

Note: The original online questionnaire has been transferred to a Word file to reflect skip patterns that were programmed into Survey Monkey. The survey is reproduced here as a PDF file.

Patient, Caregiver, and Provider
Treatment Information and Support Survey

Introduction

The purpose of this survey is to help the National Brain Tumor Foundation (NBTF) and the Brain Tumor Society (BTS) better understand the needs of patients and their families as they cope with a brain tumor diagnosis. Your responses will guide the efforts of our organizations in helping to develop services to better support the brain tumor community.

Your decision to participate in the project is voluntary. You can choose to not answer any questions you would like and you can stop the survey at any time. Your responses will be kept confidential and will not be connected to your name. The patient/caregiver portion of the survey takes about 30 minutes to complete. The health professional portion of the survey only takes 5 minutes to complete.

Thank you in advance for your help with this important project!

1. Which of the following best describes you? (Please select only one response).

- A health professional who works with brain tumor patients (Go to Question #2)
- A person who has been diagnosed with a brain tumor (Go to Question #11)
- A relative (e.g., spouse/partner, sibling, parent, child) (Go to Question #11)
- Friend (Go to Question #11)

Other (Please specify): (Go to Question #11)

Please note:

Section I is for health professionals only.

If you are a patient or loved one, please skip to Question #11 (Section II).

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Section I: Questions for Health Professionals

**THESE QUESTIONS ARE FOR HEALTH PROFESSIONALS ONLY.
If you are a patient or loved one, please skip to Question 11 (Section II).**

As a health professional, we see you as a stakeholder in the brain tumor community. Your responses will help us better serve patients and families coping with a brain tumor diagnosis.

2. Are you a:

Primary care physician

Neurologist

Neurosurgeon

Oncologist

Nurse or nurse practitioner

Social worker

Occupational, physical, or
speech therapist

Patient educator/ patient
navigator

Neuropsychologist

Counselor or therapist

Other (please specify):

3. In which state do you practice?

(If you practice outside the United States, please write "Outside the U.S.")

4. Approximately what is the total annual number of brain tumor surgeries performed at the treatment center where you practice?

- Up to 50 surgeries
- 51 to 100 surgeries
- 101 to 150 surgeries
- 151 to 200 surgeries
- 201 to 300 surgeries
- More than 300 surgeries
- Don't know / Not applicable

5. What percent of the patients you see have been diagnosed with a brain tumor?

- 0% to 25%
- 26% to 50%
- 51% to 75%
- 76% to 100%

6. What are the most common services / programs / departments that you refer brain tumor patients and caregivers to? (Please check all that apply).

- Benefits counseling
- Financial counseling
- Brain tumor patient education
- Home health
- Hospice
- Neuropsychological testing
- Psychiatry or Psychology
- Social work
- Support group
- Brain tumor organizations
- Cancer organizations
- Not applicable

Comments:

7. How can brain tumor patients and their families be better served by patient advocacy and support organizations?

Outreach and Collaboration

Our organizations work hard to spread the word about resources that are available to the brain tumor community. We are always looking to collaborate with health professionals to better support the patients they serve.

8a. Would you be interested in receiving a sample of patient / family brain tumor education materials from either NBTF or BTS?

- Yes
- No (Go to Question #9)

8b. If yes, whom should we send the educational materials to:

Name: _____

Title: _____

Address 1: _____

Address 2: _____

State: _____

Zip: _____

Telephone number: _____

E-mail: _____

9a. Would you be interested in learning more about any of the following collaboration opportunities offered by our organizations?

	Yes	No
In-service presentation at your treatment center concerning our services	<input type="checkbox"/>	<input type="checkbox"/>
Free caregiver training workshop for family caregivers	<input type="checkbox"/>	<input type="checkbox"/>
One-day informational conference for patients and families	<input type="checkbox"/>	<input type="checkbox"/>

9b. If yes to any of the above, who would be the best contact person at your treatment center for an in-service, caregiver workshop, or patient conference? (If no, please go to Question #10)

Name: _____

Title: _____

Address 1: _____

Address 2: _____

State: _____

Zip: _____

Telephone number: _____

E-mail: _____

10a. Are there any other ways that NBTF or BTS could collaborate with your treatment center to better support the brain tumor patients and families you serve?

10b. Please include any additional comments below.

Thank you for your participation!

We very much appreciate your time. The results of this project will be described in an upcoming publication. If you have any questions or additional comments, please feel free to contact the NBTF at 1-800-934-2873 or nbtf@braintumor.org.

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Questions for Patients and Loved Ones

Section II: Patient Diagnosis and Treatment

The first set of questions concern your / the patient's brain tumor diagnosis and treatment.

11. What type of brain tumor do you / does the patient have?

- Acoustic Neuroma or Schwannoma
- Astrocytoma, grade 1 or 2
- Anaplastic Astrocytoma (grade 3 Astrocytoma)
- Glioblastoma Multiforme (grade 4 Astrocytoma)
- Oligoastrocytoma / Mixed Glioma
- Oligodendroglioma
- Meningioma
- Metastatic brain tumor
- Pituitary tumor (Pituitary Adenoma)
- Don't know

Other (please specify):

12. Please check the box below that best describes the current stage of your / the patient's medical treatment:

- Just diagnosed / have not yet started treatment
- Currently undergoing active treatment (chemotherapy, radiation therapy, or other medical treatment directly related to the tumor)
- Completed treatment / being monitored
- Recurrence / receiving further treatment
- Patient no longer living
- Don't know

Other (please specify):

NEXT →

13. To date, which treatments have you / has the patient received?

(Please check all that apply).

- Surgery
- Chemotherapy
- Radiation
- Stereotactic radiosurgery (e.g., GammaKnife, Cyberknife)
- Experimental therapies (i.e., clinical trials)
- Complementary and alternative treatments (e.g., acupuncture, dietary supplements, homeopathy, massage etc.)

Other (please specify):

14. How long has it been since your / the patient's initial diagnosis?

- Less than 6 months
- 6 months to 1 year
- More than 1 year, but less than 2 years
- 2 to 5 years
- More than 5 years

NEXT →

15. In the first 6 months since diagnosis or recurrence, how often did you / did the patient see the following types of healthcare team members?

	Often	Sometimes	Rarely	Never	Not Applicable/ Don't Know
Primary care physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neurosurgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Oncology doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurse / nurse practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rehabilitation specialist (e.g., occupational, physical, or speech therapist)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient educator / patient navigator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neuropsychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counselor / therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support group leader	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify):

NEXT →

16. What factors did you / did the patient consider when choosing a treatment center?
(Please check all that apply).

Referral from my / patient's primary care physician

Insurance covered treatment at this center

Reputation of center and its medical staff

Having a brain tumor clinic

Distance from my home/patient's home

Referral from someone I know / patient knows

Availability of housing near the treatment center

Care received from medical staff

Other (Please specify):

NEXT →

Section III: Receiving Information and Support

The next section includes questions concerning how patients and caregivers have and would prefer to receive brain tumor and treatment-related information and support.

17. To date, how have you / how has the patient received brain tumor-related information?

(Please check all that apply).

- The healthcare team (i.e., doctors, nurses)
- The resource library at the treatment center
- Support group / other brain tumor patients
- Internet websites
- A non-profit organization (e.g., NBTF, BTS, American Cancer Society)
- Family, friends, acquaintances
- Not applicable, no information received

Other (please specify):

18. Where did you turn for information and support outside the cancer treatment center?

(Please check all that apply).

- Brain tumor organization (e.g., BTS, NBTF, ABTA)
- Cancer organization (e.g., American Cancer Society)
- E-mail listserv or online message board (e.g., T.H.E. Braintrust, Yahoo groups)
- Peer support program (“buddy” or “pen pal”)
- Online support group
- In-person support group
- Family
- Friends, colleagues, or acquaintances
- Community organization (e.g., church, club, or team)

Other (please specify):

NEXT →

19. Information can be provided in many different ways. What are all the ways you prefer to receive brain tumor-related information? (Please check all that apply).

During an in-person meeting with a healthcare provider

Brochure / booklet / factsheet / handout

Videotape / DVD

Finding information myself on websites

Downloadable audio/video file (e.g., podcast, mp3, etc.)

Telephone helpline provided by a brain tumor organization

Brain tumor conference for patients and families

Teleconference / webconference with brain tumor experts

Other (please specify):

NEXT →

20. How easy or difficult has it been to find the following types of brain tumor-related information?

	Very Easy	Somewhat Easy	Somewhat Difficult	Very Difficult	Don't Know/ Not Applicable
Tumor type information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to choose a treatment center	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical trials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medication information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Necessary follow-up care (e.g., MRIs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cognitive changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seizures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify):

21. What other types of information would be helpful concerning brain tumors or treatment?

NEXT →

22. If the following services were available in your community free of charge, how likely would you be to use these services?

	Already Using This Service	Very Likely	Somewhat Likely	Not Very Likely	Would Not Use Service	Don't Know
Meeting with a patient navigator	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information and referral hotline provided by a brain tumor organization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A listserv or message board sponsored by a brain tumor organization to help you connect with other patients and families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Neuropsychological testing/cognitive therapy for the patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brain tumor specific "caregiver/family training" in your community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Informal events and activities to get to know other patients and families in your community sponsored by a brain tumor organization	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Brain tumor conference for patients and families	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NEXT →

23. If the following support services were available in your community free of charge, how likely would you be to use these services?

	Already Using This Service	Very Likely	Somewhat Likely	Not Very Likely	Would Not Use Service	Don't Know
Brain tumor in-person support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A brain tumor support group held over the telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Online brain tumor support group	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A "pen pal" who you can contact via email or phone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Telephone counseling services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In-person counseling services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services to support children of brain tumor patients (counseling, support groups, camps, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. What other types of services and support are needed for families of brain tumor patients?

NEXT →

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NEXT →

Section IV: Your Thoughts

The questions in this section deal with your thoughts about the experience of coping with a brain tumor diagnosis.

25. What are the biggest challenges you have faced in coping with your/the patient's brain tumor diagnosis?

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26. Families often experience significant changes in family roles when a family member is diagnosed with a brain tumor. For example, a breadwinner may need to stop working and older children may need to take on more responsibility.

a. What are the most significant changes you have noticed in your family as a result of the brain tumor diagnosis?

b. What has your family done to try to cope with these changes?

NEXT →

Section V: Practical Impact of Care

The next set of questions concern the practical impact of the brain tumor diagnosis.

27. The brain tumor diagnosis has affected your / the patient's ability to pay for which of the following expenses?

Basic living expenses (e.g., rent/mortgage, utilities, food, etc.)

Health insurance

Medical bills

Home health care bills (i.e., home health aide)

Credit card bills

Transportation expenses (e.g., buy gas, make care payments)

Other (please specify):

28. Has the patient ever delayed getting medical care since diagnosis due to the cost of care?

- Yes
- No
- Not applicable

Comments:

NEXT →

29. Has the patient ever chosen one medical treatment over another since diagnosis due to cost?

- Yes
- No
- Not applicable

Comments:

30. To what extent has lack of adequate transportation been a barrier to:

	Large Extent	Some Extent	No Extent	Not Applicable
Getting to medical appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using support services (e.g., support groups, counseling, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Performing necessary errands (e.g., grocery shopping, going to the pharmacy etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

Special Instructions:

If you have a brain tumor (i.e., patients, survivors):
Go to Question #32 (Section VII).

If someone you know has a brain tumor (i.e., caregivers, family, friends, loved ones):
Go to Question #31 (Section VI).

Section VI: Questions for Caregivers/Loved Ones

This section is for CAREGIVERS/LOVED ONES of brain tumor patients only.

If you have been diagnosed with a brain tumor,
please skip this section and proceed to Question 32.

31. (FOR CAREGIVERS/LOVED ONES ONLY)

How prepared did you feel to cope with the following:

	Very Prepared	Somewhat Prepared	Not Very Prepared	Not Prepared	Not Applicable
Patient personality changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient cognitive changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patient physical changes (e.g., difficulty driving, seizures, or fatigue)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changes in family roles (i.e., changes in day-to-day and/or job responsibilities)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments:

Please go to Question #32 →

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NEXT →

Section VII: About You
For BOTH patients and caregivers/loved ones.

The final questions are for descriptive purposes only to help NBTF and BTS describe the groups of patients and caregivers who completed the survey. All responses will be kept confidential.

32. What is your gender?

- Female
- Male

33. What is your age?

- Under 18
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 and above

34. Which of the following best describes the community where you live?

- Rural
- Suburban
- Urban

35. Do you live in the United States or outside the United States?

- In the United States
- Outside the United States (Go to Question #38)

36. In which state do you live?

37. What is your United States zip code?

NEXT →

38. Which of the following best describes your race/ethnicity? (Please check all that apply).

- African American or Black
- Alaskan Native or Native American
- Asian
- Caucasian
- Hispanic, Latino or Spanish
- Pacific Islander

Other (please specify):

39. What is your current marital status?

- Single, never married
- Living with a partner
- Married
- Separated
- Divorced
- Widowed

40. What is the highest level of education you completed?

- Less than high school
- High school diploma or GED
- Vocational, trade, or technical school
- Some college
- 2 or 4-year college degree
- Graduate or professional degree

NEXT →

41. How frequently do you use the Internet?

- One or more times a day
- A few times a week
- A few times a month
- Almost never
- I don't use the Internet

42. Any additional thoughts or comments?

43. Our organizations work hard to spread the word about resources that are available to the brain tumor community. If you think your doctor or treatment center could use additional educational materials for patients and/or caregivers, please provide their contact information below:

Health professional name: _____

Name of treatment center: _____

Address line 1: _____

Address line 2: _____

State: _____

Zip Code: _____

Telephone number: _____

NEXT→

Thank you for your participation!

We very much appreciate your time. The results of this project will be described in an upcoming publication. If you have any questions or additional comments, please feel free to contact the NBTF at 1-800-934-2873 or nbtf@braintumor.org.