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## THYMECTOMY

Answers to questions  
you may have about  
thymectomy



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The following are answers to some of the most common questions asked when a thymectomy is being considered for adult and younger patients with autoimmune myasthenia gravis (MG).

The answers supplied below are presented in general terms as background information only and should not be used to make specific decisions. Since each patient's situation is unique and the types of thymectomy being performed vary, it is essential that you discuss in detail these and all other questions about the surgery with your MG specialist and surgeon.

### **What is a thymectomy and why is it performed?**

A thymectomy is the surgical removal of the thymus gland. The thymus has been demonstrated to play a role in the development of MG. It is removed in an effort to improve the weakness caused by MG, and to remove a thymoma if present. About 10% of MG patients have a tumor of the thymus called a thymoma. Most of these tumors are benign and tend to grow very slowly, however occasionally, a tumor is malignant (cancerous). Every person diagnosed with MG should have a CT scan of the chest to check for a tumor.

### **What is the function of the thymus? Is its removal harmful?**

The thymus gland plays a major role in the development of the body's immune system. Its job is to train immature T-cells to develop into mature T-cells which are then circulated in the body to help activate the immune

system's B-cells to fight infections. The thymus gland enlarges throughout childhood and starts shrinking during puberty. By the time adulthood is reached, the thymus gland's function is no longer needed. Removal of the thymus in the treatment of MG in adulthood does not affect the immune system thereafter.

### **Exactly where is the thymus located?**

The thymus is located in the front portion of the chest (anterior mediastinum) with "finger-like" extensions into the neck and consists of multiple lobes (two to five or more). In addition, varying amounts of thymic tissue may be present in the fat surrounding the lobes, both in the neck and chest.

### **Who should have a thymectomy?**

A thymectomy is frequently recommended for patients under the age of 60 with moderate to severe MG weakness. However, it is recommended for patients of any age who present with a thymoma or thymic tumor. It is sometimes recommended for patients with relatively mild weakness, especially if there is weakness of the respiratory (breathing) or oropharyngeal (swallowing) muscles. A thymectomy is usually not recommended for patients with weakness limited to the eye muscles (ocular myasthenia gravis).

In a recently completed randomized trial of extended transsternal thymectomy in patients without thymoma, patients aged 18 to 45 and who had a positive AchR blood test and who had presented with generalized symptoms within the last 5 years prior to the surgery were found to have the greatest benefit from thymectomy. These patients had reduced hospitalizations

due to MG exacerbations, and reduced requirements for prednisone and other immunotherapies. Older patients were also randomized in the study, but their numbers were too small to make definitive statements about the benefits of thymectomy above age 45. [See *New England Journal of Medicine*, August 11, 2016, Volume 375, No. 6, *Randomized Trial of Thymectomy in Myasthenia Gravis*, G.I. Wolfe; H.J. Kaminski, et al.]

### What should I expect as I consider a thymectomy?

When a thymectomy is being considered, you will be referred to a surgeon. It is important to choose a surgeon experienced in performing thymectomies for patients with MG. The surgeon will review your clinical records, examine you, discuss your surgical options and make a recommendation. The surgeon also explains the anticipated pre- and post-operative courses, possible complications, and the anticipated results. You, in consultation with the neurologist and surgeon, will then make a decision: whether or not to proceed with a thymectomy and if yes, the type of surgery to be used.

### What are the goals of a thymectomy?

The neurological goals of a thymectomy are significant improvement in the patient's weakness, reduction in the medications being employed, and ideally a permanent remission (complete elimination of all weakness and off all medications). A thymectomy is usually not used to treat active disease but rather it is believed to improve long-term outcome. Results may not be seen for one to two years or more after the thymectomy.

### How is the surgery performed?

There are three basic surgical approaches explained in the paragraphs below, each with several variations. Regardless of the technique employed, the surgical goal is to remove the entire thymus. Many believe this should include removal of the adjacent fat; others are less sure.

#### Transsternal Thymectomy

- **Incision:** Vertical (lengthwise) on the anterior chest; the sternum (breastbone) is "split" vertically.
- **Thymus Removal:** The chest and neck portion of the thymus are removed through this incision.
- **Extended Form:** The fat located in the front part of the chest next to the thymus, as well as the thymus, is removed. Complete removal of all tissue containing thymus is believed ensured. This is the approach that was used in the randomized trial mentioned above.
- **Combined Chest and Neck:** A few MG Centers add a formal neck dissection to the sternal technique to also ensure the removal of all the thymus in the neck.
- **Thymoma:** Most recommend the transsternal approach for removal of a thymoma.

#### Transcervical Thymectomy

- **Incision:** Transverse (horizontal) across the lower neck.
- **Thymus Removal:** The chest portion of the thymus is removed through this incision.

- **Extended Form:** The “extended” form allows improved exposure of the thymus in the chest with more complete removal of the thymus. Although the adjacent fat is also removed, less is removed than in the extended transsternal thymectomy.

## Videoscopic (VATS) Thymectomy

- **Incision:** Several small incisions on the right or left side of the chest.
- **Thymus Removal:** Fiber-optic instruments are used. These are small flexible tubes with a light at the end through which small instruments can be passed. The amount of thymus and fat removed is variable.
- **Extended Form:** In the “VATET” form, incisions are made on both sides of the chest, as well as in the neck, for “more complete” removal of the thymus.

## What are the results of a thymectomy?

Many neurologists experienced in the treatment of MG are convinced that a thymectomy plays an important role in the therapy of MG, although the benefit is variable. The randomized trial of thymectomy mentioned above has provided evidence to back up this conviction, at least in AchR positive patients with generalized MG.

In general, most patients begin to improve within one year following a thymectomy and a variable number eventually develop a permanent remission (no weakness and no medication). Some physicians believe the remission rates after surgery are in the 20-40% range regardless of the type of thymectomy performed. Others believe that the remission rates following the more

extensive procedures are in the 40-60% range five or more years after the surgery.

It is important to note that rigorous scientific studies are needed to resolve the debate concerning the best method of performing a thymectomy in the treatment of MG patients.

## What type of thymectomy should I have?

Since there is no universal agreement, or unequivocal proof, as to which type of thymectomy is best, it is difficult for patients to decide what is best for them. There is, however, general agreement that the entire thymus should be removed and that the patient should select the procedure that ensures as much as possible that this is accomplished. Some surgeons believe that all the surrounding fat should be removed as well, because it frequently contains microscopic (very small) amounts of thymus; others believe this may not be necessary.

There is growing evidence that “minimally invasive” procedures (transcervical and videoscopic) are as effective as more invasive approaches. The evidence for this is mainly through retrospective comparisons of patients who underwent different types of surgery during different eras in the last two to three decades. As of yet, there are no prospective, randomized studies comparing different surgical techniques which would provide a higher level of evidence.

Since there is no absolute proof as to which type of thymectomy is the procedure of choice, it is up to you to become fully informed, review the evidence presented by the neurologist and surgeon caring for you, and perhaps obtain additional consultation (second or even third opinion). Again, the key to the

optimal outcome is to remove as much thymic tissue as possible in the safest way possible for a particular patient. It is important that you have your questions answered, and confidence in your medical team and the decisions about your plan.

### **What can the MG patient expect in the pre-operative, anesthesia and post-operative periods?**

In general, MG Centers have developed protocols for the care of MG patients and have a team of neurologists, surgeons, pulmonologists, intensive care and respiratory care specialists, nurses and anesthesiologists caring for MG patients undergoing a thymectomy. To ensure that you are fully prepared, ask for time to discuss all aspects of the pre-and post-operative care and anesthesia with the surgeon, anesthesiologist and neurologist.

To reduce the risks of post-operative respiratory complications or the post-operative need for prolonged respiratory support with a ventilator (breathing machine), your doctor may require pre-operative plasma exchange (PLEX) or intravenous immunoglobulin (IVIg), and some require immunosuppressive therapy as well. If you are taking pyridostigmine (Mestinon) your medical team will advise on what to do both in the weeks before, and the day of and the days after surgery. The surgical team will also advise on all medications you may be taking--not just for MG, but for other conditions such as blood pressure, pain (like aspirin, NSAIDs, etc.). Be sure to have these discussions.

The anesthesia for patients with MG is similar to the anesthesia given to other

patients. An endotracheal tube (tube in the windpipe) is inserted after you are asleep. Muscle relaxing drugs, however, are usually avoided. You may or may not be extubated (removal of the endotracheal tube) upon awakening, depending on your strength. If the endotracheal tube is not removed on awakening, the tube will be attached to a ventilator.

Ordinarily after the surgery, you will go to a Recovery Room, Respiratory Care Unit, or Intensive Care Unit depending on each hospital's method of taking care of MG patients following surgery. A ventilator may be required depending on the type of operation and the severity of your weakness. As soon as the breathing tube has been removed, you will be asked and helped to deep breath and cough frequently to keep the lungs clear of secretions. One or two chest tubes (small tubes exiting the chest and attached to drainage bottles) are usually used after the transsternal and videoscopic operations, and removed soon after surgery.

Medications used to manage MG before surgery are usually continued after surgery. The neurologist will decide how to taper your medications after surgery in subsequent follow-up appointments.

Pain is minimal following transcervical thymectomy and usually mild following videoscopic thymectomy, although some patients have reported late pain. The pain associated with transsternal thymectomy is temporary and well controlled with medication and gradually resolves within 3-5 days. Patients typically require minimal pain medication on hospital discharge. If your pain is not well-controlled, talk with your doctors about options.

The length of time in the hospital will vary depending on the type of surgery and your overall weakness. In most cases you will be ready to go home in a few days to a week. Your preoperative medications, immunosuppression and other forms of therapy are usually resumed after surgery for variable periods of time depending on the MG symptoms and the neurologist's recommendations.

### When can I return to my usual activities?

It is hard to predict the recovery time for any individual patient. And the return to work, school and other responsibilities and activities will also vary—as certainly some jobs and life responsibilities are more physically demanding than others. It may be best to plan for the worst (when working with both health and disability insurance) and still hope for the best. Your physician can provide an estimate, based on your expected responsibilities, as well as your normal level of weakness and the surgical plan—but no one really knows how any given person will react to and recover from surgery—especially someone with MG.

A patient who does heavy lifting or construction work, or is a school teacher or hospital nurse on his/her feet all day, may need to be off work longer than someone who has a desk job. And the mom or dad whose day job is taking care of a toddler may need extra help until he/she is able to safely lift 25-30 pounds. It is also hard to predict the fatigue factor with MG. It is better for those who are employed and planning to return to work to ask your physician to write for a longer time off for your short-term disability. If you feel great and are ready to go back, no one will argue if your doctor reduces the needed

time off. It is encouraging to note that most patients have very few problems after the surgery and are able to return to their usual pre-operative activities.

### Will my insurance pay for the surgery?

Health insurance companies do pay for thymectomies. Since there may be questions concerning insurance coverage with specific surgeons and specific institutions, it is a good idea to check with your insurance company as soon as a thymectomy is being considered to make sure that the coverage is in order. Some insurance companies may require additional consultation and some type of prior authorization. In some instances, letters from the neurologist and surgeon will be required to defend the procedure selected.

### Summary

This brochure covers just a few of the many considerations you may have while deciding if thymectomy is the right path for you. Physicians and nurses want their patients you to do well and a large part of that means that you and the others they treat are as informed and involved in your own care as possible. Please reach out to MGFA if you have questions, or need more information about this or any other aspects of your MG treatment.