



Skeletal Features:

How Marfan Syndrome Affects Bones and Joints

Marfan syndrome often causes problems in people's bones and joints. These problems are referred to as "skeletal features." These happen when bones grow extra long or ligaments (connective tissue that holds joints together) become stretchy—like loose rubber bands. Many people with Marfan syndrome have more than one skeletal feature. Very few people have them all. Here are some problems that can happen.

WHEN BONES GROW EXTRA LONG:

- Your chest may sink in (pectus excavatum) or stick out (pectus carinatum, or pigeon breast). This happens when your ribs grow too long.
- Your arms, legs, fingers and toes can be very long and thin. Your doctor may check whether they are extra long by using any of these measures:
 - o "Arm span greater than height" (When you stretch out your arms to the side and the measurement from finger tip to finger tip is more than your height.)
 - o "Reduced upper to lower segment ratio" (When the length of your torso [shoulders to legs] is much shorter than the length of your legs.)
 - o "Positive wrist sign." (When the thumb and little finger overlap if one hand grasps the other wrist.)
- Your teeth may be crooked and crowded because the roof of your mouth (palate) is high and arched.
- Your hip sockets (where the thigh bone fits into the hip) are extra deep. Doctors often find this problem by doing a hip x-ray.

WHEN LIGAMENTS ARE STRETCHY AND LOOSE:

- You may have a very low foot arch (pes planus, or flat feet) or very high foot arch.
- Your spine may curve to the side (scoliosis) or forward (kyphosis).
- Bones in your spine (vertebrae) may slip over each other (spondylolisthesis). This most often happens in the lower spine.
- You may have extra movement (hypermobility) in your hand and wrist. This can make it hard to hold pencils or pens.
- Your knees, hips, shoulders, or other joints may slip out of place (dislocate).
- You may have claw or hammer toes (abnormal bending of the toes).
- You may get arthritis as early as your 20's or 30's. This can be caused by deep hip sockets or unstable joints.



National Marfan Foundation

Education • Research • Support

Serving the needs
of people with
Marfan syndrome
and related disorders

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OTHER SKELETAL FEATURES MAY INCLUDE:

- Reduced bone density (which can make your bones less strong). Doctors are studying whether people with Marfan syndrome are at greater risk for getting broken bones or if their broken bones heal more slowly.
- Swelling or bulging of the sac (dura) around your spinal cord (dural ectasia). This is common in people with Marfan syndrome. Doctors test for dural ectasia with MRI or CT scans of the lower back.

MANY TYPES OF DOCTORS TREAT PEOPLE WITH MARFAN SKELETAL FEATURES. THEY INCLUDE:

- Orthopedists, who help people with back problems, joint dislocations, and foot or toe problems. Orthopedists also provide care for a person's whole skeletal system.
- Pediatric surgeons, who do pectus repair surgery on children and adults.
- Neurosurgeons, who treat people who have dural ectasia.
- Rheumatologists, who help people who have arthritis.
- Pain management specialists, who can suggest medicines and other ways to help with pain. They sometimes work in special pain management clinics.

WAYS TO LEARN MORE ABOUT MARFAN SKELETAL FEATURES:

- Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 26. You will speak with a nurse who can answer questions and mail you information.
- Visit the NMF website at www.marfan.org. You can find more information on the "Living with Marfan Syndrome" pages. You can also ask questions online at "Support Services: Ask a Question."
- Talk with a doctor. Sometimes it helps to take Marfan information with you when you visit your doctor.