

Exercise and Dietary Intervention in Slowly Progressive Neuromuscular Diseases (NMD)

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Very little is known about the physical activity pattern of persons with neuromuscular diseases, but it is generally accepted that those with disabilities are at the forefront of having a sedentary lifestyle. Our past research indicates that persons with NMD are significantly more sedentary than a comparable group of controls. While they spend the same amount of time sleeping, NMD subjects were found to spend less time engaged in light, moderate, or strenuous activities while awake. Consequently, we found that NMD subjects have significantly lower 24-hr energy expenditure than control subjects. We also know from our own survey of 1169 persons with NMD that over 65% responded to the question "Did you feel full of pep in the last 4 weeks?" with "none of the time" or "a little of the time" and nearly 50% reported being dissatisfied with recreational activities in their lives.

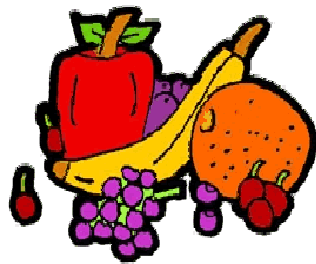
This physical inactivity has been implicated as a major contributing factor in the deteriorating physical health of persons with disabilities and could be due to a lack of knowledge concerning the importance of exercise in overall health, limited access to transportation to and from the exercise site, inaccessible facilities and equipment, and a perception by some individuals that they are not able to exercise as a result of their disability. Furthermore, the medical profession's lack of working knowledge in this area, possibly coupled with the fear of doing harm, contributes to a general failure of the medical professionals to consider or promote exercise and nutritional interventions in persons with neuromuscular diseases.

This study was designed to evaluate a simple, practical dietary and exercise program that applies the best knowledge currently available on diet and exercise to promote healthy behavior in adults with neuromuscular disease. Adults with NMD face the risk of declining strength, reduced aerobic capacity, and altered body composition due to the disease process. Consequently, they may be among the group most in need of function-enhancing activity and a healthy diet. To accomplish this change a program must be developed that is easily understood without the need for extensive training. To be readily incorporated into patients' daily lives it must also be practical, low-cost, and must lead to positive outcomes.

For those who are able to walk, even on a very limited basis, walking was used as the activity. A simple protocol was established based on each individual's abilities and baseline fitness. First, we measured how much walking each person did in their typical daily life by asking them to wear a pedometer for 3 days during their waking hours. We included two weekdays and one weekend day. This allowed us to know how much walking activity each person was achieving on their own, and the average values ranged from 200 steps per day to over 10,000. We then gave each person a prescription that increased their walking by 25%, but on a gradual basis. So if someone started with 100 steps, their training goal was to achieve at least 125 steps every day.

Each participant was given 2 pedometers (costing less than \$20) to take home, a primary and a backup in case of loss. At the end of each day, the number of steps accumulated was recorded in a notebook. We monitored our participants over 6 months, with frequent contact by telephone to check on progress, and a mid-way laboratory evaluation.

In addition to this activity prescription, we also assessed the diet of the participants at the start of the 6-month study. We monitored each participant's typical diet by asking them to record the type and amount of food ingested over 3 days. We also gave them surveys to determine what foods they liked and disliked. Comparisons were made with recommended nutritional guidelines such as the Food Guide Pyramid. Each participant was then given a short list of simple recommendations, typically no more than 3-5 specific suggestions, based on dietary analysis and discussion with the participant. The recommendations fell into common categories, such as increase intake of fruits, vegetables, and whole grains; reduce intake of calorie-dense foods like French fries, pastries, and other desserts; or reduce high sugar soft drinks. The participants also received nutritional support throughout the study. Outcomes evaluated were body fat, lean body mass (muscle), blood pressure, serum lipids (total cholesterol, high density lipoprotein, low density lipoprotein, triglycerides) and nutritional measures such as caloric intake based on a dietary log and a food frequency questionnaire, macronutrients in diet, adherence to recommended dietary standards and measures of quality of life. This study was designed with an emphasis on simplicity and practicality, so that, if it proved successful, practicing health care providers, who may have no background in exercise or nutritional programs for those with NMD, could easily use it in their practices.



Preliminary Results

Preliminary results looking at the effect of the exercise program on daily activity found that the participants had a significant increase in their total daily step activity as determined by the total steps taken each day. After 3 months of the program the number of steps taken each day increased by approximately 26%, a significant amount. The simple twelve-week diet and exercise program resulted in a very small reduction in percent body fat after 6 months, which was considered a significant outcome because most Americans gain fat over 6 months (the phenomenon called “creeping obesity”). The simple act of being enrolled in a monitoring program may have contributed to increased awareness (of activity and diet) on behalf of the participants. Although there was a significant

increase in the activity of the participants, there was no demonstrated change in any of the serum lipid measurements at either 3 months or 6 months. There was a general trend toward improvement in the lipid measurements, but none was changed significantly. This preliminary data represented a small number of persons with NMD. It is possible that when there is analysis of the data from more patients, reductions in the serum lipid measurements may be observed. These preliminary results give an indication that a simple dietary and exercise regimen may be successful in improving the health status of patient's with slowly progressive neuromuscular disease. Further study is necessary to validate these preliminary findings, but this study offers hope that simple, home-based intervention programs to improve quality of life via activity and dietary changes may be beneficial.