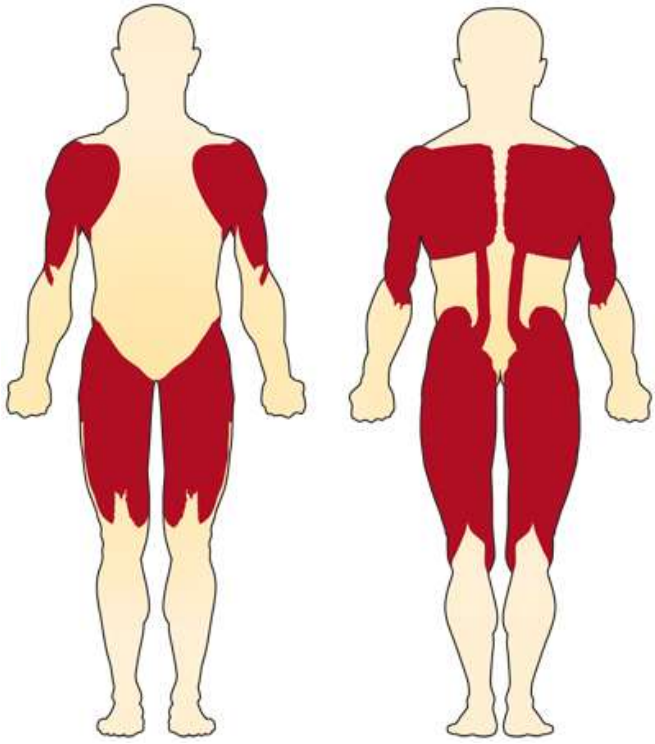

Multiple Sclerosis, Cerebral Palsy, Muscular Dystrophy

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Multiple Sclerosis

What is Multiple Sclerosis?

In some ways, each person with multiple sclerosis lives with a different illness. Although nerve damage is always involved, the pattern is unique for each individual with MS.

Specific experiences with MS may vary widely, but doctors and researchers have identified several major types of MS. The categories are important because they help predict disease severity and response to treatment.

Primary Progressive Multiple Sclerosis

Primary progressive multiple sclerosis takes up about 10-15% of the population who have MS. Primary Progressive symptoms continually worsen. There are no well-defined attacks, and there is little or no recovery. The population with primary progressive MS are an average 40 years of age at the time of diagnosis, which is an older age than for other types of MS. Men and women about equally have this form.

Perhaps the most upsetting difference in primary progressive MS is its poor response to treatment. So far, no treatments have been shown to help, although studies are ongoing.

Relapsing-Remitting Multiple Sclerosis

About 90% of people with MS have the relapsing-remitting type. Symptoms usually start age is in the 20s. After that, there are periodic attacks (relapses), followed by partial or complete recovery (remissions). The pattern of nerves affected, severity of attacks, degree of recovery, and time between relapses all vary widely from person to person. Eventually, most people with relapsing-remitting MS will enter a secondary progressive phase of MS.

Secondary Progressive Multiple Sclerosis

After living with relapsing-remitting MS for many years, most people will develop secondary progressive MS. In this type of MS, symptoms begin a steady march, without relapses or remissions. (In this way, secondary progressive MS is like primary progressive MS.) The transition typically occurs between 10 and 20 years after the diagnosis of relapsing-remitting MS.

It's unclear why the disease makes the transformation from relapsing-remitting to secondary progressive MS. A few things are known about the process:

- The older a person is at original diagnosis, the shorter the time for the disease to become secondary progressive.

- People with incomplete recovery from initial relapses generally convert to secondary progressive MS sooner than those who recover completely.
- The process of ongoing nerve damage changes. After the transformation, there's less inflammation, and more slow degeneration of nerves.

Secondary progressive MS is challenging to treat -- and to live with. Treatments are moderately effective at best. Progression occurs at a different rate in each person and generally leads to some disability.

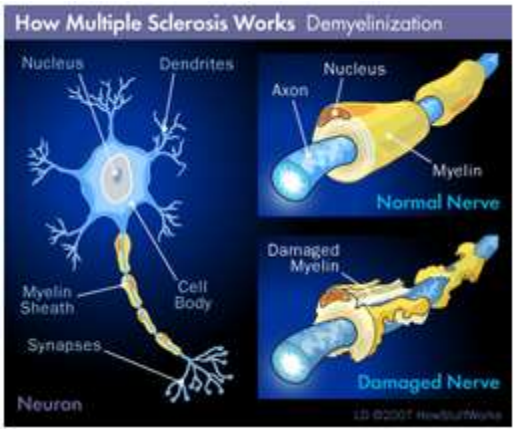
Progressive Relapsing Multiple Sclerosis

Progressive relapsing MS is the least common form. Relapses or attacks occur periodically. However, symptoms continue and are progressive between relapses. Due to rarity—only about 5% of people with multiple sclerosis—little is known about this form. Progressive relapsing MS seems similar to primary progressive MS.

What Causes Multiple Sclerosis?

No one knows what causes multiple sclerosis. Tantalizing clues have sparked research in many areas but no definite answers. Some theories have included:

- **Geography.** People in the northern U.S. develop MS more often than those in the warmer south. Research into vitamin D and sunlight as protective factors is ongoing.
- **Smoking.** Tobacco may increase the risk slightly. But it's not the whole story.
- **Genetics.** Genes do play a role. If an identical twin has MS, the other twin has a 20% to 40% chance of developing it as well. Siblings have a 3% to 5% chance if a brother or sister is affected.
- **Vaccines.** Extensive research has essentially ruled out vaccines as a cause of MS.



Multiple sclerosis is probably an autoimmune disease. Like lupus or rheumatoid arthritis, the body creates antibodies against itself, causing damage. In MS, the damage occurs in the lining, or myelin, of nerves. Due to the damage, the neurons face problems communicating, therefore causing the symptoms of Multiple Sclerosis.

How is multiple sclerosis diagnosed?

Multiple sclerosis is generally diagnosed after a person has experienced troublesome symptoms related to nerve damage. Vision loss, weakness, and loss of sensation are common complaints. The most common tests used to diagnose MS are scans of the brain and spinal cord with magnetic resonance imaging (MRI) and lumbar puncture or a spinal tap.

Unfortunately, the time between the first appearance of symptoms and diagnosis of MS can be prolonged. Studies show that because symptoms are often low-grade or vague, doctors may miss the diagnosis.

Even when symptoms are definitely consistent with MS, the diagnosis still can't be made right away. This is because, by definition, multiple sclerosis is a long-term illness. After the first symptoms, there's an often frightening and frustrating period of waiting until more symptoms occur and the diagnosis becomes clear.

What equipment is used?

There are special types of adaptive fitness equipment that can help with your exercise or recreation program. These are too numerous to list here, but include such things as adaptive gloves and straps that will keep your hand(s) connected to an exercise machine or piece of equipment, and various types of exercise equipment made specifically for people with limited use of their arms and legs. A list of these adaptations and equipment can be found on the NCPAD website at www.ncpad.org or by calling its toll-free number at 800-900-8086. See Resource Appendix for additional places to obtain assistance.

What are the TR implications?

Recreation and leisure activities are usually not done as regularly as fitness activities. Examples include taking a weekend ski trip, hiking, going for an occasional bike ride or walk, bowling, boating, and sleigh riding, among many others. Highlighted below are some enjoyable recreational activities that can be performed by individuals who have various levels of ability. Note that some recreational activities, such as swimming, if done regularly, can improve your fitness level and will most certainly improve your general well-being.

Improving Endurance (Aerobics)

Endurance-type physical activity refers to activity that involves large muscle groups and is sustained for a few minutes at a time to 30 minutes or longer. Examples of endurance activity include cycling, swimming, walking, and lifestyle activities such as gardening and yard work that incorporate large muscle groups. The key to performing endurance activity is to make sure

you don't experience too much fatigue immediately after the activity or a day or two later. It is important to balance the amount of activity with how you feel. Some days will be better than others, so adjust the amount of endurance activity depending on how much energy you have that day. Don't hesitate to adjust your daily routine from a few minutes a day when you are tired or fatigued, to 30 to 60 minutes a day when your energy level is good. Any amount of exercise is good, and moving a few minutes a day is better than doing nothing.

Strengthening Activities

Strength activities increase your muscle strength and help you perform more easily various activities such as climbing stairs or carrying various items like groceries, luggage, or handbags. You can improve your strength in a number of ways, such as using weight machines, elastic bands, or lifting 1-gallon milk containers filled with water (one full container weighs 8 lbs.). The amount of resistance and number of repetitions you should perform will depend on your current level of strength. In general, one to three sets of 10 to 12 repetitions are recommended for improving or maintaining your strength. As your strength increases, the amount of weight that you lift should also increase. Ideally, strength training should not be performed on consecutive days, in order to allow the muscle groups being used to recover between sessions. While both upper and lower body muscles should be included in a strengthening program, this will depend on how much use you have in each set of muscle groups in your upper and lower body. Muscles in the lower body (ankles, hips, and legs) are particularly important for mobility, and muscles in the arms are important for performing transfers, getting up from the floor, and lifting and carrying various objects. And remember to strengthen the muscles in your stomach and back area. They are important for maintaining good postural alignment.

Flexibility Activities

Flexibility activities will help you maintain or increase your range of motion around various joints in your body. It is a good idea to get into a routine of daily stretches, especially if you have a lot of tightness in various parts of your body such as your hips or legs. Some people like to stretch for a few minutes a day before going to work or getting out of bed. They find that it helps "loosen up" tight or spastic muscles. Flexibility activities can be incorporated into your daily routine at work or home, or may be done as part of an exercise class during the warm up and/or cool down phases of the class. Stretching should include both static and/or dynamic exercises. In dynamic stretching, the muscle moves through the full range of motion of a joint, such as when you perform arm circles. A static stretch is when the muscle is lengthened or stretched to the point where there is some discomfort or tension, but it is not painful, and you are able to hold this stretch for around 15 to 45 seconds. Static and dynamic flexibility are both very important for keeping your joints moving through their full range of motion.

Balance Activities

There are two types of balance: static balance and dynamic balance. Just as the name implies, static balance is performed by moving into various positions and holding them for a certain amount of time (a few seconds up to a minute). Dynamic balance is the ability to maintain your balance while moving. Static balance activities are commonly used in various types of yoga positions, which is an excellent way to maintain and improve your static balance. Yoga can be performed in a chair, lying on a mat, or standing.

Dynamic balance can be improved by decreasing your base of support while walking, such as walking between two narrow lines, walking on a straight line, or walking heel-to-toe or on your toes or heels. If you are having trouble with your balance, try static balance activities holding onto a chair, and dynamic balance activities sliding your hand along the wall as you move across the room. Try not to get frustrated. Some days your balance will be better than on other days. Balance is also affected by the type of medication you're taking. If you have a change in medication, you might notice that your balance has changed. On days when your balance is not so good, try doing sitting balance exercises from a chair or on the floor. It is important that you make balance exercises a regular part of your daily routine. The National Center on Physical Activity and Disability (NCPAD) can provide you with a variety of balance activities that will keep your balance program both interesting and challenging (see Appendix A, Resources).

Aquatics

Aquatic exercise is an excellent low-impact activity for individuals of all abilities and can be performed in either indoor or outdoor pool facilities. There are many different kinds of aquatics activities, from structured classes that improve all aspects of fitness, to swimming laps. If you swim outdoors, be sure to stay out of the sun as much as possible. Also, make sure the pool temperature is at your comfort level. Pools that are too warm can increase your fatigue, and pools that are too cold can increase stiffness in your muscles and tendons. Everyone has a slightly different preference regarding pool temperature, so experiment with what temperature is most comfortable for you. In general, the pool temperature should be less than 85 degrees Fahrenheit. If you have difficulty getting in and out of the pool or the pool does not contain a lift, contact NCPAD and they will explain what options are available for making the pool accessible.

T'ai Chi

T'ai chi is an ancient Chinese activity and philosophical exercise aimed at harmonizing the mind and body. These series of movements are performed at a moderate intensity and steady rhythm. The exercise builds strength, balance, and endurance. Its smooth, relaxed movements make t'ai chi suitable for individuals with varying levels of MS. T'ai chi can be practiced outdoors or indoors, and does not require any equipment. If necessary, the ways in which the movements are performed can be easily adapted to your specific needs. T'ai chi classes are available at fitness or

wellness centers, as well as at park districts or your local YMCA. If you prefer to practice tai chi at home, a number of instructional videos are commercially available. NCPAD contains a library of these videos and can be contacted at 800-900-8086 for more information.

Yoga

Yoga is an ancient Indian discipline designed to integrate the body and mind. The word yoga literally means “to yoke” or “union.” The basic components of yoga include breathing techniques (pranayama), relaxation, and performing the different postures or movements called asanas. Movements can be performed while seated, standing, or in a reclined position, and at a slower pace if you have trouble performing certain movements. The benefits of yoga include increased flexibility, balance, muscle strength, and endurance. There are many different styles of yoga, so find the appropriate style that matches your needs.

Hand cycling

Hand cycling has become a very popular activity for many individuals who do not have good balance or cannot use their lower legs to propel a bike. Hand cycles are just like bicycles, except that the exercise is performed with your arms instead of your legs. The other difference is that you are in a recumbent (seated) position with a supportive backrest. The seats are very comfortable and many people with lower extremity disabilities enjoy taking their bike out to the park and hand cycling for a couple of hours on the weekend.

Exerstriding

Exerstriding is a type of walking activity that involves holding a set of poles (similar to ski poles). The poles were originally developed for injured athletes who were not able to run or jog, but are extremely beneficial to anyone who has difficulty with their balance. They can even be used by wheelchair users and present an exciting way to “power walk” or wheel. Visit the Exerstrider website at www.walkingpoles.com for an example of how this inexpensive equipment is used.

Chair Exercise

When feeling too tired or fatigued to perform your regular exercise routine in a standing position, try a few different variations of chair exercises. Numerous chair exercise videos on the market can be used by individuals with varying levels of movement. Several exercise videos allow you to work out in a wheelchair or regular chair. Many of these videos have been adapted for individuals at various levels of fitness. Visit the NCPAD website to access two video clip series: Quick Seated Stretching Exercises and Strengthening Exercises.

What are some safety reminders?

Fatigue

Obviously, you know all about fatigue and how much of an impact it can have on your day-to-day activity. Don't assume that exercise is going to cause you to become more fatigued. Some people have noticed that exercise helps them cope better with their fatigue and that they feel better overall after a good workout. However, many people have also expressed that they feel more fatigued after exercise, so make sure you include time to rest after your workout. The key to avoiding and/or managing fatigue is to perform various types of exercise that are challenging yet do not totally exhaust you. Because everyone is different, experiment with various types of physical activities and select those that make you feel good and do not cause unusually high levels of fatigue. Keep in mind that everyone gets fatigued after a good workout, so expect some temporary fatigue immediately after you exercise. However, if the activity causes you to become excessively fatigued, find a better balance of activities that are more conducive to your ability level. The key is not to overdo it. One way to reduce fatigue is to break up your activity into small segments throughout the day. Most of the research indicates that you'll obtain the same benefits if you exercise three times a day for 10 minutes per session (i.e., 10 minutes before work, 10 minutes at lunchtime, and 10 minutes before dinner), or 30 minutes per day in one session. Find the program that is most suitable to you. On days when you are very tired, reduce the amount of exercise to a few minutes at a time and do light activities such as stretching or performing various balance exercises, rather than your more vigorous workout. Speak with your doctor if you are experiencing a high level of fatigue after exercising.

Avoid the Heat

Heat is clearly your nemesis when it comes to exercise. Make sure the environment you are exercising in is cool and that air circulation is good. Avoid stuffy, warm rooms. Find the right temperature that works for you. In general, temperatures in gyms and workout rooms should range between 67 and 72 degrees. If the facility is too warm, let the manager or owner know that it is too warm, and if he or she is unwilling to accommodate you, find another exercise facility. Also, avoid exercising outdoors when it is very warm and use air-conditioned facilities during hot and humid weather.

Drink Plenty of Water

Water intake is often avoided by many individuals who have difficulty controlling their bladder. Unfortunately, dehydration and lack of fluid intake can be a problem for individuals who are sensitive to the heat and cold. During the warmer months, the body needs an adequate balance of water to dissipate heat and cool the body, and during the colder months, adequate hydration is needed to keep the body warm and insulated. Before embarking on an outdoor recreational activity or joining a gym, make sure adequate bathroom facilities are available, which, of course, should be accessible.

Vision

If you are experiencing blurred vision in one or both eyes, make sure you exercise in a seated position to avoid a fall, or switch to an aquatics program where there is no risk of falling and injuring yourself. If you are participating in a fitness program in a health club, make sure the instructor is aware of your condition so that objects are not left in your path of travel.

Bladder

Exercise can often bring about a spontaneous need to void your bladder. Sometimes certain positions place pressure on the bladder, causing it to empty. Don’t worry about accidents. These things are common and should in no way prevent you from exercising. If you are exercising in a facility or a class, let the instructor know that you may have an accident or may need to leave the class on a couple of occasions.

Cerebral Palsy

What is cerebral palsy?

Cerebral palsy (CP) is a broad term used to describe a group of chronic "palsies" -- disorders that impair control of movement due to damage to the developing brain. CP usually develops by age 2 or 3 and is a nonprogressive brain disorder, meaning the brain damage does not continue to worsen throughout life. However, the symptoms due to the brain damage often change over time -- sometimes getting better and sometimes getting worse. CP is one of the most common causes of chronic childhood disability.

About 10,000 infants are diagnosed with CP and up to 1,500 preschoolers in the U.S. are recognized as having it each year. The United Cerebral Palsy Association estimates that more than 764,000 Americans have CP.

Between 35% and 50% of all children with CP will have an accompanying seizure disorder and some level of mental retardation. They also may have learning disabilities and vision, speech, hearing, or language problems.

Much remains unknown about the disorder's causes, but evidence supports theories that infections, birth injuries, and poor oxygen supply to the brain before, during, and immediately after birth result are common factors. Premature infants are particularly vulnerable. Severe illness (such as meningitis) during the first years of life, physical trauma, and severe dehydration can cause brain injury and result in CP.

Spastic (pyramidal) cerebral palsy

Spastic cerebral palsy is the most common type.
A person with spastic CP develops tight muscles in some parts of the body that are unable to relax. Affected joints become stiff and hard to move. Usually, a person has problems controlling movements, poor coordination and balance, and difficulty talking and eating.

There are four types of spastic CP, grouped according to how many limbs are affected.

- **Hemiplegia or diplegia**: One arm and one leg on the same side of the body (hemiplegia) or both legs (diplegia or paraplegia) are affected. These are the most common types of spastic cerebral palsy.
- **Monoplegia**: Only one arm or leg is affected.
- **Quadriplegia**: Both arms and both legs are affected. Usually the trunk and muscles that control the mouth, tongue, and windpipe are affected too. This makes eating and talking difficult. Babies with spastic quadriplegia may:
    - Have problems sucking and swallowing.
    - Have a weak or shrill cry.
    - Have a very relaxed and floppy body or a very stiff body. When held, they may arch their backs and extend their arms and legs.
    - Be irritable and jittery when awake. For example, they may startle easily.
    - Sleep a lot or show little interest in what is going on around them.
- **Triplegia**: Either both arms and one leg or both legs and one arm are affected.

Nonspastic (extrapyramidal) cerebral palsy

The nonspastic forms of cerebral palsy include dyskinetic cerebral palsy (subdivided into athetoid and dystonic forms) and ataxic cerebral palsy.

Dyskinetic cerebral palsy is associated with muscle tone that fluctuates between being loose and tight. In some cases, rapid and jerky or uncontrolled slow continuous movements occur

involuntarily. These movements most often affect the face and neck, hands, feet, arms, legs, and sometimes the torso.

- Athetoid (hyperkinetic) CP characteristics include relaxed and limp muscles during sleep, with some involuntary jerking (chorea) or writhing (athetosis). If the face and mouth muscles are affected, problems may develop related to unusual facial expressions, drooling, speaking, and choking when sucking, drinking, and eating.
- With dystonic CP, the body and neck are held in a stiff position.

Ataxic cerebral palsy is the rarest type of cerebral palsy and involves the entire body. Abnormal body movements affect the trunk, hands, arms, and legs. Ataxic CP causes problems with:

- Balance.
- Precise movements. For example, the person may reach too far or too close to touch objects and may also have poor hand control (intention tremor).
- Coordination. A person with ataxic CP may walk with the feet unusually far apart.
- Hand control. Often only one hand is able to reach for an object; the other hand may shake with attempts to move it (intention tremor). The person may not be able to button clothes, write, or use scissors.
- Depth perception.

Mixed cerebral palsy

Some children have symptoms of more than one type of cerebral palsy. For example, spastic legs (symptoms of spastic diplegic CP) and problems with facial muscle control (symptoms of dyskinetic CP) may both develop.

Total body cerebral palsy

Total body cerebral palsy affects the entire body to some degree. Complications of cerebral palsy and other medical problems are more likely to develop when the entire body is involved rather than isolated parts. Total body cerebral palsy may include any of the following:

- Spastic quadriplegic CP
- Dyskinetic CP
- Ataxic CP

What causes cerebral palsy?

Congenital cerebral palsy results from brain injury during a baby's development in the womb. It is present at birth, although it may not be detected for months. It is responsible for CP in about 70% of the children who have it. An additional 20% are diagnosed with congenital cerebral palsy

due to a brain injury during the birthing process. In most cases, the cause of congenital cerebral palsy is unknown. Some possible causes are:

- **Infections during pregnancy** that may damage a fetus' developing nervous system. These include rubella (German measles), cytomegalovirus (a herpes-type virus), and toxoplasmosis (an infection caused by a parasite that can be carried in cat feces or inadequately cooked meat). Other infections in pregnant women that may go undetected are being recognized now as an important cause of developmental brain damage in the fetus.
- **Severe jaundice in the infant**. Jaundice is caused by excessive bilirubin in the blood. Normally, bilirubin is filtered out by the liver. But often, newborns' livers need a few days to start doing this effectively, so it's not uncommon for infants to have jaundice for a few days after birth. In most cases, phototherapy (light therapy) clears up jaundice, and there are no lasting health effects. However, in rare cases, severe, untreated jaundice can damage brain cells.
- **Rh incompatibility between mother and infant**. In this blood condition, the mother's body produces antibodies that destroy the fetus's blood cells. This, in turn, leads to a form of jaundice in the newborn and may cause brain damage.
- **The physical and metabolic trauma of being born**. This can precipitate brain damage in a fetus whose health has been threatened during development.
- **Severe oxygen deprivation to the brain or significant trauma to the head during labor and delivery**.

What causes cerebral palsy? Continued...

According to the United Cerebral Palsy Association, about 10% of children with CP in the U.S. acquire the disorder after birth. It results from brain damage in the first few months or years of life. CP often follows infections of the brain, such as bacterial meningitis or viral encephalitis, or it may be the result of a head injury.

Some risk factors that increase the possibility that a child will later be diagnosed with CP include:

- Breech births (with the feet, knees, or buttocks coming out first).
- Vascular or respiratory problems in the infant during birth.
- Physical birth defects such as faulty spinal bone formation, groin hernias, or an abnormally small jaw bone.
- Receiving a low Apgar score 10 to 20 minutes after delivery. An Apgar test is used to make a basic, immediate determination of a newborn's physical health. For the test, the infant's heart rate, breathing, muscle tone, reflexes, and color are evaluated and given a score from 0 (low) to 2 (normal).
- A low birth weight (less than 2,500 grams, or 5 lbs. 7.5 oz.) and premature birth (born less than 37 weeks into pregnancy).
- Being a twin or part of a multiple birth.

- A congenital nervous system malformation, such as an abnormally small head (microcephaly).
- Seizures shortly after birth.

Mothers who had bleeding or severe proteinuria (excess protein in the urine) late in their pregnancy have a higher chance of having a baby with CP, as do mothers who have hyperthyroidism or hypothyroidism, mental retardation, or seizures.
Not all children who are exposed to these risk factors develop CP. However, parents and doctors should be aware of these risks and watch an at-risk child's development carefully.

Cerebral palsy (CP) is classified according to the type of body movement and posture problem.

How is cerebral palsy diagnosed?

Diagnosis of Cerebral Palsy usually happens within the first 2-5 years. In severe cases, it can be diagnosed soon after birth. Mild cases may sometimes wait until the development of the brain, usually occurring between three and five years. On average, a common form, spastic diplegia, is diagnosed at about 18 months. The diagnosis usually starts as parents notice their children missing developmental milestones.

What equipment is used?

Floor mats

Firm, padded, washable floor mats should be used when treating all young children. They will feel safe on these and also be free to move.

Medical plinths (padded tables)

Low plinths (not more than 45 cm in height) are useful for older children, and also for working with children in standing and some sequences of movement. The medical plinths that are normally used in physiotherapy departments are too high and too narrow for young children. They serve to reinforce the perception that therapy is a medical cure: that the therapist is going to ‘do something’ to the child while the mother sits apart, detached from the procedure. Most children, when they are put in lying on a high medical plinth, are aware of this and become fearful. These plinths should therefore not be used for children.

Rolls

Rolls are firm foam rubber cylinders covered in plastic. Rolls are useful during treatment because they lift one part of the child’s body up, and because they can be moved easily. The lifting up of the child’s body breaks up the abnormal pattern and gives her the experience of a more normal posture. The movement of the roll can further reduce spasticity and the child can be

facilitated to carry out active movements in this new position. It is important to use the right size of roll for each child. If the roll is too small the child may not be lifted up high enough and not experience a useful new posture. If it is too big the child may be lifted too high for him to be able to be active.

Wedges (plastic-covered firm foam rubber)

Wedges can be used, like rolls, to support parts of the child's body. The difference is that a wedge is not mobile. In treatment, wedges are most useful in testing out positions in which the child may be placed at home. For example, a child who sits on the floor with a rounded back because she cannot flex well enough at her hips may be placed in sitting on a forward-sloping wedge to see if this helps her to keep her back straighter. If it does, then we can experiment with different angles to see what works best. When we know the angle that works best, we can design a chair or floor cushion for the child that incorporates this angle. Other uses for wedges at home will be described later in this chapter

Benches and stools

Strong, fairly heavy wooden stools and benches are essential for giving children the experience of sitting, and of changing position from the floor to sitting and from sitting to standing. Every center should have a good selection of these so that it is possible to place children of all ages in sitting with their feet flat on the floor. Some of the taller stools can be used as tables to find the best height for arm support for a child who is sitting, or to give the child the possibility of using his hands.

Standing table

These are electrically operated tables that can change height at the touch of a switch, but if these are not available an equally effective solution is to have a carpenter make a square wooden table large enough for one or two children to sit at each side. The top and sides of the table should be covered first by a thin layer of sponge, and then a washable material. Each side of the table should accommodate children of different heights. On all sides there should be openings for the children's feet to pass through, so that the padded side of the table can hold their knees in extension. The problem is that you can never have just little foot-sized openings that will be right for children with a great variety of heights. So it is more practical to leave one side of the table completely open for a wheelchair to go under, and have rectangular openings from the ground upwards at different heights in the other three sides for the various-sized standing children. But in order to get their feet through the openings and their knees supported, some of the children will need to stand on stools of various heights. It is more practical to use stools of varied heights than to design a table to accommodate all possible sizes, especially if the space in a treatment center or school is limited. The biggest children will have their feet flat on the floor. The smaller children will stand on stools and the openings in the side of the table will be higher up. The aim

is to place the children in a semi-supported standing position so that their feet, hips and head are in alignment. The therapist will most likely need to use the pelvis as a key point of control to reduce flexion in the hips and facilitate the children's active extension, or to give them stability in the trunk and shoulder girdle.

Walking aids

Most centers have parallel bars. But these, in the way that they encourage the children to grasp and hang on with their hands, may not facilitate active mobile weight-bearing and balance reactions in the legs and trunk. It is worth trying to replace the normal hand rail with a flat plank so that, instead of grasping and pulling with his arms, the child can be facilitated to take weight on open hands and extended arms. Before he starts taking steps forwards, he should learn to take steps sideways inside the bars. Later, when he can balance with one foot in front of the other, he can learn to shift his weight from foot to foot. In children with spasticity, this weight shift will reduce the spasticity as long as the child is not fearful. Athetoid and ataxic children will benefit from the weight-bearing on both arms and legs, and also from experiencing the feeling of being upright and beginning to have some coordinated co-contraction in the trunk.

In addition to parallel bars, there should be walking aids to try with children who are beginning to be able to take steps. These should only be of the kind that the family is allowed take home. It is cruel to have an expensive walking aid, kept only in the center where the child can use it maybe for 10 minutes once a week, while at home he can only get about by crawling or holding on to the furniture. Some children, particularly those with athetoid or ataxic CP, learn to walk by pushing a fairly heavy object, a chair or small table, in front of them. Holding on to the chair gives them symmetry and a steady point from which to move their legs. But children with spasticity need walking aids that facilitate hip extension. Walkers that the child pushes in front are more likely to facilitate hip flexion, and they will not enable him to develop balance reactions and eventually walk alone. Walkers that support the child from the back, and have a ratchet on the wheels to prevent them from being pushed backwards, do facilitate hip extension. Every effort should be made to develop cheap, local versions of this aid for those children who can take steps in them without their spasticity increasing.

Splints

Sometimes, it is helpful to use light splints to keep a child's limb in extension to free your hands to work on another part of his body. For example, if you are working with a child with low tone

in standing, you can free your hands to help him reach by putting gaiter splints on his legs to keep his knees in extension. These can be made of fabric with lightweight metal strips incorporated to hold them straight or, in a very young child, a few layers of newspaper fastened with sticky tape will be just enough to stop him from collapsing.

Toys

The right kind of toys in a therapy department has a good impact on children and their families when they first attend. Seeing other children actively playing during therapy motivates both the child and his family to be actively involved. A broken doll and a therapist desperately snapping his fingers to attract a child's attention are very poor substitutes. It is very important to keep the toys in a cupboard and take out only what is needed for a particular child at a particular time. Too many toys at once can be distracting and counterproductive. Having the right containers for the toys is also important, so that all the toys do not end up in a jumble of mixed pieces. Jigsaw puzzles need to be kept separate, with all their pieces intact. A set of blocks should be kept in one container, a set of objects specially collected for texture in another. Toys that are broken or incomplete should be repaired or thrown away.

What are the TR implications?

Cerebral Palsy International Sports and Recreation Association

http://cpisra.org/dir/

Our Vision

A world where people who have cerebral palsy or a related neurological condition have the opportunity to participate in the sport and recreational activity of their choice.

Our Mission

Is to promote and develop the means by which people throughout the world can have access to opportunities for participation in sport and recreational activities. We will seek to increase the number of National Members and promote with and through them the value of sport and recreation for those with cerebral palsy or a related neurological condition. We will encourage and facilitate the organization and running of more World, National and Regional Games.
We will continue to work within the International Paralympic movement to ensure that those we serve are not disadvantaged on the world's sporting stage. We will challenge attitudes and assumptions and will work co-operatively, with other organizations to achieve our vision.

Our Core Values Inclusive: Involving everyone in all that is done and by our actions promoting disabled people's involvement in sports and recreation.

Athlete centered: Our focus will be driven by our athlete's needs and wishes.

Partnership: Working with member nations, athletes and other agencies in pursuit of our mission.

Quality: To do things well, and always to be looking to do them better.

Openness: We will be open as possible. We will be listen, be open to change and always be open to dialogue. We will share information and make our decision-making transparent.

Innovative: We will always seek to identify new ways to do things.

Robotic-assisted treadmill therapy improves walking and standing performance in children and adolescents with cerebral palsy

http://www.sciencedirect.com.erl.lib.byu.edu/science/article/pii/S109037981000022X

Objective
Task-specific body-weight-supported treadmill therapy improves walking performance in children with central gait impairment. The aim of the study was to investigate the effect of robotic-assisted treadmill therapy on standing and walking performance in children and adolescents with cerebral palsy and to determine parameters influencing outcome.

Methods
20 Patients (mean age 11.0 ± 5.1, 10 males and 10 females) with cerebral palsy underwent 12 sessions of robotic-assisted treadmill therapy using the driven gait orthosis Lokomat. Outcome measures were the dimensions D (standing) and E (walking) of the Gross Motor Function Measure (GMFM).

Results
Significant improvements in dimension D by 5.9% (±5.2, $p = 0.001$) and dimension E by 5.3% (±5.6,$p < 0.001$) of the GMFM were achieved. Improvements in the GMFM D and E were significantly greater in the mildly affected cohort (GMFCS I and II) compared to the more severely affected cohort (GMFCS III and IV). Improvement of the dimension E but not of D

correlated positively with the total distance and time walked during the trial ($r_s = 0.748$, $p < 0.001$).

Conclusions
Children and adolescents with bilateral spastic cerebral palsy showed improvements in the functional tasks of standing and walking after a 3-week trial of robotic-assisted treadmill therapy. The severity of motor impairment affects the amount of the achieved improvement.

Keywords
- Driven gait orthosis;
- Body-weight-supported treadmill therapy;
- Task-specific learning

Muscular Dystrophy

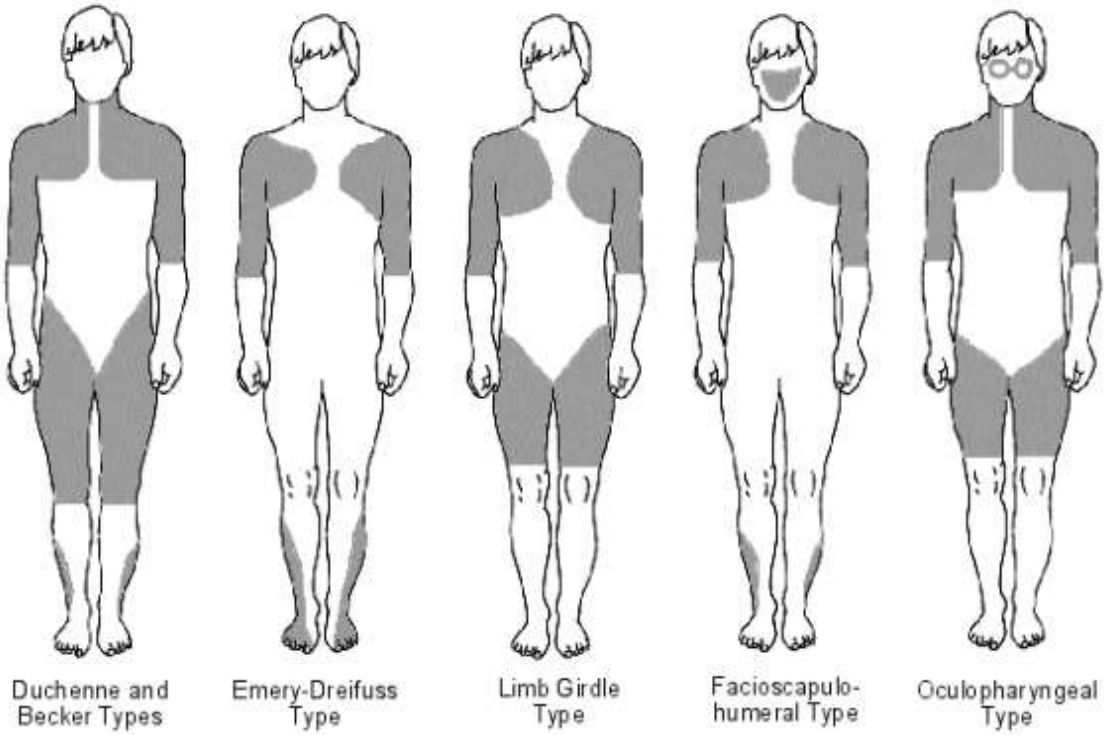
What is muscular dystrophy?

Muscular dystrophy (MD) is a group of inherited diseases in which the muscles that control movement (called voluntary muscles) progressively weaken. In some forms of this disease, the heart and other organs are also affected.
There are nine major forms of muscular dystrophy:

- Myotonic
- Duchenne
- Becker
- Limb-girdle
- Facioscapulohumeral
- Congenital
- Oculopharyngeal
- Distal
- Emery-Dreifuss

Muscular dystrophy can appear in infancy up to middle age or later, and its form and severity are determined in part by the age at which it occurs. Some types of muscular dystrophy affect only males; some people with MD enjoy a normal life span with mild symptoms that progress very slowly; others experience swift and severe muscle weakness and wasting, dying in their late teens to early 20s.

The various types of MD affect more than 50,000 Americans. Through advances in medical care, children with muscular dystrophy are living longer than ever before.



Main areas of muscle weakness in different types of dystrophy

Myotonic (also called MMD or Steinert's disease)

The most common form of muscular dystrophy in adults, myotonic muscular dystrophy affects both men and women, and it usually appears any time from early childhood to adulthood. In rare cases, it appears in newborns (congenital MMD). The name refers to a symptom, myotonia -- prolonged spasm or stiffening of muscles after use. This symptom is usually worse in cold temperatures. The disease causes muscle weakness and also affects the central nervous system, heart, gastrointestinal tract, eyes, and hormone-producing glands. In most cases, daily living isn't restricted for many years. Those with myotonic MD have a decreased life expectancy.

Duchenne

The most common form of muscular dystrophy in children, dystrophy affects only males. It appears between the ages of 2 and 6. The muscles decrease in size and grow weaker over time yet may appear larger. Disease progression varies, but many people with Duchenne (1 in 3,500 boys) need a wheelchair by the age of 12. In most cases, the arms, legs, and spine become progressively deformed, and there may be some cognitive impairment. Severe breathing and

heart problems mark the later stages of the disease. Those with Duchenne MD usually die in their late teens or early 20s.

Becker

This form is similar to Duchenne muscular dystrophy, but the disease is much milder: symptoms appear later and progress more slowly. It usually appears between the ages of 2 and 16 but can appear as late as age 25. Like Duchenne muscular dystrophy, Becker muscular dystrophy affects only males (1 in 30,000) and causes heart problems. Disease severity varies. Those with Duchenne can usually walk into their 30s and live further into adulthood.

Limb-girdle

This appears in the teens to early adulthood and affects males and females. In its most common form, Limb-girdle muscular dystrophy causes progressive weakness that begins in the hips and moves to the shoulders, arms, and legs. Within 20 years, walking becomes difficult or impossible. Sufferers typically live to middle age to late adulthood.

Facioscapulohumeral

Facioscapulohumeral refers to the muscles that move the face, shoulder blade, and upper arm bone. This form of muscular dystrophy appears in the teens to early adulthood and affects males and females. It progresses slowly, with short periods of rapid muscle deterioration and weakness. Severity ranges from very mild to completely disabling. Walking, chewing, swallowing, and speaking problems can occur. About 50% of those with facioscapulohumeral MD can walk throughout their lives, and most live a normal life span.

Congenital

Congenital means present at birth. Congenital muscular dystrophies progress slowly and affect males and females. The two forms that have been identified -- Fukuyama and congenital muscular dystrophy with myosin deficiency -- cause muscle weakness at birth or in the first few months of life, along with severe and early contractures (shortening or shrinking of muscles that causes joint problems). Fukuyama congenital muscular dystrophy causes abnormalities in the brain and often seizures.

Oculopharyngeal

Oculopharyngeal means eye and throat. This form of muscular dystrophy appears in men and women in their 40s, 50s, and 60s. It progresses slowly, causing weakness in the eye and face

muscles, which may lead to difficulty swallowing. Weakness in pelvic and shoulder muscles may occur later. Choking and recurrent pneumonia may occur.

Distal

This group of rare diseases affects adult men and women. It causes weakness and wasting of the distal muscles (those farthest from the center) of the forearms, hands, lower legs, and feet. It is generally less severe, progresses more slowly, and affects fewer muscles than other forms of muscular dystrophy.

Emery-Dreifuss

This rare form of muscular dystrophy appears from childhood to the early teens and affects only males. It causes muscle weakness and wasting in the shoulders, upper arms, and lower legs. Life-threatening heart problems are common and can also affect carriers -- those who have the genetic information for the disease but do not develop the full-blown version (including mothers and sisters of those with Emery-Dreifuss MD). Muscle shortening (contractures) occurs early in the disease. Weakness can spread to chest and pelvic muscles. The disease progresses slowly and causes less severe muscle weakness than some other forms of muscular dystrophy.

What causes muscular dystrophy?

Muscular dystrophy is caused by defects in certain genes, with type determined by the abnormal gene. In 1986, researchers discovered the gene that, when defective or flawed, causes Duchenne muscular dystrophy. In 1987, the muscle protein associated with this gene was named dystrophin. Duchenne muscular dystrophy occurs when that gene fails to make dystrophin.

Becker muscular dystrophy occurs when a different mutation in the same gene results in some dystrophin, but it's either not enough or it's poor in quality. Scientists have discovered and continue to search for the genetic defects that cause other forms of muscular dystrophy.
Most of the muscular dystrophies are a form of inherited disease called X-linked disorders or genetic diseases that mothers can transmit to their sons even though the mothers themselves are unaffected by the disease.

Men carry one X chromosome and one Y chromosome. Females carry two X chromosomes. Thus, in order for a girl to become affected by muscular dystrophy, both of her X chromosomes would have to carry the defective gene -- an extremely rare occurrence, since her mother would have to be a carrier (one defective X chromosome) and her father would have to have muscular dystrophy (since men carry just one X chromosome, the other is a Y chromosome).

A female who carries the defective X chromosome can pass the disease to her son (whose other chromosome is a Y, from the father).

A few muscular dystrophies aren't inherited at all and occur because of a new gene abnormality or mutation.

How is muscular dystrophy diagnosed?

The diagnosis of muscular dystrophy is based on result from several tests:

- Muscle biopsy
- Increased creatine phosphokinase(CpK3)
- Electromyography
- Electrocardiography
- DNA analysis

Can you prevent muscular dystrophy?

If you have a family history of muscular dystrophy, you may want to consult a genetic counselor before having children. The odds of passing the disease on to your children range from 25% to 50%. Carriers -- typically sisters and mothers of those with MD -- usually don't have the disease, but they may exhibit mild symptoms that give hints of it. They can pass the disease on to their children; their sons will get the disease and half the time, their daughters become carriers. For Duchenne and Becker muscular dystrophies, protein and DNA tests can identify carriers, and DNA probes can provide prenatal diagnosis. Tests for carriers of other forms of muscular dystrophy are under development.

What are the treatments for muscular dystrophy?

There is no cure for any form of muscular dystrophy, but medications and therapy can slow the course of the disease. Human trials of gene therapy with the dystrophin gene are on the near horizon. For instance, scientists are researching ways to insert a working dystrophin gene into the muscles of boys with Duchenne and Becker muscular dystrophies.
Researchers are investigating the potential of certain muscle-building medicines to slow down or reverse the progression of muscular dystrophy. Other trials are looking into the effects of the dietary supplements creatine and glutamine on muscle energy production and storage.

Conventional Medicine for Muscular Dystrophy

Symptoms often can be relieved through exercise, physical therapy, rehabilitative devices, respiratory care, and surgery:

- Exercise and physical therapy can minimize abnormal or painful positioning of the joints and may prevent or delay curvature of the spine. Respiratory care, deep breathing, and coughing exercises are often recommended.
- Canes, powered wheelchairs, and other rehabilitative devices can help those with MD maintain mobility and independence.
- Surgery can sometimes relieve muscle shortening. In Emery-Dreifuss and myotonic muscular dystrophy, it's often necessary to surgically implant a cardiac pacemaker.

In some cases, disease progression can be slowed or symptoms relieved with medication:

- In Duchenne muscular dystrophy, corticosteriods may slow muscle destruction.
- In myotonic muscular dystrophy, phenytoin, procainamide, orquinine can treat delayed muscle relaxation.

Medications also can be prescribed for some muscular dystrophy-related heart problems.

What are the TR implications?

All students, whether disabled or not, have a need to feel part of their peer group. Sport is a great way that students can get involved with each other in a fun and active way. Self-esteem is also increased when they feel they are making a worthy contribution. It is easy for MD students to miss out on this opportunity. This is where you can help. In the PE Program, by modifying game rules or using different equipment, you can involve the MD student physically in part of your session. This is important as they are particularly at risk of becoming socially isolated. If play is not possible they should be encouraged to be part of the group by umpiring, scoring and coaching.

Schools are in a unique position, to introduce students to a variety of sports from which they can make decisions as to which community sports they wish to pursue. This should be true for MD students too. There are sporting clubs for individuals with MD where games are designed for them and competition is between MD players only. However if MD students are not introduced to these sports at school they may never discover the enjoyment that can be experienced through playing them.

Below is a list of sporting games that form a part of the secondary school curriculum and suggested changes that can be made to include the MD student. Remember that the emphasis should be on enjoyment and play rather than competition for the MD student and the others involved.

Softball

Set up a tee (normally used in tee ball) and have a lightweight bat and ball for the MD student when it is his turn to bat. (Use a plastic bat, a foam ball, a large rubber ball or plastic ball with holes). These can be purchased from service stations, toy shops or sports stores. This equipment should only substitute normal playing equipment for the MD student. Also give him an opportunity to have a ball thrown to him (The ball should be bigger and the throw should be much softer).

To overcome weakness in shoulder movements, advise MD students to hold the bat with one hand and swing their wheelchair around. The force of the swing to hit the ball will come from the wheelchair momentum, not the strength of their arm. To make it possible for him to reach first base rule that the ball must be thrown to 2 people before it reaches first base.

When fielding, attach a piece of foam to the wheelchair in front of the student's legs so that they can move around the outside of the diamond and stop the ball. A bike basket could also be attached to the side of the wheelchair so he can move into positions under the ball for a catch. If the ball touches the bike basket on the full the batter is out.

Soccer

Include the student in the soccer drills with a big balloon soccer ball or physio ball. These can be purchased from Ansell. MD students can practice head-butting, and kicking using his wheelchair, to other students or the aide.

Half field balloon soccer, can be played for about 20 minutes to involve the MD student for part of the session. It can also utilize skills the other students have learnt in an easy and fun way. Another option is to divide the class into those who want to play a fun game of balloon soccer with the MD student and those who want to play a full field game of soccer.

Hockey

To modify hockey to suit an MD student, quite a few changes need to be made and special equipment must be used. The game can be played in a similar way to soccer. It is played on an indoor or outdoor netball or basketball court, with five players in each team. Each has a lightweight hockey stick. A plastic ball with holes is used and witches hats can mark the goal area at each end.

Golf

For a higher functioning MD student position him forward in a wheelchair to make access to hitting the ball possible. Support his arms to make shoulder movement easier for him, and if necessary allow him to use lightweight hockey stick.

For a lower functioning student limit golf to putting only. Use the practice green at the beginning of the golf course or put the ball at the edge of each putting green and score the amount of hits it takes him to get the ball into the hole (so he does not have to drive it down the range).

Orienteering

This is a great sport for MD students to be involved in because it does not require much modification. Because of this MD students are made to feel a part of the group and can compete against the other students on the same level

Prepare well. Organize the course so that a wheelchair can get around it. Have simple codes at each checkpoint that can be copied by the MD student.

Have students go out in pairs. This is safer for all the students but particularly for the MD student. Encourage the MD student's partner to allow him to do as much as possible. A compass can be fixed to the arm of his wheelchair with a suction cap or some blue tack. The map can be laid flat and stuck to his table that fits into his wheelchair.

It is understood that modifying games may take away a sense of competition for the other students. Therefore games will need to be played without the MD student being physically involved. However when this occurs engage him in other ways. Encourage him to know the rules well and become a good umpire.

Teaching Umpire Skills

Take time to teach the MD student the rules of each sport. This can be done whilst explaining the rules to the other students. Give them a set of rules and go through these with the student to make sure he understands.

Video replays of the television coverage of sports is another way of teaching sporting skills to students and umpiring skills to the MD student. Student's learn by example so while the MD student is learning what is required to be a good umpire, his classmates are learning specific skills such as footwork and racket swing.

Umpire with the MD student until he is confident. Give encouragement and praise.

An alarm (for example, a self-defense alarm) may need to be used if the MD student cannot use a whistle comfortably as he may find it difficult to continually bring it up to his mouth.

Beanbag Hockey

This game should be played indoors on a wooden court. Divide the group into 2 teams and give each student a number. Use rolled up newspaper for 3 hockey sticks, a beanbag, and 2 chairs for goals. Place the beanbag and 2 hockey sticks in the middle of the chairs and then call a number. The people from each team with that number run to the middle and aim to score a goal for their team by hitting the beanbag under their chair.

Allow the MD student to hold a hockey stick so that he doesn't have to reach down and pick one up when his number is called.

Balloon Volleyball

This game should be played indoors on a wooden volleyball court. Divide the group into 2 teams and have each team stand down their side line except 1 player who stands in the center of the court with a badminton racket. Play starts when 1 player hits a balloon over the net. After playing he runs to the end of the line and the person at the beginning of the line runs on to the court to play next. Meanwhile the player of the side must try to hit the balloon back over the net. If that player does not get if over the next person in line tries. The side has 3 chances to hit the balloon over. Play continues until one side scores 11 points

Obstacle Course

An obstacle course can be set up by using witches hats, chairs, gym mats, landmarks and anything else in the sports store room. Two similar courses can be set up and the class can be divided into two teams. The MD student can be one team and an able-bodied student in a manual wheelchair on the other team. Using this method, the competition between the teams will be equal. All the players on each team must complete the obstacle course. The team that finishes first is the winner. The obstacle course van be modified to teach a number of different skills. An example is to hit a ball with a hockey stick or kick a soccer ball around the course.

What are some safety issues?

Some games could possibly be modified for the MD student, but because he is in a wheelchair it would be dangerous to have him on the field competing against other students for the ball. Therefore safety of the other children must be considered.
Safety of the MD student is also important. Remember that:

- Balance is easily lost.
- Fatigue is a serious hazard. Only moderate exercise should be done.
- No strain should be exerted.
- Strength exercises are contraindicated.
- Consultation with the student's doctor or parents is recommended to ensure that activities and planned modifications will have no adverse effects.
- Although safety of the MD student is essential, it does not mean that he should be over protected. All MD students are likely to fall at some stage but like other individuals recover quickly.

Further Guidelines for Teachers

As integration into normal sport for the MD students is relatively new, you will need to discover their interest and work with them to make participation appealing and accepting. Praise and encouragement are essential in motivating them to be involved.
It is important to have an understanding of which muscle groups are more severely affected and which movements are possible. This allows you to concentrate on what they can do rather than on

what they cannot. Through this, their abilities will be strengthened and realistic goals will be obtained.

Do not underestimate what they can do.
Motivate the MD student to participate as much as possible. When the other students go for a jog around the oval or run a cross country event, encourage the MD student to drive around in his wheelchair with them.

Put some thought into how you can modify further sporting activities to allow even some types of participation of the MD student with the group. This is important because as his peers are expanding their experiences and skills in sport, he is progressively becoming limited in his movement and therefore experiences and skills.

The whole class can also be involved in setting the rules so the MD student can participate. In this way competition can still be maintained and the MD student will be accepted by his peers.
Muscular dystrophy progresses at different rates in each MD student therefore each child will have a different degree of muscle weakness. Using the pamphlet will give you an understanding of how to integrate them into a normal sport program, however it is by no means comprehensive. Sport programs must be planned on an individual basis according to the child's abilities and limitations.

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Cerebral Palsy

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