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Cyndi Desjardins lost the lower portions of all four limbs to flesh-eating disease.

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Life goes on after amputation

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Two weeks after the Boston marathon bombings, the legions of police that swarmed the city have given back the streets, and the news crews that dogged their every move have mostly melted away. Life is returning to normal.

But for the victims who lost one or more limbs to amputation – the only life-saving answer to flesh and bone shredded beyond repair by exploding shrapnel – the long road to recovery has just begun.

For them, normal will never be quite normal again.

Cyndi Desjardins knows what the 15 amputees in Boston are going through – and then some.

Two years ago, she awoke from a month-long medically induced coma to be told that surgeons had

had to perform amputations to save her life after necrotizing fasciitis, or flesh-eating disease, had overwhelmed her body.

The lower portions of all four limbs were gone.

Desjardins recalls the moment “clear as day” when her husband gently gave her the news: Doctors had removed both legs below the knee, and both arms below the elbows.

“I remember an incredible feeling of heartbreak,” she says.

“And I know exactly what goes through your head when you’ve had a life-altering situation like this: ‘What kind of life am I going to have?’”

Six months earlier, she’d given birth to her son Liam, a brother for six-year-old Cienna, whom the couple had adopted as an infant.

“My thought was how am I going to hold my children? My son doesn’t know who I am; my daughter misses me terribly. How was I going to make my daughter lunches? How was I going to do her hair? And how was I going to do anything for my children, let alone I was going to have to learn how to brush my teeth, brush my hair and do everything for myself all over again?”

“And I knew, too, that the only way I would get through is if I was going to set very specific goals to recapture my independence and reclaim our lives,” says Desjardins, 45, of Holland Landing, Ont., north of Toronto.

“I’ve been raised with faith. And in that moment, thank God I’d been raised with it, because it was going to carry me through.”

As with any loss, amputees typically go through a period of mourning; some will also experience depression as they grapple with their altered physiology and the frustration of adapting to the new reality of their everyday lives.

About 85 per cent lose a limb because of complications from diabetes or peripheral vascular disease, explains Dr. Michael Devlin, a physiatrist at West Park Healthcare Centre in Toronto who specializes in amputee rehabilitation.

“For the most part, they knew the amputation was coming. They’ve had open sores or gangrene, they’ve been house-bound, they’ve been having home-care nurses coming in to do dressing changes,” he says. “Their life had gone down the drain already, and an amputation for that particular population is a step ahead and a step up.”

The other 15 per cent will have suffered a sudden health threat or trauma that led to amputation: bone cancer; a rampaging infection; a traffic or work-related accident; or a blast injury while in a war zone like Afghanistan.

For these patients, the first reaction is shock, says Dr. Sally MacLean, a psychologist at Glenrose Rehabilitation Hospital in Edmonton. “You’re just amazed: ‘How could this happen?’ And the whole notion of how fast things can change and how things can change inevitably for the future.”

Emotions run the gamut from denial to ruminating about such questions as “why me?” – all of which are normal reactions, says MacLean, adding that psycho-behavioural therapy can help a patient work through their grief and fear.

Concerns arise if the person gets stuck and can’t move forward, putting them at risk for depression, anxiety or post-traumatic stress disorder, she says.

The latter, which can manifest itself months down the road as flashbacks or reliving the injury or accident, is more likely to occur when the event was perceived as life-threatening.

Peer support also can be critical for speeding emotional healing, adds Devlin.

“Someone comes in and they’ve just had an amputation and they see a guy down the hall who’s been here for, say, three weeks and he’s got his prosthesis, he’s up and walking around, he’s going home for weekends,” he says.

“So your more recent amputee says: ‘Okay, I’ve seen Joe Blow down the hall and this is what my future might look like, and it doesn’t look as bad as I anticipated.’”

Physical recovery has its own trajectory, and it’s one rehab professionals want to start as soon as possible, in part to help mitigate the psychological blow delivered by the amputation.

Devlin says that depending on how much residual limb exists and how well the site is healing, fittings for a prosthesis can start as early as five to seven days after amputation.

Most amputees have lost a lower limb, so rehabilitation initially involves learning to walk again, first along hospital corridors, then outside on the grounds, going up and down stairs, and getting in and out of a car.

A patient can be home wearing their prosthesis and walking with the aid of a cane, crutches or a walker within an average of four weeks, returning as an out-patient to work with physios, occupational therapists and other rehab team members on optimizing function.

“There’s multiple little steps and multiple little goals which can be checked off and you can say: ‘Hmm, did that.’ And each successful goal you achieve, it’s one more feather in the cap,” says Devlin.

Jason Naval opted for amputation after his lower left leg was mangled when a car collided with his motorcycle in 2009.

“For me it was the logical choice because I wanted to still run and play ball, and I knew that if I kept the leg I would be cradling it. I would have to take care with every step I take.

“But with the prosthetic, I would just put it on and go as normal, as far as normal can be.”

Naval, 27, has not let his amputation stop him: he is a member of Canada’s national sitting volleyball team, rock climbs and runs using a prosthesis like those used by Olympian Oscar Pistorius.

Still, as with any amputee, there are discomforts: blisters and bleeding in his stump caused by chafing from his artificial leg, fatigue that can lead to muscle weakness in his sound leg from being overworked.

“You have to constantly take care of it. You’re very careful not to injure it since you only have one.”

And cruelly, it seems, there’s the ghost-like reminder of what has been lost – what’s known as phantom pain or sensation in a limb no longer there.

“It’s not as bad as it was in the beginning,” Naval says of the pain. “In the beginning, it was almost constant. It would be like electricity running through my leg. But now it’s every so often I will get a shock here and there. And I know it’s going to go away after a few seconds or a few minutes. So you just take it.

“It’s like you can trace your foot, your toes where the pain is.”

Devlin says amputees describe the sensation variously as an ache, sharp pain, squeezing, burning or numbing, and though it diminishes over time, it rarely disappears. Certain medications can help, but he admits they aren’t very good.

That’s because the pain or sensation is being “felt” by the brain, which is not getting any input from the missing limb and keeps on “firing more frequently or at a higher level.”

“Mostly they describe that as ‘I feel my leg is still there.’ And they can wiggle their toes, they can move their ankle up and down,” although the anatomy no longer exists, Devlin explains. “If you ask them to move their ankle up and down, you can see the muscles in the residual limb contracting.”

But it’s often the little things that amputees find most frustrating.

“When I cut my toenails, every time – every time – I gesture to cut my left foot,” Naval says. “But it’s not there and I have this inadequate feeling that it’s not complete because I haven’t cut my other toenails.”

For Desjardins, every day is a learning experience as she figures out how to use her myoelectric arms.

She is driving again with an adaptive device on her steering wheel, though her son’s car seat defeats her.

She has periodic phantom pain, a stabbing that can stop her in her tracks.

Yet each day brings another victory: she recently managed to crack an egg so she could make her kids a hot breakfast.

“Everything I do takes me at least five and up to 10 times or more longer. But I just remind myself I am alive. I’m here to do it and the honour of being alive is much more important than whether I drop this juice box five times or can’t seem to get the door open on the first try.”

Desjardins, who spent almost six months in hospital recuperating, has turned her experience into a positive, working as a motivational speaker to groups and providing one-on-one peer counselling to other amputees.

When news broke about the Boston bombings and the number of injured who had lost limbs, she knew the devastation they would feel. But she also knows what is possible.

“I wanted to get on a plane and walk into their hospital rooms ... to show them what faith and hope and love and being surrounded by caring people can do to help them find their purpose,” says an upbeat Desjardins.

“I wanted to show them that it’s temporary, that it’s horrific, but there is life after a life-altering event.”