

COMPLIANCE WITH HOME CPAP: ONE PATIENT'S PERSPECTIVE

by Roland Bates



I read *Focus Journal* regularly because I am a vendor in the health-care profession (cardiology is my company's specialty) and I like to keep up with the latest news, information and articles. I am also a CPAP patient at home and have been thinking for quite awhile about furnishing FOCUS with an article that speaks to the patient's perspective regarding the procedure and mechanism involved in becoming a CPAP patient. I am not a writer per se, especially of scientific articles (which I certainly don't claim this to be). The following, then, are my comments, observations and opinions of my experience with CPAP in the home. It is my hope that some clinicians will garner insight from it.

My venture into the world of CPAP came about as a result of my wife's complaining about my incessant snoring. No physician had ever inquired, and, of course, being asleep, it certainly never bothered me any. Since my wife was increasingly complaining and on numerous occasions moving to the guest bedroom for the night, I figured I would start reading the articles and advertisements pertaining to sleep apnea and sleep products that I saw in FOCUS more closely. Upon doing so, I noticed an ad for a simple device called a Sleep Strip, manufactured by Medline Industries, Inc. In a nutshell the Sleep Strip is a disposable sleep apnea screener, designed to help physicians screen patients for sleep apnea syndrome. I checked out the device on the internet and found it promising, so, not having a respiratory or sleep physician, I persuaded my cardiologist to order one of these strips for me. The strip seemed to work well and ended

up showing a moderate number of apnea episodes. That was enough for my cardiologist to prescribe a sleep study for me. Even though he is not involved in Respiratory Care or Sleep Medicine, he is well aware of the effect that sleep apnea can have on evoking cardiac arrhythmias.

The appointment was made and I went in for the test armed with my teddy bear, my warm milk and a good boring book that would put me right out. All of the people I encountered in connection with the sleep study were kind and professional. It's not a fun test, but it isn't painful either. The sleep lab used a CPAP mask with a nasal cushion for the test. There were no discussions of my preferences or other options. To make a long story short, the study indicated moderate obstructive sleep apnea, which resulted in a second "titration study" and a prescription for CPAP.

Not long after, I got a call from a home care company that the hospital had arranged. They made an appointment to meet with me at my workplace (my preference) to show me the system that was prescribed. The unit was from a major manufacturer and the mask was the same one I had used for the sleep study.

Perhaps I'm being overly critical (or even conspiratorial), but I got the feeling that the reason I used that mask at the lab, and the reason that I had that mask prescribed for me, was because it was this mask and system that someone

continued on page 68

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like me had sold to the sleep lab. I've been involved in medical sales and marketing for quite a while, and I know well that there are a number of reasons for a facility to use a particular brand of equipment, only one of which is medical.

Anyway, the home care respiratory therapist was excellent. While I didn't have a choice of equipment, I did get a very thorough and careful presentation of how to fit and wear the mask and operate the CPAP unit. It's not brain surgery, but it was nice to be shown in detail the things I needed to know.

After about a year, things took a slight turn for the worse. My original mask was leaking more and more. The reason was the stretchable cloth used to secure the mask and headgear. The adjustable straps had only Velcro hooks. If Velcro loops had also been sewn onto the cloth, it would have been more secure. They weren't, so I had to get my cardiologist to prescribe a new mask. I also had to decide what type of mask would be best for me. I called the home care company, and made an appointment to see what was available. They showed me about eight different cushion masks including full-face, nasal, and an unusual mouth type mask. These choices were fine except for the fact that each mask was in a plastic bag that the homecare company refused to open. I could not then, try any of them on! Looking at a mask in a bag is not useless, but it's close. You really have to try one of these things on to see if it fits your particular face, but this was not an option. After much time online at various CPAP sites, I finally decided on a brand new design from a major manufacturer.

It took two months to get the prescription, get the mask ordered and see its delivery to me. There was a design problem, however. Mine was a mask in which the hose went over the wearers head. The problem here was that the swiveling hose connection went too far over the crown of the head. This made the connector and the hose press on the pillow, which pushed the cushion off of my face.

I liked this hose layout, anyway, however, because I didn't get my arms or legs tangled in the hose. It's out of your way, and it turns easily when you do. So, I was persistent, and finally able to make it work without leaking. It was not terrific, but it was better than nothing, and I didn't want to go through that mask prescription/ordering scenario again.

After eight months, or so, the "new" mask had several broken plastic pieces. One of the hose-mounting brackets broke, but I held

it on with nylon ties and a short connector hose had developed a split that I repaired with duct tape (what else?), but it was clear that I was going to have to obtain still another mask.

The third "new mask" experience was better. I still couldn't try on new mask types; as unfortunately, the home care company still wouldn't allow that. With nothing to lose, I embarked on several days of Internet browsing turning up a new design that seemed to correct the faults of the earlier unit. I decided to try it and I'm pleased to report that it is working quite well. The company's experience was that many people were having problems alleviated now by their new design. Now, I use it regularly and only have minimal leakage. For some reason, some nights are better than others. Some nights it works perfectly, and others, it is a bit of a pain.

That's my two-year-plus experience, but I have some direct knowledge of the experiences of a few other people. My younger brother has sleep apnea also. He was also prescribed a nasal mask. It made him feel claustrophobic, and he stopped wearing it. I tried to talk him into trying other types, but he had had difficulties with his doctor, and home care company, and he didn't want to pursue it any further. This is not good, because he is not only stubborn but he is an overweight smoker.

An aunt was also recently diagnosed with sleep apnea. The nasal mask that she was prescribed also made her claustrophobic. Her doctor put her on oxygen therapy, and that seems to have improved her situation. She reports sleeping better now, but the sleep apnea remains unresolved.

A family friend was prescribed a full-face mask. He likes it, because it keeps him from breathing through his mouth. (No one had, or to this day has ever discussed chinstraps with me.) The last time I spoke with him, he told me he's still using it on a relatively consistent basis.

A longtime friend is currently on a REMstar (Respironics) Auto M-Series machine. He is on this machine because he refused a second overnight CPAP-titrating Sleep Study. It's not my intention to promote a specific product, and there well may be similar machines available, but since he is using this one, I'll use it as an example. The "M" part of the product name refers to the fact that it has a Memory card that records the status of the device in use. Among many other things, it records the maximum pressure required to overcome the breathing obstruction. This history enables the setting of the pressure on a simpler, less expensive machine in the very same way that a titrating Sleep Study would. I have found this system online for less than \$1,000.

Of five people that I know personally, three are compliant with their prescribed CPAP therapy. Two of those three are compliant only because they were personally persistent and demanded the proper care. That's not a terrific record. The reasons seem quite obvious to me, though. The most important factor in compliance in my opinion is the fit of the mask. If it's comfortable, if it doesn't leak, if it matches your sleeping style and routine, you'll wear it. If it doesn't do those things, you won't.

In my opinion, the inability to be able to try on masks of different designs, sizes and selections of cushions, (if this is indeed the norm in homecare), is THE major reason for non-compliance. I do understand the importance of cleaning and sterilizing masks after use, especially when they are used by different people. And, I understand that masks aren't cheap, but if a good fit is going to determine whether CPAP therapy is complied with, then someone should figure out how to do it. At least, that's one man's opinion.



***"I reviewed your salary requirements.
We're only about five or six digits apart."***