

Emergency Respite Care

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Early last December, my wife, Charlotte, and I discovered a large gap in our contingency plans for the home care I need.

False Security: The Old Plan

I have no use of my arms and use a Bi-PAP® for sleep. Charlotte has been my caregiver since we married in 1967. She is almost supernaturally healthy and we have rarely faced the need to “outsource” my care—even as we aged, and even as I have increasing problems with balance and weakness in my legs due to post-polio.

Beginning in the mid-’80s, I began to hire assistants to help with some routine tasks at work (e.g., around lunchtime; in running errands). In 1989, I started to do all my professional travel with a male companion who could manage the increasing number of strength moves required to get me in and out of cars, airplanes and hotel rooms. In the late ’90s, by a fortunate fluke, I was able to get a long-term health care policy through my employer.

And the final big piece of the plan (or so we thought) came about when we discovered, also in the late ’90s, that it was going to be difficult to get me into an assisted living facility if I needed one, given my need for nighttime ventilation. In Virginia, and many other places in the US, the label “ventilator-dependent” excludes you from anything but a skilled care facility.

Our response to this, in 2001, was to use the money we had saved for buying into a retirement community to finance a major addition to our modest bungalow—

one that nearly doubled its size by adding a large master bedroom with roll-in shower and a suite of rooms with a separate deck and private entrance that could be used by a live-in caregiver.

We were, and continue to be, very pleased with this addition. It will work well if we have to go to a permanent arrangement with a full-time caregiver.

The Rude Awakening: Gap in the Plan

In early December of 2005, however, we suddenly found ourselves in the emergency room of a local hospital late at night. Charlotte had what turned out to be a ruptured appendix. She was very ill for several days and had to be quite careful with the recovery for six weeks afterwards. My doctor had assured me some years ago that in an emergency like this, he would admit me to the hospital for a couple of days while I worked out other arrangements. So we thought we had a workable emergency plan. We were wrong.

What happened was this:

1. Charlotte was the one with the medical emergency, and we all needed to focus on her problems, so the ER staff and I took steps to make it look as though the backup plan for



me was working brilliantly. That is, we lied to her. Because insurance rules and hospital practices have changed, the old plan no longer worked.

2. The ER physician couldn't get me admitted, but worked out a temporary arrangement to get me hooked up to my Bi-PAP® for a few hours in Charlotte's room until the next morning (Monday), when the hospital social workers would be on duty. This depended on the good will of the nurses caring for Charlotte, and my willingness to ask for very little from them.

3. My internist was away at a medical conference. The physician making rounds for him on Monday morning decided that the only solution was to force the hospital to admit me. He went all-out to get this done, while I did what I could to stay with Charlotte immediately before and after her emergency surgery.

4. I was in fact admitted to the hospital later in the day on Monday, but in order to accomplish that, the physician wrote orders without my knowledge indicating that he thought I had "chronic respiratory failure" requiring the use of a "ventilator" for substantial portions of the day (for rest) and night (for sleep).

5. Then the comedy began. The hospital—a large, regional medical center and teaching institution—reacted by focusing on the words "respiratory failure" and "ventilator." I was whisked away from Charlotte's room, where she was awaiting the call for surgery, and taken to the spiffy unit where patients are evaluated for placement in various versions of intensive care. The staff there decided to admit me to a "monitored" bed.

6. From my fancy monitored bed, I was dependent on the hospital social workers for help in working out alternatives and on the nursing staff for sneaking me off the ward to visit Charlotte. When the social workers started calling around town using the term "ventilator-dependent," my alternatives quickly got limited to three: staying in the hospital indefinitely (Plan A); around-the-clock care at home with a licensed nurse (prohibitively expensive for me); or admission to a skilled care nursing facility. The only nursing homes willing to take me on such short notice were locked-ward private pay dementia units that did not accept Medicare. (I am not making this up.)

7. So, by Wednesday afternoon the social workers had more or less decided on Plan A with a twist. I would stay in the hospital until after Charlotte was discharged and had spent a few days at home recuperating and setting up an affordable homecare arrangement. When consulted, Charlotte firmly rejected that plan in favor of her own, which was, "When I go home, he goes home." (The social worker escaped without injury, and there was only minor damage to the hospital room.) Back to square one.

8. Later Wednesday afternoon, three other things happened. Mercifully, they occurred outside Charlotte's hearing.

The first was that Medicare retroactively denied my admission to the hospital, and my secondary insurance followed suit.

The second was that the hospital decided to treat the first three days of my stay as free of charge, opening

continued, page 6

the money drain only after the denial by Medicare.

The third was that the hospital decided I didn't need a monitored bed after all and could be moved to a much less expensive room.

9. In that room, I finally managed to focus on my own situation and set up Plan B. It was a combination of unskilled homecare, several days of help from my out-of-town brother, visits from housekeepers, and various other bits and pieces related to my work. Charlotte and I went home together on Friday.

We were greeted by my brother and, moments later, by homecare workers. By the end of the weekend, my brother and I had figured out how to reduce my care (in the house, at least) to zero strength moves. The need for homecare workers evaporated by Monday, and the need for housekeepers diminished steeply over the next two weeks. Charlotte's activities were limited for another month after that.

We were lucky, overall, but it's best not to rely on luck. We needed a better plan for emergencies. Here's what we came up with.

Useful Facts about Respite Rooms

An increasing number of full-service retirement communities—as well as some smaller, assisted living facilities—set aside a few rooms for “respite care.” They are typically used by families that need to place cognitively disabled relatives in temporary care while the family travels or just takes a break.

These respite facilities can respond to emergencies best if they are dealing with people who have already gone

through a “prior approval” screening process. That involves touring the facility with its marketing director to find an appropriate unit; having a personal interview with the nurse in charge of the unit during which the details of your care can be discussed frankly; filling out a variety of forms asking for financial, medical, daily care and “social” information; and having your primary care physician give you a routine physical examination in order to describe your current medical needs directly to the facility, as well as to certify that you are free of TB and other infectious diseases.

On that prior approval basis, you can get on the assisted living facility's active list for respite admissions. Then if there is an emergency that disables your primary caregiver or defeats your other backup arrangements, and if the facility has an available room, they will take you, no questions asked.

For obvious reasons, it's best to be on the active list at several assisted living facilities, just to be sure at least one of them will have a room when you need it.

Staying on these active lists requires a recertification from your primary care physician every six months, and that means an office visit. One of the best facilities in my area also requires people on their active list to make at least one overnight stay within 30 days of the first physician certification. This is, I suppose, a good test run for both sides.

Cost: Make up your mind that it's going to be private pay.

If you have been living at home, your dependence on a caregiver will not qualify you for admission to a

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hospital when that caregiver becomes disabled. At least this is true for Medicare, and probably for many private insurance plans. You would probably be qualified in those circumstances for admission to a skilled care unit, but that's no help if the insurance rules require an approved hospital admission prior to transfer to skilled care. Catch-22.

The good news is that these respite rooms are reasonably priced, and they don't seem to vary much according to the level of care needed by the client. I need quite a lot of help in the early morning and the late evening, a little help around mealtimes and with transfers. Prices by the day, for the level of care I need, range from \$85 to \$130 in my area.

But Will They Take Us?

Most of the places I called were very receptive to considering me for prior approval and were not at all concerned about my use of a Bi-PAP® as long as nobody said the word "ventilator-dependent."

I went to visit four places that were willing to let me go through the admission process in advance. One turned me down because I answered "no" to the question, "Can feed self?" Another rented respite rooms only by the month and rarely had one available. The other two, however, were fine. Making these visits was psychologically demanding. Depressing, even. But I'm glad I did all of them.

My New Plan for Emergencies

Step One: Getting a respite room. I'm now on the active list at two large retirement communities, at least one of which will almost certainly have

a room for me in an emergency (or be able to make one available). That will take care of the first few days.

Step Two: Setting up homecare. One of these retirement communities also has a large homecare operation, and I filled out the forms necessary to get on their active list of clients as well. (This involved having the nurse manager visit our house to take a tour and to assess my physical abilities.) Once in the respite room, I am assured it will be an easy matter to interview homecare workers and agree upon—and test—a reliable schedule.

Step Three: Working on financing. I'm trying to get an exception made to my secondary health insurance policy so that emergency respite care and homecare would be covered, at least partially. In lieu of that, I will do what I can to set aside enough to cover the costs for the three months of respite or homecare it will take for my long-term health care insurance to take over.

I think it's basically sound, as plans go. If anyone sees any flaws, other than the fact that even the best laid plans sometimes fail, let me know! ▲

"At home, I use the new BiPAP® S/T System with Encore® Pro Smart Card® with integrated humidifier. When I first got this machine I was unpleasantly surprised to find that there was no pure "timed" option but a timed backup rate that required some getting used to.

"For travel, I use a 10-year-old BiPAP® S/T®, set to the timed option.

"In the hospital, I used the old machine, and that was a good thing, since that helped convince them it wasn't a "ventilator." The new machine has a fancy set-up screen which apparently persuades the nursing staff to call in respiratory technicians. My old machine simply has an on-off switch, with other controls hidden behind a panel on the back."

-Lawrence C. Becker