



Dr. Shabib Alhadheri, MD

Advanced Pediatric Cardiology

Compassionate Care.
Advanced Expertise.
Stronger Hearts.
Brighter Futures.

MARFAN SYNDROME

Management & Activity Limitations/Restrictions

Marfan Syndrome is a genetic connective tissue disorder that affects the heart, eyes, skeleton, and blood vessels. Early diagnosis, regular monitoring, and appropriate management help prevent complications and support a healthy, active life.



SYSTEMS COMMONLY AFFECTED



CARDIOVASCULAR

- Aortic root dilation
- Aortic aneurysm/dissection
- Mitral valve prolapse



MUSCULOSKELETAL

- Tall stature, long fingers
- Scoliosis & chest deformities
- Joint hypermobility



EYES

- Lens dislocation
- Myopia
- Retinal complications

GOALS OF MANAGEMENT

- ✓ Protect the aorta and prevent dissection
- ✓ Monitor and manage disease progression
- ✓ Support eye and skeletal health
- ✓ Promote safe physical activity
- ✓ Improve quality of life and longevity

CARDIOVASCULAR MANAGEMENT

1 REGULAR CARDIOLOGY FOLLOW-UP

- Echocardiogram every 6–12 months
- Cardiac MRI/CT as needed
- Monitor aortic size, valves & heart function

2 MEDICATIONS TO PROTECT THE AORTA

- Beta-Blockers (Atenolol, Metoprolol, Propranolol)
Reduce heart rate and aortic wall stress
- ARBs (Losartan, Irbesartan)
May slow aortic enlargement
Often used with beta-blockers

3 SURGICAL MANAGEMENT

- Considered when aortic root is significantly dilated or enlarging
- Procedures include valve-sparing or composite graft replacement
- Early surgery saves lives

4 LIFESTYLE & PREVENTIVE CARE

- Control blood pressure
- Avoid smoking/vaping
- Maintain healthy weight
- Stay hydrated & well-rested
- Seek care for sudden chest/back pain, shortness of breath, fainting, or stroke symptoms



EYE CARE

Regular eye exams to detect:

- Lens dislocation
- Retinal detachment
- Glaucoma & cataracts

Treatment may include glasses, contact lenses, or surgery.



MUSCULOSKELETAL CARE

Monitor for scoliosis, chest wall deformities, joint instability & flat feet.

Treatment options include physical therapy, bracing, and orthopedic care.

ACTIVITY RECOMMENDATIONS



ACTIVITIES ENCOURAGED

Safe, low-to-moderate dynamic activities:

- ✓ Walking & hiking
- ✓ Recreational biking
- ✓ Leisure swimming
- ✓ Golf & bowling
- ✓ Light aerobic exercise
- ✓ Yoga (avoid extreme straining)
- ✓ Light resistance training with low weights

Promotes fitness, heart health, and emotional well-being.



ACTIVITIES TO AVOID

HIGH-INTENSITY & CONTACT SPORTS

- ✗ Football
- ✗ Basketball
- ✗ Soccer
- ✗ Hockey
- ✗ Wrestling
- ✗ Competitive track
- ✗ Gymnastics
- ✗ Martial arts

HEAVY ISOMETRIC ACTIVITIES

- ✗ Heavy weightlifting
- ✗ Powerlifting
- ✗ Maximal resistance training
- ✗ Straining / Valsalva maneuvers

HIGH-RISK EXTREME ACTIVITIES

- Scuba diving
- Skydiving
- Rock climbing
- High-intensity interval training
- Contact sports



These activities can cause dangerous blood pressure spikes and increase risk of aortic dissection.



ACTIVITY DECISIONS DEPEND ON

- ✓ Aortic root size (Z-score in children)
- ✓ Rate of enlargement
- ✓ Valve disease severity
- ✓ Heart function
- ✓ History of dissection or surgery
- ✓ Arrhythmias
- ✓ Symptoms



Participation in sports and exercise should be individualized by a pediatric/congenital cardiologist familiar with connective tissue disorders.



SCHOOL & CHILD CONSIDERATIONS

- Modified physical education
- Self-paced aerobic activity
- Avoid maximal exertion & dehydration
- Coaches and staff should be aware of emergency symptoms and restrictions



PREGNANCY CONSIDERATIONS

Pregnancy increases stress on the aorta. Requires high-risk obstetric care, cardiology monitoring, and imaging surveillance—especially with significant aortic dilation.



LONG-TERM OUTLOOK

With early diagnosis, regular monitoring, medical therapy, and timely intervention, most individuals with Marfan Syndrome can live long, active, and fulfilling lives.



KEY TAKEAWAY

Protect the aorta. Stay informed. Follow your care plan. Choose safe activities. Act early when symptoms appear.

Your heart. Our priority. Their future.