
Questions for your Medical Team

The following questions have been documented to help ease stress and so that you can have the tools you need to ask all the questions that are relevant to you and your condition. Bring these questions with you and ask you Neurosurgeon, Endocrinologist, ENT, assisting nurse, Anesthesiologist, etc.

Recommendations for your appointments:

- If possible, take a voice recorder with you, ask permission to record the consultation with them, at home download MP3 to computer (this way you have a File you can refer back to), Listen carefully making notes. You can backtrack if you need to understand something better.*
- Bring a friend or family member*
- Take Notes*
- Don't be afraid to ask any questions*

Medical Team / Experience

- What are the action steps we should take?
- What treatment options might be right for me?
- What do I need to know about the treatment recommended for me?
- If I have questions, can I call you or email you? What is the best time and way to reach you?
- How many pituitary tumors do you see a day / week / month?
- How many patients with Acromegaly have you seen?
- How many tumors have you operated on that were excess growth hormone producing?

Questions for your Medical Team

- What is your experience with Acromegaly?

Medical Team

- Should I seek out any other specialists to help in my treatment?
- Who is your Medical Team?
- What is their experience?
- Can patients meet the team and ask questions?
- Will they be assisting during surgery?

Endocrinologist

- What are the action steps we should take?
- What treatment options might be right for me?
- What do I need to know about the treatment recommended for me?
- If I have questions, can I call you or email you? What is the best time and way to reach you?
- What is the difference between Gigantism and Acromegaly? Can someone be diagnosed with both? If so, how is that possible?
- Are there different / multiple types of growth hormone? If so, what are they and what is the difference?
- What is your definition of Remission?

Questions for your Medical Team

- What role does diet play in Acromegaly?
- What about naturalpathy, holistic therapy, supplements?
- Can Acromegaly be genetic? Are there areas of the where Acromegaly is more prevalent? Why?
- How does sleep affect Acromegaly?
- How common is 'brain fog' with patients? is this due to the tumor?
- Will any of the Acromegalic symptoms dissipate post surgery? For example, enlarged hands / feet / tongue, sleep apnea, fibroid, fatigue, joint pains, headaches, etc.
- How soon should you do your colonoscopy after diagnosis?
- Is there any pre-screening that can be done to see if you or your family has the propensity of Acromegaly?
- What is adrenal insufficiency? How common is it? How does it occur? What are the chances of getting this?
- Does consuming alcoholic beverages have any negative / adverse affects on Acromegaly? For example, does it increase growth hormone excretion?
- Does consuming alcohol have any negative side effects while on medical therapy?
- What are the connections with pregnancy?

ENT

- What is your role in the patient's surgery?

Questions for your Medical Team

- What procedure do you use during surgery?
- How do you know if you have nose polyps? Can these be removed during surgery?
- What is turbinoplasty?
- If someone has had previous nose surgery, will this present an issue? Can you tell if the surgery was done well?
- If I have questions, can I call you or email you? What is the best time and way to reach you?

Therapy

- Do you feel that patients should speak to a therapist? If so, why?
- How soon do you recommend speaking to a therapist?
- How do you find a good therapist?
- What should you look for in a therapist?
- Can you recommend someone in the area?

Physiology

- What is physiology?
- Do you recommend working with a physiologist (Pain Specialist)?
- Can you recommend a ?physiologist

Questions for your Medical Team

- How soon do you recommend seeing a physiologist?

About Surgery / Recovery

Surgery

- Which procedure does your center use, transsphenoidal (nose) or sublabial (lip)? Why?
- How long does the surgery take?
- What procedure is used during this surgery? Explain in details.
- Are the surgeries recorded (audio / video)? If so, can patients request a copy?
- Are there any stitches in your nose post surgery? Do they dissolve or will they need to be removed?
- What is Craniotomy surgery and why would you need this?
- What are rescue flaps, and why are they important?
- During the surgery, the bone flap is removed. How is this put back into place and anchored back down? Are there any risks / complications that may occur?
- If the pituitary has been flattened by the tumor, does it reform after the tumor has been removed?
- If there has been excess bone growth, can this be seen in an MRI? Why would this occur? Can it be fixed?

Questions for your Medical Team

- How can you tell if the mucosa has been damaged? What are the complications should this happen? Will the mucosa repair itself?
- How is the mucosa moved out of the way to successfully perform the surgery?
- If the patient uses a CPAP, should they bring that to the hospital? If not, why?
- When can the patient continue to use their CPAP?

Risks & Complications

- What is a brain stem injury? How does this affect the patient long/short-term? How often has this occurred in your surgery room?
- Are there any issues with intubation if your tongue is enlarged? What are the risks, issues?
- If there is scar tissue from previous surgeries, can this be cleaned up/removed? Does the scar tissue present any complications?
- Has there ever been a time where the patient's nose was damaged during surgery? If so, what happened?
- How often did you hear that people have lost their sense of smell? If so, will this return?
- What are the possibilities of nerve damage post surgery?
- What is a CSF leak? Why would this not be presented as a possibility that it may occur? Seems a few people had this happen and woke with nasal

Questions for your Medical Team

packing, a scar on their stomach, a drain in their spine, and a Foley catheter.

- What is Diabetes Insipidus? Why does this happen? How common is this?
- What percentage, roughly, of your patients have experienced CSF leaks or Diabetes Insipidus?
- How likely does meningitis present itself post surgery? How many times has one of your patients contracted this?
- What are the complications / risks if the tumor is wrapped around the optic nerve?

Recovery

- What is the recovery time for surgery?
- What are the limitations post surgery? (lifting, straws, bending, sneezing, coughing)
- What is the % chance of a cure after surgery?
- How long will the patient be required to remain in the hospital?
- How soon can you drive / fly after surgery?
- What should the patient expect post surgery?
- What is your definition of Remission?
- When can the patient expect to see the symptoms ease / cease after surgery?

Questions for your Medical Team

Tumor

- What grade is the tumor?
- Based on what you know of the patients tumor, what are possible complications?
- Will you be able to get ALL of tumor? If not why?
- If the tumor is around the carotid artery / optic nerve, how close can you safely get to the artery?
- In the past, has the carotid, pituitary gland, optic nerve, etc. been damaged during one of your surgeries?
- How much (%) of the tumor is pushing on / wrapped around the carotid artery or optic nerve?
- Can you tell how long the tumor has been present by looking at the MRI? After de-bulking?
- If the tumor grows upward, and cannot be de-bulked during surgery, do you need a second surgery?
- If the tumor is wrapped around the carotid, or too high to remove, will it potentially move to a better position?
- If a second surgery to de-bulk the tumor, is there a waiting period?

Head Stabilizer

- Do you stabilize a patient's head down, and if so, what do you use?

Questions for your Medical Team

- Who clamps the head down?
- Would the patient be sedated or awake when the clamp is put on? If it's too tight it seems to leave long term damage / pain with people
- What type of head clamp does your center use? (brand / model)
- If you do not use a clamp, how do you stabilize a patient's head?
- What is the head moves during surgery if it is not stabilized?

Testing

- How soon until we can retest hormone levels?
- Why do levels go back up? At what point is it concerning?
- Why do IGF-1 levels fluctuate throughout the day?
- What is the difference between the tests conducted by different labs? why do these numbers fluctuate so much?
- Which Lab does your team use, and why?
- Is it possible for your IGF-1 is within normal range, but your GH is still high (or vice versa)? What would cause this?
- Do I need a glucose tolerance test done?
- Do you have a high resolution MRI machine? 3D? 4D?
- Which lab does your team use to test IGF-1, GH, etc.?
- What type of test is used to test hormone levels?
- How long does it take to get the results back?
- Are results posted to patient portals? How quickly are they posted?

Questions for your Medical Team

- What is the link to your patient portal?

Postoperative Therapies

- What are the remission rates?
- When and how often does a patient need to conduct MRIs post surgery?
- What medications do you recommend beginning with? and why?
- Why do you believe all the medications are all injectibles at this time?
- At what point do you recommend putting the patient on medical therapy?
How many weeks post surgery?
- Is there any long term damage that can come about from a lifetime of medication for Acromegaly?
- How does exercise impact Acromegaly?
- Does exercise increase the production of growth hormone?
- Should weightlifting be avoided? Running? etc.
- What do you recommend?

Radiation Therapy

- What are your thoughts on radiation therapy?
- What type(s) of radiation does your team use?
- What is gamma knife radiation?

Questions for your Medical Team

- How effective is radiation?
- Why is the recovery period so long with radiation therapy?
- Should you continue medication during radiation?
- How much does radiation damage the pituitary? other parts of your body?
- How many rounds of radiation are required?
- How often do you see that patients experience strokes, brain dysfunctions, and / or new tumors developing due to radiation?
- Do you have any written stats for any of your results that can be shared?
- When do you recommend radiation therapy and why?
- What are the side effects of radiation? Related Diseases
- What is Acromegaly-induced cardiomyopathy?
- If family members have had other brain tumors, how likely is it that these are related to the pituitary tumor?
- Tinnitus - why are so many people experiencing this after surgery?

Additional Resources

- Acromegaly.care, “Talking to Your Doctor” -
<https://www.acromegaly.care/wp-content/uploads/2015/10/Dialogue-Guide-for-Acromegaly-Patients.pdf>
- AcromegalyCommunity.com, “Thoughts for the Medical Office” -
<http://acromegalycommunity.com/new-patients/thoughts-or-the-medical-office>

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