Program to Coordinate Helper Teams for HMV Users in East Denmark

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In 1990, Denmark passed a law that funded two respiratory centres for individuals who needed mechanical ventilation. Respiratory Centre West is located in Århus and Respiratory Centre East is located in Copenhagen, each serving half of the country. The purpose of the centres is to provide treatment and follow-up for patients receiving home mechanical ventilation (HMV). The centres also were charged with the education and supervision of the helper teams or the individuals who provide personal assistance to the ventilator users.



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Over the last two decades, there has been an increase in numbers of patients needing HMV, such as individuals with post-polio, muscular dystrophy, tetraplegia, complex sleep apnea and children with craniofacial and neurometabolic disorders, causing a need for a separate system to administer the program that trains and coordinates the helper teams.

In January of 2009, a new program, headquartered in Glostrup Hospital, was started. The staff includes a supervisor, an administrator, an administrative coordinator and a nurse. As the nurse, my duties include selecting and organizing the helper team for the ventilator user, developing contracts between the helper agency and Glostrup Hospital, entering user information in a database, meeting with the teams' supervisors to match up teams with HMV users and reviewing and paying the monthly agency invoices. Since 2009, the region has saved 20 million Danish kroner (DKK) or \$3.6 million USD per year.

The goal is to improve the quality of life of Denmark's HMV users in a cost-effective way and to improve the quality of the helper teams. Today there are 121 patients in the program. The HMV users are referred to the respiratory centre from a neurologist, pediatrician or pulmonologist. At the respiratory centre, diagnostic procedures are carried out including sleep studies, blood gases and pulmonary function tests. HMV prevalence in Denmark is 22 per 100,000 population.

During 2012, 53 more HMV users will be moved to the program. Most are living in their own homes. The 2011 budget for assisting 175 HMV users is 300 million DKK (\$54 million USD). This includes education and training, salary and benefits for the helper teams and administrative costs. A team with nurses costs 3.4 million DKK (\$618,000 USD); without nurses, 2 million DKK (\$363,500 USD) per year for 24-hour care. For 2012, the budget will be 330 million DKK.

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Besides living in their own home with their families, another advantage for Danish ventilator users is that hospital treatment is done in the home supervised by Respiratory Centre East.

The program contracts with and oversees an agency to provide the daily care after the ventilator user provides a profile, so the best qualified persons are hired. All the helpers are trained both in practical and theoretical knowledge at Respiratory Centre East. Each team is coached to guarantee good care. Helpers work a maximum of 12-hour shifts, and the helpers are required to be in constant contact with the ventilator user for safety reasons. Relatives cannot be employed as a helper. The helper agencies report to my team at Glostrup, and of course the patient is still seen in the Respiratory Centre.



Hanne Birthe Bruun, 69, benefits from the Danish government program. She contracted polio as a child and has been an HMV user for more than 30 years, first with nasal ventilation, and, for the last 13 years, she has had a tracheostomy. She is an active woman and enjoys traveling with her husband to Mallorca each year.

This program only serves the area around Copenhagen. The program has spread to half of Denmark (Region Copenhagen and Region Sjaelland).



Breathing and Sleep Symposium

Fang Han, MD, The People's Hospital in Beijing, at the Breathing and Sleep Symposium held at the Salk Institute in La, Jolla, California, on October 29, 2011. Dr. Han, himself a polio survivor, is a sleep medicine specialist who discussed his treatment of polio survivors in China.

Other presenters included Josh Benditt, MD, on the mechanics of breathing in neuromuscular disease, Anthony De Maria, MD. on hypertension and sleep apnea, and Angela King, RRT-NPS, and Karyl Scott, RRT, who described ventilator and mask options. The symposium, held annually since 2009, was cosponsored by ResMed and the Salk Institute. Presentations are online: www.poliotoday.org, click on Videos. 🔺

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