

Exercise for IBM Patients New to Exercise



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Why Exercise?

- ▶ There is no drug available - no other options!
- ▶ Based on preliminary results and our experience, it is possible that exercise may *slow down* the progression
- ▶ There are additional benefits to general health - preventing cardiovascular events, slowing down age-related muscle weakness, etc.



How Do I Start It?

- ▶ Find a therapist or trainer - exercise should be supervised!
- ▶ Home exercise - consider getting some exercise equipment, such as therabands, small weights, stationary bikes, etc.
- ▶ **START EARLY** - once muscle becomes a fat tissue, it can't go back to muscle
- ▶ Be organized - consider having exercise journal; use apps; wearable technology, such as fitbit or smart watches

What's the Prescription for IBM?

For _____
Address _____ Date _____

R_x *3 sets of 15-20RM, EVERYDAY*

*In the muscles that are affected
(proximal and distal)*

Rest if Borg scale > 7

Re-assess every 16 weeks

REFILL _____ TIMES _____, M.D.
DEA NO. _____ Address _____



What Does That Mean?

- ▶ Concept of Repetition Maximum (RM)

- ▶ Borg Scale

How Do We “Dose” Exercise?

- ▶ Exercise can be “dosed” just like drugs
- ▶ The problem is some are much stronger than others at baseline
- ▶ Then how can you determine what’s “too much” for one, and “too easy” for another?
- ▶ Using repetition Maximum



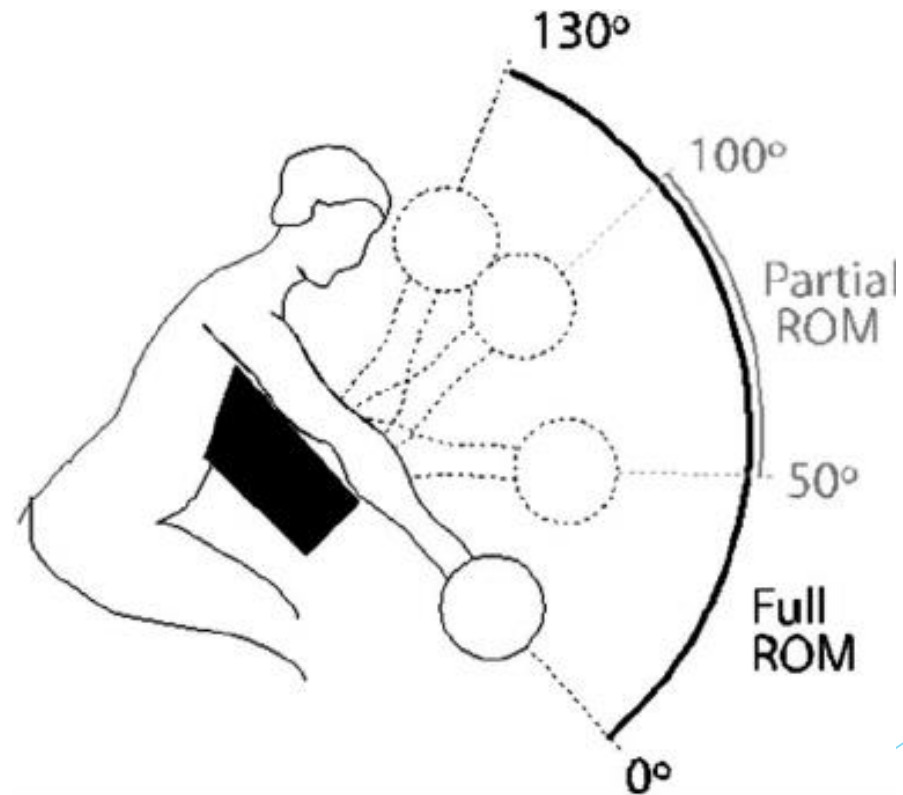
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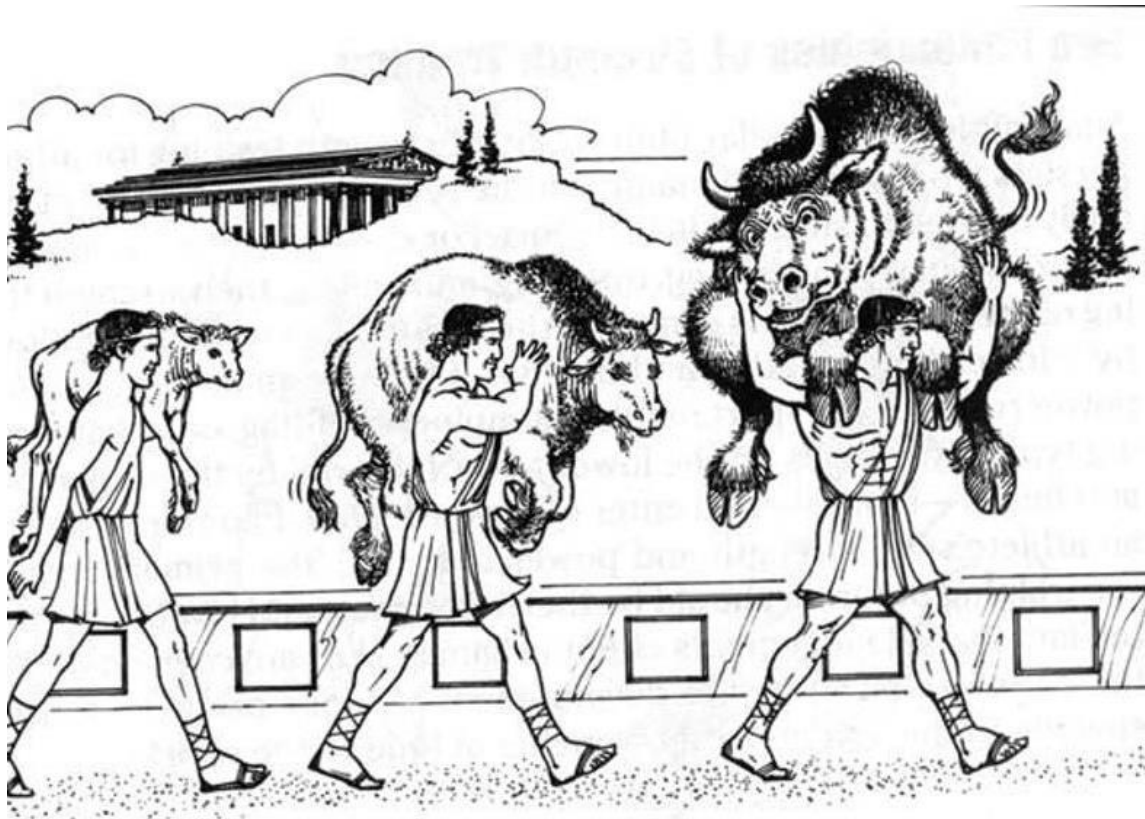
THE MYOSITIS ASSOCIATION

Repetition Maximum (RM)

- ▶ **One RM:** the most weight that can be lifted throughout the entire range of motion
- ▶ The higher the RM, the lower the weight
- ▶ High intensity, typically < 5 - 10 RM
- ▶ Low intensity or endurance typically > 15 to 20 RM
- ▶ Well validated



Exercise Needs to Progress!



- ▶ One RM can change over the course of exercise!
- ▶ Need to re-measure RM every 3-4 months



For IBM - How to Progress

- ▶ Instead of increasing weights, aim to increase the repetition!
- ▶ For example, start with 50-70% of 15-20RM x 3 sets per muscle. Slowly advance to 100% of 15-20RM x 3 sets by 16th week. Re-assess the RM at 16 weeks and go up to 70-80% of 20 to 25RM x 3 sets and increase slowly to 100% of 20- 25RM x 3 sets by the next 16 week.



What is Borg Scale?

- ▶ Rating of Perceived Exertion (RPE)
- ▶ Visual analog scale of how exerted one feels during exercise
- ▶ Reliably reflex the intensity and also reproducible!
- ▶ Two versions: 6-20 scores (original) and 1-10 scores

Borg Scale

0	Nothing at all	
0.3		
0.5	Extremely weak Just noticeable	
0.7		
1	Very weak	Very Light Activity: anything other than sleeping, watching TV, riding a car, etc.
1.5		
2	Weak Light	Light Activity: feels like you can maintain for hours. Easy to breathe and carry a conversation
2.5		
3	Moderate	
4		Moderate Activity: feels like you can exercise for hours. Breathing heavily, can hold short conversation
5	Strong Heavy	
6		
7	Very strong	Vigorous Activity: on the verge of becoming uncomfortable. Short of breath, can speak a sentence.
8		
9		Very Hard Activity: very difficult to maintain exercise intensity. Can barely breath and speak a single word
10	Extremely strong "Maximal"	Max Effort Activity: feels almost impossible to keep going. Completely out to breathe, unable to talk.

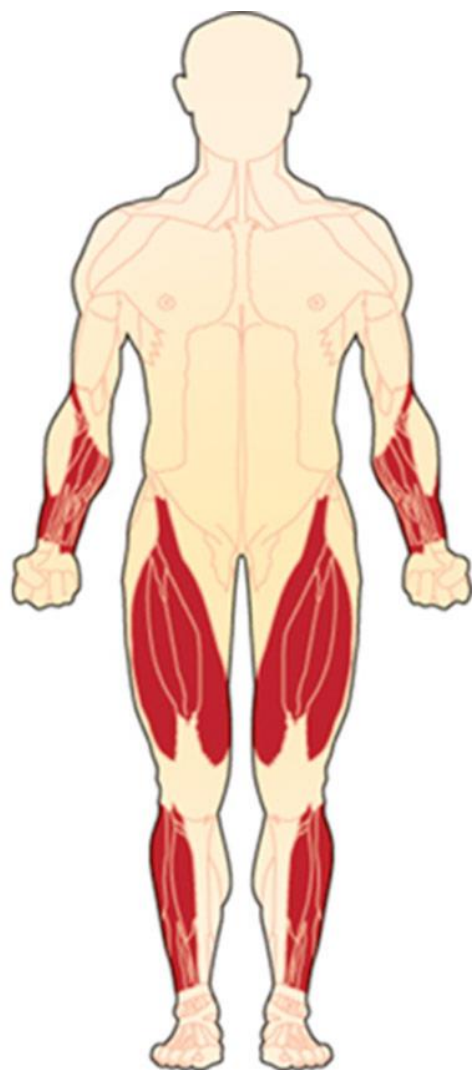
What Muscles Should I Start With?

- ▶ It depends!
- ▶ Prioritize the muscles that are affected before the muscle goes atrophied
- ▶ If muscles are too weak, focus on the muscles for compensatory function

SAID Principle

- ▶ Specific Adaptation to Imposed Demands (SAID)
- ▶ Training in certain muscle will only improve that specific muscle
- ▶ You have to target the muscles of interest!

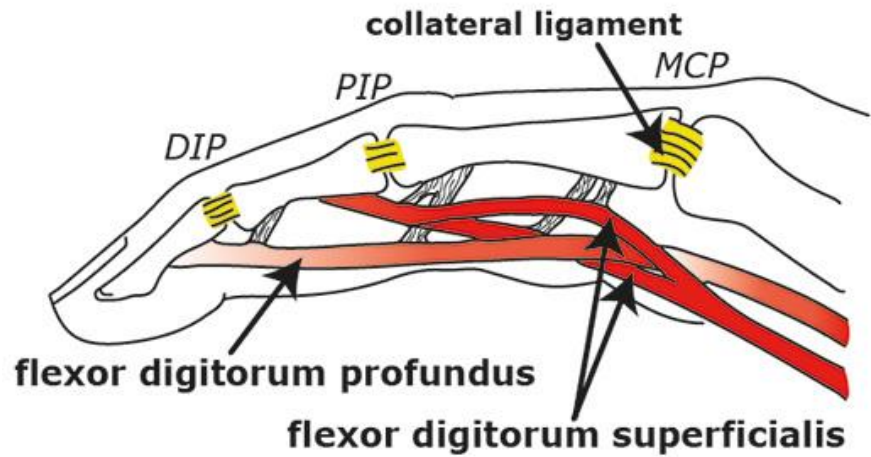




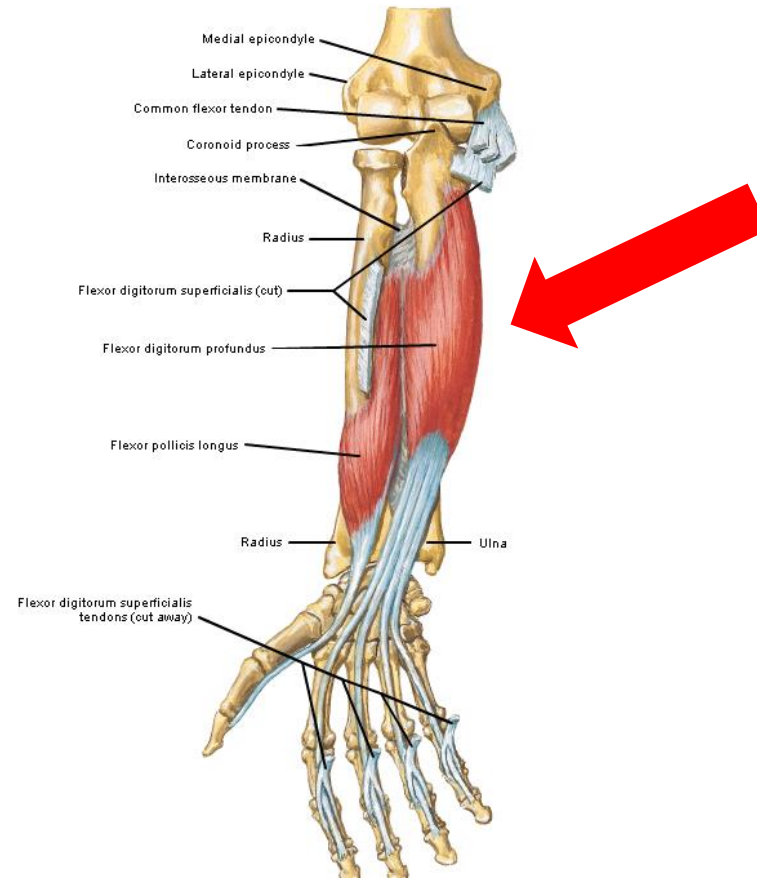
IBM Pattern of Muscle Weakness

- ▶ Distal Finger Flexors
- ▶ Quadriceps Muscles (Knee Extensor)
- ▶ Ankle Dorsiflexor
- ▶ Swallowing muscles (neck flexor)

Distal Finger Flexors - Mainly Flexor Digitorum Profundus



Individual Muscles of Forearm
Flexors of Digits (Anterior View)



How To Train Distal Finger Flexors?

- ▶ Using exercise putty
- ▶ Make sure to use finger pinch!
- ▶ Playing musical instruments, such as guitar
- ▶ Any ideas?



Fingertip Pinch

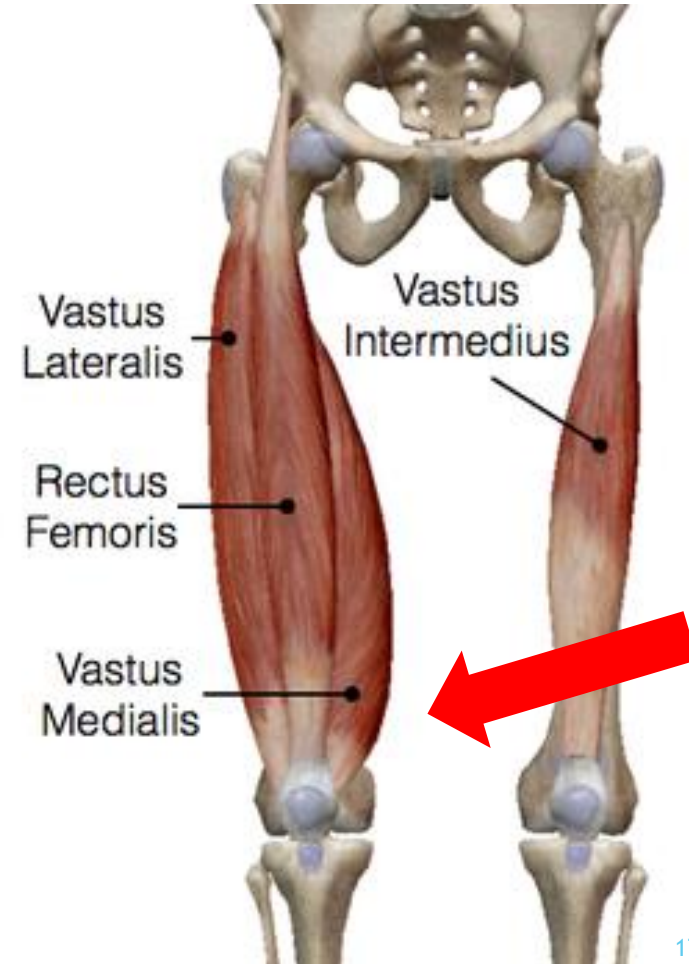


Power Grip

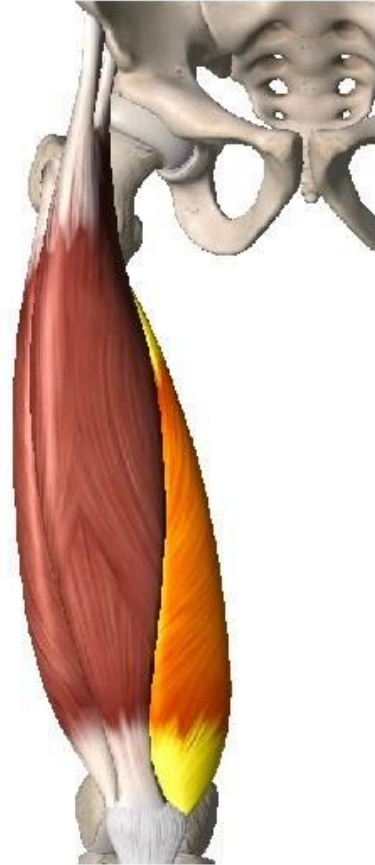
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Quadriceps = Knee Extensors

- ▶ Consist of 4 muscles
- ▶ Vastus Medialis (VM) seems to get affected the most
- ▶ VM muscle is responsible for the last 15 degree of knee extension
- ▶ Note that rectus femoris muscle crosses two joints, acting as hip flexor as well!



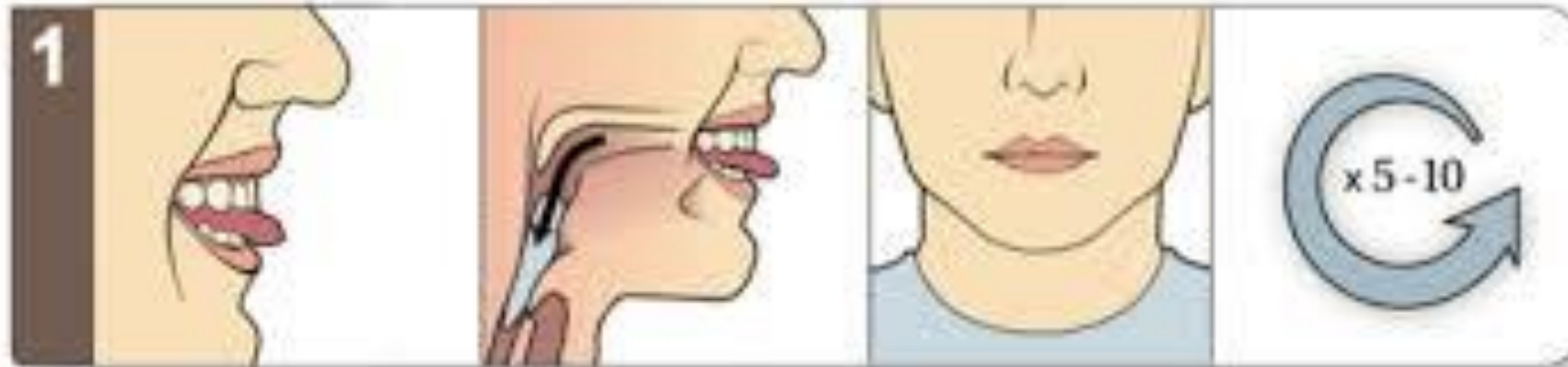
How To Train Quadriceps (esp. VM)?



How About Swallowing?

- ▶ It appear to be related to neck flexor muscles
- ▶ More research is needed
- ▶ Needs Video Swallowing Study before planning for exercise

Example: Masako Maneuver



1 Stick out the tip of your tongue. Hold it between your teeth or lips.

Now, try to swallow your spit with your tongue in that position.

Relax.

Repeat 5 to 10 times.

Example: Shaker Exercise

**Hold for 30 seconds
to 1 minute**



Example: Mendelsohn Exercise

- ▶ Put one hand on the larynx and swallow - did you feel larynx going up and down?
- ▶ Then, swallow again, and this time, don't let the larynx go down and hold it for 2 seconds
- ▶ Repeat 30-40 swallows per session



Issues with Exercise

- ▶ Muscle pain - is it safe?
- ▶ Fatigue - follow Borg scale
- ▶ Too many exercises - break it up or periodization
- ▶ Boring!!! Combine with fun activity, exercise buddy, etc.

Thank you!
Questions?