FIVE QUESTIONS FOR…
TREATMENT OF CAVERNOUS AND ARTERIOVENOUS MALFORMATIONS

Shared decision-making helps patients and their health care providers make decisions together. Health care decisions should consider the best evidence and the patient’s health care goals. This guide will help you and your doctor talk about:

- Whether treatment is needed, and if so, what treatment options work best
- The side effects and risks
- How the treatment might affect your quality of life
- How cost will affect your decision

1. WHAT ARE VASCULAR MALFORMATIONS?

Vascular malformations are defects of veins (which carry blood to your heart) or arteries (which carry blood away from your heart) or both. They also can involve capillaries (tiny blood vessels). Vascular malformations are usually present when you are born, but there are several types and causes. Vascular malformations are common and may be hidden for years. Two types of malformations in the brain and spine are discussed here: Cavernous malformations and arteriovenous malformations.

- Cavernous malformations are usually harmless and involve tiny blood vessels. However, they can cause bleeding or seizures in some patients. Up to 4 percent of people are estimated to have a cavernous malformation. It is important to ask your doctor about current treatment options.
- Arteriovenous malformations (AVMs) are abnormal connections between arteries and veins. Depending on their size and location, these may require surgery or radiosurgery. Others may require no treatment. Some AVMs may not cause any problems, but some can cause bleeding, stroke-like symptoms, or seizures. The risk of rupture or bleeding from AVMs is estimated to be about 2 percent per year. For AVMs not bleeding, recent research indicates a do-nothing or wait-and-see approach is the best treatment. In a recent study, for patients with no bleeding from their AVM, the risks from treatment were higher, indicating a ‘wait and see’ approach may be the best option.

Your doctor may order brain imaging to find the malformation. This could include computed tomography (CT), magnetic resonance imaging (MRI), ultrasonography, or angiogram.

- A CT, or computed tomography, uses x-rays to take pictures of your brain and skull. It takes only a few minutes to complete. Fear of small spaces or of no escape (claustrophobia) is not a problem with CT. It is good at looking at very solid objects like bone or clotted blood. Although CT does give a good picture of the brain, it is not very detailed. CT scans do expose people to radiation, but it’s only a little bit more than a chest x-ray. If you are pregnant, you should not have a CT. Rarely, your doctor may consider the test absolutely necessary; and then shielding of the abdomen from the x-rays is necessary.
- An MRI, or magnetic resonance imaging, uses magnets and radio waves to create very detailed pictures of the brain. It is good for looking at soft tissue such as muscle or the brain. A lot more information is provided than with CT. MRI takes much longer than a CT scan; sometimes even an hour or more to complete all images. The machine is very noisy; you may desire ear plugs. Consider instead your favorite music CD and have the MRI technician play it for you. You have to lie still in a narrow tunnel for the entire test. If a tight space might be difficult for you, tell your doctor. Fear of small spaces or of no escape is a frequent problem with MRI. A sedative drug(s) may help. If used, you will need to have someone drive you to and from the facility. Another option is an “open-sided” MRI. Many doctors consider open-sided MRI to be inferior to standard MRI for details of the brain. Since the test quality is not as good, open-sided MRI is typically avoided. People with pacemakers, metal heart valve, or certain brain clips currently cannot have an MRI.
- Ultrasonography uses sound waves to find abnormalities. A small device placed on your skin sends sound waves through the body. This test is painless. You cannot hear or see the waves. The waves bounce off arteries and veins to give a picture of the defects. There is no radiation with an ultrasound and it is usually fast and easy.
- Angiogram is an x-ray test that uses a special dye and camera to take pictures of the blood flow. It may be used to look at blood flow in your head, arms, legs, chest, back, or belly. A thin tube is placed in the groin or elbow and eased to the area to be studied. A dye is then inserted to make the area show up on the x-ray pictures. There is a small amount of radiation and it typically takes between 45 minutes and one hour.
2. HOW MIGHT VASCULAR MALFORMATIONS AFFECT ME?

Most vascular malformations do not affect individuals and cause no problems. However, this often depends on size and location. They may cause blood to flow faster or slower through the arteries or veins. Fast-flowing malformations may lead to heart failure and require specific treatments to manage the problem. Some vascular malformations also have a higher risk of rupture, or bleeding, which may require further treatment.

3. WHAT ARE MY OPTIONS FOR TREATING VASCULAR MALFORMATIONS?

Options will depend on the type, size, and location of the defect.

- **Do nothing.** Sometimes it may be best to leave the malformation alone, and visit your doctor periodically to monitor it.
- **Medications**—In most cases, medications do not make the vascular malformation go away; however, medications may control problems caused by the malformation, such as seizures.
- **Embolization**—Embolization involves placing a wire or tube through the groin and easing it up to brain or spine arteries. Through the tube, a doctor can inject a substance to close off the vessels. This treatment may require a short hospital stay and may not cure the vascular malformation, but is often very useful in reducing the blood flow.
- **Gamma knife or radiosurgery** is a non-invasive procedure which provides focused beams of radiation with high precision onto the vascular malformation. Patients may require one or more treatments to completely destroy the malformation. Following radiosurgery there is a high likelihood the malformation will close off, but there is still a chance of bleeding while receiving treatments. Long-term side effects are rare, but can occur.
- **Surgery**—During surgery, a neurosurgeon removes the vascular malformation in an operating room. Once removed, the malformation will not grow back and risk of bleeding is gone. Surgery is not appropriate for all vascular malformations and there are risks, including long hospital stay, infection, or stroke.

4. HOW CAN I TALK WITH MY DOCTOR ABOUT REACHING A TREATMENT DECISION?

- Ask for detailed information on the type of vascular malformation and problems that may occur.
- Ask if treatment is needed for your malformation or if it would be better to do nothing.
- Talk with your doctor about the possible risks and benefits of these treatments.
- Decide if you need more information to make the decision. You may want to talk with a surgeon if your doctor recommends surgery.
- Discuss which risks concern you more than the others.
- Ask about the cost of these treatments and if your insurance will pay for them.

5. WHAT IS THE EVIDENCE?


Disclaimer: The American Academy of Neurology recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, based on all of the circumstances. This statement is provided as an educational service of the AAN. It is based on an assessment of current scientific and clinical information. It is not intended to include all possible proper methods of care for a particular neurologic problem or all legitimate criteria for choosing to use a specific procedure. Neither is it intended to exclude any reasonable alternative methodologies.