

Myositis Support Group

Monthly Meeting Summary October 9, 2013

Please note that, due to the length of this issue, the last two pages of our usual format is not included.

- **Ground rules:** This group is a supportive environment where you can learn about myositis from one another. Each person's experience with myositis is unique. Therefore, it is not a forum for providing specific medical advice; this is best done in consultation with your own physician. Confidentiality is essential. Although members may share what they heard or learned with others outside the group, please try to remember not to identify the speaker. It is important to consider time when individuals are speaking, as we wish to give all who choose to share an opportunity to do so.
- **Next meeting: Wednesday, November 13.** As we do every year, this meeting will be about our members presenting highlights of TMA Conference. This is always an exciting and dynamic meeting, as we hear from our own members what was most relevant and interesting for them, bringing the conference back to us!
- Our KIT representative had asked for ideas to take back to TMA on how TMA might better serve the needs of people with myositis. At this meeting, two additional ideas were added: audio recording live webinars for future use by members and information on sex for people with myositis.
- **Great News! Myositis Support Group article by Dr. Robert Kaner on Pulmonary Issues and Myositis up on our website: http://www.hss.edu/conditions_pulmonary-issues-and-myositis.asp**
- Best wishes to those members who have recently experienced physical setbacks and for those planning to have surgery in the near future and to their families and loved ones. We wish you a speedy recovery and hope to see you back at group soon!
- Congratulations and best wishes to members who are celebrating weddings, births, and other joyous events!

Meeting Summary

This meeting was a discussion about "Coping with Fatigue." The meeting began with my presenting some material from previous speakers on helping to cope with fatigue and to conserve energy through the use of occupational and physical therapy and breathing techniques. In addition, I found an article by Roberta Horton, LCSW, ACSW, Director of Social Work Programs, at HSS that discussed coping with fatigue in women with lupus: http://www.hss.edu/conditions_understanding-fatigue-lupus.asp. We began with this last piece, because it distinguishes between mental and physical fatigue.

It was stated in this article that **physical fatigue** is easier to recognize than **mental fatigue**.

We know when we are physically tired: we are unable to walk any further, stand up, or continue with chores. When this happens, it is important to listen to your body and rest, or take a nap. Take as much time as you need until you feel more energized.

Mental fatigue can contribute to being physically tired but you may be less aware of it. This can result from pain, depression, and less satisfaction from social networks. It is important, then, to discuss with your doctor how you might better manage your pain, and to seek help for your depression and seek help in reconnecting with your social supports.

We then discussed ways to increase energy from the physical therapy and occupational therapy perspective:*

- From September's presentation on "Myositis and Physical Therapy", we learned that exercise may help increase energy levels. One way in which this happens is that, through exercise, flow of oxygen through the bloodstream is increased which may provide more energy.

It is important to know; however, the right amount of exercise for you. Exercise should help you feel more energized and not more tired.

- The presentation on "Myositis and Occupational Therapy," (July, 2012) provided suggestions on how to conserve energy:
- Pace yourself. If you know that you have more energy in the morning, try to accomplish the tasks that require more energy at that time or, if you are an afternoon or evening person, tasks can be done later.
- Many people try to do too much when they are feeling better or having a "good" day. Try to "**re-train**" your brain to do less, even when you are feeling that you can do more. As many of us know, this can cause us to feel overly tired and incapable of doing anything in the days that follow.
- Physical and occupational therapy can help you learn to complete tasks in more efficient ways, thereby conserving energy and help to reduce the risk of injury, such as by learning correct posture, bending, walking, and lifting.
- Use assistive devices when needed, as these will help save energy.
- Adapt your tasks. In the kitchen, for example, arrange your work station; do as much food preparation while seated; take as many items as possible from the cabinet or refrigerator in one trip.

When dressing, do as much as possible from a seated position as well. Again, there are many devices available to help with these tasks. A prescription from your doctor is needed, and you can ask your physical or occupational therapists which suppliers they recommend.

➤ **Reducing Stress**

- In our April, 2013 meeting, Dr. Richard Brown presented on "The Healing Power of the Breath. He described the possible positive effects that proper breathing can have on restoring energy and vitality.

- Exercise is another means by which we may reduce stress. Again it must be tailored to fit your individual needs and abilities.
- Find activities that are relaxing for you: talking to friends and family, browsing the internet, reading, watching TV, listening to music. It is helpful to find **indoor activities** that you can enjoy and find relaxing, so that this is available in bad weather or when you just don't feel like going out.

➤ **Sleep**

- Getting enough sleep is a great way to reduce both mental and physical fatigue. However, as many of us know, it can be difficult to get a good night's sleep, especially when there is chronic pain and discomfort.
- It is important, then, to discuss this, as all the above recommendations, with your doctor how to manage pain and how you might be helped in other ways in order to be able to sleep better.
- There are sleep medicine centers to which you can be referred, and health care providers who specialize in this area, to assess your particular sleep issues and develop a plan to address.

*It is important to remember that this should be discussed first with your doctor.

Go-arounds: following this discussion, group members shared some ways in which they cope with fatigue:

Though it is understood that it is important to accept your limitations, members expressed **guilt** about having others do things for them when they want to be able to participate and help.

This can be made more difficult by the **invisible nature** of myositis, as in statements expressed by others, "You don't look sick." Members expressed that they worry that others do not know they are sick and so may be thinking, "I wonder why that guy/gal is carrying so much, and the other guy/gal is not helping out." Another member expressed difficulty with limitations at work and feeling powerless at being unable to complete certain tasks. On the other hand, the member felt more empowered when he/she was able to express these limitations and requested accommodations in the assignment- which were met.

Members all nodded in agreement, understanding that they had experienced the same this feeling and acknowledging this feeling of helplessness but helped each other to understand that there is an advantage when you **ask for help** before it's needed. By being able to anticipate and ask for what you need in advance you might prevent a fall or injury. This also highlighted the benefit of using assistive devices, such as a cane, so that others are aware that you may require help and not be questioned about why you may need the step lowered on the bus.

One member stated that, at the core of this, is the need to accept- and be good- to yourself so that others can treat you in the same way.

CLOSING REMARKS

This meeting was small in number but so very large in spirit. At the start of our meeting a discussion about the difficulty in making end-of-life decisions took place, prompted by the experience of one of our group members this evening. Members related the pain and sorrow of helping loved ones at the end of life. One message that we got from this is that, given our circumstances and challenges, we still have power to determine how we choose to live. And, that this is true throughout our lives.

Wishing all continued strength,
Suzan

The following is a summary from the **September** presentation on **Myositis and Physical Therapy**:

Ms. Yanelli began with a brief overview of the functional limitations that affect those with myositis. Depending on the type of myositis, these may include: difficulty getting up from a seated position or falling and being unable to get up; progressive muscular weakness, with pain or discomfort as the muscles weaken; changes in voice and/or weakness of the vocal chords (dysphonia); difficulty swallowing (dysphasia); and generalized fatigue.

- Please note that no exercise/physical therapy program should be considered without the advice of your physician.
- For the purposes of this summary, exercise is the same as physical therapy.

Following are summaries of studies presented:

Effects of Physical Exercise Shortly an Acute Episode of Dermatomyositis/Polymyositis*¹

The objective was to study the effect of physical exercise shortly after an acute episode of dermatomyositis/polymyositis in a rehabilitation unit of a large general hospital. The subjects were ten patients 2-3 weeks after an acute phase (early recovery group) and 11 patients in the inactive stage (for at least 3 months (chronic stage group)).

For five weeks, 3 days per week, the participants followed a regimen of:

- Isotonic (working muscles through a range of motion) at 65-70% of individual maximum repetition limit (40-60 minutes/day)
- Respiratory muscle training
- Relaxing baths, mud packs, and massages

Outcome was measured by:

- Dynamometer (measures muscle strength) and spirometer (measures respiratory status)
- Disability tests: Visual Analog Scale (VAS) (evaluates the participants' responses on how they feel), Health Assessment Questionnaire (HAQ), and Functional Independence Measure (FIM)
- Lab values: ESR, CRP (measures inflammation), and CK levels

Results:

- No disease relapses or decreases in muscle function
- Early recovery group: average muscle strength improvement: 17% in the proximal (shoulders, pelvis, upper arms and thighs) muscles and 37% in the distal muscles (lower

arms and legs, hands and feet); there was also a 17% increase in vital capacity (the amount of air you can exhale).

- Chronic stage group: average muscle strength improvement: 46% in the proximal muscles and 37% in the distal muscles. There was no significant change in the vital capacity in this group.
- Both groups showed improvement in the disability tests.

Conclusions:

- Physical training starts 2-3 weeks after an acute exacerbation of the DM/PM seems to be useful and safe.
- Muscle atrophy due to lack of activity may be partially prevented.
- Level of disability can be decreased.

*It is worthwhile to address the issue of continuing physical therapy during a flare. According to Ms. Yanelli, this has been studied only on a case by case basis and the effects differ for each individual. If exercise is to be continued, it seems that isometric exercises and gentle range of motion may be a safe starting point. This requires continued discussion with your physician and physical therapist.

Intensive Aerobic Training²

A case study was presented regarding intensive aerobic training.

The objective of this study was to determine if intensive aerobic training (reaching 80% of maximum heart rate) improves motor performance and oxidative metabolism efficiency (testing blood lactate levels before and after increasing treadmill exercise).

Subject was a 64 year old female with polymyositis, who underwent 5 weeks of rehabilitation in the rehabilitation unit of a large general hospital to improve motor functional efficiency.

For 5 days per week, for five weeks, the participant followed a regimen of:

- Walking on a treadmill for approximately 20 minutes and using an upper body ergometer (measures muscle strength) for approximately 15 minutes. There was a 10-minute recovery time between use of each machine.
- Heart rate was maintained at 65-80% of maximum.

Outcome was measured by:

- Oxidative metabolism- blood lactate level. If the blood lactate level is normal, then cells and tissue are receiving adequate levels of oxygen.
- CK level
- Isometric (exercises in which muscles are contracted to maintain muscle strength) strength was measured by an isokinetic dynamometer.
- Balance function, walking speed, agility, and endurance were measured by Berg Balance Scale (BBS), 10 Meters Walking Test (10MWT), Timed Up and Go (TUG) test and 6 Minutes Walking Test (6MWT).
- Activities of Daily Living (ADL's) were assessed using the Barthel Index (BI).

Results:

- Blood values were normal before and after treatment.
- Improvement in strength

- Improvement in balance
- Improved gait velocity (walking speed)
- Improvement with activities of daily living

Intensive Resistance Training³

The objective of the following was to investigate the benefits of intensive muscular training in patients with chronic polymyositis (PM) and dermatomyositis (DM) in an outpatient hospital-based physical therapy clinic.

For 7 weeks, 3 days/week, 9 patients with chronic PM or DM, whose median age was 53 years:

- Exercised 7 weeks, 3 days/week
- Warmed up for 10 minutes on either an ergometer cycle or treadmill at 50% of their maximal heart rate
- Performed 45 minutes of weight training consisting of a 10 voluntary maximum repetitions throughout 5 muscle groups

Outcome was measured by:

- Functional Index 2 (FI 2)
- Grippit to measure grip strength
- Pain scale on the Borg CR-10
- Activity limitation (Myositis Activities Profile)
- A 6-item core set of activities measures was administered.
- Muscle biopsies of the vastus lateralis (part of the quadriceps muscle) were obtained
- All the above were measured before and after the 7 week program.

Results:

- Increased strength of the voluntary repetition maximum
- Improved FI-2 at 7 weeks
- Reduced disease activity in two patients
- No signs of increase muscle inflammation in the biopsies

Conclusion:

- Patients with chronic, stable PM and DM can perform this intensive resistive exercise program with beneficial effects on impairment and activity limitation without increased muscle inflammation.

In a literature review, which provides a summary of available research, the following results were reported:

- Exercise is an important part of treatment for people with idiopathic inflammatory myopathies.
- Improvement was seen in function, ability to perform activities of daily living, and health-related quality of life in adult polymyositis, dermatomyositis, and inclusion body myositis, with differing, individualized exercise programs.
- There were no signs of increased muscle inflammation; data suggest that intensive exercise can reduce inflammation in **PM** and **DM**, but larger studies are needed to confirm.
- Moderate to intensive resistance and aerobic exercise is well tolerated and increases function in adult, chronic, low-active myositis.
- Easy to moderate resistive exercise is well tolerated in people with active, recent-onset myositis.

- The results are encouraging for improvement in people with **IBM** by the use of resistive and aerobic exercise but need to be confirmed in larger studies.
- There is little research available regarding exercise in juvenile dermatomyositis.
- Based on research presented here and in case presentation, it has been concluded that exercise is safe and recommended for people with myositis; however, larger studies are needed to further support these findings.

It can be difficult to find a physical therapist who has had experience with myositis. One way that the information listed above can be useful is that **you can take this information to the therapist so that he/she can research further** and discuss with you and the prescribing physician.

What to expect from your physical therapist

It is essential that your therapist has knowledge of myositis; understands your limitations; assesses functional ability of upper and lower extremities, as well as pain; helps to enhance your performance and functioning; reviews expectations, prognosis, and progress with you on a regular basis, answers your questions, and sets realistic goals for you based continued discussion with you and your physician.

Based on your individual prescription and tailored to your ability, the therapist may include the following in an exercise program:

***Please note that these exercises must be done in the presence of a licensed physical therapist:**

- **Balance, coordination, and agility training**, which includes posture awareness training and task-specific training
- **Aerobic endurance conditioning**, which can be done through swimming, class-based exercises, dance, and Tai Chi (also good for balance training) and by using equipment: stationery bike, elliptical machine, and arm bike
- **Strength training**, which might include active, active-assisted, and resistance exercises
- **Non-aerobic**, might include the use of free weights, hand strengthening exercises (squeezing putty or a gripper), functional exercises (sit-to-stand training, reaching for weights on different level shelving) weight machines, and thera-bands
- **Flexibility exercises** such as muscle lengthening, range of motion, and stretching; the importance of maintaining **range of motion** was highlighted.
- **Relaxation/respiratory training** helps to educate patients to use diaphragmatic breathing in various positions to help strengthen this muscle and to learn to use movement more efficiently during exercise, transfers, and activities of daily living.
- **Gait training** to learn how to use assistive devices, use of verbal cues, and to demonstrate proper movement and use mirrors for visual feedback.

A physical therapist should be able to help minimize the abnormalities in gait to a point where a patient is able to walk as independently as possible.

Ms. Yanelli continued with a discussion of gait assistive devices and durable medical equipment, with which your physical therapist should help you learn to use. Again, a prescription by your physician is required to obtain these.

- Examples of **gait assistive devices** include: canes, rolling walkers, standard Loftstrand crutches, and platform rolling walkers.
- Some of the most common durable medical equipment for use in the home are: the tub transfer bench, grab bars for the bath, shower, and toilet area, and raised toilet seats.

- To help with **foot drop**, she suggested a carbon fiber ankle/foot **orthotic** made of solid plastic.

If you and your doctor agree to continue with exercise after physical therapy, Ms. Yanelli offered the following suggestions and resources:

- Join a gym or wellness program, sign up for exercise classes, continue to exercise at home
- Free NYC programs are offered to senior citizens through the Department of Aging.
- City-wide recreation centers can be found by logging onto:
www.nycgovparks.org/programs/recreationcenters/membership
- Most communities offer wellness and activity programs at low cost or for free.

Ms. Yanelli summarized:

- Educate yourself on the safety and benefits of exercise.
- Physical therapy should be discussed with your doctor.
- Make sure that your physical therapy program is tailored to fit your individual needs. If your therapist is not familiar with myositis, recommend the research provided in this summary.
- With the help of your physical therapist, consider ways to continue exercise after you are discharged from therapy.
- Always keep in mind the importance of “sticking with it” and never give up!

Citations

¹ Cecilia Varju, Edit Petho, Reka Kutas and Laszlo Czirjak, *Clinical Rehabilitation* 2003 17:23

² “Benefits of Intensive Resistance Training in Patients with Chronic Polymyositis or Dermatomyositis,” Helene Alexanderson, Maryam Dastmalchi, Christina H. Opava, Ingrid E. Lundberg, *Arthritis & Rheumatism* (Arthritis Care & Research) Vol. 57, No. 5, June 15, 2007, pp. 768-777

³ “Exercise as a therapeutic modality in patients with idiopathic inflammatory myopathies,” Helene Alexanderson and Ingrid E. Lundberg, 1040-8711 copyright 2012 Wolters Kluwer Health, Lippincott Williams & Wilkins



