VENTILATOR-ASSISTED

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Highly Dependent on Power!

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A massive winter storm hit the eastern United States and southern Canada just before Christmas last year, causing major inconvenience to millions of people. Power outages in some locations caused further complications, and to some, like Audrey King, created a life-threatening crisis for nearly four days.



I have lived in Toronto for 30 years, on the third floor of a condominium mainly occupied by empty nesters, older folk who enjoy the quieter lifestyle and amenities nearby. Although the building is five stories high and lacks an emergency generator, living here has suited me well.

My apartment has been renovated to meet the needs of an "independent" quadriplegic lifestyle - counters and sinks I glide under in my wheelchair, taps I can easily reach and turn on with a touch, ceiling tracks in bedroom and bathroom so I can electrically hoist myself and transfer between wheelchair, bed, toilet or bath. A remotely operated door opener enables me to let people in and out of my apartment. Battery chargers power my wheelchair and floor heaters cater to my impaired circulation. Even my Ultramatic bed enables me to shift position frequently during the night. Of paramount importance is the ventilator I am dependent on during the night, and often during the day to keep me breathing. I am highly dependent on power!

Every weather related power failure since the four-day power failure 10 years ago has prompted me to do what I can to keep emergency supplies on hand and to advocate for establishment of a vulnerable persons registry, but there has been little interest or initiative. Obviously, I was worried about the ice storm forecast.

When the icy rain started I was happy to be comfortably in bed, having made it safely back from a family Christmas party in another town. The ventilator alarmed about 1:30 am and switched to its internal battery mode — good for two more hours. Hopefully, the power will return by then, I thought. At 3:30 am as it alarmed again I woke my weekend attendant and switched to the back-up ventilator. This one had six hours of internal battery life. I slept lightly for a little longer.

As the light of dawn broke, one glimpse of the beautiful devastation out of the window made it crystal clear the situation was serious and likely to persist for some time. Neither land line nor cell phone worked ... for several days as it turned out. I could listen to radio reports, sparingly, on my cell phone but could not call for help. No batteries could be recharged.

Staying alive, breathing, was essential! The first priority was to find a source for recharging the ventilators and enabling at least eight hours of further breathing support. The superintendent located a working telephone at a neighbor's down the hall. Phone calls to my book club friends at the church across the street led to the church turning on their generator continued from page 1

periodically so Rebecca, my amazing attendant, could transport my ventilators up and down the pitch-black stairwell and back and forth across the icy street to recharge its batteries.

The superintendent and property manager regularly checked on our status. One neighbor brought hot water, another



candles. Yet another 84-year-old neighbor drove Rebecca to get supplies and food, until he too was evacuated by his family. As the building emptied, it became even more frightening and difficult to be alone. I was getting exhausted and feeling helpless,

huddled in my down duvet, unable to even open the door.

On the second day, other long time attendants arrived unannounced, with hot water bottles and thermos. One stayed with Rebecca and me. Given the situation, it was now a two-person job.

Phone calls to my city councillor and the Ontario Premier's office triggered urgent pleas from them to call 911 and get myself to a warming center. But this was no solution. Warming centers had power and heat but not the resources to handle dependent quadriplegic persons such as myself. Going to a hospital was no solution either. Already overwhelmed emergency room staff would not welcome a "non-sick" person to clutter up their halls and protocol. As my out-of-town family became increasingly aware of my plight, they too pitched in by arriving in person. One niece and her family appeared on Christmas Eve with a hot turkey dinner, which we ate bundled up in blankets and coats by candlelight! Another arrived early Christmas morning with breakfast before her own children had even awakened to open their stockings!

By Christmas Eve, with the delivery of backup ventilator batteries from Kingston's Ventilator Equipment Pool in just a few short hours as well as the help and caring of so many people, I went to bed feeling more secure and believing I might actually survive.

Early Christmas morning, as I lay completely cocooned (head and all) under my extra thick duvet and blankets, feeling snug, warm and safe with the hose from my ventilator delivering breaths from outside the blankets I felt akin to a miner trapped underground yet safe and warm in my little womb cave - "umbilical cord" and all. I listened to incredibly beautiful Christmas music via the earbuds and radio receiver buried with me. The pure pristine words of "Away in a Manger" and then "Rejoice" (Handel's "Messiah") transported me to yet another realm of the soul. I felt I was experiencing, seeing, absorbing the light and warmth of that Bethlehem scene so very long ago.

It was indeed a Christmas to remember — four days of destruction, fear, helplessness and terror. Yet, in the midst of it all, it was a "true" Christmas, one of genuine giving, unselfish caring and coming to the aid of someone in need. ■



Audrey King is a psychologist and internationally known writer, speaker and advocate on disability issues.