



Experiences Adapting To BiPAP+Mask Technology

David Ronfeldt

The following memorandum was prepared by David Ronfeldt at Joan Headley's request for a recent [GINI](#) conference.

MEMORANDUM

TO: Joan Headley (GINI)
FROM: David Ronfeldt
DATE: May 1997 (revised and updated from earlier versions)
SUBJECT: Experiences Adapting To BiPAP+Mask Technology

At your request, this memo elaborates on my difficulties adapting to the BiPAP+mask technology, and offers some points that may be useful for other people to read who are concerned about adapting with difficulty.

BACKGROUND

After getting out of the iron lung, in which I spent many months during 1949-1950, I was able to breathe quite well on my own, despite limited vital capacity, until 1978. That year, I was hospitalized twice with respiratory failures due to a loss of ability to breathe and sleep at the same time--the onset of PPS, I eventually learned. After that, thanks to the care of my Kaiser-Permanente doctor and to assistance at Rancho Los Amigos, I began using a cuirass (chest shell) to sleep at night. This (and related support provided by Lifecare) proved an excellent solution until 1994, when my cuirass ceased to fit well, and I was unable to find a replacement in my size or to have a custom cuirass made competently by an outside vendor.

Thus began my effort to switch to mask ventilation and a BiPAP machine available through a Kaiser-related vendor, Homedco (now APRIA), in December 1994--an effort my doctor had actually begun suggesting months earlier. I rushed into the transition, trying to force my way during the holiday break while taking time off from work. It turned into a major ordeal; and after a couple weeks of uncertain ventilation, mounting sleep deprivation, and erratic progress despite efforts by all parties to give me good advice and get me going in the right direction, I retreated back to a modified old cuirass for several months.

Then I renewed my effort to make the shift, this time using a gradual approach in which I typically tried to start a night's sleep on the mask and switched to the cuirass after a few hours to complete the night. I also

used afternoon catnaps to gain additional experience adapting to the mask. Eventually, over about a six week period, the time spent on the mask lengthened.

By now (May 1997), I have spent about two years straight using only the mask for the respiratory support I need at night and with daytime naps. I have been fully adapted for at least a year. I cannot say that I really like this new technology as much as I did the old, but it works, and I am doing well on it.

THREE STEPS TO ADAPTATION

Because of this experience, I'd say that the process of adaptation--at least for individuals who, like me, have a difficult time--may be broken down into three steps (or tasks, or phases). And I would urge patients who have a rough time at first to persist, while keeping in mind that the process could--even should--involve a gradual transition spread over a few months. It may require occasional retreats to an old technology, and considerable experimentation with the machine settings.

Step One: Get Accustomed To The Mask

The first step is to get used to the mask--that wheezing, pulsating, grating thing on the face. Part of this task is to just spend time on the mask, so that the face gets accustomed to it. This can take a few weeks. But another important part is to get the right mask--and the right size of the right mask--so that one does not have to put up with problems like leaks and skin abrasions, however minor. Otherwise, one can easily end up fiddling with pieces of tape, daubs of salve, and other things to try to turn a faulty fit into a satisfying fit.

I initially tried a few masks (and nasal pillows) from various makers, and none fit or felt quite right until I obtained a Sullivan "bubble mask," which I have used ever since. Indeed, I've been using the very same mask for two years now--it is still in pretty good shape despite the claim that most masks deteriorate after about six months. Besides, a replacement I once ordered turned out to reflect a design change in the opening that made it fit less well than my original mask, so I've kept using it. I'm not necessarily recommending this mask for others; I'm just saying it has been the right one for me. Other people may, and do, prefer other masks (and nasal pillows). Indeed, my impression is that all the masks (and pillows) I have tried are good; which one is right for a person depends on that person, particularly on the shape of his or her face.

Fortunately, in my case, my doctor initially recommended that the vendor provide several different masks for me to work with. I gather this is not a standard practice, but I think it should be. Perhaps a "beginners package" of several different masks should be available (at a beginner's price)? How does an industry go about considering such a proposal?

One early weirdness of the mask experience was a sensation that the air inside it, after exhalation, was not real fresh. It seemed a bit close, a bit stifling--I even wondered whether there was a bit too much CO₂ in it. I was reassured that this was not the case, and that the sensation was common for first-timers. What I did to relieve it was to open one of the tiny ports I found on the mask, a port that is evidently for inserting an oxygen tube if needed, but is otherwise supposed to be kept closed. Opening it provided a nice sensation of fresh air circulation, which gave me some relief. A few weeks later, once I got quite used to the mask, I found no reason to continue keeping the port open and closed it back up. Meanwhile, I was told I shouldn't have done this, because it has the effect of reducing the air inflow pressure. But I couldn't feel much difference in the pressure--nothing I could not compensate for by slightly increasing the IPAP setting--and I preferred the temporary relief. A bit of relief here and there made it easier to cope, and to focus on coping, with other trying aspects of the mask experience.

A couple of side points: I encountered a tendency in some therapists to fit me with mask sizes that were a bit small, whereas in my view a bit large may be preferable. (However, other people report a tendency to be fit with masks that are a bit too large.) Meanwhile, I also encountered remarks that I would surely have to shave off my mustache for a mask to fit well. But my mustache never proved a source of leaks. I have an explanation that some readers may find relevant. If the mustache hairs are fairly thick (but not bushed out) and longish (down to the top of the upper lip), the mask may press down on the hairs lengthwise and not lose a seal. But if the hairs are trimmed short, then the mask may ride on the stubby tips of the hairs and then lose a seal (while creating an odd tickling in the mustache).

A couple more side points, of a more technical, improvisational nature: I was typically instructed to connect the rubbery hose from the BiPAP directly to the mask intake. But this was not easy for me to do, often resulted in my ending up with a twist in the hose once I lay down, and just made life a little more complicated when I wanted to get up in the night and briefly detach then re-attach the hose without taking the mask off. In time, I found a simple solution--I got a plastic adapter (or connector) that mated to the mask intake, shoved it into the end of the hose, stuck a small dot on the adapter so I could feel with my finger the proper alignment, and never had a problem after that with attaching and detaching the hose and the mask. Maybe now it is standard practice for therapists and vendors to anticipate this issue; but if it isn't, patients should be aware of ways to deal with it. Meanwhile, over time the side walls of my mask started to sag and distort, such that the mask would lose its seal under pressure. So far, I've been able to correct for this by wrapping wide, strong rubber bands around the side walls.

I've added these last points here because they relate to maintaining a good fit in the mask. But they are side points, and the reader should keep in mind that my main point is to get over the hurdle of learning to live with the mask as step one. A related overall point is to expect to have to be a bit improvisational at times to make the mask fit and work comfortably.

Step Two: Learn To Fall Asleep

The second step is to fall asleep on the mask. This was no small step for me. I couldn't do it for more than a few minutes (seconds?) at a time in my first effort. The breakthrough occurred months later in the second effort. Part of this step was, again, just sticking with the process. But it was also a matter of getting the settings right on the machine I use, a Respirationics BiPAP S/T. While I had some good general guidance on the settings, I had to do the refinements on my own through a lot of trial-and-error to figure out what worked best for me.

Should I use the S/T or the T setting? I found the T setting worked best at first--partly because on the S/T setting every swallow or other movement would trigger an untimely, disorienting blast of air, but maybe also because I was accustomed to a timed setting with the cuirass.

Meanwhile, neither the directions that came with the machine nor the therapists told me about the %IPAP knob. Yet, it plays a crucial role in the T setting, by determining the length of time air is pushed into the mask during the inhalation cycle. It took me a while to discover this--and then to find the right setting for me (40-45%).

At the same time, I also had to realize that I should increase the IPAP setting from about 10, which was fine while I was awake (pulse oximeter readings showed so), to a bit more than 12, in order to compensate for the fact that my respiration gets shallower once I fall asleep.

Meanwhile, as I varied the IPAP setting, I was also having to experiment with the BPM setting. Yet, I generally kept returning to 20-21 BPM, which is about what I used with the cuirass. (Curiously, I got

exactly the number of breaths I set when the machine is in the T mode, but two breaths less per minute for the same setting when I switched to the S/T mode, perhaps due to something about the length of time it takes me to complete an inhalation.)

Gradually, as I got used to the mask and made small improvements in the machine settings, I started falling asleep for brief periods with less and less delay, both at night and for afternoon naps. Another threshold was being crossed--but it had taken several weeks, and I still was not staying asleep for long.

Step Three: Stay Asleep

The third step was to stay asleep--meaning much more than a few minutes at a time, say at least a couple hours. This took another couple weeks.

By now, I had a good mask, and the IPAP, %IPAP, and BPM settings were about right. And I was getting used to the fact that the machine ramps up the inhalation pressure very quickly, a bit too much for my comfort (at times I wished the machine had a knob that would allow me to soften the impact rate).

Meanwhile, I had been using an EPAP setting of 4, a sensible choice. One night, I dropped it to 3--and immediately had my first good night's sleep. This experience, and earlier ones with the other knobs, lead me to conclude that a change of just one point on any setting may make a substantial difference, for better or worse.

Another change that helped during this third step was to shift from the T to the S/T setting. By now, I was adapting enough that I felt the T setting was not quite matching what my lungs wanted to do. More to the point, the S/T setting was feeling a bit better; I now had enough experience to know when to swallow so as not to trigger, or not to be disoriented if I did trigger, the inhalation cycle in the S/T setting. Again, this suggests that patients who are having difficulty adapting should try experimenting with the settings--and perhaps should expect that the settings that work best at first may not remain the best as the process of adaptation advances.

I gather that many doctors and therapists would prefer to determine the settings. My experience may imply that, in cases where a patient is having trouble adapting, the doctor(s) and therapists are essential as advisers and collaborators for helping to determine the best settings--the patient cannot do without them. But at the same time, the patient may have to take an active role in figuring things out, even if this means lonely trial-and-error experimentation by oneself--a point my own doctor agrees with.

RETROSPECT AND PROSPECT

Those three steps--getting used to the mask, being able to fall asleep, and then being able to remain asleep, against a background of getting the right mask and getting the machine settings right--pretty much describe the process of adaptation in my case. The process took many months during 1995, but today (May 1997) I consider myself adjusted to, and thankful for, the BiPAP+mask system.

However, this does not mean I am a completely happy user. I continue to have a difficult time with what I call "parched mouth syndrome"--an extreme dryness in which my lips, gums, tongue, roof of my mouth, and front of my throat are all dried out and stuck together, and saliva flow has ceased. This is evidently not a problem that affects other mask users--and thus may not be of interest to most readers of this memo--but I'd like to mention it anyway. Who knows, maybe the problem is more widespread than I realize, and maybe someone already has an explanation and a solution!

I've had this problem from the beginning. It seems to start right after I fall asleep and continue through the night (unless I lie awake so that saliva begins to flow anew). It helps explain why I constantly wake up, sip water from a bicyclist's "Camel Bak" (neat device), and rarely get a good, long night's sleep. Professionals and patients I have consulted ordinarily insist that I must be leaking air through my mouth--but I am convinced this is not the case. A humidifier can help with nose and throat dryness--but I'm not bothered by that, and the humidification I've tried has had no effect on my mouth dryness. I have had occasional nights when it has not been a problem, but have not been able to figure out why. I know what may make it worse (e.g., some foods and drinks, most medications, and higher IPAP and EPAP settings). But I cannot find a way to resolve the problem, though at times I have had hopes for a chin strap (which I use), an interior lip seal, hose positions that ease the mask's pressure on the upper lip, herbal syrups, certain foods, etc. I once thought I'd found an answer--consuming lots of water--when the problem disappeared for five days during an effort to counter a minor cold; but the problem quickly returned. Meanwhile, no one I have talked to has been able to account for the possible physiology behind this problem. I have also learned that a few other mask users may be having the problem the bit, and that it does not seem to go away with time.

Sometimes this parched-mouth syndrome is bad enough to make me wish for a good cuirass. I never had a moment's difficulty adapting to it, once I got a good fit. By comparison, moreover, I liked the fact the cuirass and its machine went to work immediately as soon as I put it on, to my great relaxation; the BiPAP takes a few moments, sometimes discomfiting moments when I am very tired, to calibrate its settings and settle into a rhythm. I also preferred the way the cuirass hugs the chest, over the way the mask clutches the face. And while I'm at it, let me mention that I never had to worry about a stuffy nose with the cuirass--I could always just breathe through my mouth. I would hope, therefore, that the cuirass makes a comeback as an alternative technology, since I wish I had it available once in a while.

Even so, I know I get better ventilation from the BiPAP+mask system than I ever did from the cuirass. I also know that I am in better shape now than when I was on that increasingly ill-fitting cuirass. Furthermore, this new technology is a lot easier to travel with than was the old--it is far less bulky and heavy, and so much more reliable and sturdy that I don't have to carry a backup machine. These are decisive pluses.

CODA: ADVICE AVAILABLE ON THE INTERNET

Joan, in keeping with the fact I am sending you this memo by email, I'll conclude by pointing out that there are a lot of resources accessible on the Internet that can help first-time as well as experienced ventilator users. These resources include:

- email lists for subscribers (e.g., the [one on post-polio issues at St. Johns University](http://maelstrom.stjohns.edu) available via listserv@maelstrom.stjohns.edu);
- postings in Usenet news groups (e.g., alt.support.post-polio, though it is quite inactive by now, and alt.support.sleep-disorder, although it is more about CPAP than BiPAP issues);
- World Wide Web pages (e.g., not only the ones maintained by persons, such as Tom Dempsey at <http://www.eskimo.com/~dempt/polio.html>), and by organizations, such as at <http://www.skally.net.net/ppsc/>, but also the ones maintained by vendors and manufacturers, including for Respironics [<http://www.respironics.com/> *LincsPPN Web Adm.*] and Sullivan equipment).

For a good guide, one should get a hold of the periodic posting by Ernie Wollering on PPS Internet resources (the latest one is available at his site, <http://www.i-sites.net/ppsr/reslist.html>).

Few of the discussions and postings on the Internet focus on ventilator issues, and fewer still on BiPAP, mask, and related technologies. But what's there can be quite useful, for everything from requesting an answer to a particular question, to finding ideas and observations that may prove useful for coping with problems like leaks and abrasions and stuffy noses, to finding out about the latest developments in ventilator technology.

Finally, please feel free to distribute this memo as you see fit. If anyone wants a copy by email or has comments for me to consider, I can probably be reached at [<ronfeldt@rand.org>](mailto:ronfeldt@rand.org) or [<ronfeldt@well.com>](mailto:ronfeldt@well.com).

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Document preparation: Chris Salter, [Original Think-tank](#), Cornwall, United Kingdom.

Document Reference: <URL:<http://www.zynet.co.uk/ott/polio/lincolnshire/library/usa/bipap.html>>

Created: 22nd June 1997.

Last modification: 31st January 2010.

