



I am a board certified pediatrician practicing in West Palm Beach, FL. I was diagnosed with Chiari malformation in July, 1988 and have undergone a cervico-syringorachnoid shunt in 1990 and decompression surgery in 2003. I take medications daily to enable me to be present for my patients. I hope that in this occasional article series that I might "bridge the gap" between patient and doctor.

Finding A Doctor

January 31st, 2009 - Most patients with Chiari 1 malformation (CM) have been to numerous doctors. Patients with a new diagnosis or who may have recently moved may need to determine what type of physician do they need to see.

All patients with CM should have a general or primary care physician-family practitioner, internist, or pediatrician. This physician should have a general knowledge of CM and should help coordinate the general care of the patient. They may not be knowledgeable about all of the specific treatments for CM but should be able to coordinate the care depending on the patient's symptoms.

Patients with CM have a broad range of symptoms. At least half of patients with CM report neurological symptoms. These may include headache, weakness, numbness and/or tingling, swallowing difficulties, hoarseness, etc. Most patients are diagnosed by MRI imaging of the brain. If there are neurologic symptoms and abnormal MRI findings, the patient should be evaluated by a neurologist and/or neurosurgeon. Which doctor to choose may depend on the severity of the symptoms and their progression, the availability of physician in the patient locale, and the expertise of the particular physician in the treatment of CM.

Neurologists are able to document abnormalities and provide medical management of particular symptoms, such as headache. They are able to do additional testing of nerve and muscles, brain wave studies (EEG) and follow the progression of the patient and their symptoms. Follow-up MRI testing should be done if symptoms are increasing and at several year intervals (despite lack of specific guidelines).

Other medical specialists may be needed to deal with specific symptoms. An endocrinologist may be needed to deal with hormonal disorders. An ophthalmologist may be needed to evaluate blurred vision and/or nystagmus. An otolaryngologist may assist with choking/swallowing issues. Cardiologists may evaluate heart rhythm abnormalities as well as variations in blood pressure. All specialists should be made aware of the CM diagnosis and should report to your primary care physician as well as other specialists you are seeing.

Despite appropriate medical management, some patients with CM have progressive symptoms. If this occurs or if a MRI reveals hydrocephalus or spinal cord syrinx, neurosurgical evaluation is indicated.

Neurosurgeons are trained in surgery of the brain and spinal cord. However, neurosurgeons may have additional expertise or interest in specific nervous system disorders like CM. Those neurosurgeons would be more likely to attend regional and national meetings concerning CM, perhaps publish their surgical observations results and be up to date in the diagnosis and treatment of CM. Some neurosurgeons have dedicated their practices and research to understanding CM and treating only patients with this disorder. Some physicians have established specialized centers to treat patients with CM.

Choosing a physician is not an easy decision. Sometimes choice may be limited by insurance plan. Sometimes choice is limited to geographic area. The ideal is to find a physician that has an increased level of expertise in CM. How does one do this? Well, because you are reading this you have already been on line researching Chiari malformation and that is a reasonable first step. You may see names of physicians, as you are researching, who are actively caring for patients as well as writing of their medical results. You may be referred to a specific neurosurgeon by your primary care physician or your neurologist. You may ask your insurance company for a recommendation or referral to a qualified neurosurgeon. You might look to your nearest medical school. You might find help through a CM support group. The physicians' office staff may not be the best source of information concerning the doctor's level of expertise with CM.

Once you have scheduled an appointment, it is important to gather copies of all MRI studies related to your CM and pertinent medical records. If records are requested in advance, it is important to send an additional copy and retain your copy of records for yourself. Some neurosurgeons may request additional studies either before or after your visit to assist them in understanding your particular problem. You should expect your neurosurgeon to review your studies and pertinent medical records with you and decide if surgery might be appropriate in your case. Most surgeons will not operate without evidence that CM is causing a significant level of impairment to the patient. If your neurosurgeon suggests surgical care, it is important to understand what the surgery might accomplish. The patient should understand the proposed surgery, the possible benefits as well as the possible risks associated with the surgical procedure. Not all symptoms improve with surgery and there may be complications associated with the surgical procedure itself. Therefore, the decision to have surgery should not be undertaken lightly.

There is no recognized "best" operative procedure for the treatment of Chiari malformation and the patient must find a neurosurgeon that they can trust. While information about surgical procedures may be found on line and through published literature, each surgeon's wisdom comes through his surgical training, his continuing medical education, as well as his surgical knowledge that comes through repetitive surgical procedures. If a surgeon suggests a particular surgical procedure for you, it is based on his complete surgical knowledge base-you may

question why he chooses a particular procedure over one you might have read about. But you must trust him/her to choose and recommend the surgical procedure that he believes is best for you.

Because there is no agreed upon "best" operative procedure, some patients desire to see more than one neurosurgeon-that is obtain a second opinion. Again the same decision making process occurs for choosing a second neurosurgical physician.

One obvious difficulty in choosing a neurosurgeon is determining the extent of your insurance coverage. Some insurance policies have very different payment arrangements if you see a physician that is not in a particular insurance network. This may also extend to all providers that might be associated with the proposed surgery (eg anesthesiologists, physiologic monitoring, etc) as well as the hospital involved. Sometimes these costs are difficult to determine in advance and may be significant in the end.

It is imperative to have all doctors communicating because some symptoms respond better to medical management while others may require surgical intervention. Some symptoms may recur or persist after surgery-even after what seems like a perfect procedure. While the decision of physician selection can be complicated, it is very important in patients with ongoing medical problems such as CM.

Ed. Note: The opinions expressed above are solely those of the author. They do not represent the opinions of the editor, publisher, or this publication. Anyone with a medical problem is strongly encouraged to seek professional medical care.

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