

Exercise & Physical ACTIVITY

With the right guidance, children and adults living with **Marfan syndrome**, **Loeys-Dietz syndrome (LDS)**, or **Vascular Ehlers-Danlos syndrome (VEDS)** can — and should — safely include movement and exercise in their daily lives.

Shared Decision-Making

Because recommendations are individualized, shared decision-making is the foundation of safe activity planning. Shared decision-making means you and your healthcare team work together to:

- Review your health status, limitations, and goals
- Understand which activities are likely safe for your condition
- Create a plan that balances safety with enjoyment and independence
- Revisit and update the plan as your health and life change

KEY TAKEAWAYS

For Children

- ▶ Most children with these conditions can and should be physically active.
- ▶ Activities should match age, growth, and medical needs.
- ▶ Encouraging movement early builds healthy habits for life.
- ▶ Shared decision-making helps balance safety and enjoyment.

For Adults

- ▶ Physical activity is important and encouraged for most adults.
- ▶ Moderate activity at a comfortable pace is often safest.
- ▶ Exercise choices should be individualized.
- ▶ Shared decisions balance safety, independence, and enjoyment.

When a Diagnosis Is Suspected but Not Confirmed

Shared decision-making is especially important in these situations. Your team will consider: strength of suspicion, family history, age, aortic measurements, physical findings (eye, skeletal, heart, lung, joints), and type and intensity of activity. Together, you can balance caution with quality of life while monitoring continues.



High-Risk Activities

Some activities involve heavy strain, rapid pressure changes, or higher risk of injury and may require extra caution. These include:

- Powerlifting
- High-impact contact sports (e.g., tackle football)
- Scuba diving
- Flying in an unpressurized aircraft

For many adults, these activities may place extra stress on the aorta, blood vessels, or lungs and should be avoided.

Marfan Syndrome

- ▶ Focus on controlled breathing and steady, mid-range strengthening movements.
- ▶ Avoid extreme joint stretching or pushing joints to their limits.
- ▶ Check with your care team for temporary restrictions after eye surgery.
- ▶ If you have or had a hernia, avoid activities with heavy abdominal strain.

ACTIVITY TIPS

Loeys-Dietz Syndrome

- ▶ Guidance is similar to Marfan syndrome; aneurysms in smaller arteries may require extra imaging.
- ▶ Use a physical therapist to find safe activity options for joint or back pain.
- ▶ Modify movements as needed for cervical spine instability.
- ▶ Aneurysms or dissections in the head, neck, abdomen, or pelvis may require activity adjustments.

Vascular Ehlers-Danlos Syndrome

- ▶ Guidance is similar to Marfan syndrome; fragile tissues and vessels may require extra caution.
- ▶ Risk of bruising, bleeding, or tendon injury may favor lower-impact activities.
- ▶ Arteries in the head, neck, abdomen, and pelvis may be monitored with extra imaging.
- ▶ Aneurysms or dissections may require modifying some activities.



College & Elite Athletes

A diagnosis during high-level competition — especially with a scholarship — is deeply challenging. Decisions about continued participation should involve the athlete, their institution, and appropriate specialists (sports cardiologist, aortopathy expert, and/or medical geneticist), weighing the specific condition, aortic size and growth rate, and the sport's type and intensity.

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