

National MALS Foundation

Team Approach for MALS - Establish a CARE TEAM

MALS is an isolating medical condition because it can be challenging to diagnose, and because its rarity means that very few clinicians have first-hand knowledge or are up to date on the latest research. The team approach is the best approach to managing MALS symptoms, securing a MALS diagnosis, finding the right surgeon, and having strong follow-up care post-surgery.

What kind of team should you create around you or your loved one? A team that is willing to learn, willing to listen to the patient, and willing to talk with each other. Sometimes, it is helpful to work within a network of people that ideally already have communication established with each other as they practice within the same provider network. However, it is most important to secure a team of doctors that are knowledgeable, willing to stick with you and work with your other specialists to provide the highest level of communication and quality of care.

Here are the important partners you need on your care team, ideally all of which can be initiated and managed by your primary care physician. We have tried to provide direct perspective from a real-life example of each of these clinical partners—click on the hyperlink to see stories of how these clinical partners have seen their role with their MALS patients.

PRIMARY CARE PROVIDER and PEDIATRICIAN: to initiate and manage the exploratory process and advocate for you as the patient in need. Primary Care Providers are generalists who look out for your overall health, and should work with you to find the right specialists you need. The right PCP or pediatrician will help you get to a diagnosis, help coordinate your care with your larger medical team, and then help guide you through post-surgical healing.

GASTROINTESTINAL SPECIALIST: to run routine GI tests and explore other possible GI diagnoses. You will likely need to go through a full set of gastrointestinal (GI) tests that look at how your stomach, intestines, pancreas, gallbladder and other GI organs work. Very rarely will MALS show up on GI testing, so don't get discouraged. MALS is a diagnosis of exclusion, so it is critical to have the full battery of tests to make sure you do not have other diagnoses that are causing your symptoms or are

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complicating them.

CARDIOLOGIST—to rule out cardiac issues because some MALS symptoms manifest as chest pain/pressure and/or discomfort. In some people you can also get a fast or slow heartbeat and/or blood pressure issues.

PAIN MANAGEMENT SPECIALIST: to help manage the pain in a thoughtful way that minimizes the bias against drug-seeking patients.

DIETITIAN: to help create a diet that will maximize the nutrients your body needs while minimizing pain. Pain from MALS is caused in part when the digestive system calls for blood, which then rushes through the compressed celiac artery. Fatty foods take longer to digest, so when you eat fatty foods, your system calls for blood more frequently causing more pain. In addition, the celiac supplies blood to your pancreas which is responsible for producing enzymes which break down your food in order to be absorbed. In some people, the lack of blood flow has caused their bodies to stop or limit production of these enzymes. Dietitians will tell you that the key to maintaining muscle, organ health, and nutrients is to eat very small portions of 4-5 bites with enough protein to maintain your height and weight.

COGNITIVE BEHAVIORAL THERAPIST: to provide you with tools to manage the anxiety and pain involved in MALS. The mind-body connection is powerful, and coping tools can help the MALS patients deal with chronic pain as well as the mental preparation needed for major surgery and post-surgical healing.

PHYSICAL THERAPIST: to help prior to surgery and post surgery to combat the pain of tightened chest muscles due to being curled up in pain; to reduce the painful effects of costochondritis or tietze syndrome after surgery; and to build up muscle functioning again after long months of atrophy and nutrient deprivation. Find an orthopedic physical therapist in your area if possible, who can evaluate you and give you tailored exercises to loosen up the cartilage and muscles between the ribs, to relax the abdominal muscles, and to build back up your core muscles. Physical manipulation after surgery can also help reduce the development of scar tissue and provide a better recovery.

ACUPUNCTURIST: to help treat various conditions by inserting very thin needles through a person's skin at specific points on the body, to various depths. Research

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suggests that it can help relieve pain and nausea. Also, used for a wide range of other complaints.

MASSAGE THERAPIST: incorporates various clinical and relaxation soft tissue manipulation techniques to help reduce tension and pain from tightened neck, back, abdominal and thoracic fascia and muscles from the physical stress of living with a chronic pain condition and to help following surgery during the healing process.

VASCULAR SURGEON: Once a MALS diagnosis is confirmed. To reconfirm the MALS diagnosis and create a surgical plan and post-surgical long-term monitoring. The surgery for MALS is conducted best when a vascular surgeon leads the team or is present during the surgery.

TRANSITION OF CARE: after surgery is important to consider. You want to have specialists near your home whom you can see as your healing progresses, and particularly if your healing doesn't seem to progress.

Many surgical patients develop issues after surgery that need attention from a PCP, pediatrician, or GI specialist. These can include issues such as:

- Small Intestine Bacterial Overgrowth (SIBO) which can be remedied by diet and antibiotics
- Costochondritis or Tietze Syndrome which can cause pain the thoracic area and can be remedied by antibiotics and physical therapy
- Gastroparesis which needs special dietary attention
- Muscle atrophy which needs consistent physical therapy
- Hernias at surgical site
- Among other things

WHEN SHOULD YOU FOLLOW UP WITH YOUR SURGEON?

MALS symptoms and surgery are complicated. The celiac artery can recompress after release of the median arcuate ligament causing renewed symptoms. This recurrence of symptoms is not necessarily a reflection on the skill of your original surgeon. The best surgeons acknowledge that MALS surgery might not resolve symptoms and that further interventions might be necessary. Such interventions after surgery might include:

- Angioplasty or placing stents in the artery to keep it open
- Performing a celiac plexus block to cut off nerve pain
- Surgically bypassing the celiac artery

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It is critical to select a surgeon who will follow you over the long term. Repeat ultrasounds over a year or two can monitor the velocities of the artery. Recompression of the artery can happen months or years after “successful” surgery.

At the same time, however, the healing process is long. Many physical sensations during healing can mimic MALS symptoms, as can many of the issues listed above. It is important to give time for the full healing process before jumping to the conclusion that surgery didn't work. And it is important to have a team of doctors who can investigate the ancillary issues that can be triggered by surgery before jumping to the conclusion that surgery didn't work. If your Primary Care Provider and GI specialist have investigated all of your follow-on symptoms after surgery, and you have found no other cause, then it could be time to consult your surgeon again to explore if recompression has occurred.



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