Amalie HENZE

Difficult Roads to Promising Destinations

By Max Warfield

She's an Ontario teen who loves to hike trails, dance, paint, read and put on make-up… and trying new things. She loves high school but misses time when dealing with a nagging health issue. Her Crohn's condition has landed her in the hospital many times since she was fifteen, each visit serious, and each a marathon of needles and tubes and new medicines. But Amalie Henze's spirits always remained bright.

One October she is doing well, working at a wedding and then the next day she is in intensive care fighting for her life. She had stomach pain again but this time it was a different issue. Infection raged quickly into sepsis.

The fight for survival threw Amalie's life in a new direction. She was just eighteen when doctors confided to her parents, as they wheeled her away for surgery, "She's not going to survive this, but we will at least find out what caused it," shares Amanda Henze, Amalie's mother. "Crohn's is a quality of life issue, not… this… sepsis," continues Amanda, remembering her bewilderment. "But Amalie, bright and beautiful, is a fighter. She came through."

She came through, but at the expense of both of her hands and feet. Now a four-way amputee, a daunting path of difficulty and uncertainty lie ahead but her strong will and buoyant ways predict that her future remains bright.

"There was so much grief during that time," Amanda explains, "and at the same time, pure joy that she made it! I remember a doctor saying, 'I cannot believe that this child lived. There is no reason other than this kid is destined for something. This kid has purpose!'"

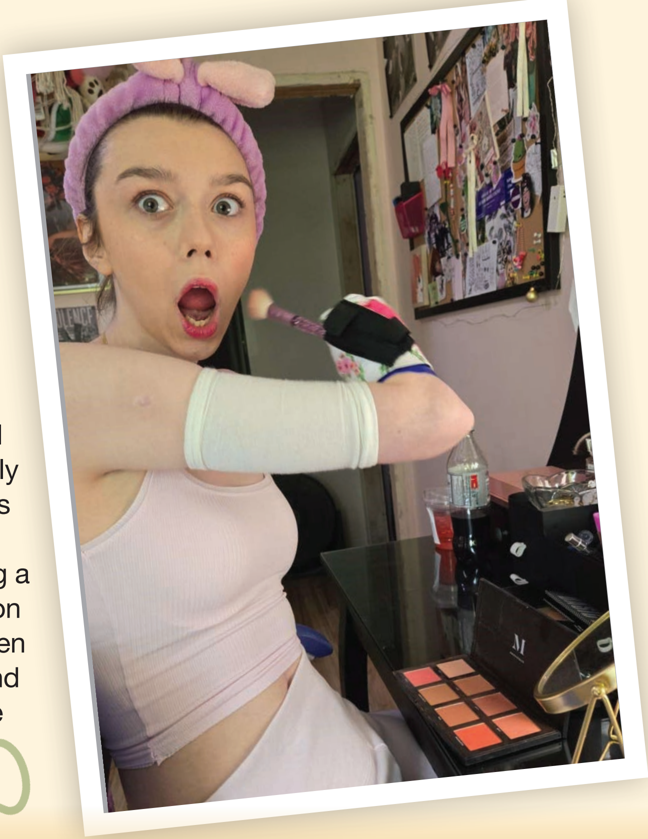
Many months later Amalie is putting the pieces back together. Her Crohn's disease has greatly improved, always giving her hope that it's in the past before it flares back up. "That's okay," tells Amalie in a cheerful tone. "It's a process."

Amalie is working hard to do her best on many fronts now, including finishing high school with the same optimism. "I am waiting for a specific I-pad to do my work on and it has been hard to get connected with a school board that wants to take me on as a student. They might assume the worst or might not realize how much I can do or they might be afraid that they won't be helpful enough," she ruminates as Reyna, the family's orange cat, interrupts with noisy mewing. Amalie giggles along with her mom and sister Anais in the background. When her health and the red tape allows, she is ready for class.

"I'm antsy to get back into it. I really liked school when I was able to actually go. My favourite subject is English, but I like others, too. I wouldn't mind being a writer. I like art but more on my own time, doing it when I don't have a deadline and I can put my own creative spin on things.

"Plans?" she asks out loud. "I want an online school; I'm not going back to class in person. I didn't really thrive in that environment anyway."

She explains that there was a lot of pressure to figure out her life at age eighteen and know exactly what she wanted to do. Sharing that now with a disability, there is more of a challenge. "But this [surviving sepsis] gave me time to think about what I want to do. Less what my teachers think I would be good at and more what I think I can do. More me. I am figuring out what my passion is. I'm hoping that



finishing high school will give me a better idea of what I want to do.” Reyna meows in agreement, met with a laugh from Amalie, Amanda and Anais. Their pet dog Hiro, a husky, behaves quietly in another room. “She’s worth the allergy aggravation we have,” Amalie laughs.

When asked about her passions, Amalie says she used to be a gymnast and worked at a fancy hotel setting up for weddings. “But that was just a job. I am a perfectionist and I *did* thrive in that environment.

“I grew up in the YouTube generation. We would watch a lot of stuff on the internet growing up. Career-wise I would like to do more videos… the only thing, in Canada, it’s difficult to monetize.”

Amalie is using social media to share her story of sepsis recovery publicly, creating videos that can be seen on TikTok, Instagram, YouTube and other sites. Educating others about sepsis is important to her.

“Amalie is great on Instagram,” applauds Ottawa’s Christine Caron, a board member with the Amputee Coalition of Canada and the Canadian Sepsis Foundation. Caron lost both of her legs and one arm after a dog bite sent her into septic shock.

Amalie met Caron through a mutual doctor. “Christine visited me,” said Amalie. “She’s so funny. She taught me about prosthetics. She’s been a big help because we have similar amputations. She’s been so helpful.”

Christine Caron, Amputee Coalition of Canada and Canadian Sepsis Foundation

“A tall, pretty girl educating people about sepsis and recovery while putting on make-up who is not all about herself!” enthuses Caron about Amalie’s commitment to more awareness.

Sepsis education is Caron’s passion as well. “You can’t ‘catch’ sepsis,” she says, insisting that everyone should know that any infection can progress to it. Misconceptions about sepsis fuel Caron’s determination to clarify the issue to patients and medical professionals, as it can be complicated and misunderstood. Miscommunication, fear of lawsuits, and the need for more science, seems to slow progress.

“Sepsis is not an infection,” emphasizes Caron. “It’s the body’s own toxic response to an infection – viral, bacterial, fungal or parasitic – that has breached the body’s safety barriers like the skin, or mucosal lining in the nose and mouth or digestive system.”

This response involves inflammation and clotting that damages tissue and organs. Sepsis is the pathway between infection and death for most infectious diseases. Anyone can develop an infection; it does not discriminate. Sepsis is a medical emergency that impacts people of all ages and all areas of healthcare. Diagnosis can be tricky, but early recognition of the infection’s progression and timely medical intervention can save lives and limbs.

“Sepsis has been my main focus on social media because my situation sounds crazy, like getting that much infection was a one-off, but it’s not,” asserts Amalie. “I am one of the lucky ones. Not lucky in all ways, but most sepsis victims pass away, unfortunately. I want to help those who research sepsis. I hope to do more with the Canadian Sepsis Foundation.

"Everything is a slow process; I am new to everything," understands Amalie. "I'm waiting on my new prosthetic arm. There is a five-year window for sepsis before all the dust settles. I'm still working through a lot of things. Health first!"

The youngest of three, with a sister and a brother, Amalie feels fortunate to have wonderful family support. Her support system however, branches out beyond family. "I have two friends who I've been close with since Grade 10. One is in college, and the other works full-time in a hair salon which is very helpful. I did lose some friends through this whole thing but it might be for the better anyway. I'm happy with the ones I still have."

She also brags of her fine health care at Hamilton General Rehabilitation Centre. Reyna the cat chimes in again with a loud meow. "And the other patients who were there with me were really supportive too, especially because I was the youngest one there. They would look out for me.

"Nicole is my prosthetist who I see on a regular basis. Now it will be more often. My arm fitting process is starting to pick up and I am really excited about that. I will have a lot of new myoelectric technology. The arm I'm getting is high tech. I had special surgery for it called TMR [targeted muscle reinnervation] where doctors rerouted my nerves so I can have better control over my prosthetic arms with less pain. It's going to allow me to have more freedom."

Amalie first experimented with prosthetic sleeves with her lower limb prostheses but moved to a pin mechanism which has provided her with much more independence. With a little creativity, a loop replaces the button which she can manage with her elbow to pull and release the pin herself.

When it comes to cosmetic attributes of her new arms, Amalie was asked if she wanted more realistic looking prostheses, an offer to match her skin tone. "I didn't," she says adamantly. "I want to lean into the robot look. Like steampunk. Everyone knows that you have a prosthetic device anyway, so why try to hide the fact. I want to be just like… 'Yeah, I've got a cool robot arm!' I can then just share my story with everyone."

Amalie's mother Amanda reflects after a sigh. "This could have happened to anybody… it's almost like, we were the family that could handle it. I have some medical experience. I know how to transfer her. I know how to be a caregiver. Her dad is a really big guy, which helps get her around too." Add to that, Amanda's company specializes in adaptive clothing, and was recognized with an award for its accessibility work a number of years ago.

But the family needed to make changes. Amanda explains that their home needed to be completely renovated to meet Amalie's needs. "Nothing was accessible. There is not a single thing that wasn't changed or paused. I had to stop working. My son moved home from college… came back home to help. We had to rip out all of the carpet and get hardwood floors. We got a stair lift, with all of the bedrooms being upstairs. Not a single thing in our lives was the same.

"Amalie is very determined," Amanda attests. "We get creative

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trying to get things right. At first, we were like, ‘Oh, she can’t turn a door handle.’ So we got differently shaped handles. Every little thing, we try to make it work.”

“I am going to be super independent, even though I need help right now,” assures Amalie. “I’m going to figure it out! When I get my prostheses, they will open up my world.”

Although it’s taking a long time, Amalie has her componentry picked out. She’ll be fit with a special suction mechanism to accommodate the loss of both hands. Usually, when missing one hand, an amputee has the other hand to help put it on and take it off.

“It will be mentally exhausting, learning this new skill,” acknowledges Amanda, “but it’s a learning experience for the professionals too because with that level of septic shock, typically you don’t survive. Whatever happens, we’ll figure it out.”

Amanda consistently tells Amalie that she is going to be okay. “I tell her, ‘you are just going to have a different story, an interesting story’… like, I am 5'1'' and my husband is 6'9'' and our girls are tall like super models. Amalie was insecure about it and hadn’t quite embraced being tall. Her prosthetist has suggested starting her out shorter until she gets her balance. Amalie was amazed – now, she can pick her height!”

“I’ve seen accessibility and inclusion being a big thing in the fashion world,” Amalie notes. “I wouldn’t mind getting into modeling. My sister’s been in the modeling industry. I know she could help me out with it. I’ve always had an interest in doing it. I want to try out everything that comes my way. Trying everything once is a good goal in life that everyone should have,” she professes.

Amalie has not done a lot of traveling but it is something she wants to do too, particularly seeing Europe where she has family. A recent New Brunswick trip to attend a wedding was her first taste of traveling outside of Ontario with a disability. Her mother shares a family laugh that transpired at a rest stop when Anais popped the trunk to get her sister’s legs to the watchful stares of strangers.

With increasing confidence as her life as an amputee evolves, Amalie has already constructed a motivating message for others who are new to the journey like her: “It might be scary at first, but it does get better. There’s still plenty of opportunities in the world, even with disabilities. And I think that with time, we’re only going to come that much further when it comes to having a disability and what we’re able to do. So, I feel like we should be excited for the future, not upset that it is over.”

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.