

# Truly Personal Attendant Care

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**P**art of my daily morning meditation is to give thanks and hold in the Light my team of attendants – past, present and future. They are the key to my survival and my “thrival.” Without them I could not live one hour; they make possible my productivity and my joy.

My household consists of me at the helm (when I feel like it) with Perla, my ace Number One helper for the past 12 years, and her three children: Aldo, who is almost 6; Gina, 4; and Edwin, 18 months, who live in the now three-year-old upstairs addition. Perla gets me up and works until three o'clock every weekday.

Gaby joined us last summer to be my weekday afternoon and night-time helper. She and her one-year-old daughter, Shabana, live downstairs with me. My third helper, Amalia, has been with me for six years and comes in to work on the weekends. In addition, I have several women who have worked for me in the past who are available to substitute when necessary. The chaos is delightful.

A combination of advertisements in the Spanish-language newspaper and word-of-mouth referral among friends has brought these ladies to me. My ability to speak Spanish and the fact that I have a house large enough to accommodate them has met their needs as well as mine. I pay \$50 for one half-day shift, or \$100 for a 24-hour period.

Calculating this as an hourly rate would indicate that I pay less than minimum wage, but there are many other benefits that I offer. I provide housing and all of the accompanying expenses, including food. There are large parts of the day when I ask for nothing other than their presence in the house, so they are able to take care of their children and their other needs in what would technically be considered “work” hours.

I require no qualifications on their part other than honesty, integrity and a willingness to learn. I prefer to have Perla do all of the training of new attendants. The total expense for supporting three full-time workers consumes two-thirds of my total income. Because I am employed, albeit only part-time, I am not eligible for any government assistance.

Life was a lot easier, and my attendant needs were much less before I used a trach. Spinal muscular atrophy, which has shown its presence in my life gradually since birth, has had its most life-threatening effect on my muscles of respiration.

The nasal mask and bilevel ventilator I used during the night for 10 years were becoming less and less effective. Finally, seven years ago, a respiratory infection evolved into pneumonia and caused both of my lungs to collapse.

Since I was already in the hospital, the emergency tracheotomy was conducted just in time to save my life. There was no hesitation in my consenting to have the procedure, much to the dismay of the resident on duty; I had made the decision and communicated it to my physicians many years ago that living by whatever means was my priority.

Left to right: Edwin, Peg, Aldo, Rosemary Hughes holding Shabana, Perla holding Gina.

After two weeks in the ICU, I had eight weeks of comprehensive rehabilitation at The Institute for Research and Rehabilitation (Houston) to learn how to live with my new method of breathing. The outstanding respiratory therapists taught my attendants how to do suctioning and trach care and operate the new ventilator, the nicely compact and relatively quiet LTV®950 ([www.pulmonetic.com](http://www.pulmonetic.com)). There is one on the back of my power wheelchair and another one in the bedroom.

It's amazing how clearly you can think when your brain gets enough oxygen. With the trach my productivity has soared, and my health is more robust. I have no desire whatsoever to wean off the ventilator.

In the first several years I had two hospitalizations because of respiratory infections. Since then I have been able to manage them at home with oral antibiotics. However, my best defense is using alternative therapies, including vitamin C, echinacea and a variety of medicinal teas that aid breathing.

As my wise pulmonologist advised me – some pretty heavy bacteria are constantly residing in the trach and the best way to hold them at bay is to eat well, sleep well and stay active.

My attendants have a good routine for changing the filters and cleaning the circuits that connect to the trach. I asked a colleague of mine who specializes in prosthetic infection the best way to minimize problems with a trach. He advised me to clean it with ordinary antibacterial soap once or twice a week. I ran into a lot of problems with the hard plastic trach tube rubbing on my curved trachea (due to scoliosis) and creating an irritation that attracted bacteria. Switching to



a flexible trach tube made by Bivona has solved that problem nicely. It is such a relief to know that my attendants can help me raise the secretions, as long as my machines are in working order, that is.

I'm still chicken when it comes to traveling. Although I'm not anxious to resume the insane travel schedule I followed at the midpoint of my career, I would like to engage in more travel for fun. On an adventurous whim, two of my attendants, two of their kids and I took off on a road trip last summer to Matamoros, Mexico. The folks in the markets gradually overcame their shock at seeing someone using a ventilator with a pyramid of kids riding on the back of her wheelchair.

I still work parttime. This enables me to continue my career, maintain my private health insurance, and receive Social Security disability insurance plus long-term disability benefits from my employer. Whenever I earn any extra income from consulting or writing, the long-term disability payments are reduced by half of what I make.

I continue my work on developing health promotion interventions for women with disabilities while enjoying my kids, my garden and all the fun things I let myself do now. I am forever grateful for this second chance at life. ▲