

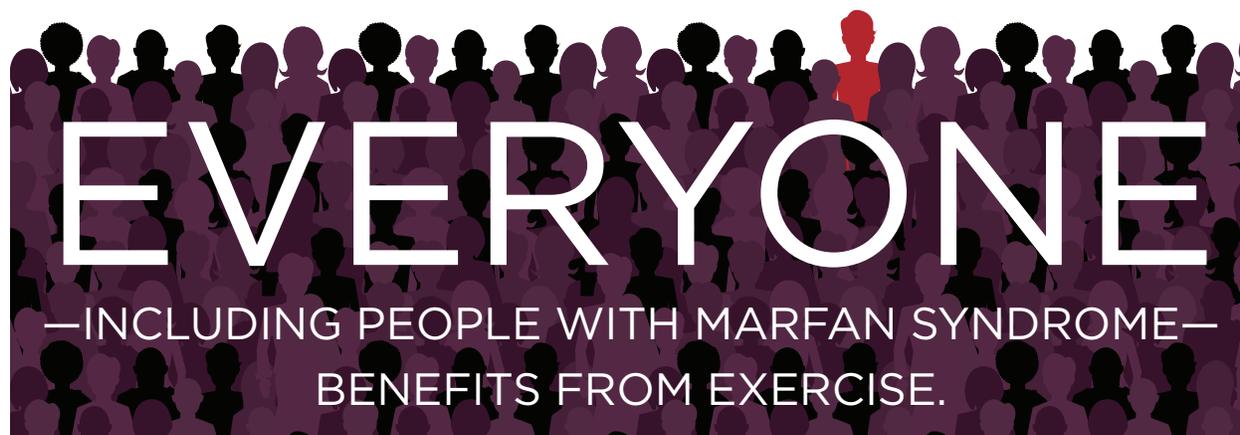


NOV 2017

# PHYSICAL **ACTIVITY**



# GUIDELINES



Regular exercise improves both physical and emotional well-being and can be incorporated safely into the routine of people with Marfan syndrome. Therefore, they are encouraged to adapt health measures that protect them from Marfan features that can worsen and from medical conditions that are simply part of the aging process. With an early diagnosis, treatment, and lifestyle adaptations, many people with Marfan syndrome can now expect to live a normal life span.

These guidelines are intended for those with Marfan syndrome and related disorders, however, individuals may have unique disease-specific manifestations that require additional consideration and restrictions. For example, those with Loeys Dietz syndrome may have cervical instability, which impacts guidelines on certain exercise and physical activity. Please consult with your physician about your individual case.

## **WHY DOES PHYSICAL ACTIVITY HAVE TO BE MODIFIED FOR PEOPLE WITH MARFAN SYNDROME ?**

Marfan syndrome is a disorder of connective tissue. Connective tissue holds all parts of the body together and helps control how the body grows. Because connective tissue is found throughout the body, Marfan syndrome features can occur in many different parts of the body, including the heart, blood vessels, bones, joints, and eyes. Sometimes, the lungs and skin are also affected.

Anyone with a health concern should learn about self care for their condition. An important part of self care is physical activity.

**Physical activity guidelines are important because they enable people to achieve the benefits of safe levels of exercise and, at the same time, ensure that they don't add to medical problems related to Marfan syndrome.**

Doctors recommend these guidelines for people with Marfan before they've had aortic surgery as well as after they've had aortic surgery. Recommendations are not exactly the same for all affected people, as there are differences in organ system involvement and the severity of involvement among people with Marfan syndrome.

# WHAT ARE THE DIFFERENT TYPES OF EXERCISE ?

Exercise can be classified by several characteristics. It is important to know how exercise is classified to best understand why certain activities are safe for people with Marfan, which are safe in moderation, and which should be avoided.

**1. Aerobic** activities are low intensity activities or exercises that can be performed for longer periods of time such as walking, long slow runs, swimming, or cycling. These exercises stimulate and strengthen the heart and lungs, thereby improving the body's utilization of oxygen. This type of exercise is, therefore, often termed cardio exercises. If you can carry on a conversation while you are performing these types of exercises, you are at an aerobic level.

**2. Anaerobic** activities are usually higher intensity and require short bursts of exercise usually less than two minutes each. This type of exercise usually involves muscle straining and can involve heavy weight lifting or sprinting. Anaerobic exercises are more stressful to tissues and the cardiovascular system. This type of exercise leads to a much greater level of excess post-exercise oxygen consumption than aerobic exercise and requires the body to do a lot of work to bring itself back to the normal state.

**3. Dynamic** (isokinetic or "moving") exercise is when a muscle contracts through much of its full range of motion, such as arm muscles when throwing a ball and leg muscles when running. With dynamic exercise, blood vessels dilate (enlarge) and there is a modest increase in blood pressure.

**4. Static** (isometric) exercise is when a muscle is contracting without moving, such as when you strain to lift a heavy weight or push a heavy piece of furniture. In general, an increase in blood pressure, which stresses the heart and aorta, is greater with isometric exercise than with dynamic (isokinetic) exercise. When a muscle group reaches fatigue and straining is required to continue exercise, there is an increase in blood pressure.

Most exercises and athletic activities involve a combination of dynamic and static muscle work and aerobic and anaerobic energy use. In general, exercise and physical activity that involves movement at a comfortable pace (during which a normal conversation can take place) is safe. **Exercise that leads to straining, grunting, and bearing down or to levels of exhaustion are to be avoided.**

# Metabolic Equivalent Task

The Metabolic Equivalent of Task (MET), or simply metabolic equivalent, is a physiological measure expressing the energy cost (or calories) of physical activities.

One MET is the energy equivalent expended by an individual while seated at rest. While exercising, the MET equivalent is the energy expended compared to rest; so MET values indicate the intensity.

An activity with a MET value of 5 means you are expending 5 times the energy (number of calories) than you would at rest. The higher the MET value, the more intense the exercise or activity, and in general, the higher the blood pressure (and aortic wall stress).

**In general, one with Marfan syndrome would want to keep the intensity of exercise and physical activity in the low to moderate METs range (<6 METs)**

The following table lists MET values for common physical and recreational activities based on intensity.

<b>LIGHT</b> <3.0 METs	<b>MODERATE</b> 3.0–6.0 METs	<b>VIGOROUS</b> >6.0 METs
Walking (leisurely) Sitting (desk work) Light housework (dishes, sweeping) Fishing Playing a musical instrument Gardening (light) Golf (with cart) Boating Bowling 	Walking (briskly—4 mph) Heavy cleaning (mopping, vacuuming) Mowing lawn (using power mower) Bicycling (leisurely pace—10-12 mph) Dancing (leisurely pace—ballroom) Badminton (leisurely) Golf (pull cart, walking) Doubles tennis (leisurely) Yoga Pilates Water aerobics (leisurely) Swimming (recreational, light) Calisthenics (light, without weights) Hunting Raking lawn	Hiking (moderately up steep grade) Jogging moderately (6 mph) Shoveling Farming (baling hay) Singles tennis Basketball Soccer Bicycling at a fast pace (14-16 mph) Swimming (fast) 

Source: <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5009a3.htm>

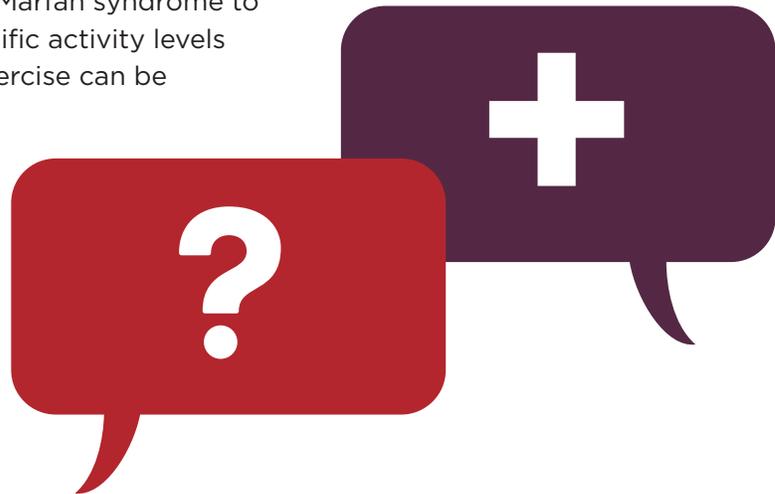
The proportion of work and energy is determined by the nature of the activity, how strenuously a person is participating, and, in team sports, even the position being played. Sports are classified based on the risk of collision (contact) and how strenuous they are.

## WHAT SHOULD YOU KNOW ABOUT PHYSICAL ACTIVITY IF YOU HAVE MARFAN SYNDROME ?

In general, most people living with Marfan syndrome should exercise regularly through low-intensity (aerobic), low-impact activities adapted to meet their specific needs.

Nearly every activity can be done at different intensity levels, and no recommendation holds true in all circumstances. For example, shooting baskets in the driveway is different from playing a full-court basketball game and bicycling ten miles in one hour on a level course is different from competing in a triathlon.

It is essential for each person with Marfan syndrome to discuss physical activities and specific activity levels with his or her physician so that exercise can be incorporated safely into the regular healthcare routine. This should be an ongoing conversation with your doctor as you age because your medical status can change.



## WHAT DOCTORS WORRY ABOUT

Competitive and contact sports can put people with Marfan syndrome at increased risk of injury. Doctors worry about:

- Increased heart rate, increased blood pressure, and bearing down because they can put **added stress on the aorta**.
- Head impact that can damage the eyes directly or indirectly, through deceleration or acceleration, because this may lead to **worsening lens dislocation or a retinal detachment**.
- Extensive stress on the bones and joints, which can lead to **added pain and dislocations**.
- **Bruising and internal hemorrhaging** due to certain medications (i.e., anticoagulants).

## WHAT ARE SOME GUIDELINES AND MODIFICATIONS THAT PERMIT SAFER EXERCISE FOR PEOPLE WITH MARFAN SYNDROME ?

There are several guiding principles to consider when deciding whether or not a sport or activity is safe for you.

### GUIDELINES FOR SAFE EXERCISE

- **Favor non-competitive activity performed at a non-strenuous aerobic pace.** Sports in which you are free to rest whenever you feel tired and in which there is a minimal chance of sudden stops, rapid changes in direction, or contact with other players, equipment, or the ground are especially well-suited for people with Marfan. These include brisk walking, leisurely bicycling, slow jogging, shooting baskets, leisurely tennis or swimming, and use of light weights without straining.
- **Choose an activity you enjoy that you can perform 4–5 times per week for 30 minutes at a time.** If time is a major constraint, three 10-minute sessions are nearly as effective as one 30-minute session.
- **Stay at an aerobic level of work (about 50% of capacity).** One rule of thumb is that, if you can talk in a conversational tone of voice during the activity, you are likely to be exercising at a reasonable level. If you are on a beta-blocker, try to keep your pulse under 100 beats per minute, or try to keep the heart rate from increasing more than 30% from baseline. (It is often easier to feel the pulse over arteries in the neck than at the wrist.) Take your time and choose your activities wisely. With everyday activities, ask for help, make several trips carrying parcels rather than carrying everything at once, use your legs rather than your back to lift, exhale when lifting, and refrain from heavy straining.
- **Make sure you wear protective gear.** For example, high-quality helmets should always be worn while bicycling. Correctly sized and appropriate protective eye wear should be utilized in certain circumstances to help protect against dislocation of lenses and retinal detachment.
- **Consider traditional yoga (hatha) for relaxation and mental/emotional stress reduction.** Yoga can also improve muscle strength and balance. Individuals with Marfan syndrome should avoid hot studios (e.g., vinyasa), strenuous forms of yoga (e.g., ashtanga), headstands, and shoulderstands. Physicians should be notified and instructors should be informed about underlying heart disease(s) prior to participation.
- **Do not test your limits.** This is particularly difficult for children during physical fitness tests in school and for people who once were competitive athletes. Be sure your child with Marfan syndrome has a physical education program in place that is adapted to minimize his/her health risks.

## ACTIVITIES TO AVOID

In general, avoid activities that can be considered competitive or can cause collision or contact (the three C's).

### AVOID:

- Intense isometric exercises leading to muscle fatigue or straining. An isometric exercise is when a muscle is contracting without moving, such as when you strain to lift a heavy weight, do pull ups, or climb steep inclines. During this type of strenuous exercise, you tend to hold your breath while pushing to complete the movement. These exercises lead to an increase in blood pressure which causes unwanted strain on the heart and blood vessels.
- Contact sports that have a high potential for a blow to the head because of the risk of injuring the eyes.
- Activities that risk rapid changes in atmospheric pressure, such as scuba diving and flying in unpressurized aircraft. People with Marfan syndrome are prone to the collapse of a lung in these situations.
- Exercise to the point of exhaustion where you are not able to catch your breath and unable to speak.



# C C C

Competitive  
Collision  
Contact

## WHAT IF MARFAN SYNDROME IS SUSPECTED ?

Sometimes Marfan syndrome is suspected, but has not been firmly diagnosed. In other cases, a diagnosis of Marfan syndrome has been made, but the individual currently doesn't have aortic enlargement. In these instances, determining whether or not to follow the physical activity guidelines is particularly confusing.

Doctors take several factors into account when offering recommendations about safe activities. These include: how strongly a diagnosis is suspected; whether or not there is family history of Marfan syndrome or a family history of early cardiac death; the age of the person; and the level and intensity of activity planned. The individual's particular eye, skeletal, heart, aortic, and lung condition are important to consider when deciding on safe levels of physical activity.

It is best to speak with your cardiologist (heart doctor), medical geneticist, or specific medical specialist to determine what is considered safe for you.

## WHAT ARE THE CLASSIFICATIONS OF SPORTS AND ACTIVITIES ?

Sports are classified based on the risk of contact and how strenuous they are. Note that many sports can fall within several categories, depending on the intensity of participation. In general, participation in recreational sports and exercise as a young child does not involve the same level of stress on the aorta as the stress experienced during training or competition for the high school, collegiate, or professional athlete. However, the specific health status of the individual at any age is important to consider when providing recommendations about physical activity. **The general guidelines for people with Marfan syndrome are to avoid competitive and contact sports and enjoy recreational non-competitive sports and exercise.**

The following table of competitive athletics or sports is modified from a classification devised by the American Academy of Pediatrics. Activities that have a high risk of contact and are considered very strenuous are generally not advised or strongly discouraged and are noted in red. Activities that pose an intermediate risk and should be assessed clinically on an individual basis are noted in orange. Activities that pose a low level of risk and generally accepted are noted in green.

<b>CONTACT/ COLLISION HIGH POTENTIAL: STRENUOUS</b>	Basketball Boxing Field hockey Football Ice hockey Lacrosse	Martial arts Rodeo Skiing (water) Soccer Wrestling
<b>CONTACT LIMITED: STRENUOUS</b>	Baseball Bicycling (intense) Gymnastics Horseback riding Skating (ice & roller)	Skiing (downhill & cross-country) Softball Squash Volleyball
<b>NONCONTACT: STRENUOUS</b>	Aerobic dancing (high impact) Crew	Running (fast) Weightlifting
<b>NONCONTACT: MODERATELY STRENUOUS</b>	Aerobic dancing (low impact) Badminton Bicycling (leisurely) Jogging	Swimming (leisurely) Table tennis Tennis Hiking
<b>NONCONTACT: NON-STRENUOUS</b>	Golf Bowling	Walking

To maximize the safety of low intensity, non-contact activities, it is important to take necessary precautions—for example, use a golf cart or a cart on wheels when golfing and use a light ball when bowling.

It is essential to talk to your doctor about the sports and activities that are safe for you and how to monitor your exertion level so that exercise remains safe throughout your involvement.

## **HOW DOES YOUR MEDICATION IMPACT YOUR PHYSICAL ACTIVITY ?**

Before beginning or increasing any exercise program, it is important for your doctor to assess your current level of physical fitness, your health, and your medications. The advice offered here is general and is not meant to substitute for the recommendations of your personal physician.

Many people with Marfan syndrome take a beta-blocker medication to reduce stress on the aorta. This medication lowers the pulse at rest and during exercise, and makes it somewhat more difficult to achieve a given level of physical fitness for the amount of physical work performed.

**Taking these medications, however, does not allow a person with Marfan syndrome or other aortic aneurysm syndrome to perform very strenuous exercises or play contact sports.**

Some patients with Marfan syndrome take medications called angiotensin receptor blockers (such as losartan) or angiotensin converting enzyme (ACE) inhibitors.

**These medications do not protect the aorta from strenuous exercise.**

People who have artificial heart valves usually take an anticoagulant medication, warfarin (Coumadin®). This medication interferes with blood clotting and increases the chances of bruising and internal hemorrhages.

**People taking this medication should avoid contact sports and any activity with a moderate risk of a blow to the head or abdomen which could lead to internal bleeding.**



## **HOW CAN PARENTS GUIDE A CHILD TO SAFE PHYSICAL ACTIVITY AND EXERCISE ?**

Adults who are newly diagnosed are usually able to reconcile the need to modify their exercise; however, modifying activity is a greater concern to parents who have a child who is newly diagnosed.

Sports are a big part of childhood in many families. Being part of a team helps develop social skills and self-esteem. It is understandably frustrating or upsetting to children who suddenly have physical activity restrictions (and for their parents), particularly if the child already has a passion or talent for a particular sport.

The general guidelines for people with Marfan syndrome are to avoid competitive and contact sports that would put added stress on the aorta, cause chest or eye trauma, or be potentially damaging to loose ligaments and joints. However, there are also concerns that go beyond the potential physical dangers.

Consider youth soccer, which is not an intensely competitive sport; it's more recreational and is not regarded as dangerous for children with Marfan syndrome because aortic dissection in a young child with Marfan syndrome is very rare. However, youth soccer, basketball or volleyball may progress to more competitive levels in middle school and beyond. Asking a child to give up a sport after he or she has been involved for many years impacts their social circle and their self-esteem, and removes from their life an activity for which they have developed a passion and skill.

When children are diagnosed at a very young age, parents are encouraged to provide guidance for activities that are appropriate for the long-term. Golf, bowling, archery, piano, art, and music are just a few alternatives that can provide an outlet for creativity and competition while still providing the interaction and socialization a child needs.

A diagnosis of Marfan syndrome made when someone is on an athletic scholarship in college can be particularly devastating and life-changing given the new physical activity guidelines. Yet, the alternative can be deadly.

If you or your child is having difficulty adjusting to the restrictions or becomes depressed about necessary lifestyle changes, speaking with a therapist may be helpful. You can also talk to others in the same situation as you through our in-person and online support groups, mentor program, annual conference, regional events, and local community group gatherings.

## DO YOU HAVE QUESTIONS? WOULD YOU LIKE MORE INFORMATION?

- Contact our Help & Resource Center: 800-862-7326, ext. 126, or [support@marfan.org](mailto:support@marfan.org). Our on-staff nurse can answer your questions and send additional information.
- Visit [marfan.org](http://marfan.org). You can print information that interests you and ask questions online.
- Talk with your doctor. Sometimes it helps to take our information with you when you speak with your doctor.

