

HUMPHREY HANLEY

Life on the Upside

by Sarah Connor



Imagine if you couldn't dress yourself or pack your own school bag. Imagine losing skin every time you bumped into something – or starting each day having your limbs wrapped in bandages.

Humphrey Hanley lives with a rare skin condition called epidermolysis bullosa (EB). From the moment he was born, it was obvious something was wrong. Skin was missing on his feet. Google wasn't around in 1982, so Humphrey's parents couldn't do their own research. "It was my grandfather who finally worked it out," Humphrey explains. "He was a pathologist – a doctor who studies and diagnoses diseases."

For some people, EB is a bit like mild eczema. But for Humphrey, the disease is more severe. Any kind of friction or bump can make his skin blister. Humphrey puts it another way. "If you think of most people's skin as being attached with glue and staples, mine is stuck on with butter." EB is genetic. It can be inherited in different ways. Humphrey's parents aren't affected by the disease, but both of them carry the gene. They had a 25 percent chance of passing that gene on to Humphrey.

EB

Epidermolysis bullosa (*ep-ih-dur-MOL-uh-sis buhl-LOE-sah*) has been called the worst disease you've never heard of. Worldwide, EB affects around half a million people, which makes it rare. In New Zealand, around 150 people live with the condition. EB causes fragile, blistering skin, especially on the hands and feet. In severe cases, these blisters also form inside the body.

Some people with EB only live for a few weeks, months, or years. Most people don't live past their mid-twenties. There is no treatment or cure, but there are lots of ways people can manage their pain, treat their wounds, and protect their skin.

Up for anything

Humphrey was born with hands, but over time, his fingers fused together. Eventually, he says, his hands just disappeared. Now, with only a tiny part of one thumb left, he can't do simple things like have a shower or cook meals. Humphrey's partner, friends, and parents support him in different ways, and every morning, nurses come to his house to help him shower and dress his wounds – a process that takes up to four hours. "My day starts when most people are stopping for morning tea!" Humphrey says.

One of the main challenges of having EB is the way it eats up time. Humphrey's intense morning routine means fewer hours for work and play, but once he gets going, life is good. Ironically, getting help allows him to be independent. "It means I can get on with what I want to do, live the kind of life I want." While Humphrey's constantly weighing up any risks – and some days "don't go brilliantly" – he doesn't let EB limit him. "I'll give anything a go."

Problems have solutions

New Zealanders are famous for their "can do" attitude, and Humphrey appreciates this outlook. He remembers being at school and wanting to snowboard with his friends, so he wrapped himself in layers of puffer jackets. Looking back, he says it was a great moment (but probably terrifying for his parents). Photography, another interest, also came with an obvious problem. Humphrey solved it by attaching his camera to his arm using cable ties.

Being inventive, and making do with things like cable ties, has its place. So does technology. Humphrey says it's given him a lot of opportunities. He was one of the first in his class to have a computer, and from a young age, he was drawn to online gaming. The first touch screens were great for Humphrey, but over time, he says gaming has become faster. Gamers need to use multiple buttons – too many for someone without hands.



Humphrey was quick to take on this problem. Together with a friend, he used a 3D printer to make a plastic shell for his mouse. The shell contains magnets to help Humphrey move the cursor, and a Velcro strap helps the shell stay connected to his wrist. The designer mouse is still a prototype, but Humphrey would love to see it mass-produced. In the meantime, he helps tech companies with their user-testing. "Sharing my ideas with designers helps them make products that are more accessible for people like me." Humphrey also works as a videographer and runs his own business.

Looking for the upside

Most people are either confused or fascinated by Humphrey's skin. When he was younger, bullying was a problem. "It was tough back then for kids who were different. It feels better these days. Kids seem more inclusive and are generally nicer to each other." These days, Humphrey says, people go out of their way to help. The barista at his local cafe knows to make his coffee lukewarm – it's safer. Shop assistants avoid using tape, which he won't be able to peel off, and Humphrey can order taxis with a driver who's prepared to help. His friends are thoughtful, too. In a crowd, they always stick close – like a human bumper bar – so he doesn't get hurt.

Humphrey reckons Covid has also made a difference. "Everyone knows about learning and working from home now. It's the new normal, which is good for people like me. The pandemic has given people with disabilities a louder voice."

Working to make a difference

Humphrey didn't grow up with any disabled heroes, but now he sees trailblazers everywhere, especially in online communities. Humphrey's a big fan of Steve Spohn from the charity AbleGamers. Spohn uses gaming to reduce social isolation and to support people with disabilities.

Humphrey's determined to be a role model himself. He has always spoken up for people with disabilities, and he's made loads of videos to share online and inspire others. He also ran for his local council. "One in four New Zealanders is disabled, yet I noticed no one on the council identified as disabled." Humphrey campaigned for a city that was more people-friendly, with better disability access. He also wanted greener public transport. He missed out on becoming a councillor but is now on Wellington's Accessibility Advisory Group. "I want to give disabled people a voice so they can live their best life," he says.

More recently, Humphrey became the vice-president of DEBRA International, a charity that helps people around the world living with EB. Humphrey feels lucky to live in New Zealand. "I know I can always get the care and things I need."

Being yourself

There was a time when Humphrey was sensitive about his disability defining him. He spent a lot of time on the internet, a place where difference couldn't be seen. "I liked that I could just be myself," he remembers. Now, Humphrey sees EB as part of who he is – and not something he needs to keep hidden. He says it's up to individuals to define what their disability means. "No one should feel pressured to do things a certain way – there's no right or wrong. Disabled people need space to discover who they are."

Humphrey has also learnt to accept there are some things he can't do, like backpacking. "It's not the safest way for me to travel," he says. But because of EB, he's been a guest speaker all over the world. "I've stayed in nice places and met interesting people. I've shaken hands with Prince William and been on the same poster as Ryan Reynolds!"



Advice from Humphrey

Life doesn't always go to plan. Sometimes you might want to make a change that feels impossible. Other days, life just feels hard. Humphrey's attitude is proof that challenges can be turned around.

1. Find one thing in every day that makes it worth being awake.
2. Have a vision and find a way to make it happen. Focus on how you can do what you want to do. If something you need isn't available, try making it yourself. Or find people to help you make it.
3. Imagine that opportunities are endless. Be prepared to embrace your difference and say yes to new ideas.
4. Find a way to tell your story, to support yourself and others. Most of all, be kind.

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