

## Home Mechanical Ventilation in Finland

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It is estimated that about 1,000 persons in Finland receive mechanical ventilation because of hypoventilation. All neuromuscular disorders in Finland are considered rare disorders, with a prevalence of less than 1 in 10,000 people. People with neuromuscular disorders who receive home mechanical ventilation are a growing group.

Finland has legislation that dates back to the 1950s when polio was prevalent and there was interest in guaranteeing good care for people with polio using ventilators. Legislation includes the concept of respiratory paralysis and the according of “respiratory paralyzed person” status. It is used in administrative decision-making.

The interesting point about this concept is that people are registered as in-patients, even when living at home.

Respiratory paralysis patients get all treatment and services from a hospital. They are entitled to five helpers for assistance 24 hours per day. All costs are paid by hospitals. In order to be accorded status as a “respiratory paralyzed person,” one must use invasive ventilation, and the need for ventilator support must be almost 24 hours per day.

All ventilator users do not meet the criteria and are not accorded this status. As a result, they have to organize to obtain helpers. The Act on Services for the Disabled was renewed this fall with the provision that people with disabilities have the right to get personal assistance, with salaries for that assistance paid by social services.

Since the 1950s, it seems that at least once a decade there has been interest in home mechanical ventilation, especially concerning services for ventilator users. During the last nine years there has been more interest, because mechanical ventilation saves lives and provides quality of life to many people, and also because of the high costs of the homecare.

There are 20 hospital districts, and people with hypoventilation are treated in both central and university hospitals. Hospitals are responsible for diagnostics, treatment, equipment and homecare plans whatever the ventilation interface. Ventilators are provided at no charge. Nobody can buy or change a ventilator without a doctor’s prescription.



**Current members of the Ventilator Users Association** founded in 1956 by polio people living in Aurora Hospital in Helsinki. Their main goal was to get home to live with their own families. In 1962 a law was passed that enabled ventilator users to receive needed services at home. Photo credit: ResMed Finland

continued, page 3

Since 2000, central and university hospitals have opened service units for ventilator users, especially for those who have the status of respiratory paralysis. These clinics don't have beds. Most of these clinics have only one head nurse working fulltime and a consulting doctor. Only three university hospitals have a doctor working halftime. Hospitals have also founded VENHO (Ventilation Treatment) working groups, consisting of a multi-professional team that serves all ventilator users with hypoventilation.

Officers from the Ministry of Social Affairs and Health found that in 2004 there were 135 people in Finland accorded respiratory paralysis status. The cost of the treatment of those 135 amounted to 27 million euros. Out of those 135, fewer than 10% had polio.

In 2006, the Ministry appointed a national expert working group on the treatment of patients with respiratory paralysis in order to examine their status as well as the legislation and care recommendations in the present social welfare and healthcare system.

Based on the report's recommendations for further actions, one university hospital team started to develop guidelines and recommendations for quality care.

### Meet Artist Kaija Pöytäkiivi

Life changed for Kaija Pöytäkiivi when she was a little girl in the 1950s. She contracted polio and became a ventilator user before her 10th birthday. Today she is living independently in her own household. She does not feel sick or disabled. "Maybe I am blind concerning my own disability," laughs Kaija.

Kaija has had her own helpers since 1968 when she moved back home from the hospital, where she lived for 12 years. This year one of Kaija's helpers retired after working for 40 years for her. Kaija has had seven different ventilators. Her current ventilator is the PLV®-100, which she considers to be the best. She also uses the smaller and lighter Elisée 150 when traveling.

Kaija is very active, and her days are full of different activities. She visits her elderly mother in the countryside and godchildren in a nearby city.

"Music is important to me and I like to go to concerts," says Kaija. "My enthusiasm is also porcelain painting. I have been fascinated with painting ever since I was a young girl. I started to paint small gifts for my friends but for the past 10 years, people have given me orders to make gifts for them."

Five years ago, Kaija won first prize in a porcelain painting contest. The jury members were surprised to hear that she paints everything by holding the paintbrush with her mouth.

Kaija's motto is "Take care of each other!" ▲



*Kaija Pöytäkiivi was named "Artist of the Year" and awarded a €2000 scholarship at a recent art exhibition.*



*Jukka Sariola, chairman for Ventilator Users Association, is an active electric wheelchair hockey player.*

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