### FEATURE



For Stelly's Secondary School student Andrea Swallow, a shy, blond-haired girl growing up in Victoria, British Columbia, possibilities in life were boundless. As a Stelly's Stinger, she immersed herself in running and dreamed of working with animals. Significant life decisions were on the sixteenyear-old's horizon.

Schooling and career choices pressed upon her heavily when she felt overwhelmed and underprepared to deal with them. She experienced angst from the usual teen grief – like the anguish of both real and imagined parental pressure to succeed, fear of being judged, desire to look good and fit in socially, pressure to drink or do reckless things to be popular, and of course, the dread of embarrassing situations.

All the while, her social, athletic and academic endeavours felt terribly competitive. Life felt so daunting and dramatic. Then she became an amputee, a survivor of a motorcycle accident. To MA Source of the second sec

The pressure went from a stone in her shoe to a slab of granite the size of Squamish's Stawamus Chief pressing upon her shoulders.

Decades later, Andrea lives a happy life enjoying beautiful B.C. She loves being a mom, works at the local secondary school, volunteers, runs. An above-theknee amputee, she is the National Peer Visitor Coordinator for the Amputee Coalition of Canada and busy as an advocate with Amp Unity Canada and various amputee support groups that provide volunteer peer visitation.

She is doing great. She navigated the minefields of young adulthood as a relatively new amputee. When recently asked, "If it were possible, what would you tell your younger amputee self?"... a litany of thoughts flooded her mind. "I would say," she starts, "the world can be unkind to those who look 'different' and being on the receiving end of such unfairness will sometimes cut deeply and knock you down — but be reassured, it has absolutely no relation to who you are. You decide who you are. Imperfection is what is so captivatingly beautiful about this world and all it encompasses."

She pauses. "What I wish I had known? I wish I had known that there are many ways that trauma impacts our body and mind. The way that it alters your sense of being, your nervous system, emotional responses, the way you

communicate, and how you navigate and perceive the world around you." When led to the topic of adversity Andea responded with a reminder to herself that adversity has the capability to bring both despair and joy, liabilities and assets, misfortune and gifts. "Healing requires us to feel all emotions, including the difficult ones. The more it unfolds and the less you avoid it, the more you diminish the fear and negativity and encourage self-acceptance and growth. Resiliency is a double-edged sword, a true asset and an incredible life skill, but acquired through hardship unfortunately."

She believes maintaining good mental health is crucial. "I am thirty-five years in as an amputee,

## "movement is medicine"

## "find others with lived experience"

but it still surprises me a bit," she says, speaking about mental health. "I am proactive, aware and engaged, and yet my emotional health can still be challenging. I am a huge advocate of taking care of myself. I can talk about it, but when it comes to applying it, to how you move forward in life, it can be difficult. There is no template; we are all different."

She would also tell her younger self to "allow yourself rest and grace from being strong and independent all the time. It takes great physical and mental fortitude to live with limb loss, so go easy on yourself when you feel weak or vulnerable. We are resilient and we are human too. Always remember that mental health care is vital. Dealing with daily chronic pain, trauma, societal barriers and stigmas - including our own - and a challenged healthcare system can diminish our psyche and resiliency. Safeguard and invest in your mental and emotional health with the same care you do for your body."

Andrea felt alone in the beginning. It was pre-internet days and there were limited opportunities to connect with other amputees.

"Back then, there was a lack of support in Canada, particularly in Victoria, which is really small. I had to navigate by myself back then; there were no in-person support groups. A lot has changed. I don't know that I always did it the right way — the most healthy way, or the best way. I don't know. So, yeah, there are times I wish I knew what I know now when I was younger.

"Soon after my accident, a nurse

suggested The War Amps Child Amputee Program and I told her to sign me up. Right away I knew what a difference the support made, a group where I actually belonged. It was a place to fit in somewhere after massive trauma. It was great; however, I was only offered two or three annual Western seminars with the CHAMP program. There was a small support group here in Victoria thirty-ish years ago, one that lasted a few years until it gradually dwindled to nothing. When that dropped off, I wondered 'where do I fit in?' I didn't have a community anymore. It's a lonely journey at times."

Being an amputee teen was especially lonely for her, yet she has good memories. "Not only was I very lucky to have family and community rally around me after my accident, I also had incredible support from my teachers and staff at my high school. They were empathetic, respectful and concerned about how best to support my adjustment back into mainstream high school life. This

was new for all of us.

"I would want my younger self to fully realize that there is understanding and peace in finding others with lived experience. The community is vast, generous and compassionate and can provide more than you can discover on your own. Whatever you do, do not isolate yourself from connection to others. I would tell myself to 'volunteer'. Giving of yourself has an underlying and quiet reciprocal nature that ends up subtly softening the hardships we endure, reminding us that we belong and always have something to contribute."

Andrea always loved running. She found solace in staying fit and would tell her younger self to embrace it even more. "Movement is medicine," Andrea says. "Never underestimate the simple way that movement can quickly sidetrack a low mood, help process difficult emotions and remind us that we alone have the ability to reset and support ourselves."

That said, she hesitates to use the words "physical activity" or "exercise" when speaking to new amputees. She observes that some can feel deflated or discouraged because they don't consider themselves athletic, or have no interest in being active. "Movement can be as simple as 10 extra steps in a day, chair yoga, talking to your neighbour at the end of the driveway, tending to garden pots, going to the grocery store — any little action that propels you to not stay stagnant



in body or mind," she explains. "It's too easy to get stuck in life when you struggle with constant cycles of pain or mobility challenges or financial hardships or lack of resources."

Andrea also emphasizes the importance of creating small habits or opportunities that help form a new relationship with your body to learn how it operates with an amputation for comfort and confidence in it. "Appreciate what it can do, distracting from what it can't do. Becoming attuned to how it functions and what it needs helps us develop more of a proactive approach to looking after it when situations arise.

"Also, advocate for yourself. There is no template for life with limb loss and information can be overwhelming at times. It is a strength to ask for what you need and if you require support. Find someone you trust. Sometimes our support network will need direction on how to provide the help we actually want or need. It's okay to be honest and clear about this. You are worth this. And remember to draw on the positive and joyful aspects of life. Fuel your mind and soul with more of these moments."

Andrea would also speak to her younger self about "loss"

and how it challenges everything someone has been and previously known. "One size certainly does not fit all, nor is there any handbook," she asserts.

"Have compassion for yourself. Talk about it. Write about it. Rip it up. Walk it out. Cry it out. Do what you need to, to express yourself. It will evolve and gradually soften. Avoid comparison. Amputees achieving grand physical accomplishments is not a realistic representation of what life is like for the vast majority. We are individuals with truly distinct stories, doing the best we can with what we've got. Climb your own mountains. Even when our bodies and minds are challenged beyond what we think we can control or handle, we still have choices. The elusiveness of autonomy and independence during setbacks can be disheartening but the way we respond is ours to choose. Listen to what feels right for you. Understand that healing is your responsibility - this is where you have power."

While Andrea admits that challenging times can seem neverending, her amputation, in a strange sort of irony, forced her to step out of a comfort zone which built confidence in her along the way. Adversity contributed to her struggles with anxiety and depression.

But it also lent to her fierce desire for independence and brought her the gifts of compassion and strength, and an unwavering love for life, diversity and simple things.

"The bottom line," she sums, "is that it takes enormous effort to look after the ever-changing needs of a body that compensates so extraordinarily. Some days you will win at this. Other days you will feel like you're desperately failing. This is normal. The more we actively participate in the journey and explore ways to support it with bravery, humour, vulnerability and a heck of a lot of tenacity, the more we thrive."

# "have compassion for yourself"

Younger amputees can benefit so much by listening to those who have traveled before them. Seniors have savvy and a lot of wisdom to offer, even if they became an amputee in later age. **Dr. Kirsten Woodend** has held academic administrative positions (Dean, Associate Dean, Director) at both Ottawa and Trent University, and is on the board of directors for the Amputee Coalition of Canada. Her accident came much later in life.

When she hears, "If I could tell my younger self", she thinks of

learning to be more patient. To live in the moment. "I felt such angst in how long my healing was taking," Kirsten remembers. "I was always pushing and pushing. Now I teach nursing students who get their knickers all twisted into knots over nothing. I see all of that wasted energy — like I would do early on in my amputation recovery."

Doctors told her that the complications from her motorcycle accident meant there would be a two-year recovery period before she could even think about working



again — advice she would have nothing to do with. She pushed herself to be back much sooner. For her, it helped to write poetry. Two of her poems were published in peer-reviewed publications.

Kirsten experienced great healthcare and mentorship, yet she says that she refused to fall into the trap of being a "good little leg amputee," meaning relying on caregivers rather than finding her own way. "Many amputees feel less important," she describes, "like broken parts. Yet, we the amputees are the most important part of the healthcare team. It is a constant fight to find your own way, which is difficult, because it is so easy to just nestle into relying on the system."

Thanks in part to Kirsten's positive attitude and drive, she found the strength to be resourceful during her painful and long recovery. "If you feel that your healthcare team or support groups aren't working for you, look around. Try something new that does work," she recommends.

She has seen how lesspositively-minded others have struggled. "How easy it can be to wallow and doom-scroll on Twitter and become tied to the negativity of it all. Amputation is not fun. It is bad. But you have to rise up. Find what is good around you."

### **Climbing Back into the World**

By Kirsten Woodend, PhD, RN, MSc

It's hard to get back into the world when you've been broken. It's not so much the challenge of your mangled restructured body – you can control how you cope with pain, how hard you push yourself forward.

You think the "system" is set up to support you as you surmount these challenges; in reality it adds another set of hurdles to those you are already trying to clear.

You suffer a multitude of indignities in the process of body repair; mostly, these are inevitable – though many did not need to happen. Surprise, surprise. These indignities do not end when you leave the hospital. If anything, they become more challenging, more deeply hurtful.

It's amazing how, in other's eyes, you suddenly become a child incapable of coping mentally or physically; how often you are patronized in "your best interests"; how often, in the name of caring, you are prevented from exploring what you are capable of; how is it OK that your colleagues have been told not to talk to you about work to protect your sick leave and recovery. (at what point did I become incapable of making these decisions for myself?); how invisible you are as you negotiate your walker through the aisles in a store; how many places are inaccessible to you. How ...? How ...?

But worse than this are the barriers to reengaging in your life. The decision is not yours (remember you are a child again) – it rests in others' hands. You need to smile and "play nice" to ensure that all the forms and letters you need are signed, that all the correct boxes are ticked so that more barriers to re-entry are not "triggered." It feels like a never-ending game of "whack-a-mole."

Do I not have enough to cope with? I want to contribute to the world again. Why do you insist on making this so difficult for me with your low expectations and your petty bureaucracies? Don't you want me back?

### **Sending My Regrets**

Like in any age group, some seniors sit themselves on pedestals and preach, which can be off-putting to the young and uninitiated. Some young people simply and foolishly reject any counsel from seniors. But when generations respect one another, ideas and experience can be passed between, both ways, and understanding is nurtured and grows.

Without knowledge sharing, we are all more inclined to regrets. Regret behaviour is becoming a growing area of study in science.

"Regret is a comparison-based emotion of self-blame, experienced when people realize or imagine that their present situation would have been better had they decided differently in the past," say Marcel Zeelenberg and Rik Pieters of Tilburg University.

Consumer regret has long been studied by economic establishments such as schools of business. Today it is studied as a mental health area. Regret is a reflection-based emotion that arrives late in development (arises roughly at the age of seven).

"People have a natural tendency to focus on the foregone instead of the obtained," add Zeelenberg and Pieters. "The mere act of choosing already produces a sense of immediate regret accompanied by an increased attractiveness of the non-chosen alternative."

Missed opportunities cause rumination with emotional distress in the short run but with motivational benefits in the long run.

Other research has grouped

regret into four different types: Foundation regrets — regrets from not working to lay down a foundation. Moral regrets — doing the wrong thing. Connection regrets — wishing we made room in our schedule for someone. And Boldness regrets not taking the leap through the window when it was presented (*The Power of Regret* by bestselling author Daniel H. Pink).

A significant statistic emerged. Regrets of inaction outnumber regrets of action two to one, a ratio that increases as people age. One reason for this is that many action regrets can be undone or produce things of value even when considered a mistake. Regrets of inaction seem less beneficial when wrong and sting more.

#### Pink makes the following suggestions:

#### 1 Look Inward

Reframe how we think about our regrets. We speak to ourselves more cruelly than we'd speak to anyone else. Practice self-compassion.

#### 2 Look Outward

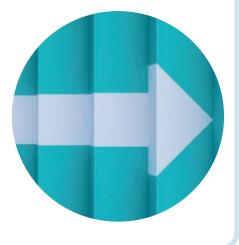
Practice disclosure. Sharing your emotions is a form of unburdening. We can make sense of regret through talking or writing.

#### **3** Move Forward

Extract a lesson from your regret. Create distance to help yourself process.





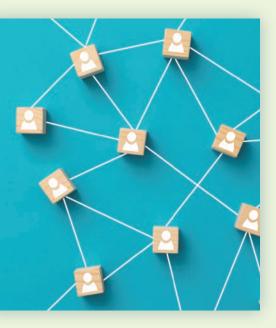


Arm amputee **Ralph Billing** also lost his limb later in life. An arm amputee, he went through a range of emotions after his injury, namely, "Why me?" and "Woe is me!" before settling on "Life must go on."

With that mantra in hand, the Ontario man pressed ahead with the same vigour that he applied to his ladder-climbing corporate life. He inherited his father's business acumen and drive. He energetically grappled with obstacles associated with his amputation, always in his own way, whether it was by tossing a prosthetic limb into the closet or by enlisting his best attribute, that being working at it harder.

Now 85, after a long and very successful career with General Mills and other business ventures, Ralph looks at his life – amputation and all – joyfully. "I have great relationships. Put the utmost effort into finding those," Ralph would tell his younger self.





Anne Bell is a retired schoolteacher from Toronto. She too became an amputee later in life, her left leg. Anne is quick to offer this advice to young people: "Don't be too hard on yourself. Some days, unexpected obstacles would just send me into a tailspin. I remember my prosthetic training. I was so excited. I remember all of the little steps... and I was so excited for each one! I was getting my new leg. I would be walking without an aid. I would be getting back to work — what I thought would be a normal life. Then, I tried the new leg and it didn't work properly. I was back to a walker. I got really upset. Now I realize, don't be too hard on yourself - there will be setbacks at times. You move on again.

"My other thing is to listen to other amputees. They are the best source of support. I was lucky. My neighbour was an amputee. He gave me the best advice. When I would ask him things like, 'Should I try this?' he'd always say, 'At least, try it! The worst that will happen is that you won't be able to do it.' When people would ask what I was doing I would answer, 'Trying to be just like my neighbour!'

"I also have a huge support network, which I really think is key. They encourage me. I went back to teaching after my amputation. The kids were great. They were so curious. They asked to see my new leg, and asked questions. Kids hold nothing back... 'Is your leg going to grow back? Did it hurt when it happened?' They would come to my desk and knock on my prosthesis for attention. I was open to their curiosity which was very significant for me."

Anne also explains that when she first went back to work, she was afraid to ask for accommodation. "Now I can do it, but I couldn't then. I think, before, why couldn't I just say, 'I can't do that?' I do regret not being strong enough to say that, but I wasn't in the right frame of mind. Like doing yard duty in the winter at school on a new prosthetic leg. It was icy. Dangerous for me. I should have spoken up; but I never did."

Experienced amputees can offer new perspectives. What they would tell their younger amputee selves after years down the road is so valuable for others to hear, to understand and in which to find comfort, trust and hope. The road to recovery can be a journey without end. But it need not be laden with pitfalls and surprises only. It can be spectacular too. So say many who are seasoned travelers, pioneers and peers, on that pathway.

#### **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 numerous novels.