Questions for Your Health Care Team

It is understandable that after your diagnosis you may have left your doctor’s office or hospital not knowing what questions to ask. You may be concerned about your symptoms, want clarification on your diagnosis or want to discuss treatment options. The ABTA encourages you to take these questions to your health care team, who can provide personalized answers. Below are some suggested questions you can ask your health care team.

Questions about your diagnosis:

- You performed a number of tests. What did you learn about my tumor?
- Do you need to do any more testing? What tools or tests will you use?
- What is genotyping* and what will it tell you about my tumor?
- Does your center/hospital offer genotyping*?
- When is the optimal time to have genotyping*?
- If your center doesn’t provide genotyping, where do you refer patients who desire this testing?
- What are biomarkers and what will it tell you about my tumor?

*Tumor-specific questions:

- What can you tell me about my brain tumor?
- How do you expect my brain tumor to progress?
- What is my prognosis?
- How likely is recurrence?

Some people – and some doctors – are reluctant to talk about serious and painful issues. However, an open, communicative relationship between patients and doctors will lead to the best outcome. You may need to advocate for yourself to get the answers you need. No question is too silly or too trivial.

Tumor-specific questions:

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- How do you expect my brain tumor to progress?
- What is my prognosis?
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Questions about treatments options:

- What are the treatment options available?
- Can treatment wait?
- How long do I have to make decisions about my course of treatment?
- Are there alternative treatment options?
- How do you determine if the treatment is effective?
- What are common treatment side effects?
- Can I work and/or resume activities while in treatment?

*Genotyping: testing that can reveal the specific genetic mutations within a patient’s brain tumor from tissue that is collected at the time of surgery and then frozen and/or embedded in.

Biomarkers can then help predict the response and sensitivity of the tumor cells to certain treatments. Research has shown that doctors may be able to use biomarker information to guide the optimal course of treatment that is individualized for the patient.
If surgery if recommended, what to ask prior to the procedure:

- Where the tumor located and what is its size?
- What are the risks of removing the tumor? In other words, will surgery impact my memory? My ability to think? My physical movement?
- How can I ensure enough of the tumor is removed so that I have the option to have genotyping?
- If the tumor is inoperable, what treatments do you recommend?
- What happens after surgery?

To learn more about clinical trials:

- What clinical trials are available and when would I be eligible to participate?
- Where can I find information about clinical trials?
- What are the possible risks and benefits of participating in a clinical trial?
- How will the clinical trial doctors coordinate with you while I participate in a clinical study?

General questions for your healthcare team:

- How many brain tumor patients with my tumor type do you treat each year?
- What other specialists will be a part of my healthcare team? (Neuro-oncologist, Neuro-surgeon, radiation oncologist, nurse, social worker, nutritionist, physical therapist)
- What do they do?
- How will each of these specialists communicate with you about my treatment?
- If I am hospitalized, will you be my doctor?

How to get support:

- Where can I get more information about my diagnosis?
- What support services are available to me and my family/caregiver?
- How do I talk to my employer about my diagnosis?
- How do I talk to my family and friends about my diagnosis?

Lifestyle questions:

- Do I have to change my diet?
- Do I have to make any lifestyle changes?

Questions to ask yourself:

- Does the health care team seem interested in my questions?
- Does my health care team spend enough time with me and address my concerns?
- Do I feel comfortable with the doctor’s recommendations?
- Is the doctor open to me seeking a second opinion?