

Marfan Syndrome:

How to Care for Cardiovascular Problems

Cardiovascular (heart and blood vessel) problems are common in people with Marfan syndrome. In fact, cardiovascular problems affect about 9 out of every 10 people diagnosed with Marfan syndrome. It is important that people with Marfan syndrome know about cardiovascular problems and ways to prevent or manage them. This sheet has facts you need to know.

MEDICATIONS

Medications (drugs) can help treat many types of cardiovascular problems. Medications include:

- **Beta-blockers.** These help lower blood pressure and reduce the force of heartbeats. These medications may help prevent or slow down aortic dilation (enlarged aorta) and can reduce the risk of aortic dissection (tears between layers of the aorta). For many people with Marfan syndrome, beta-blockers are a first choice medication.
- **Calcium-blockers** (such as verapamil). These help lower blood pressure and make heartbeats less forceful. This medication is often used by people who have depression, asthma, or severe side effects from beta-blockers.
- **Angiotensin receptor blockers** (ARB's). Recent research has shown that one ARB drug, Losartan, can prevent aortic growth in special Marfan mice. A clinical trial is now underway to compare this medication to beta-blockers in people who have Marfan syndrome.

TESTS TO MONITOR CARDIOVASCULAR PROBLEMS

People with Marfan syndrome must have tests to monitor (watch for) cardiovascular problems. These help find problems before there is an emergency. Here are some tests doctors often use:

- **Echocardiogram.** This shows all the heart structures including blood valves and the part of the aorta closest to the heart.
- **MRI or CT scans.** These show all segments of the aorta.
- **TEE.** This is a special type of echocardiography that shows the ascending and descending thoracic aorta in addition to the heart valves.

SURGERY

Most people with Marfan syndrome who have heart problems are helped by “planned surgery.” This means having surgery before there is an aortic dissection or other life-threatening problem. After surgery, people must take blood pressure medication and will need tests (such as CT or MRI scans) at least once a year. Some people need more surgery later on. Here are some common types of surgery for people with Marfan syndrome:

- **Repair of the ascending aorta.** This is done when the aorta reaches a certain size. Doctors know this by looking at: the size of the aorta; rate of aortic growth; whether the valve is leaking; and family history (if other family members have had aortic dissection). While surgery has risks and benefits, studies show that this type can be very helpful when done by doctors experienced in treating people with Marfan syndrome.

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- **Repair of the descending thoracic or abdominal aorta.** This surgery is done when there is a sudden or large change in the size of the descending thoracic or abdominal aorta or if these parts of the aorta reach a very large size. As with the other types of surgery, it has both risks and benefits and should be done by doctors experienced in treating people with Marfan syndrome.
- **Aortic or mitral valve repair or replacement.** Aortic valve surgery is often done along with surgery to repair the ascending aorta. A person needs mitral valve surgery if the mitral valve leaks so much that the heart must pump extra hard. People whose heart valves are replaced with a mechanical valve must take blood thinners for the rest of their lives. They also will need to take antibiotics before any dental work.

WHAT YOU CAN DO

Here are some ways to help:

- **Have an echocardiogram (echo) or other heart study at least once a year.** Your doctor may want you to have more frequent echos (every three to six months) to make sure your aorta is growing very little or not at all.
- **Do not put extra stress on your aorta.** You should only do gentle exercise such as going for a walk instead of a jog or riding your bicycle slowly, not fast. Do not play basketball, football, soccer, or other competitive sports. Make sure that your job does not require any heavy lifting.
- **Learn about cardiovascular problems and ways to treat them.** People with Marfan syndrome often need to teach others about this condition. You can help by talking with family members and your health care team about cardiovascular problems that may affect you.
- **Talk with the healthcare team if your child has Marfan syndrome.** Sometimes doctors suggest medication for very young children.
- **Let your doctor know if you are, or plan to be, pregnant.** There are special risks and treatments for pregnant women who have Marfan syndrome. (To learn more, read “Obstetric Concerns Brochure” available at www.marfan.org or from the NMF Information and Resource Center at 1-800-8MARFAN ext 26).

WAYS TO LEARN MORE

- Contact the Marfan Syndrome Support Group Ireland at info@marfan.ie.
- Talk to your doctor. Sometimes it helps to use information like this fact sheet when you speak with the doctor.
- Visit the Marfan Syndrome Support Group website at www.marfan.ie.