

Take Charge, Not Chances: In Practice

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I use mechanical ventilation for sleep, and for rest. I've been at this for a long time – since the polio epidemic of 1952. My health and my equipment have been pretty stable except for the fact that I switched from a chest shell to a BiPAP® in 1994. Of course all sorts of things, including breathing-related ones, are getting harder as I age (I am 68), but otherwise my life is going along fairly smoothly.

I thought I was pretty well prepared for emergencies of various sorts. So when I downloaded the **Take Charge, Not Chances** documents and started to do them, I didn't expect that it was going to take much time. After all, I have a backup unit, as well as a backup power supply. I have a good internist whom I see regularly. He and the local medical center have the relevant information about my medical condition, along with copies of my advance medical directive. We all have a good understanding about oxygen, anesthesia and positioning issues, among other things. If none of that had been in place, the process would have been harder. (I regret to say that 10 years ago, none of the preparations would've been in place except for the backup unit. Some things get shoved aside.)

But even so, as it turned out, there were significant gaps in my supposedly good, recent planning:

In all these years, I had never signed up with a medical alert service, or bothered to assemble a complete set of documents to take with me on business trips.

I had never made sure that the fire department, and local paramedic service, had the relevant information about my condition.

I had never discussed emergency medical care issues with the health care aide who travels with me.

And actually, my wife and I had never had a sustained conversation about these matters. For 40 years, we've simply dealt with things as they came up.

My pulmonologist had retired three years ago (without my permission), and I hadn't gotten connected with another one.

I've now fixed all of this, and I'm very grateful to have had these documents. They did a great deal to organize my thinking about preparing for emergencies, and they did even more to motivate me to go beyond the preparations I had previously made. That motivation was important, because it turned out to require some significant effort over several weeks.

Several matters were particularly instructive, and different from what I anticipated.

■ **Medical alert record.** For one thing, it turns out you can negotiate with the medical alert people about how precisely to describe your condition so as to get what's most important engraved on the bracelet. At least MedicAlert®, the system I chose, does this through their medical review committee. It takes a few days to get the answers, but it's worth it, because the standard options they offer are not very useful for neuromuscular ventilator users. MedicAlert® will also upload all of these **Take Charge, Not Chances** documents after you fill them out, and the people on their answer-line will then be ready, 24/7,

to download them or fax them or read them aloud to any EMS or medical personnel who need them. This alone simplifies a lot of things about travel. DONE.

■ **Fire and rescue.** I called to arrange a time to drop off the documents to the local firehouse, which also houses the EMS people. One thing led to another, and we finally decided that it was better for them to get a group together to come out to our house. A very good reason for this is that (as they explained) if we call 911 we might get any of three nearby rescue squads. Another reason was their desire to look at the house with respect to ease of access and safety generally.

So we arranged a time, and five people from three different stations arrived. They found the **Take Charge** documents very useful, especially with respect to oxygen use, positioning, normal blood gas values, and contact information. They suggested that I place a summary on the refrigerator (where they always look for instructions), or even **in** the refrigerator (in something they called the Vial of Life, which they also look for).

They seemed satisfied to have the documents and to have spotted the ready-packed case containing my backup ventilator and packet of medical documents. It was also reassuring to have their enthusiastic blessing about the entrances and exits and general safety of the place. I got the idea that they might have liked to practice lifting me from the floor onto a gurney, but I changed the subject. DONE.



Photo credit: Sam Dean/The Roanoke Times

■ **Conversations with caregivers.**

Useful. A good idea. ONGOING.

■ **Pulmonologist.** I asked my internist to recommend a pulmonologist who has experience treating neuromuscular problems requiring mechanical ventilation. He suggested several. One in particular interested me.

“These documents are excellent,” said my new pulmonologist. He was looking at them during my recent office visit, after the physical and baseline studies. He signed the “Patient’s Vital Information for Medical Staff” document, and immediately gave me not only his home phone number but his cell phone as well. (When was the last time a physician gave you his cell phone number?) And he wrote instructions on a prescription form that he wants me to carry in my wallet. He then made copies of the IVUN materials for my chart, and additional blank copies for some other neuromuscular patients.

“Who did this?” he asked about the documents, and then answered his own question by turning to the back page. “Good for them,” was his final remark. (He doesn’t waste words.) DONE. ▲



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