

How I Learned to Stop Worrying and Love Technology

Daniel J. Wilson, PhD, Professor of History, Muhlenberg College, Allentown, Pennsylvania, dwilson@muhlenberg.edu



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I have now been struggling with the effects of polio for nearly twenty years. These first appeared as a weakness in my right leg, the one most affected by polio, in 1987. Over the ensuing two decades, the leg got weaker, and I began to have breathing problems at night. The physical problems have led to an increasing reliance on technology to help me breathe at night and to move around during the day. I began using a BiPAP® in the fall of 2000, and since August 2006 I have used both a scooter outside my home and stair glides in the house.

Like some other polio survivors, I resisted getting the breathing machine, the scooter and the stair glides. I was proud of my ability to get around on my own without assistance. I could never walk very far – no Appalachian Trail or marching band for me – but I got around quite easily. I associated assistive devices with disability, and I didn't consider myself disabled. Inconvenienced at times, but not disabled. Using the technology of assistive devices was something I resisted. I wanted to do it my way, even if that was increasingly painful.

My first concession to the encroaching post-polio syndrome was the BiPAP®. I had spent part of the summer in the year 2000 at San Francisco State University studying disability and disability history with 25 other scholars, some of whom had disabilities of various types. I not only studied the way in which disability is constructed by society and the ways in which those with impairments are made to feel inferior, I also observed the ways in which my colleagues used their assistive devices to function effectively and easily.

When I returned to my home in Allentown, Pennsylvania, I had a sleep study done, which revealed

serious sleep apnea, explaining why I was waking up tired. I wasn't happy about the doctor's recommendation of a BiPAP®, but decided to try it. Getting used to the mask was not easy. The first couple of nights I did not get through the whole night with the mask on. By the end of the first week, I began to notice a real difference. I was sleeping through the night. And in the morning I was more wide awake and less tired. I have used it every night since, both here and in Europe, except when we have had a power outage. It goes with me when I travel, and I rely on it to help me get a restful night's sleep.

In some ways the BiPAP® was easy. No one had to know except my doctor, my wife, Carol, and our dog, Abbey – who thought it was a vacuum machine when I first turned it on and fled the room. Because I used it only at night, it was a hidden technology unless I revealed the secret. Fortunately, Carol and Abbey both adjusted to the noise of the machine.

My next device would be more public – using a walking stick when there was snow on the walks. As my leg weakened, it became problematic to walk on uneven pavement such as that covered by snow and ice. So, about five years ago I began using a

bright red walking stick in winter. It was one I had purchased in the early 1990s in Zermat, Switzerland, which made it easy to delude myself that I was getting ready to scale the Alps. At least it didn't look as if I had purchased it at a medical supply store. For the last two years I have used the stick whenever I have any distance to walk. It has helped give me stability and has prevented several falls. But I was experiencing increasing pain and was walking decreasing distances. I realized I needed to think about getting a scooter. In the summer of 2004 I purchased a Volvo station wagon that was capable of hauling a scooter – but I wasn't yet ready to get the scooter.

Finally, this past summer I decided it was time to get serious about a scooter and stair glides. I could see I made too many decisions not to do things because of the pain it would cause. I checked with friends in the support group about reliable suppliers as well as with colleagues at the Lehigh Valley Center for Independent Living, where I serve on the board of directors. I was able to try out three different scooters to see what worked best for me and which fit in my station wagon. My wife and I also decided to put in two stair glides. In August both were installed so that I could easily get to the upstairs and to the basement (that way I could help with laundry). I also bought a scooter (a Pride Revo) and had a lift installed in the Volvo, so I could get it in and out easily. I began using these new devices immediately.

I think my biggest anxiety about these new technologies was using the scooter. It's right out there in public – no possibility of hiding if it was going

to be useful. I was apprehensive about using it at Muhlenberg College where I teach, but I had a few weeks before classes started so I could adjust to using it on campus. I need not have worried. My colleagues and the students have been very accepting. Some have been interested in the scooter itself, others have asked about the reasons I use it, but most have simply accepted it as part of the scenery. I decided to be very open about why I need it and don't really mind the questions.

The scooter has made it much easier and much less painful to get around campus. I no longer have to think “do I really need to go to the library” or “do I really want to go to lunch in the union.” I just get on the scooter and go. My only challenge has been the automatic door openers. The maintenance staff is very good at fixing them, but the doors do seem to stop working all too frequently. Winter and snow will pose another challenge, but the crews have traditionally done a good job on clearing the walks, so I am optimistic.

In addition to using the scooter at school, I have used it at Wegmans, Target, and the mall at King of Prussia. I took it to Valley Forge Park and the Allentown Art Museum. And I have been walking our dog Abbey with the scooter. For several years our walks had been more of the “stroll and sniff” variety. She adjusted to the scooter very quickly and now enjoys longer and more vigorous walks.

As I got used to the new technologies and discovered that they were liberating in many ways, I began to think about why I, and perhaps others, so

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often resist using assistive technologies. After all, there are many other technologies I use without a second thought. I have worn glasses since second grade. This essay is written at the computer while listening to the radio. Technologies all. We use technology to heat and cool our homes and to transport us.

But we resist when the technologies can help us deal with the impairments of post-polio. In part, that is because so much of society still views scooters or wheelchairs as emblems of disability. But if we buy into those social attitudes about assistive devices, we are the ones who become disabled. We are the ones who choose not to go places because it is too tiring or too painful. We are the ones who miss

out on things we enjoy if we don't adopt the available technologies.

Surely, if it is normal for many people to walk around the store talking on their cell phones (one more piece of technology), it is normal for me – or you – to scooter through the same store.

I know I waited too long to get both the scooter and the stair glides, in large part because I didn't want to admit that I needed them. Polio survivors, and others who need them, will be better off if we can think of assistive technologies as just another modern technology that helps us live better and easier lives. Cell phones make for better and easier communication. Scooters and stair glides make for better and easier mobility.

I am not sure I really love technology (and that includes computers, cell phones, and scooters), but I know that all three have made my life easier. We don't have to embrace technology, but at least let us use the technologies that improve our lives without fear or trepidation. ▲

Wilson, a member of PHI's Board of Directors, has authored many articles about the history and the impact of the polio epidemics. His most recent book, *Polio Voices: An Oral History from the American Polio Epidemics and Worldwide Eradication Efforts* (Praeger Publishers) was co-authored with Julie K. Silver and released in 2007.

Wilson's earlier book, *Living with Polio: The Epidemic and Its Survivors* (The University of Chicago Press, 2005), has been favorably reviewed and widely quoted in later works.

Have a personal story to tell about living with the late effects of polio?

Have the late effects of polio affected a relationship, job or lifestyle? Have you found a solution? Do you have an experience to tell that would benefit others? If so, send your story ideas to editor@post-polio.org.