

National MALS Foundation

ADULT SYMPTOMS: Common Symptoms experienced after eating, exercise, positional movement

- Epigastric Pain or Pressure
- Postprandial Pain or Pressure
- Chest Pain or Pressure
- Nausea
- Diarrhea
- Constipation
- Bloating
- Vomiting
- Weight loss
- Radiating right or left flank and or back pain
- Blood Pressure and Pulse issues

Diagnosis & tests / imaging: Once MALS is suspected, a diagnostic work up is initiated to include various tests indicative to a diagnosis of MALS and rule out cardiovascular and gastrointestinal issues which may include

- Duplex or Doppler Mesenteric Ultrasound w/breathing protocol
- Computed Tomography Angiography (CTA) w/breathing protocol
- Catheter Abdominal Angiography w/contrast dye
- Magnetic Resonance Angiography (MRA)
- CT scan with or without contrast dye chest, abdomen and pelvis
- Gastric Emptying Transit Motility Study with Small Bowel Follow Through
- HIDA scan of gallbladder
- Endoscopy (EGD) and Colonoscopy with Biopsies
- 24 hr pH Impedance Probe
- Esophageal Manometry
- Gastric Tonometry
- Blood work panels
- Chest x-ray
- Electrocardiogram (EKG)
- Splanchnic Nerve (SNB) or Celiac Plexus Block (CPB)

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www.malsfoundation.org



MANAGEMENT and SURGICAL TREATMENT: The standard treatment is surgical release of the celiac artery by division of the median arcuate ligament (MAL) including overlying lymphatics and soft tissue with or without neurolysis of the compressed nerves and removal of scar tissue. When surgery is not an option due to risk factors outweighing the benefit a comprehensive conservative approach may be incorporated to help with symptom management.

- Laparotomy (open)
- Laparoscopic
- Robotic

PSYCHOSOCIAL ASPECTS OF RARE DISORDER: MALS and its impact on our mind, body, and soul

Living with a chronic illness can be isolating, scary, and frustrating. With MALS, you may look great on the outside, but feel like death on the inside. Many people slowly start to turn down social invitations due to fatigue, inability to eat without pain, nausea, etc. Friends may start to fade as you sink further into life with illness. Relationships change. Our own way we cope can change. We can feel as if we don't fit in any more with our partner, our family, our friends, and our peers. It's important that we recognize how illness impacts our cognitive, social, emotional, and behavioral health needs. While our mental health is not the cause of our illness, it can certainly impact how we function and manage life with MALS. Self-care is vital.

If you look for information on how to take care of yourself when living with a chronic illness or pain, you will see things like ***eating healthy, engaging in social activities, and exercising on a regular basis***. For MALS patients, that seems impossible. Eating can be debilitating and it seems that all the healthy foods are difficult to digest. Usually, there are consequences to eating healthy foods . . . well, any food really. You get horrific pain and many times a bathroom must be nearby . . . not exactly a scenario we want to endure. So, sometimes, we avoid food and any activity that involves food like going out with friends, family gatherings, dinners out, etc. Let's be honest, most social events involve food! Food is everywhere and, with MALS, tolerating this necessity is difficult. It can also feel like torture when we have to watch others enjoy a nice steak and salad. With MALS, this can send us into the fetal position. So, we slowly turn down invitations and sometimes, we stop getting invited or we choose to just stop answering the invitations. Then there is exercise . . . well that is difficult too. When you feel like it takes all your energy to get out of bed and take a shower, who feels like running or biking?? When exercising causes your heart rate to do crazy things and your blood pressure to do weird things, exercise is not exactly stress reducing.

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So, what do we do? What do MALS patients do to reduce stress and take care of ourselves? Well, the answer is that we are all different and we need to find activities that reduce our stress levels and take care of our mind, body, and soul. We too deserve these things! Here are some tips:

Eating: Find what works for you. This may not be much. For some, we need feeding tubes and for others it is an all liquid diet monitored by doctors. Do what works. Try to get enough protein. Try to get enough vitamins and minerals to keep your body functioning. See a nutritionist or doctor for support if you need it. Malnourishment is real and MALS patients are at high risk for not getting enough nutrients for our body to function

Exercise: Every little bit helps. On a “good” day, do what your body let’s you. Walk, go to the gym, take a bike ride and get some fresh air. If your good days are still bad . . . do what you can. Stretch, do yoga, practice mindfulness. These too are good for the mind, body, and soul. On the bad days, rest. Listen to your body. No matter what people say to you, it is okay to rest. MALS can trigger debilitating fatigue. We must find a balance between rest and getting enough to sustain us. So, if that means your exercise is walking to get the mail today and that is it. Then that is enough for today. Tomorrow, do some mindfulness. Sit on the steps and breathe in the air (even though this may be hard too). Do what you can and do it for you. You deserve it.

Socializing: It’s okay to turn down social events. It’s okay to go and bring your own food or not eat at all. Illness can definitely be isolating, especially if the impact of MALS goes on for a long period of time before treatment. Have limits and boundaries. It is okay. Be careful with over committing yourself out of guilt! Plan for rest. It will catch up to you. Stop being so hard on yourself! When your illness becomes so isolating, it may be time for some professional support. Isolation can contribute to and trigger loneliness, depression, anxiety, and poor coping which can actually make you feel like your medical symptoms are worse. That’s because they probably are! Our bodies are closely connected to our thoughts and feelings. MALS is not in our heads, but we do need to take care of our mental health. Sometimes, counseling to help with coping skills can be very helpful. Did you know that there are clinical therapy treatments that can actually help you with pain management? They even have neurofeedback options which can help you actually lower your blood pressure and heart rate? Mindfulness practices can help bring calmness to a body that is in constant distress.

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