INSIDE

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Inside this edition

It never ceases to amaze me how diverse our community is. We are privileged to hear people's stories and learn of their journeys post amputation. Their experiences are very different and vast. In this edition we feature stories from some of our peer support volunteers and learn of some of their incredible achievements. For others, it can be the simple joy of giving back to others and sharing their own experiences. Regardless, they all form part of the very rich tapestry that is our community.

Which reminds me, early bird tickets for AMP-ed Up! close on September 30, so don't miss the opportunity to purchase your registration ahead of time and save a few important dollars in doing so. Our AMP-ed Up! merchandise has arrived so if you're in the market for a new polo, t-shirt or cap, give as a call!

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James's first anniversary

The most vivid memory my neighbour has of THAT NIGHT isn't mine. She remembers it as the jubilant shout of "He's conscious!", uttered by an emergency worker. Since arriving back from an overseas holiday, I had been feeling unwell, which I had put down to the flu or maybe COVID. More seriously, as a result of a cut foot, an infection was taking over my body, eventually resulting in a lower right leg amputation. Another contributing factor was undiagnosed diabetes. Upon entering the hospital, I had a blood glucose level of 78, meaning there was a high risk of death or brain damage. Each year over 8,000 people in Australia have some kind of amputation, with varying causes including accidents, cancer, and the combination of infections and diabetes.

My own experience was similar to that of Clayton, a Peer Support Volunteer with Limbs 4 Life, who called me to provide Peer Support during those early days in hospital. He described his own life-changing experiences following his amputation, including changes to his personal life and career.

Fuelled by powerful pain medication during the early weeks of my hospitalisation, I found it hard to think clearly. Simple emails and messages of support required multiple readings before I could even attempt a response. I also had to put modesty concerns aside as nurses helped me with the most basic of human functions.

"How are you REALLY?" was a frequent early question from concerned family, friends, and medical staff. At first, their responses to my "I've had a couple of tough days, but mostly I feel pretty good," seemed laced with disbelief. I noticed that there were two main ways in which people responded. First, there are those who take my positivity at face value, offering enthusiastic support like, "You've got this!". And secondly, there were others who approached the situation with a different perspective, perhaps wondering if the full weight of what happened might hit me later, once the hospital's comfort and support system faded. And maybe that's a possibility, even now, a year later.

In the weeks leading up to my illness, I visited Vietnam and Cambodia. Among the people I met were some who had lost limbs to landmines. In the grand scheme of things, millions around the world have lost limbs, some even more than me. And they've faced this without the privileges I've had, living in an affluent country with a top-notch health system. "I feel lucky to be alive," I told my friends, "like I've been given a second chance."

The period at Sydney's Sacred Heart Rehabilitation wasn't merely about physical therapy. Mindfulness techniques helped me manage the mental toll, while mirror therapy aimed to retrain my brain to accept the new reality of a missing lower leg. In total, I spent close to four months in hospital. Preparing for discharge was always at the forefront of my mind, including whether I could navigate in and out of my apartment independently? Would I be able to shower independently? What modifications, if any, might be necessary for me to live on my own? A good friend stayed with me on the first night back home. Although I went to bed feeling good about things, I quickly found myself in tears, comforted by her. "I don't want everyone to worry about the tears on the first night," I told her the next day. "I don't want them to think I've fallen into a deep depression now that I'm home after the safety of hospital life." My friend responded, "The tears are perfectly normal," and "maybe there will be more tears in the future, it's likely there will be difficult days."

Early on, I realised it wouldn't be a simple linear progression from amputation, to wheelchair, to prosthesis. As I've read in online amputee forums, many people find their prosthetics don't fit well, or they cause irritation to their stumps. Recently, after heavy rain, the lift in my apartment block stopped working, which meant it was harder for me to get in and out of my apartment. It was a reminder that I could easily find myself housebound, despite my apparent mobility.

The NDIS has also provided me with a transportation allowance, allowing me to catch taxis and ride shares. Mostly though, I use public transport where the interactions have been both good and bad. Sometimes people don't notice I still have mobility requirements, especially now that I'm walking independently, without crutches. Even though my prosthetic remains fairly obvious, many people never look down (especially when they're using their mobile phones).

After my amputation, I had four months away on sick leave (as a long-time public servant I'm lucky to have plenty of reserves), I returned to work part-time in November 2023. At first, it was really hard balancing work, managing my diabetes and the additional demands surrounding amputation. It often felt like twice the effort compared to someone without an amputation. For example, walking 5,000 steps for me is akin to 10,000 for others.

Having a dedicated Wednesday off work for medical appointments and rehabilitation activities like swimming and physiotherapy has been a welcome relief. However, fatigue persists, sometimes forcing me to spend most weekends resting in bed. My workplace (the ABC) has been wonderful, both at a personal level (lots of colleagues reaching out, visiting, and sending gifts) and at a more institutional level by allowing me to work part-time. Progress is evident, and I'm optimistic about returning to full-time work later this year.

The amputee Facebook group I joined, Amputees - Limbs 4 Life Australia, has been invaluable as a guide. Discussions there shed light on the varied experiences of returning to work. Some, like a bank employee facing ongoing medical challenges, have struggled for years even with a part-time return. Others, like a remarkable quad amputee, transitioned from part-time to full-time office work. Challenges abound, though. One small business operator spoke on the group about a gradual return to running his business, until ultimately closing it due to compounded difficulties including pandemic-exacerbated mental health issues. However, there are also inspiring stories. A few weeks ago, the Sydney Morning Herald featured Joey, a young man from Newcastle who returned to work as a plasterer after two years. Now, he's even training for the Paralympics! Go Joey!

For many, the journey back to work is arduous, and for some, it remains unattainable. The Facebook group has truly helped me understand that everyone's experience is different. There's no single answer to the ever-present question for new amputees; "When can I return to work?"

As I approach my "stumpiversary" (as it's sometimes known in amputee circles), I'm feeling both positive and reflective. I'm consciously aware of how lucky I have been, supported both institutionally and personally. But not everyone is so lucky. Many people struggle, find themselves isolated, or are unable to navigate the associated complexities.

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