



MINISTRY OF SOCIAL AFFAIRS
AND HEALTH, FINLAND

Advisory Board on Health Care Ethics
(ETENE)

OPINION

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Ministry of Social Affairs and Health
Health Department
Kimmo Leppo, Director-General
POB 33
00023 GOVERNMENT, FINLAND

OPINION ON THE REPORT OF THE NATIONAL EXPERT WORKING GROUP ON THE CARE OF RESPIRATORY PARALYSIS PATIENTS

The Ministry of Social Affairs and Health has asked the National Advisory Board on Health Care Ethics to issue an opinion on the report of the above-mentioned National Expert Working Group regarding the status of respiratory paralysis patients, relevant legislation and recommendations for care within the present social welfare and health care system (Reports of the Ministry of Social Affairs and Health 2006:61). The Advisory Board discussed the Working Group's proposals at its meeting on 20 March 2007 and states as its opinion as follows:

The report of the Working Group is carefully and thoroughly thought over and drawn up. At present respiratory failure patients are in an unequal position depending on their place of residence, and so the aim of the proposals is to make the national practices uniform. The Working Group also sees it necessary that the state contribute to financing the costs so that for instance the possibilities to employ a personal assistant would be similar throughout the country. An effect of the present legislation is that, on the one hand, respiratory paralysis patients have had a special status but, on the other hand, they have been left without certain benefits that support the welfare of other groups of people with disabilities.

The Advisory Board considers it sensible to propose that the concept of respiratory paralysis patients should be abandoned in legislation (proposal 5.1) and that the present provisions on respiratory paralysis patients in the Act on Client Fees in Social Welfare and Health Care (section 5 (4)) and the related Decree (section 23) should be repealed (proposal 5.3). Since the number of patients with a serious respiratory failure is low and there is a wide variety of conditions that cause that failure, national medical recommendations for the care of chronic respiratory failure patients and quality recommendations for the services needed by the clients are justified with a view to making the care practices uniform (5.2). For this reason, a centralisation of care in greater centres as proposed in the report is likewise justified.

At its meeting the Advisory Board discussed most the subjective right of patients with a serious respiratory failure to a personal assistant. When reforming the relevant legislation patients with a chronic respiratory failure cannot be given a special status in this respect but the disability groups with similar needs should be taken into account equally. In 2004 the patients who had got a decision on

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Postal address: POB 33, 00023 Government, Finland
Visiting address: Kirkkokatu 4, Helsinki

Tel. (09) 160 01
Direct telephone number: (09)
160 73834
Telefax (09) 160 74312

E-mail:
ritva.halila@stm.fi
www.etene.org

respiratory paralysis numbered 135 in Finland. It is estimated that the number of people with serious disabilities in need of personal assistants is about 4,000, according to some estimates as much as 15,000. In the context of the reform of the legislation on disability services the right to a personal assistant and the costs of that reform have been pondered in a working group preparing the reform appointed by the Ministry of Social Affairs and Health. The Advisory Board considers that also the reform regarding the total care of patients with a serious respiratory failure should be implemented consistently in the context of reforming the legislation on services for people with disabilities.

The Working Group proposes that the suggested amendments should be adopted as an entirety so as to secure the right of patients with a serious respiratory failure to good care. That entirety presupposes changes in both social security and health care systems, and therefore the Working Group proposes abandoning the term 'respiratory paralysis patient' in the legislation on client fees only after the other relevant amendments have been made. If so will be decided, the Advisory Board considers that sufficient attention should accordingly be paid to securing the care provided during the period of transition.

On behalf of the Advisory Board

Markku Lehto
Chairman
Advisory Board on Health Care Ethics

Ritva Halila
General Secretary