

Diagnosis

SYMPTOMS

- Is there anything else that could be causing my <u>symptoms</u>?
- What should I be watching for to call for immediate help?
- How does the location of my tumor impact symptoms?
- What can you tell me about <u>palliative</u> <u>care</u> or other options to help manage my symptoms?

PATHOLOGY AND BIOMARKER TESTING

- What types of tests will be needed for a proper diagnosis?
- What is the difference between <u>pathology</u> and <u>biomarker testing</u>?
- Will I need a biopsy or surgery to get a tissue sample for testing?
- Will you use the <u>2021 WHO Classification of</u> <u>CNS Tumors</u> to diagnose my tumor?
- Do you conduct biomarker testing at this facility, or will my tissue be sent to an external company? Is there enough tumor tissue for additional biomarker testing if we want to send it for external testing?
- How can I get a sample of my tumor tested



for biomarkers to learn if any <u>targeted</u> <u>therapies</u> might treat my <u>tumor type</u>?

- Which biomarkers should be tested for my tumor type? Can you explain how they might affect my response to therapy and treatment?
- Are there any reliable sources where I can read about the biomarkers you explained?
- What is the process for determining the pathology of my tumor?
- How long will it take to get results from the pathology and <u>biomarker testing</u>?
- What do the results indicate about my prognosis?
- Who will go over the results of my pathology and biomarker reports with me and explain what they mean for my diagnosis, treatment, and prognosis?
- Does my insurance cover the costs of biomarker testing? If not, is there financial assistance available?
- Are there targeted therapy drugs, <u>immunotherapies</u>, <u>clinical trials</u>, or other treatments I might be eligible for based on the results of my biomarker tests? If yes, what is this drug or treatment called, and do you recommend it?
- Should my family and I see a <u>genetic</u> <u>counselor</u>?

Diagnosis

TUMOR TYPE

- What is the name of my tumor type?
- What is the grade of my tumor?
- What is the location and size of my tumor?
- How might the location of my tumor impact my symptoms?
- How many patients have you treated with this <u>type of tumor</u>?
- What biomarkers are present in my tumor?
- What were the results of the <u>methylation</u> analysis? Will these results affect my treatment plan?

SECOND OPINION

- Is it safe to delay treatment to pursue <u>a</u> <u>second opinion</u>?
- Who would you recommend for a second opinion?
- Should I consider visiting a <u>National Cancer</u> <u>Institute Designated Cancer Center</u>?
- Is there a specialist in our region for this type of tumor?
- Who are the top three clinical and research experts on this tumor type?
- How do I obtain access to my medical records? Can I get copies or access my electronic file? (*This can help when you meet a new specialist or if you'd like another opinion.*)

• Would you be willing to work with another provider in a collaborative manner should I pursue a second opinion elsewhere?

TREATMENT

- What are the standard of care (SoC) guidelines to <u>treat my tumor</u>, and what do you recommend for my treatment plan?
- What are the risks and benefits of the standard <u>treatment</u>? What are the risks and benefits of the treatment you recommend (if different from the standard treatment)?
- Would any <u>advanced imaging</u> help better determine my tumor's response to treatment?
- Are all of the standard treatment options suggested for my diagnosis available at this center? If not, what center do you suggest I go to for treatment?
- How will the results of <u>biomarker testing</u> affect my treatment plan?
- Are there mutations present in my tumor? Will mutations affect your approach to treating my tumor?
- Do I qualify for any available clinical trials and, if so, what are they testing? Does that include trials outside of this institution? (*You* can also visit the <u>NBTS Clinical Trial Finder</u> to search for clinical trials you might qualify for.)
- Will treatment impact my ability to enroll in clinical trials in the future?





Diagnosis

- What are <u>novel treatments</u>, and are there any you would recommend for my specific case?
- What are the potential short-term and long-term <u>symptoms and side effects</u> I may experience from treatment?
- What can I expect at the time of treatment, just after treatment, over the course of recovery, and in the long term?
- Will <u>treatment affect my fertility</u>? Is there an oncofertility specialist or reproductive endocrinologist I could speak to before I begin treatment?
- Will treatment affect my ability to exercise?
- Will treatment affect my ability to have sex?
- Will I be able to work while I am in treatment?
- Will treatment affect my appearance?
- Can we discuss my goals and priorities regarding quality of life?
- How will <u>palliative care</u> be part of my treatment plan?
- What can I do to prepare for treatment?
- How long will my treatment last?
- What will my recovery look like?
- What is the likelihood this tumor will return after treatment?
- Will I need rehabilitation services, like speech, physical, or cognitive therapy? Are

there rehabilitation centers that focus on neurological recovery that you recommend?

• What additional treatments might I need?

QUALITY OF LIFE

- What is palliative care?
- What is the difference between palliative and hospice care?
- Will palliative care be a priority throughout my brain tumor experience?
- Can we discuss my goals and priorities regarding quality of life?
- Will I have access to social work support?
- What <u>additional resources and organizations</u> are available for support?
- Can you suggest <u>support groups</u>, <u>financial</u> <u>assistance services</u>, and/or a cancer resource center in the area for me and my caregiver?
- Does your office or health system have an online portal that we can use for communication? How do I access an account?
- Will there be enough time during appointments to talk through my questions, or should I schedule an additional appointment to discuss them? Who is the best person to connect with after this appointment to answer follow-up questions, and what is their name and contact information?



NOTES

Diagnosis

- What is the best way to reach you if I have questions after today?
- How will we address <u>mental health support</u> throughout my brain tumor experience?
- To what extent will I need caregiver support throughout my brain tumor experience?
- Does your health system offer spiritual support through a spiritual care advisor?
- What is the potential impact on <u>my</u> <u>insurance coverage and financial situation</u>?