

Aging Well with Muscular Dystrophy

Growing older comes with a number of benefits, including increased wisdom and experience. But growing older also can pose challenges that can limit participation in many valued life activities. These challenges can be particularly difficult in people who have muscular dystrophy (MD), who not only have to face the effects of aging, but who continuously deal with the symptoms associated with MD, such as muscle weakness, pain, and fatigue. Problems associated with aging can include increased sleep and mood disturbance. Researchers have not given adequate attention to identifying, developing, and testing effective treatments for these problems in people with muscular dystrophy.

To address this gap in understanding, the National Institute on Disability and Rehabilitation Research has recently funded a Rehabilitation Research and Training Center (RRTC) at the University of Washington's Department of Rehabilitation Medicine. The purpose of this Center is to study the challenges faced by those aging with MD and other physical disabilities. The target objectives of the RRTC are to better understand the natural course of aging with a disability (including those with MD), to test the effectiveness of interventions in managing depression in people with disabilities as they age, to enhance the employment experience of those with a physical disability, and to publish our findings to people with disabilities, their family members, and their health care providers.

To aid in the goal of disseminating our findings, we plan to publish a quarterly informational column called "Aging Well with MD" through the NIH National Registry of Myotonic Dystrophy and Facioscapulohumeral Muscular Dystrophy. These columns will be posted on the website of the National Registry every 3 months. Additionally, all of the columns will be printed in the Registry's annual newsletter. Each column will focus on a specific topic of interest to those with aging with MD, along with a description of the findings from our RRTC as they

become available. The goal will be to provide information that is directly practical, informative, and based on the best science available.

When possible in our columns, we will summarize important new findings from the research literature as they are published, making them directly accessible to patients. But we also plan to include practical information that may be well known to health practitioners and the research community, but perhaps less well known to patients and their family members (for example, scientifically proven methods for helping improve sleep or manage pain). We strongly encourage input from our readers to help guide the content of our column. If you have a specific topic of interest relating to aging with MD that you would like to see highlighted in a future column, please send an e-mail to agerrtc@u.washington.edu.

The summaries and recommendations that appear in this column are based on the expertise of the University of Washington's Aging Rehabilitation Research and Training Center and not directly from the Registry or endorsed by NIH. The contents of this column were developed under a grant from the Department of Education, NIDRR grant number H133B080024. However, those contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.