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## Home exercise program for individuals with inclusion body myositis (IBM)

The program has been evaluated in a small open study (*Johnsson LG et al. Clin Neuromusc Dis 2007;8(4):187-194*) reporting significant improved muscle strength in all tested muscle groups including quadriceps and the hand grip together with improved ability to walk in flat ground and to climb stairs.

**The program should be performed twice a day for 16 weeks**, however, starting on lower intensity slowly increasing to goal intensity during weeks. If possible, have a physical therapist assess muscle strength and function at baseline.

It is important that the exercises and loads are adapted to each individual's capacity and frequent follow-up are important to ensure safety and optimal exercise loads. Thus starting with once a day could be a good start if twice a day is too demanding.

Exercising twice a day can be a challenge and therefor an exercise diary can help to keep up the motivation and keep record of exercise frequency, as well as possible changes in number of repetitions or exercise loads.

A vast majority of individuals with IBM tolerate this program very well, however clinical experience indicate that reduced muscle strength or increased pain have occurred in rare cases. If you have previously experienced these symptoms after moderate physical activities, start on an even lower exercise dose than suggested in this program and be sure to have frequent follow-ups and measure strength regularly.

**The Borg CR-10 scale could be used to determine initial and long-term exercise loads.**

- 0 No exertion
- 0.5 Extremely light exertion
- 1 Very light exertion
- 2 Light exertion
- 3 Moderate exertion**
- 4 Somewhat heavy exertion
- 5 Heavy exertion**
- 6
- 7 Very heavy exertion
- 8
- 9
- 10 Extremely Heavy exertion (almost maximal)

# Maximal exertion

If you have questions about this program and how to assess muscle function or other outcomes, please email: [helene.alexanderson@karolinska.se](mailto:helene.alexanderson@karolinska.se), and I will try to answer.

Good Luck!

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### 1. LOWER EXTREMITY STRENGTH - GETTING UP FROM A CHAIR

Sit on a chair with the back of the chair against the wall.

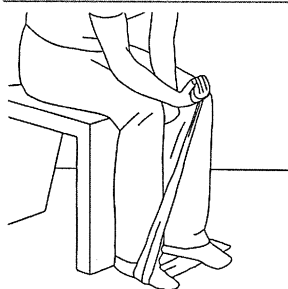
Stand up and sit down. If possible, adjust the height of the chair to be able to stand up without help of arms.

If that is not possible, use a chair with armsupport (see Picture) and push away with your arms.

Try to sit down slowly, using your thigh muscles to resist gravity.

Week 1-2: Performe twice a day, repeat until moderate muscle exertion (3 on the Borg scale, 0-10)

Week 3-16: Performe twice a day, repeat until Heavy exertion (5 on the Borg scale).



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### 2. WRIST AND FINGER FLEXOR STRENGTH

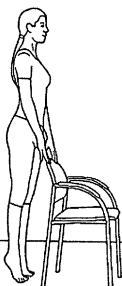
Sit down with you underarm supported on your thigh with the palm of your hand facing up. Hold a rubberband (as in picture) or a free weight. This exercise can be performed against gravity without extra loads.

Bend your wrist up while keeping your underarm tightly againsts the thigh and go back slowly.

Week 1-2: Perform twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 3-16: Perform twice a day, repeat until heavy exertion (5 on the Borg scale)

Change sides and repeat the above.



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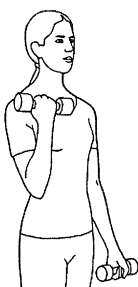
### 3. PLANTAR FLEXOR STRENGTH - HEEL LIFTS

Stand up with support of a stable chair (as in picture), other stable furniture or againsts the wall.

Get up on your toes and go back slowly. Try to keep the knees straight.

Week 1-2: Twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 3-16: Twice a day, repeat until heavy exertion (5 on the Borg scale)



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#### 4. UPPER EXTREMITY STRENGTH - BICEPS

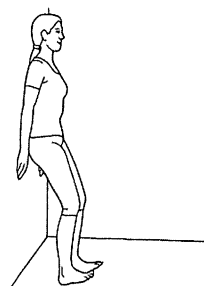
Stand up or sit down with your arms along side the trunk. Hold a rubberband with the other end under your foot, or a free weight (as in the Picture) or exercise just against gravity.

Lift one hand up to the shoulder, try to keep the elbow still against the trunk. Go down slowly.

Week 1-2: Twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 1-16: Twice a day, repeat until heavy exertion (5 on the Borg scale)

Change sides and repeat.



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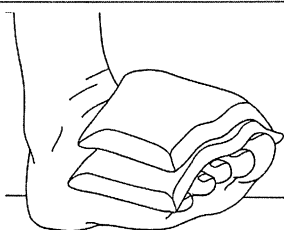
#### 5a. LOWER EXTREMITY STRENGTH - TOE LIFTS

Stand with back and hips against the wall with feet about 30 cm from the wall.

Holding this position, lift the toes and the front of the feet up so you are standing on your heels. Go down slowly.

Week 1-3: Twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 3-16: Twice a day, repeat until heavy exertion (5 on the Borg scale)



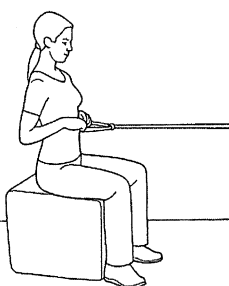
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#### 5b. LOWER EXTREMITY STRENGTH - TOE LIFTS **only if 5a is too demanding.**

Sit down with feet on the floor. Lift the toes and front of the foot up and down. Use extra weight (weight cuffs or other) or exercise only against gravity. The exercise is more demanding with the feet close to the chair and easier with feet further away from the chair. Exercise both feet at the same time or one at the time.

Week 1-3: Twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 3-16: Twice a day, repeat until heavy exertion (5 on the Borg scale)



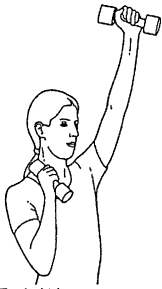
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#### 6. UPPER BACK AND SHOULDER STRENGTH

Sit down. Wrap the middle of the rubber band around for example a door knob. Hold the ends of the band in your hands. Pull your arms backwards (rowing). The tighter rubber band the more demanding,

Week 1-3: Twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 3-16: Twice a day, repeat until heavy exertion (5 on the Borg scale)



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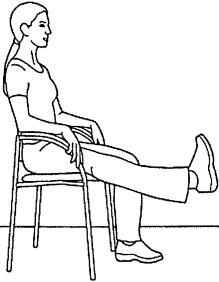
## 7. UPPER EXTREMITY STRENGTH - SHOULDER FLEXORS

Sit down or stand. lift one arm up to the ceiling and go down slowly. Important to bend the elbow on the way up and down. If needed hold a free weight in hand (as in Picture) or use a rubber band or another object.

Week 1-3: Twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 3-16: Twice a day, repeat until heavy exertion (5 on the Borg scale)

Change sides and repeat.



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## 8a. LOWER EXTREMITY STRENGTH - QUADRICEPS

Sit down with most of the thigh supported in the chair or bench. Lift the foot up and extend the knee. Try to lift as high as possible, but remember to keep the thigh supported. Go down slowly. Perform against gravity only (as in Picture) or use weight cuff or a rubber band around the ankle.

Week 1-3: Twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 3-16: Twice a day, repeat until heavy exertion (5 on the Borg scale)

Change sides and repeat.

## 8b. LOWER EXTREMITY STRENGTH **only if 8a is too demanding.**



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Lay on your back with one knee bent. Lift the other leg up about 40 cm from bed with the knee as extended as possible. Go down slowly.

Week 1-3: Twice a day, repeat until moderate exertion (3 on the Borg scale)

Week 3-16: Twice a day, repeat until heavy exertion (5 on the Borg scale)

Change sides and repeat.

If needed, rest for a while after completing the exercise program before getting up again.