

Chapter 18

The Median Arcuate Ligament Syndrome Journey: A Patient Perspective



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Pre-Diagnosis

Deciding to Seek Help

MALS patients often feel as though their bodies have betrayed them. Initial symptoms might present in a manner that most write off as nothing serious. Minor stomachache, difficulty running, or struggling to catch a breath going up the stairs are minor symptoms that might continue for years before patients seek professional care. Patients need medical providers who are willing to listen to their full history and who are dedicated to helping them find the answers to their symptoms with a proper diagnosis and treatment plan. For some patients, this might be a short process, but for many, a MALS diagnosis is a journey that takes years of self-advocacy and perseverance in the face of symptoms that do not clearly indicate the necessity of a clinical diagnosis.

Struggle of the Diagnostic Process

The challenge of connecting all the dots related to symptomology and receiving the correct diagnosis and treatment plan is difficult due to perceptions that MALS is exceedingly rare or not an actual diagnosis. Patients might be told they do not fit the perception of standard parameters for weight, age, or gender that might indicate a MALS diagnosis and leave appointments without answers. This lack of support often leaves patients feeling demoralized and hopeless.

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Patients often have appointments with multiple specialists who conduct various tests that frequently appear “normal.” When symptoms remain unresolved or worsen and diagnostic criteria are variable between providers, patients sometimes need to locate a different provider in order to secure appropriate testing and an accurate diagnosis. The years of continued searching and testing coupled with a diminishing quality of life exact an unquantifiable mental, emotional, and physical toll on both the patient and their caregivers until a diagnosis is finally made and treatment begins.

Recognizing the Burden Experienced by Patients and Caregivers

MALS patients and caregivers often learn strong advocacy skills, and sometimes this can present as frustration, strong opinions, hopelessness, and fear. The cycle of appointments and testing without answers frequently results in patients and caregivers feeling defeated, so they begin looking to support groups and online sites for answers. Engagement on social media platforms typically includes the patient journey, education, and research, even as this can sometimes lead to misinformation as well. Patients and caregivers often feel more empowered and hopeful through the knowledge they gain, which can enable further communication with their doctors. Research through both Internet and social media resources is not a replacement for clinical advice, but it can help patients and caregivers find the right doctors or facilities with the necessary experience for a MALS diagnosis. Finding the right provider for a particular MALS presentation is often the most challenging part of the MALS Journey.

Patients often try to hide the worst of their challenges from those around them. This can include their caregivers as they want to avoid becoming a burden. Caregivers can also struggle emotionally during the diagnostic process as they can feel helpless in watching their loved one suffer debilitating symptoms. Having support for caregivers as well as the patient is essential. Caregivers play a significant role in ensuring that patients do not feel isolated and have someone to support them through their journey. Thus, it is important that they also are included in clinical discussions so that they too do not feel isolated.

Diagnosis and Surgery

Relief of Diagnosis

Being an undiagnosed patient is profoundly isolating. Not having an official diagnosis makes it harder to explain symptoms to caregivers, educators, coworkers, managers, and other people in the patient’s life. This can result in feelings of isolation, depression, anxiety, and physical depletion. Ironically, a diagnosis often

provides a much-needed morale boost to the patient. In addition to relief, they might also feel fear when receiving their diagnosis as their journey to feeling better has just begun and the prospect of surgery can seem overwhelming.

Reality of Finding Treatment

Once MALS is diagnosed, finding a doctor to pursue treatment is the next challenge for the patient. Many patients consult multiple surgeons and often feel as though there are conflicting opinions on treatment. Due to the history of diagnostic struggle, conflicting clinical opinions can often leave the patient feeling unsure of how to proceed. Having a provider who recognizes this struggle and reassures the patient with clinically accurate, factual information can be reassuring and can help feel as though there is a partnership between the doctor and the patient. It is this partnership that moves MALS patients closer to better health, healing, and well-being.

Choosing the Right Operative Treatment

The National MALS Foundation works hard to combat misinformation in the patient community regarding surgical approaches. The choice between open, laparoscopic, or robotic surgery is often confusing for the patient in light of misinformation online, challenges with finances, and fear about not having positive outcomes. Patients feel uncertain about which approach is optimal for them and benefit from having open and honest conversations about all the different surgical approaches.

Importance of Managing Patient Expectations Prior to Surgery

Prior to surgery, patients appreciate having discussions regarding expectations for recovery and management of symptoms. Helping patients understand the differences between surgical healing time and the time it takes their bodies to feel the full benefits from surgery is critical in postoperative outcomes. Discussions about defining a successful surgery are also beneficial as often this might be different for the surgeon and the patient. Patients and their caregivers struggle with the reality that MALS symptom resolution can vary due to individual circumstances. Clear communication between the doctor and patient/caregiver about these expectations can help alleviate postoperative stress and improve recovery.

Patients often report surgical pain resolving within 6–8 weeks, depending on the approach; however, symptom improvement often takes longer. Sometimes, patients report symptoms worsening within the first few months of surgery. Many patients report symptom improvement starting after surgical healing and many indicate they

do not feel the full benefit of surgery for 6–12 months or longer. These timelines are important to know prior to surgery. Otherwise, patients can feel as though surgery is unsuccessful when, in reality, there simply has not been enough recovery time.

Patients also benefit from discussing potential options should surgery not provide the outcome they hoped. If symptoms do recur, patients often think it is due to failed surgical intervention when instead it may be caused by common postoperative conditions that doctors can prepare patients for during presurgery consultations. Patients also benefit from discussing potential options should surgery not provide the outcome they hoped. Patients feel supported in postoperative symptoms management when short- and long-term follow-up is provided.

Preparing for Hospitalization and Surgery

In addition to managing the symptoms of MALS while preparing for surgery, patients report that it is essential to have information about how to prepare to go to the hospital, what to expect during their hospital stay, and how to prepare adequately for life at home following surgery. Being informed allows the patient to focus on healing and can help reduce the stress that surrounds surgery.

Here are some items MALS patients find comforting and helpful:

- Small pillow to press against the belly/incision.
- Blanket from home.
- Dry shampoo.
- Lotion for hands or face to help with dry skin.
- Long phone or iPad charger.
- Earplugs.
- Hair ties.

Surgery

Patients often need clarification about the basics of surgery. The patient community is full of misinformation and personal prejudices, which can lead to patients being unsure of what is being done during their procedure. Being clear and concise with patients about what surgery looks like is helpful.

Waking up from any surgery can be scary for patients. Discussing realistic expectations with the patient prior to surgery is helpful to prevent anxiety and patients benefit from knowing the different aspects of the surgical process, length of hospitalization, post-op pain management while hospitalized, and discharge planning.

Discharge

Patients report being sent home too quickly or with inadequate instructions for symptom management, and this can often result in ER visits. In addition, patients need to be prepared for how surgery might impact their travel home. Discussing what typical issues might arise while traveling can help ease the patient's mind.

Home Recovery

Preparing the patient and caregiver for the return home is an integral part of patient recovery. Clinicians can help by advising patients and caregivers about how surgery might limit both short- and long-term activities like driving, housework, cooking, eating, exercising, and returning to work or school. Doctors can help set the tone that healing is lengthy and that patients and caregivers need to be compassionate with themselves.

Postoperative patients frequently report difficulty with dysregulated eating and postoperative nausea. Preparing for these concerns and having a plan to support them help reassure patients during their recovery at home.

The recovery process itself can strain relationships. Not every MALS patient has adequate support at home, and even if they do, patients find online support groups vital during this time. Online groups can relieve isolation and help people connect with others who understand the MALS journey. Surgeons can help by sharing successful patient stories, connecting patients with other patients, and encouraging the patient to seek out online support groups.

Psychosocial Impact of MALS

MALS can impact a person's mental health, especially if left untreated long after symptoms begin. Isolation can form and contribute to loneliness, depression, anxiety, and poor coping skills. Relationships with partners or family members might change, and friendships might start to fade as patients sink further into life with illness. This can leave patients feeling like there is nowhere to turn.

It is essential to recognize how illness impacts the patient's cognitive, social, emotional, mental, and behavioral health. MALS and its impacts can be isolating. Many recommendations for positive mental health focus on healthy eating, engaging in social activities, and exercising regularly, but these suggestions are often difficult for patients with MALS. It is essential to help the patient understand that all patients with MALS are different and that finding activities and support to reduce stress levels, cope with isolation, and take care of their mind, body, and soul is an individual process of trial and error. When referring patients to counseling support

to help with surgical expectations, post-op outcomes, and symptom management, it is critical to validate the patient's real physical symptoms associated with the clinical condition itself. Otherwise, patients might interpret a counseling referral as a dismissal of symptoms and feel unheard.

Role of Patient Advocacy and Online Community Support

Online Support Groups

An online support group is immensely beneficial to both patients and caregivers. These groups are a safe place for patients to discuss their struggles and their MALS Journey. They allow patients to vent, ask questions, and seek support from those who understand what they are going through. These groups provide a sense of community, help patients know they are not alone, and provide ideas for activities, coping strategies, symptom management, etc. Patients and caregivers often build meaningful relationships with people worldwide experiencing a similar health journey. This can ease the emotional burden many patients experience.

Patient Advocacy

Advocates come in many forms: parents, friends, professionals, or foundations. The National MALS Foundation advocates on behalf of the MALS community. The Foundation helps to educate the MALS community with accurate information that can help them on the path to receiving answers. The Foundation also provides scientifically grounded information to doctors looking for answers for their patients.

Patient advocacy highlights the need for the patient's voice to be heard within the medical community to encourage doctor-patient collaboration and trust. By spreading MALS awareness in the medical community, the National MALS Foundation hopes to reduce delay times in getting a diagnosis and expedite the implementation of the best treatment plan for the patient. The Foundation strives to make visible the invisible as a meaningful way to show support and advocate for patients' health and well-being.

The Foundation also advocates for collaboration within the medical community. A core tenet in medicine is education, the art of discovery, and sharing that wealth of information with others. The MALS Foundation advocates for additional research, establishing standardized protocols, and standardizing the surgical process. Having doctors do the same is essential for helping MALS patients.

Conclusion

The journey of a patient with MALS is a marathon, not a sprint. Doctors play an essential role in helping patients through the diagnostic, surgical, and postoperative phases of care. Ensuring that patients are given realistic expectations about things like postoperative complications, timelines for surgical recovery, and the time it can take a patient to feel the full benefits of surgery is essential. Above all, patients value doctors who understand that they are not looking for a provider with all the answers, but one with the patience, empathy, and willingness to help them find answers and improve their daily life. The National MALS Foundation plays an important role in bringing together the community of MALS clinicians as well as patients and families to improve clinical knowledge and the patient experience.