



Mobility Aids for People with Myotonia

I am often asked what types of mobility aids would be helpful for conditions such as myotonia congenita and paramyotonia congenita. Since the symptoms can vary dramatically from day to day, someone may be able to walk unassisted on one day and look normal to family, friends and coworkers, and then appear quite disabled the next. This has led to the mistaken assumption that the person is trying to get attention or sympathy. This is particularly distressing to school children. For most of us, the last thing we want to do is attract attention, and we often go to such lengths to avoid it that we damage our muscles by attempting to hide the stiffness.

When someone with myotonia utilizes a mobility aid it is to avoid injury from falls which can be very serious and even cause concussions and broken bones. If the muscles become paralyzed, we can't break our fall. This can happen so suddenly that there is no way to prepare or brace yourself. Adrenaline, even a small burst, will keep our muscles from relaxing. We've all felt that rush when we slip, stumble, or trip on stairs. A sudden loud noise that startles will cause a release of adrenaline. Many with myotonia have fallen when someone honks while they are crossing a street. Walking through a crowd and being jostled and losing our balance can be enough to initiate the paralysis and cause us to fall. Obviously this is not only humiliating but dangerous.

Another common dilemma in public is walking up stairs. We often have to pause between each step to allow the muscles in our legs to relax, and this causes people behind us to become impatient and even rude. Using a cane can sometimes help us maintain our balance better on uneven surfaces, but for public outings and maneuvering workplace environments it may be beneficial to use a wheelchair. Since we have no way to break a fall by throwing our arms out to catch ourselves or to grab onto something, it takes away much of the anxiety and need for constant vigilance to use a wheelchair or scooter.

If someone is going to get a mobility device, it's helpful to educate others about the need and also the way our condition affects us. Just because we can get up out of a wheelchair and lift something or walk quickly down stairs in a fire drill at work or school, that doesn't mean we are faking a disability.

While some with myotonia resent being compared to "fainting goats," that is often the best way for others to understand how we are affected. The goats can look completely normal and in a split second they are on the ground paralyzed. It is exactly the same type of muscle condition.

Janet Stone, CFT, SPN
*Personal Trainer
Fitness Therapist
Sports Nutritionist
Childbirth Educator*

If you are a healthcare provider being asked to approve a disability parking placard or a script for a mobility device, please look beyond the appearance of the person and consider how their quality of life can be improved with this type of assistance.

Colorado Springs, CO 80909
www.accessfitness.com