

Maximizing Your Support and Independence through Attendant Care

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Photo courtesy Tom Olin

“At night, I use a Respironics BiPAP® S/T with a custom-molded nasal mask made by Wilma Breaux, RRT, at St. Paul University Hospital in Dallas, Texas. When I am in my wheelchair, I use a Puritan Bennett KnightStar® 330 with Nasal-Aire® nasal pillows by InnoMed Technologies.”

More and more people with significant disabilities, including ventilator users, are living longer, healthier, independent lives in their communities. A key component to this success is personal care assistance, also called attendant services.

Some conditions that compromise respiratory function also impair mobility and arm and hand movement. Many ventilator users, therefore, require assistance with using a ventilator and interface. This is where the availability and quality of attendant support becomes critically important. An attendant can perform tasks such as readying the ventilator for use, changing and cleaning tubing and filters, applying a mask, cleaning and suctioning a tracheostomy, and troubleshooting when a ventilator malfunctions.

I have a neuromuscular disability, spinal muscular atrophy, that significantly limits my physical movement. I use bi-level ventilation support approximately 20 hours a day.

I rely on my attendants to put on and take off my nasal mask, periodically adjust the straps and tubing, thoroughly wash all the components, replace disposable parts, fill the portable liquid oxygen tank that bleeds O₂ into the tubing, charge the battery that powers the ventilators, and help when the mask slips off or the tubing comes apart or the cable gets disconnected.

This is all a normal, manageable part of my daily life, attributable to a dependable team of attendants whom I have hired and trained. There are six to eight attendants on my team, working various shifts for 10 to 16 hours a day. These workers are paid by Colorado Medicaid, under a program called Consumer Directed Attendant Support (CDAS).

A vast improvement over the traditional home health agency-dominated attendant service delivery model, the CDAS program enables people with disabilities to manage their own attendants, includ-

ing budgeting, recruiting, hiring, negotiating terms, training, supervising, scheduling and, when necessary, terminating workers.

By having such a high degree of responsibility and authority for my support system, I can provide detailed training and oversight on the tasks that are most important to me, such as ventilator care. The CDAS program also fosters a greater sense of accountability among the attendants who come into my home because they recognize me as their boss, rather than reporting to a nurse or administrator.

Consumer-directed programs similar to CDAS are emerging in many states across the US. Ventilator users who do not have access to consumer direction, and who must operate within the constraints of strict nursing regulations and home health agency policies, often have a more difficult time managing their health and equipment.

Some states' nurse practice acts mandate that ventilator care must be performed by a registered nurse (RN) or by a certified nursing assistant (CNA) working under an RN's supervision. Such requirements, based on

Personal Assistance Services (PAS) are also known as long-term care (LTC), caregiving, attendant care, personal care services (PCS) or assistive care. While in some cases this assistance is formal (paid), the majority of this assistance takes the form of unpaid family or friends who give informal assistance. To find out about the programs in your state, contact the Center for Personal Assistance Services at the University of California, San Francisco, at www.pascenter.org.

a medical-model view of disability, treat people with disabilities as eternal patients in need of medical oversight. Sometimes such policies have the effect of denying ventilator users the level of care they need to maintain their independence. It's a Catch-22: ventilator care must be performed by a nurse, but home health agencies don't find it cost-effective to send nurses into someone's home every day. I've known people who ended up living in nursing homes as a result.

Tight medical regulation of attendant care is usually justified on the grounds of quality control. However, in a number of states, consumers and advocates have demonstrated convincingly that people living with long-term disabilities are quite capable of supervising the care they need.

Even if you live in a state with restrictive home care policies, you should assume as much responsibility as you can for managing your support services. Here are a few steps you can take.

■ **Learn all you can about your ventilator.** You might be able to get some training from your durable medical equipment company, although the quality of respiratory therapy personnel at these companies varies considerably. When you get a new device, ask questions and insist on complete answers. Search the Internet; you may be able to download your machine's clinical manual from the manufacturer's website. Study any information you can find about your ventilator's setup, your prescribed settings, cleaning and maintenance, power source issues such as cable connections and battery life, the meanings of different codes and alarms, and any issues involved with your interface.

■ **Translate your expertise into clear, easy-to-follow directions for others.**

Make a one-page list of instructions and post it near your equipment. Also, include a schedule for regular cleaning and changing of tubing and filters.

■ **Orient all of your personal assistants to your ventilator.** Explain the function of each part, how to attach the parts together, what might go wrong with each part, and how to fix things that do malfunction.

■ **Investigate the applicable regulations regarding in-home ventilator support in your state.** Depending on your location and your funding source for attendant services, these rules may come from your state or regional board of nursing, Medicaid or other publicly-funded program, your health insurance plan, and/or your particular home health agency. Of course, if you are paying your helpers privately, then you'll have few restrictions to worry about.

■ **If you're required to use a home care agency, push for as much autonomy and choice in your attendant services as possible.** Ask to interview new attendants before they are assigned to you. Offer to help with recruiting workers by posting ads in your neighborhood, your place of worship, local colleges, community centers, etc. This active involvement in the hiring process will give you more control over your services, and more respect from your service providers.

Whatever your attendant care arrangements, adopt the attitude that you are not only the client, but also the boss. You'll get best results if you become thoroughly knowledgeable about your ventilator needs and, within the regulatory limits, exercise the authority to get those needs met. ▲