

TEENS AND MARFAN SYNDROME

If you were recently diagnosed with Marfan syndrome or if you have known about it for years, there are probably hundreds of thoughts, questions, and concerns rushing through your head. On one hand, there is a whole new world of medical information to learn. On the other hand, there is your life as a teen.

Having Marfan syndrome is just a part of who you are. It does not have to define you.



We have so many resources to help you through this journey. Our website has comprehensive medical information, including Teen Space, which addresses teen questions and highlights inspirational teens in our community.

This resource answers common teen questions head-on so you don't have to wonder. If you have other questions, please know that the Marfan community is here for you. There is always someone to talk to who has gone through the same thing, has had similar emotions, and has overcome the same challenges.

We hope that, like many people, you will come to realize that having Marfan syndrome is just a part of who you are. It does not have to define you. This realization can help you live a full life, despite any medical challenges that come your way.

Finally, we can't emphasize enough how important it is to take the time to learn what you can. Ask questions and talk to others who are also living with Marfan syndrome or a related disorder. You are not alone. You can live a bright future, regardless of your diagnosis.

We invite you to become an active part of the Marfan syndrome and related disorders community so that you can become empowered to take control of your life and give back to others.

Marfan syndrome and your family

Your diagnosis affects your entire family, whether or not you are the only one who actually has the condition. Each family member reacts differently to how you are doing and your ongoing issues. Here are some of the emotions that arise in families.

- Some teens are angry at the parent from whom they inherited Marfan syndrome. Or, if they are the only one in their family with the condition, they are angry because they mistakenly think that their parents did something to cause the disorder.
- Some teens are jealous of brothers or sisters who do not have the same diagnosis.
- Unaffected kids in the family may be jealous of the sibling with the diagnosis because that person gets extra attention.
- Some teens are upset by parents who share medical information with relatives and friends without first asking permission.
- Some teens are angry because their parents are overprotective or constantly remind them to take medications or limit physical activity.
- Some teens are upset because their parents want to protect them from in-depth understanding of their condition.
- Parents may be upset about the diagnosis and have difficulty talking about, and coping with, the condition.

If you recognize any of these emotions in your family, be assured that they are completely normal. Often the best way to overcome the resulting family stress is to be open with your parents and siblings.

Try to address feelings and emotions when the family is calm so there can be an open discussion. Some families are better at this than others. When parents can't calmly listen, perhaps an aunt, uncle, grandparent, minister or rabbi, doctor, or guidance counselor can help. Sometimes it seems easier to just keep feelings inside, but talking about feelings usually makes them more manageable.

“Marfan syndrome brings with it the entire gamut of emotions, from tranquility to pain to anger to depression and back again. Marfan syndrome can cause any emotion at any time. Having a support team of family and friends is vital for those times when personal perspective is not enough.”

- Matt

Telling your friends about your diagnosis

You are not your diagnosis, but it is a part of you and may influence your perspective and your activities. Just as you would tell your friends if you were a vegetarian or a country music lover, it's a good idea to tell your close friends about this other part of your life. It is nothing to be ashamed of and it doesn't define you; it's just something that you have to deal with, like other teens who have diabetes or gluten allergies. The more your friends understand your diagnosis, the better support system they can be for you. And since you likely spend a great deal of time with your friends, it is good for them to know what constitutes a medical emergency so that they can call for help immediately if a situation arises.

This doesn't mean that you need to tell your friends the nitty gritty details of Marfan syndrome or the related disorder that you have. Start with the basics and follow their lead. If they ask questions, be prepared to tell them more. Realize that some of your friends may be scared about what could happen to you and may not be able to verbalize questions or even an appropriate response. Assure them that you and your family are on top of your medical needs and that you are doing everything possible to prevent complications and enjoy a long, productive life.

Talking to doctors

As a teen, you may be in a transition period between your parents taking care of your health needs and taking care of them yourself. This transition may be hard for you, as well as for your parents. You won't be under your parents' guidance forever, so it's important to build a cooperative relationship with your doctors and get comfortable talking to them and asking questions.

If your parents insist that they take the lead in your medical care, understand that they are coming from a place of love. In a mature, calm way, explain your desire to play an increasing role in your own healthcare as a step towards your independence. Be open to compromise while you slowly take the lead with your doctors.

One way to maturely assert your independence is to ask your parents for one-on-one time with your doctors. This enables you to start a new type of relationship with your doctors, in which they begin to see you (and treat you) as an adult. Show responsibility by writing down your questions before your appointment. Make sure that you understand the answers your doctors provide (and write them down). If you don't, then ask for clarification. You have a right to understand your medical condition, the medical approach, and what treatment is recommended. Only through understanding can you be your own best advocate.

“When you find out you have Marfan syndrome, it's very easy to feel sorry for yourself and be scared for the future. I suggest approaching the disorder head on. Find out as much as you can about what it is and how it can be treated. Find out your physical limitations and what you can still do without risking bodily harm.”

- Aaron

Appearance

Are you upset because you don't have a perfect body? You're not alone. Everyone—teens and adults—has at least a few things about their appearance they wish they could change, whether or not they have Marfan syndrome or a related condition.

Certain features, such as an indented chest, can be corrected through surgery. Crowded teeth can be corrected with orthodontics. You may be able to get contact lenses to replace your thick glasses. Talk to your doctor about your options and whether or not the benefits of having surgery to improve your appearance outweigh the health risks.

Some physical aspects of Marfan syndrome and related disorders are not easily changed or disguised. Stretch marks on the skin are one of the features that may upset you, but they cannot be removed or prevented. Fortunately, they do not cause medical problems or pain, and they tend to fade over time.

If you are tall and thin, like so many other teens with Marfan syndrome and related disorders, there might not be much you can do about it. Doctors do not understand why people with Marfan syndrome have so much difficulty gaining weight. There is no special diet, dietary supplement, or exercise program that adds desired pounds or muscles.

Standing out because of your height and weight is uncomfortable, but it can be more troublesome when people think you have an eating disorder. There is a lot of awareness about eating disorders and not so much awareness of Marfan and related disorders. This is an opportunity to educate the people around you about your condition, and it benefits you in the long run.

“Don’t panic! It’s not as bad as you think! It’s kind of reassuring to know there’s a reason why you can’t build muscle or why your skeleton is weird or why you are so tall.”

- Clare

Tattoos and body piercing

Are you thinking about a tattoo or body piercing? If you have Marfan syndrome or a related condition, this might not be a good idea because of the risk of infection. When bacteria enter your bloodstream, it can cause an infection of your heart valves, which is extremely difficult to treat. In fact, it could require long-term antibiotic treatment and even heart surgery. If you are thinking about a tattoo or body piercing, talk to your doctor about your specific medical situation. And if you move forward with it, make sure to find a reputable practitioner who uses only sterile supplies and equipment.

Physical activities

If you have Marfan syndrome or one of the related disorders, it is important to change your activity level and the kinds of activities you participate in. This is important to protect your heart and blood vessels, as well as your eyes, bones, and joints. If you were physically active before you were diagnosed, this can be a major change in your life. Understanding the reasons for the physical activity limitations can help you accept them and find new ways to be active.

In general, you should avoid competitive sports to eliminate situations that are very intense and drive up your blood pressure and heart rate. You should also avoid contact sports because the inevitable collisions can damage your eyes, bone, and joints.

The good news is that you can—and should—be active. For example, you can ride a bike leisurely, but avoid racing. Competitive basketball can place a lot of stress on your heart and blood vessels, but shooting hoops in your driveway or in a gym is fine because it is low intensity. A good way to measure intensity is to check your heart rate and keep it below 100 beats a minute during prolonged activity. You should also be able to carry on a conversation while you are exercising without the need to take a breath in the middle of a short sentence.

Finding safe physical activity applies to job-related physical activity, as well as recreation. It may be challenging to find activities that are both safe and satisfying, but it is also an opportunity to investigate new areas of work and recreation that you might not have considered otherwise.

Sexual activity is like other physical activity in that it can raise the heart rate. Therefore, similar precautions regarding intensity and duration should be followed. If you are worried about the effect of sexual activity on your heart, talk with your doctor about your specific situation.

Remember, the guidelines here are very general. It is critical that you talk to your doctor about your activities to ensure they are safe for you.

School issues

Middle school and high school present challenges for all teens, whether or not they have a medical condition. But it is true that you may have added stress at school because of your diagnosis. Some of the issues that may arise are:

- School officials may be worried about what to do in case of a medical emergency.
- Physical education teachers may not be sure of activity modifications you need and won't change their curriculum to accommodate you.
- Your parents may need to work with your school to obtain any disability accommodations you need (which are required by law).
- You may need to work closely with your teachers to stay on top of school work you miss due to medical absences.
- You may face bullying and negative attitudes from your peers and need help from your parents or a school administrator to confront the other student(s) and cope.

The ability of schools to deal effectively with the special needs of their students varies from school district to school district. Just as in families, some are better at dealing with issues than others.

A good place to start with your school is by providing them with information about your diagnosis to share with the school nurse and teachers. Resources for both are available at Marfan.org. When they understand your condition and how you are affected, they are best able to help you and advocate for you.

“For a long time I felt like Marfan syndrome was a burden, a hindrance that held me back, that made me stand out when I didn't want to. I came to realize that I had it completely backwards. I am different. Being different implies individuality. With Marfan syndrome came a sharp mind, determination, motivation to succeed, and, most of all, a different perspective.”

- Matt

In gym class

It is important for people with Marfan syndrome to have physical activity; therefore, finding safe ways to participate in gym class is better than not participating at all. Ask the gym teacher for a list of the activities planned for the semester. Show the list to your doctor who can indicate which activities to avoid or do at a slower pace. Learn how to check your heart rate during gym activities and keep it below 100 beats per minute. With some creative planning and flexibility by your gym teacher, you can participate in gym class. We have a resource on our website with physical education guidelines which you can download and share with your gym teacher.

In academic classes

Marfan syndrome does not affect intelligence, but you might need accommodations due to physical problems to help you reach your academic potential. You and your parents can learn about the federal laws that schools must follow to help students with special needs or disabilities. The special needs can be related to health problems or to learning. It takes extra effort for schools to make what the law calls “reasonable accommodation” for students. Families who know the law and their rights can better advocate for needed services.

Some minor adjustments in school that teens with Marfan find helpful are:

- Sitting near the front of the room to make up for low vision.
- Arranging for a second set of school books to be kept at home so you don’t have to carry them back and forth.
- Having access to the nurse’s office during the day in case of extra fatigue due to medications.

If you are facing surgery, let the school know in advance so your teachers can help you plan how and when you are going to get your work done. If you have an unplanned medical absence that is more than a day or two, let your teachers know as soon as possible what is going on so they can help you meet your academic requirements.

Bullying issues

You may look different from your peers if you have Marfan syndrome because it changes your features. If you are teased or bullied, alert your school administrators. Teasing often comes from ignorance; therefore, it might be to your benefit to educate the other students about your condition. Talk to your teacher or guidance counselor to find out if they can help you set up a classroom presentation. By taking charge, you can empower yourself and your peers won’t see your differences as a weakness, but rather as a strength.

Thinking about the future

Wondering about your future? So is every teen, whether or not they have Marfan syndrome. Where will I go to college? What kind of a job will I get? What kind of career should I pursue? Thinking ahead and planning, based on your strengths and weaknesses, is the best formula for success.

Career plans

What do you enjoy? The arts? Business? Writing? Computers? There are plenty of avenues for success within these fields, and so many more. But there are things that you can’t (or shouldn’t) do, such as a job that requires heavy exertion or lifting, such as construction work. In addition, training for the military, police, or fire department is too strenuous, as are professional sports.

Many teens in our community make their college choice based on access to doctors experienced with Marfan syndrome. If this is important to you and your family, it can certainly be accomplished as there are Marfan specialists in many parts of the country.

Having children

If becoming a parent is important to you, there is no reason not to have children. However, there are important considerations that you and your partner should discuss together and with a genetic counselor before you become pregnant or choose another option, such as adoption.

When one parent has Marfan syndrome, each child born to the couple has a 50 percent chance of inheriting it. This is true regardless of the gender of the affected parent or the child. And it is important to remember that the child may be affected in different ways than the parent, and the features may be milder or more severe. Only you and your partner can decide if this is acceptable to you. Talking to a geneticist or genetic counselor can help you understand the care a child with Marfan needs at birth and when they get older. They can also explain how prenatal diagnosis may help with the decision to have children.

“Marfan syndrome may put up walls and block off roads, but life is so full of opportunities that we have to find the open highways.”

- Micah

Building a support network

The Marfan syndrome and related disorders community is a very special group of people. It includes people of all ages available to answer questions, address concerns, and provide support. If you need to have surgery, there is a good chance you can find someone who has had the same operation. You never have to go through something alone; that is what being part of a community means. Maybe you have a question you want to ask or want to share your own stories with others. You can benefit from others' experiences and people everywhere can benefit from yours.

To get connected to the Marfan syndrome community, you can come to our Annual Family Conference (it includes a special teen program), participate in online discussions, ask us for the name of another teen to email, or join one of our local groups (if there is one in your area).

“Reach out to the Marfan and related disorders community because meeting and speaking with other kids who are in a similar situation makes a huge difference. You will realize that you are not so different. It helps to have people to talk to who can really identify with what you are going through.”

- Micah

Do you have questions? Would you like more information?

- Call our help center, 800-862-7326, ext. 126 to speak with a nurse who can answer your questions and send you additional information.
- Visit our website at marfan.org. You can print information that interests you, ask questions online, and find local support.