



Adolf and his wife, Doro

Adolf Ratzka Honored

TIME magazine, in a special Winter 98/99 edition entitled "Visions of Europe," presented visionaries in political, social, and economic experiments who will shape Europe in the 21st century. Among those selected was Adolf Ratzka, PhD, respiratory polio survivor and ventilator user. Dr. Ratzka is one of the leaders of the European disability rights and independent living movements. He is director of the Institute on Independent Living in Stockholm, Sweden.

Disabled by polio in 1961, German-born Dr. Ratzka won a scholarship to study in the United States. In Berkeley, he met Ed Roberts and other founders of the American independent living movement. He moved to Sweden in 1973 and founded an independent living center in Stockholm, which now employs 1,300 personal assistants who are hired and trained by the individuals with disabilities who use them. Ratzka has since co-founded the European Network for Independent Living (www.independentliving.org).

Dr. Ratzka says, "With the article, *TIME* recognizes disability as a profoundly political issue in contrast to the still prevailing view of disabled people as objects of care, pity, and humanitarian concerns. I am convinced that now, at the turn of the millenium, disabled people are at the threshold of a

worldwide recognition of their human and civil rights."

Of his ventilator use, Ratzka reports, "After the acute phase of polio when I was in an iron lung, I used a cuirass and rocking bed in the '60s and '70s. Since May 1983, I have used intermittent positive pressure ventilation only, via nose. First, I used homemade devices, but in 1985 I received a small grant that enabled a German friend, a physicist and great tinkerer, to work with me on a nasal mask for nocturnal use. The next year I found a Swedish dental technician, Lennart Remmer, who became interested and who has since made other custom nasal masks secured by head straps. I asked him to link the nasal mask to a dental piece that is secured to the upper teeth, fastening it there instead of using head straps. I get a rather good fit, handsome looks, and very little air leakage. However, after some months, the dental piece loses some of its tight fit, and I must use 3M's special skin tape for fastening the nasal mask to my nose. In this way I use nasal masks for several years in a row until they become too worn out or accidentally dropped and broken beyond repair.

"During the day, I use mouth intermittent positive pressure via a simple tube (internal diameter about 5 mm, altogether about 6 mm thick), without any mouth-piece whatsoever and without any of those ICU-looking coils. I get my tubing from the hospital. Before, I bought it at the gas station around the corner until somebody pointed out that the material might not be good for my health. I simply hold the hose in my mouth with my teeth. When the end of the plastic hose gets badly chewed up after a month or so, I pull out my pocket knife and cut off half an inch. (I love to do this

in public to de-mystify ventilators in peoples' minds!) The translucent hose is quite an elegant solution, comparable to sucking on a long pipe. Sometimes in a heated argument I use the hose to underline a point.

"I use the Eole 3 ventilator from the French manufacturer Saime, S.A. I did not choose the Swedish-made Breas because its soft bellows did not allow me to "save" three to four breaths for a vigorous cough. Before the Eole, I used the PLV-100, which is a very robust and reliable machine that I have had for over 15 years. The Eole is lighter, only 8 kg and draws, with my air requirements, only about 12W. Its internal battery is good for about five hours. When I fly, I carry a battery (18 amps) in the Eole's practical handbag and have over 20 hours of breathing time without ever needing to use the aircraft's power.

"Since December 1998, I have had two Eole machines, one for daytime and the other for nocturnal use, and they seem reliable, too. The Eole is a bit smaller than the PLV-100, and it is easier to mount under the seat of my electric wheelchair, the Quickie Pro 300 (1993 model). I modified the wheelchair, using smaller batteries among other things, in order to accommodate the ventilator under the seat. The Quickie has large rear wheels. Unfortunately, most wheelchair makers now sell power chairs with small rear wheels and use up all the space under the seat for batteries, motors, and electronics, leaving very little space for something as large as a ventilator." ■

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