



## Energetic Program

Aerobic Exercise Training and Energy Conservation Management to improve social participation in people with a neuromuscular disease

## Introduction

We all undertake activities to participate in daily life and fulfil social roles such as being a friend, parent, partner, student, or employee. These roles usually involve many different daily activities such as organizing household, taking care for children, going to school, or to work meetings. All these activities require energy to initiate and maintain, but successful performance of activities may provide physical and mental energy as well. The occupational balance and patterns of daily activities and, thus, the net result in terms of energy is strongly influenced by the social context and by the person's mental and physical abilities.

For many persons with a neuromuscular disease (NMD) performing daily tasks requires a disproportionate amount of energy, which affects their activities and participation. Hence, managing one's physical and mental health, social roles and daily activities becomes a prominent part of life for persons with NMD. Rehabilitation for this group should therefore focus on reducing the impact of the disease on everyday life by enabling occupations. Rehabilitation should also support people with NMD to self-manage the challenges they encounter in maintaining their activities and social roles; challenges that are often related to managing chronic fatigue.

Research showed that severe fatigue was reported by more than 60% of persons with NMD, including people with facioscapulohumeral dystrophy (FSHD), myotonic dystrophy (MD), and hereditary motor and sensory neuropathy (HMSN). In a subsequent study, an explanatory model of fatigue has been developed with several perpetuating and potentially amenable determinants based on questionnaires, clinical scales, self-observation lists, and measurements of physical activity. This model (Figure 1) showed that muscle strength, level of self-reported physical activity, sleep disturbances, and pain were all significantly associated with fatigue severity in persons with NMD.

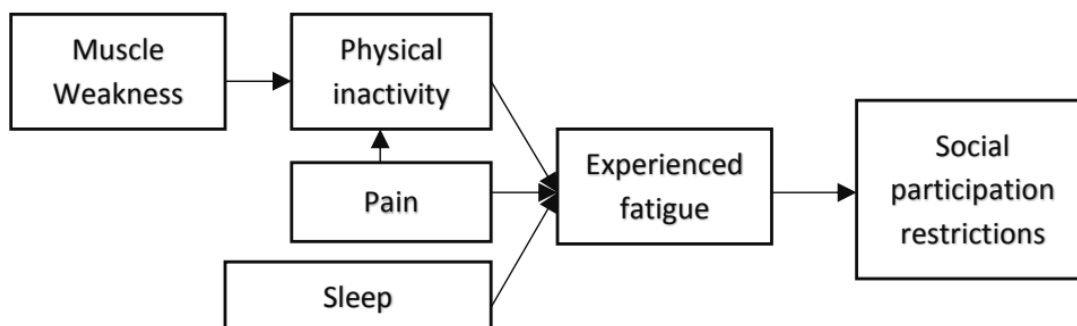


Figure 1: Model of perpetuating factors of fatigue for patients with NMD (Kalkman 2007).

In addition, level of physical activity and fatigue severity were independently associated with participation restrictions. People with FSHD describe their fatigue as an “overwhelming and unpredictable experience”. In addition, they mentioned a psychological aspect of fatigue in terms of “a fear of becoming extremely tired”, which influenced their daily activities as well. Searching for the right balance between doing too much and doing too little, setting borders, and making choices was experienced as difficult and exhausting.

## Energetic Program

To optimize social participation and functional endurance in persons with various types of NMD suffering from chronic fatigue, we have developed multidisciplinary outpatient rehabilitation group program, called Energetic. The Energetic program lasts four months and includes four modules: 1) individually adapted aerobic training; 2) education focused on aerobic training; 3) self-management training focused on applying energy-saving strategies; and 4) implementation of what was learned during the first three modules into daily life focused on relapse prevention (Figure 2). Although offered as a group program, Energetic was designed as a personalized intervention regarding the prescription of AET, goal setting, self-management training, and relapse prevention.

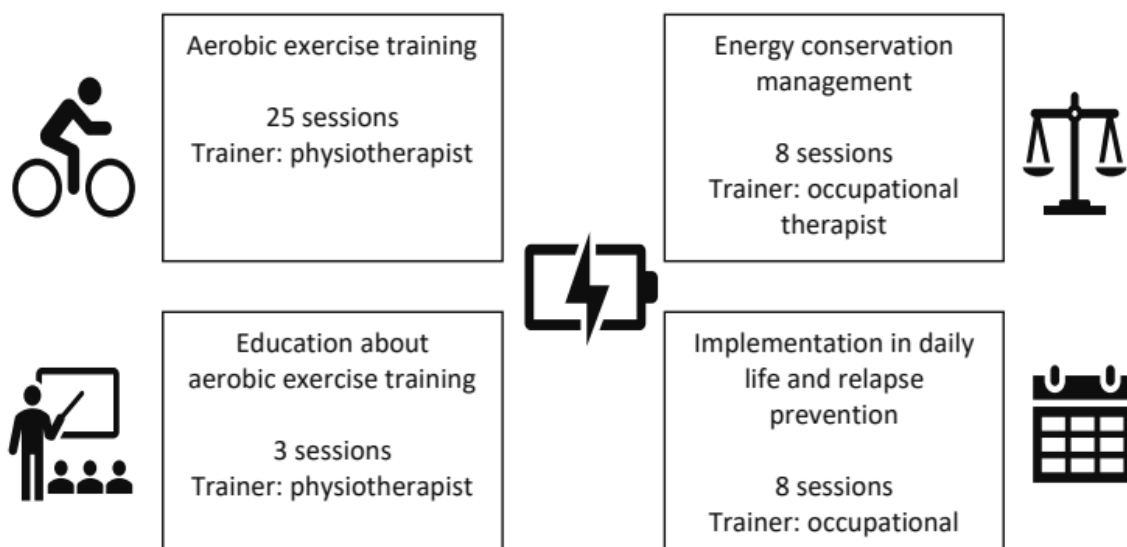


Figure 2: The four modules of the Energetic program.

Research showed that the Energetic patient group improved more in social participation and physical fitness than the patient group with usual care and that the cost of Energetic was somewhat lower than usual care. In an evaluation with the participants and care professionals, the combination approach with fitness training and application of energy-saving strategies and in addition the group setting were perceived as positive features to get a better grip on participation throughout the day.

### Research articles:

Veenhuizen et al. *Self-management program improves participation in patients with neuromuscular disease. Neurology (2019)*

Veenhuizen et al. *Effectiveness and cost-effectiveness of a self-management group program to improve social participation in patients with neuromuscular disease and chronic fatigue: protocol of the Energetic study. BMC Neurology (2015)*