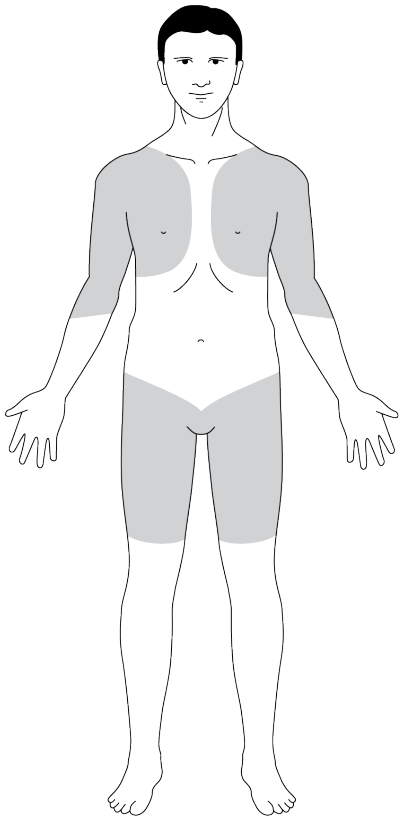
Hamilton Health Sciences
PATIENT EDUCATION

# Limb-Girdle Muscular Dystrophy

## What is limb-girdle muscular dystrophy?



Limb-girdle muscular dystrophy (LGMD) is a medical term for a condition that affects muscle strength that affects the muscles of the:

- 'limbs' – close to the body (the upper thighs and upper arms)
- 'girdle' – connecting the limbs to the body (the shoulder and pelvic girdle)

LGMD is one of several types of muscular dystrophies. There are several different types of LGMD.

## What are the signs and symptoms of LGMD?

### Muscle weakness

- LGMD commonly affects the muscles of the shoulders, pelvis, thighs and upper arms.
- Individuals with LGMD may have an elevated creatine kinase (CK) level in their blood.

# How do you know I have LGMD?

Your doctor or specialist can tell if you have LGMD from:

- talking with you about your symptoms and family history
- checking the strength of your muscles
- needle EMG to listen to your nerves and muscles
- muscle biopsy to look at your muscle under a microscope
- reviewing the results of a genetic test for LGMD
- elevated creatine kinase (CK) level in blood

### Genetic tests

- Based on the observed inheritance pattern running through your family, genetic testing can be ordered to look at the known genes associated with LGMD. Your type of LGMD will be investigated by a genetic test (bloodwork).

### Electromyography (EMG)

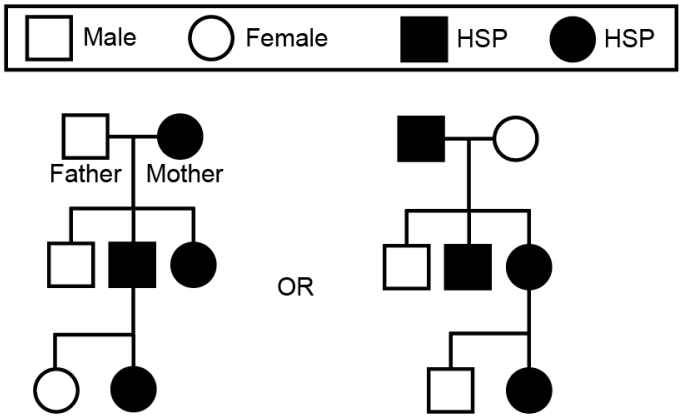
- This test measures and listens to the electrical activity in your muscles and nerves. An acupuncture needle is inserted into the muscle and used to listen for distinct sounds and patterns of the electrical activity of the muscle.

### Muscle biopsy

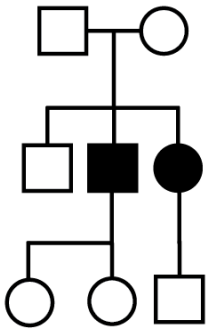
- A muscle biopsy can help with establishing the type of LGMD by observing the muscle tissue under a microscope to look for myopathic or dystrophic changes and other patterns.

# What causes LGMD?

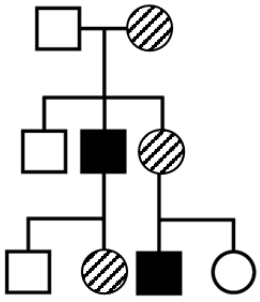
LGMD is a genetic condition that can inherited from your parents or happen spontaneously (also known as '*de novo*' gene change). There are over two dozen types of LGMD with different inheritance patterns.




1. **Autosomal dominant inheritance:** this is when the condition is seen in several relatives across multiple generations (for example your parents, aunts, uncles, children)



2. **Autosomal recessive inheritance:** this is when the condition occurs from a combination of two genetic changes, one inherited from each parent. This condition would likely only be observed in one generation (for example siblings).



3. **X-linked inheritance** this is when a woman carries the mutation in her genetic code but either does not have symptoms, or just has mild symptoms. Male relatives who inherit this genetic mutation have symptoms.



## How is LGMD treated?

LGMD is treated with a combination of methods. There are many different types of LGMD, and each subcategory may be associated with its own clinical symptoms. Your specialist will work with you to identify your particular subtype. You will visit the Neuromuscular and Neurometabolic Centre, where the health care team will plan your treatment and provide your care. Your treatment plan will be designed to meet your needs.

**The goal of treatment is to prevent or lessen your symptoms and help you retain the strength in your muscles.**

## Mobility

- It is important to have neurological and strength assessments regularly to monitor the progression of your LGMD.
- Assistive devices may be considered, depending on your abilities. This can include ankle-foot orthoses, Rollator walker, wheelchairs, or other assistive devices.

## Exercise

- We suggest that people slowly increase exercise tolerance starting off slowly and gradually to eventually attain 3 to 4 sessions per week of mixed endurance (such as biking, rowing, walk, jog, elliptical) and strength (such as weights, elastic bands, pilates) exercise.
- We provide strength monitoring and exercise advice with a DVD and exercise hand-outs.
- Learn to listen to your body. Rest and conserve your energy when you feel tired. When you are active, go at your own pace.

## Nutrition

- Your diet is also important to your treatment. Refer to **Eating Well with Canada's Food Guide** to make sure you have enough protein and calories in your diet. Ask your family doctor for a copy or visit Health Canada's website.
- We recommend that you take supplements of Vitamin D (2000 IU a day for adults and 400 IU a day for children).
- A supplement of creatine monohydrate can also help improve strength in conjunction with exercise. Take ½ tsp (2 ml) in the morning and take ½ tsp (2 ml) in the evening with food. Do not take more than this amount. You can add it to a glass of juice or sprinkle it on cereal or yogurt.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