAL WORD

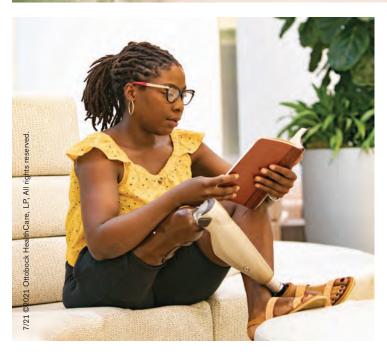
"Along with the sunshine, there's gotta be a little rain sometime."

– Lynn Anderson

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## A Foot for Every Season

The Cheetah<sup>®</sup> Xceed is just as at home with ALeah in Oregon as it is on, or off, any trail you choose. With three new members, the Cheetah family of high active feet is growing to meet your needs.

Visit go.ossur.com/ sportssolutions for more information.

The uniquely designed attachment allows users to easily snap, release and change from the Nike Traction SoleX to the Nike Spike SoleX.

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