For Friends and Family

What is Myotonia Congenita?

Myotonia congenita is a disorder that affects the muscles, making them difficult to relax after they contract. This is not a normal stiffness or muscle cramp, but a delay in the relaxation process of the muscle that forces the muscle to remain contracted longer than it should. Sometimes the person's muscles also contract very hard and/or very easily. Other symptoms of the disorder sometimes include muscle enlargement, mild permanent or transient weakness, physical fatigue, and sometimes muscle pain and joint problems.

The person I know with Myotonia Congenita doesn't seem like they have a muscle disorder and sometimes seems like they are faking or just trying to get out of doing something. Why is this?

Unlike most muscle disorders, Myotonia Congenita does not usually cause severe permanent weakness or noticeable muscle atrophy. To the contrary, people with Myotonia Congenita often look strong and healthy. Having Myotonia Congenita is often like being at the gym all the time, only instead of fighting against weights, the person fights against their own muscles to move. This is like doing an isometric exercise and can cause people with Myotonia Congenita to have very large, well developed muscles. Sometimes these muscles might even be fairly strong. But at the same time, this can be very taxing because the muscles have a hard time relaxing even when they've used up their energy and need to. The type and severity of symptoms of Myotonia Congenita can also vary depending on many factors. One curious thing about Myotonia Congenita is that the disorder has a phenomena called "the warm up effect". This is a phenomena in which it becomes easier for the muscles to relax, and the person to move, the more they move. Exploiting this effect can sometimes allow many people with Myotonia Congenita to be able to move easily enough to engage in activities such as sports. However, the warm up effect might not last very long after the person stops. The delayed relaxation often returns, sometimes worse, after the person rests for a few seconds, minutes, or hours. Because of these issues, a person with Myotonia Congenita might appear to be faking their disorder or trying to get out of doing something, when they actually are not.

What types of things do people with Myotonia Congenita often have trouble with?

Sudden movements: If a person with Myotonia Congenita attempts to move suddenly, their muscles could lock up, resulting in complete or partial rigid paralysis and a fall.

Crowds: The inability for the muscles to relax quickly can make it difficult for a person with Myotonia Congenita to navigate through crowds easily because it can impair the fine motor control needed for such a fine degree of maneuverability. Additionally, a person with Myotonia Congenita might fear being bumped into due to a tendency to lock up and fall when they attempt to maintain their balance.

Stairs and inclines: People with Myotonia Congenita often have trouble going up stairs or inclines, because their leg muscles tend to lock up on the first, second, or third step and then slowly relax until they are warmed up. This can cause problems for children with Myotonia Congenita at multi-story schools, as they must often climb stairs in a crowd and could be pushed or harassed by impatient children. They might have some difficulty going down stairs or inclines as well because of difficulties relaxing the muscles smoothly.

Slippery or Moving Surfaces: A person with Myotonia Congenita might have difficulty on slippery or moving surfaces such as iced up or wet sidewalks, and boats and buses as the disorder often impairs the fine motor control they need to properly maintain balance in these situations.

Cold Weather: It has been well documented that cold weather can severely worsen the delayed relaxation with Myotonia Congenita. Because of this, it's important that people with

Myotonia Congenita properly protect themselves from the cold.

Stressful Situations: People with Myotonia Congenita often have more trouble moving when they are stressed or under pressure because the body releases hormones in certain stressful situations that are supposed to make people be able to move faster, and stronger by making the connection between the nerves and muscles stronger. But this stronger connection has a contradictory effect in people with Myotonia Congenita and makes it more difficult for them to move because it increases the power to the muscles, without improving the muscle's ability to relax. Sometimes this increased power even makes it difficult for healthy individuals to relax their muscles, and makes them "frozen with fear", however the healthy individual is able to move normally again after the fear goes away, while the person with Myotonia Congenita might have increased difficulty relaxing their muscles long after they have calmed down. Attempting to rush a person with Myotonia Congenita, or becoming impatient with them when they are doing their best to move quickly, often just makes the situation worse for everyone.

Is there anything else I should know about Myotonia Congenita?

Because the type and severity of symptoms can fluctuate so much, it's best to ask the person with Myotonia Congenita if they need any accommodations, rather than assuming.

People with Myotonia Congenita often feel frustrated with themselves or ashamed or embarrassed about their limitations for the same reason others often doubt people with Myotonia Congenita; they often look strong and healthy, and on many occasions can engage in very physical activities. This leads to people with Myotonia Congenita frequently feeling invalidated about their difficulties when they do have them.

Not all types of movements always result in marked delayed relaxation. More forceful movements are more likely to cause problems than less forceful movements. This is one reason many people with Myotonia Congenita are safely able to drive.

In an emergency that requires sudden movement, a person with Myotonia Congenita may or may not have a "grace period" before their muscles seize up. This grace period might last 1-30 seconds, or might allow the person to make 1-3, sometimes more movements. This is another reason that many people with Myotonia Congenita are safely able to drive.

For unknown reasons, many people with Myotonia Congenita find that regular low to moderate impact activity helps minimize their symptoms in the long run.

People with Myotonia Congenita, frequently have to both rest, and move, when others don't.