

Jordan Sacks Discusses His Experience with a Very Painful, Slow-healing Wound



Jordan Sacks is a Toronto-based chartered accountant. Aged 39, he has been married for 11 years to his wife, Lisa; they have 3 children. He spoke recently with *Wound Care Canada* about his wound care experience.

When was the wound diagnosed, and what has been your reaction?

I was diagnosed with Crohn's disease in 1987. I was medically managed for more than 20 years, until I had to have a bowel resection in May 2008. Postoperatively I developed an anastomotic leak, which resulted in septicemia. I was taken back to surgery to wash out my abdomen, reverse the bowel resection and create an ileostomy. As a result of the septicemia, my blood pressure dropped significantly and my organs began to shut down. I ended up in the intensive care unit (ICU), fighting for my life for several months.

During one of my many operations while in the ICU, it was also discovered that a significant amount of muscle and tissue in my right thigh, hip and lower back was necrotic and had to be debrided. As a result, most of my back was used as a skin donor site. The donor site became my wound. Because of my poor health and the fact that I lay on my back 24 hours a day, the wound did not heal. It bled every time the bandages were changed and the more irritated it was, the more sensitive it became. After almost two years of trying various dressings, ointments and creams, my wound had still not healed. In March 2010, I began seeing a dermatologist and wound specialist who was responsible for healing my wound. After many appointments where many painful steroid injections were administered, my wound finally closed. The redness is slowly fading and the sensitivity has decreased significantly.

How did you cope with your wound care regimen?

I had a very hard time of it. Early on at the hospital, I feared the daily dressing change. I was anxious about which nurse I would have and whether he/she

would be familiar with the procedure. Because of my anxiety, I asked my wife or my parents to speak to the individual in charge of staff scheduling every day to ensure that the nurse assigned to me knew my wound care routine. I also insisted that my wife be in the room with me to hold my hand and supervise the dressing change because she knew the exact protocol. Before the nurses began (several were required to roll me over and change the dressing as quickly as possible), I was given pain medication.

My wound bled every time the old dressing was peeled off. Eventually the dressing change in the hospital became so painful that I needed a dose of ketamine prior to the procedure, which sedated me sufficiently to remove the old dressing. I would then remain on my side for about 20 minutes so the nurses could finish.

Patients at the rehabilitation hospital were not permitted intravenous lines. As such, I was prescribed strong oral painkillers such as opioid analgesics to mitigate the pain from my dressing change, which often left me feeling nauseous. The pain was worst when I showered; when the water came into contact with the wound, it felt like I was being burned. Many days, the pain from my wound was so excruciating, I couldn't do any physical therapy.

The rollercoaster ride of my wound starting to heal and then breaking down again because of malnutrition, MRSA and pseudomonas I contracted while in hospital was extremely frustrating.

After I was discharged from the hospital, home care began and a Community Care Access Centre (CCAC) nurse changed the dressing 3 days a week. My schedule on those days worked around my nurse's visit. I had to

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have my dressing changed before I could do anything else. On average, the preparation for and the dressing change itself took 3 hours, so my mornings were fully booked. On days where I had to go to therapy or other medical appointments, I had to ensure the nurse saw me early enough to get out on time. Coordinating my schedule was very stressful.

Weaning myself off the pain medication to which I had become addicted was a huge challenge, as the pain was still intense. Initially I took a lower dose of morphine and then I began using extra-strength Tylenol. I took oxycodone on the many days when the pain was excruciating. I also encountered a new issue when I got home: the constant and intense itch from my wound. The itch always began immediately after I showered and lasted several hours. On a few occasions, the itch forced me to skip my occupational and physical therapy. While my wound was open I couldn't tolerate anyone hugging me, which was difficult to explain. The wound completely interfered with my ability to live my day-to-day life.

Can you discuss the importance of family/friends/caregiver support?

I would not be here today if I didn't have the unconditional love and support of my whole family and all of my friends. My wife was my advocate when I couldn't be. She became so familiar with my wound dressing changes that the nurses often asked for her assistance. My wife also played a huge role in the decisions that were made concerning my medical care. Although I can never repay her for what she has done for me, my knowledge of her actions made me determined to recover and resume my responsibilities as her partner in life.

My parents and siblings were at the hospital every day, putting aside their own responsibilities to help take care of me. They brought me meals; they ensured that I was never alone and that I received the appropriate care when my wife was at home with our kids. Their ongoing and unconditional support was fundamental to my recovery.

My kids, too young to understand the severity of my condition, visited often and gave me the inspiration to work hard and resume my responsibilities as their father. My in-laws helped take care of our kids while my wife was at the hospital, and our many relatives and friends provided ongoing support without being asked.

What is the importance of your healthcare team?

The nursing care I received through the CCAC while

recovering at home was terrific. The nurse came every other day and spent as much time as needed ensuring the wound was properly cleaned and dressed. Having the same person handle my dressing changes was very comforting to me. We developed a relationship and I knew what to expect instead of fearing the unknown. When my regular nurse couldn't see me, she always ensured her replacement was well prepared with detailed written instructions on my dressing change and how it had to be done. When an issue arose, the nurse always contacted my attending physicians to ensure that they were fully aware of my condition and made changes to my treatment accordingly.

The nursing staff of my dermatologist and wound specialist went out of their way to make me feel comfortable. They were extremely kind and caring.

Although they weren't directly involved in healing my wound, many other healthcare professionals deserve recognition for their patience, compassion and commitment to giving me back my life: my family doctor, who assembled a great team of healthcare professionals; my colorectal surgeon, who successfully reversed my ileostomy; my gastroenterologist, who was always available to answer my questions; my hand surgeon, who restored my left hand function; my psychiatrist, who treated my depression; the occupational therapists and physiotherapists, who taught me how to walk again; all of my nurses, who were so compassionate; and the ICU staff and trauma surgeons who saved my life. These people believed in me and are all partially responsible for where I am today.

What would you like to tell other patients experiencing a similar clinical issue?

I believe that determination is the most important factor in the recovery process. My scenario was dire. I went in for a relatively routine operation and thought it was successful. I woke up a couple of months later to this terrible new reality. I had two choices – I could give up and accept my fate, or I could fight to get my life back. I wanted my life back and I was prepared to do anything to get it.

Having an advocate is also extremely important – especially when you can't advocate for yourself. My wife was heavily involved in my ongoing medical care and she was instrumental to my recovery. My family always filled in for Lisa when she was with our kids.

My wound became a huge obstacle to my recovery process. I had to heal the wound so I could focus on

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"I had a very hard time coping with my wound care regimen. Early on at the hospital, I feared the daily dressing change."

my physical rehabilitation program, the most critical part of my recovery. We went to many doctor's appointments. We tried every product available. We talked to many healthcare practitioners. Ultimately, a wound nurse referred me to a specialist who was able to think outside the box and heal the wound. Our persistence paid off.

As a patient, I believe it is very important to recognize the efforts of our healthcare providers and to ensure they know we appreciate what they have done for us. Whether it's a verbal thank you or a written note, our gratitude is extremely important. I went so far as to visit the ICU unit where I had been 3 years earlier to show the nurses and doctors the "proof" that their efforts had paid off; they were appreciative of my visit.

What would you like to say to healthcare providers about dealing with patients like you?

I have met many healthcare providers over the last three years. Fortunately, most went out of their way to help me. I believe that transparency is essential between patients and healthcare providers. Be honest with your patients immediately so a level of trust is established

early on. If need be, explain the procedure or medical terminology again and again. If the patient has an understanding of his/her illness and what your treatment plan is going to be, the element of fear is removed. Fear is a huge obstacle that has to be overcome. Finally, I believe healthcare providers should try to imagine themselves or a family member as the patient and ask themselves how they would want to be treated.

Is there anything further that you'd like to touch upon?

For a long time after I awoke to my horrible new reality, I debated whether it would have been better to die. There were many difficult days when I thought about how long it was going to take me to recover and that it would be easier to give up. Then, I thought about the many people who were counting on my recovery – my wife, kids, family and friends. I also knew that giving up wasn't part of my personality. Looking back, I'm grateful that I was strong enough to survive and know I am fortunate to have had the help of so many outstanding healthcare providers in my recovery. ☺

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