

Living with ALS

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“My PhD is in neuro-physiology, and I have a Master’s degree in the performing arts in historical wind instruments.”

I began using a ventilator in 1997. During the night, I began to awaken from sleep feeling hungry for air and unable to initiate a breath. It was, needless to say, very frightening, so I went to my general practitioner and explained what was happening. She sent me to an excellent ENT doctor who referred me for polysomnography (sleep study). It revealed severe central and moderate obstructive sleep apnea. Subsequently, a CPAP unit was prescribed for sleep and daytime use when needed.

I was still experiencing breathing problems and about five or six months later, I was retested and prescribed a bilevel ventilator (VPAP® II ST). As time went on, I began experiencing weakness in my legs and started falling, which led to ankle sprains and eventually to a cracked knee and elbow. More testing followed, and a spinal fusion was done to correct scoliosis secondary to old severe scoliosis. However, my problems continued despite the surgery.

My neurosurgeon noticed signs of trouble and performed more extensive testing. In 2004, I was informed that I have ALS. I was shocked at the diagnosis, but deep inside I had a feeling that this was the cause of my problems with breathing, chewing and swallowing. I am a professional concert flutist and artist, but gradually have lost the ability to play flute and to draw. All four limbs are seriously affected now.

Currently I use the VPAP® III ST-A with total backup (spontaneous/timed) about twenty hours a day. Settings are: IPAP 20, EPAP 6.2, 10 BPM and IPAP max = 3. I use the Mirage® Achieva nasal mask at night and the

Mirage® Vista nasal mask during the day. When I sing in the choir, I use the Mirage® Swift nasal pillows. (See photo below.) All are ResMed products.

I have hydrotherapy and physiotherapy twice a week to maintain range of motion. Both the CoughAssist® and suctioning are used as needed. I eat



both liquid and ground food for proper nutrition. My respiratory functions are followed every four to six months at Tel Hashomer Hospital, a

teaching hospital affiliated with Tel Aviv University Medical School.

In the coming academic year, I plan to pursue MA and PhD degrees in rehabilitation psychology, since I cannot work in my present field. When the time comes for a tracheostomy, I will have it done in order to have a good quality of life. ▲