



# SAN DIEGO BRAIN TUMOR FOUNDATION

Supporting the Needs of Patients & Families

## 25 QUESTIONS TO ASK YOUR DOCTOR

This is a list of questions for newly diagnosed brain tumor patients. It is designed to put you in control of your life again and help you make proactive choices.

Please take a family member or friend with you to take notes or tape the discussion at all doctor's appointments. We often are so nervous, we only hear part of what is said, or hear it differently than someone else. No one gets answers to all these questions at one doctor's appointment - they are meant for you and your family to think about and discuss with various members of your entire medical team.

Some patients find it helpful to take copies of all their current medications, allergic reactions and insurance details to their appointments to better cope with the frustration of filling out multiple forms. I hope this helps you and your loved ones discuss and make informed treatment decisions.

### **IT IS ADVISED TO START A MEDICAL NOTEBOOK, WHERE YOU CAN INCLUDE REFERENCES LIKE THIS**

Below are some questions to ask your medical team of doctors and other things to think about, especially if he or she is recommending immediate surgery or radiation for your tumor. Simply being told that surgery is required tomorrow, or that nothing else but radiation can be done, is not conducive to making an informed medical decision.

### **1. What specific operation or procedure are you recommending for my condition? If it were your son or daughter, what would you do? Who would you recommend I go to for a second opinion?**

Note: PLEASE BE SURE to get another opinion, especially if you are not satisfied with your current doctor and your symptoms are still manageable. Sometimes two or more are appropriate – remember, this is YOUR brain. You AND your loved ones want to be satisfied with your doctor and his or her team. Human error sometimes occurs, and another doctor might see something that was missed the first time. SURGERY OR RADIATION are both options for some people. Some neurosurgeons are specialists in brain surgery; make sure yours is experienced with your tumor type and location. If they tell you they cannot operate, that does not mean all neurosurgeons will have the same opinion. I think you might find that there are almost as many medical opinions and treatment options as there are doctors and equipment.



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**2. Do you have any free reading material or brochures about my tumor? Do you have photos/illustrations or any written information about this procedure or surgery? Where can I get additional reading material about my tumor and/or your planned treatment?**

**3. What kind of equipment do you use? Do you have modern MRI guided treatment? How old is your equipment? Can you explain what kind and how much radiation I will get?**

Note: Radiation is measured in units called grays. (There are several different types of brain radiation machines like Gamma Knife, Electra, Linac Accelerator, Peacock IMRT, Proton Beam, etc.)

**4. Can I have free copies of my printed MRI reports? A free copy of my own set of MRI films? Can I send my MRI films to other major medical locations that have free evaluations and consulting services?**

Here are a couple more geographic places that give free consultations - this is a good way to get information and a free second opinion from some of the best places in the country. (The only costs should be for the Fedex copies of your MRI or CT scans.)

Cedars-Sinai Neurosurgical Institute in California  
1-800-CEDARS-1 (1-800-233-2771)  
[www.csmc.edu](http://www.csmc.edu)

Duke University Medical Center in North Carolina  
[www.mc.duke.edu](http://www.mc.duke.edu)  
1-800-MED-DUKE (1-800-633-3853)

Note: If you ask for personal MRI film copies BEFORE the MRI or CT scan imaging appointment, it may be easier to get them for free or at a reasonable cost. If you keep your own sets, you are always ready for your next appointment and can learn to make your own comparisons of size and location of tumor.

**5. Are there different ways of treating this condition or doing this procedure? Will you do a biopsy first? Will hormone receptor tests be included in the pathology report? Why do you want to do the operation or procedure one way instead of another?**

Note: There are several theories and ways to access inside your skull or attach equipment depending on tumor location and brand name, etc.



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**6. Why do you think I need this operation or procedure and how soon? To relieve pain? To reduce my symptoms? To improve my body function? To diagnose my condition/problem? To save my life?**

Note: One doctor may say you need surgery immediately, while another one may say you have a few weeks, months or even more, to consider treatment plans. You will have to choose what you are going to be comfortable with, based on your own symptoms, and the information you have gathered and been given.

**7. What are the risks/side effects/complications/benefits associated with my condition or this procedure and/or medications? And afterwards? Is it written down anywhere for me in printed materials? Did I sign a release? How common are these risks/side effects/complications/benefits? What is the current location and size of my tumor? What functions and parts of my brain or spinal cord may be affected by this tumor or this treatment? Swelling or Edema? Nerve damage? Balance? Vision Paralysis? Weakness?**

**8. What are the advantages and benefits of this particular surgery or procedure you are recommending? What is the next most frequently used standard treatment? What are it's advantages/disadvantages? What will my follow-up care and medications be like? Will it include annual MRIs or medications? If so, for how long? The rest of my life?**

**9. How long do you anticipate the surgery or this procedure to take? How long will my family and loved ones have to wait? Hours, days or weeks? Where can they wait?**

Note: Most regional or national brain centers have budget housing and there are medical discount airfares and some free flights by volunteer pilots for those in financial need.

**10. Is this surgery/radiation procedure considered experimental in any way? How many times is it performed in the US each year? How about at your hospital? Is there a good reason to try something that is not standard or brand new?**

**11. How many brain tumor patients with this specific type of condition do YOU treat each month? Week? Year? Can I meet or talk to some of them? How does that compare to other doctors/facilities/teaching institutions in this area? Regionally? Nationally? What are my priorities now?**

Note: Cost wise too, can or should I travel far away to a national major medical center for the most well known doctor or treatment and be away from home, family and friends, or is the major regional medical center or university hospital going to have a skilled, competent physician, and team and be more convenient for me and my family and closer for follow-up



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visits in the future months and years ahead? What if this or complications become a medical crisis or emergency down the road?

**12. What are YOUR RESULTS with this condition and this type of surgery or treatment? Do you think the known benefits outweigh the unknown risks?**

Note: Choose a neurosurgeon, radiologist, neuro-oncologist or oncologist who has had plenty of experience. Ask how familiar he or she and their team are with your tumor location, type and their newer treatments and their own new equipment.

**13. What kind of anesthesia and pain killers will be used? Is there a choice? If so, what are they? How long will I need them? What about anti-seizure meds? Do I need them? If so, for how long? What side effects might occur?**

**14. Are there any medical chemotherapy treatments available that you know of? Clinical Trials?**

Note: You can check out [www.virtualtrials.com](http://www.virtualtrials.com) and NCI Clinical trials list.

**15. Should I continue to take all my regular and over the counter medications and supplements, including thyroid medicines, hormone replacement therapy? Birth control? What about Norplant? What if I am pregnant? Or get pregnant?**

Note: These tumors are often thought to be hormone related, and some medical researchers say are stimulated by pregnancy, progesterone, estrogen and/or perhaps pre-menopause, or menopause especially in females. Maybe ask an endocrinologist about hormone receptor drugs?

**16. If I don't do anything about this problem, what's likely to happen? What benefits can be expected from this therapy? When? What are TIA's (Transient ischemic attacks)? Stroke symptoms?**

**17. Is one alternative to immediate surgery or radiation treatment "watchful waiting"? What are the risks for me if we choose to wait and watch my MRI's for a while or for several years? What if I just want it done right away to avoid an agonizing wait? How can I reduce stress? What complementary therapies or nutritional foods can I use in addition to treatment?**

**18. How might this tumor, surgery or treatment options affect me and my family - financially? Physically? Mentally? And last but not least, emotionally? Will I have personality changes? Mild brain damage?**



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**19. What is your follow-up plan if this current surgery or treatment does NOT work? How important is this to know ahead of time? Can it be predicted by biopsy or pathology report after surgery?**

**20. How much of the cost of this treatment will my insurance/Medicare cover? How much will I have to pay out of pocket? Can I try a clinical trial treatment?**

Note: You may also have to call your insurance company or HMO for this information, especially if you decide and want to go out-of-network and/or out of town. BE POLITE AND PERSISTENT!

**21. What effect will this surgery/radiation procedure have on my other medical problems and medications? What benefits can be expected from this treatment? How long do you think I might be hospitalized? In ICU?**

**22. What other medical costs or medications will there be after the surgery or this radiation procedure? What are the correct doses? Will I need any cognitive therapy? Occupational or physical therapy? Neuropsychological testing? Before and/or after treatment? What if I still need more radiation or surgery? When? Why? Who will pay?**

**23. Can I donate blood before surgery to have on hand in case I need it? Can others donate blood for me, too? Do I have time to think about this surgery or treatment? How much time?**

Note: Donating your own blood before surgery is called "autologous donation" and is not usually needed for most brain surgery, but if done, is several weeks before surgery.

**24. When will I hopefully be discharged from this facility/ hospital/institution? How much medical care or rehab might be needed when I return home? Can my family care for me? Can I get extra help? When can I drive again? What kind of home care is available and how much will it cost?**

**25. When will I be able to return to work (either full-time or part time) and handle everyday activities again? What about Disability and Social security payments? Can I talk this over with a hospital social worker? Now? Later?**

**26. How long do you think I might need medicine afterwards? How often will I be followed up with? Who do I call and talk to about chronic after effects? How much and how many meds? What are their side effects? What if I become allergic to them? What symptoms should I look for?**



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## **27. Do you have a copy of my Advance Directives?**

Note: This is about life support decisions. This is a must before any hospital procedure and/or biopsy, no matter how minor. Usually at large hospitals, they have a legal notary public available before any surgery or procedure.

## **28. After this treatment, can I prevent this condition from happening again? Where do your opinions or statistics come from? How often will I have follow-up MRI's? Semiannually? Annually?**

## **29. Where can I get a SECOND opinion about this?**

Note: Many HMO insurance companies and Medicare options pay for a second opinion, but you must often ask specifically. If the doctor protests - instead of recommending another respected doctor for a second opinion, you probably don't want him anyway! In my humble opinion, second opinions should be standard and mandatory. You should not feel intimidated into automatically accepting the first diagnosis or prognosis when your life or the life of your loved one is at risk.