



**Pediatric  
Brain Tumor  
Foundation®**

# Starfolio

Templates and Tools

*Third Edition*

As the world's leading nonprofit dedicated to children and teens with brain tumors, the Pediatric Brain Tumor Foundation's mission is to *care* for families along their journey, *cure* all childhood brain tumors, and help survivors and families *thrive*.

Find the digital version and share feedback at  
[www.curethekids.org/starfolio](http://www.curethekids.org/starfolio)

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Project Funder:



Program Partner:



Program Partner:



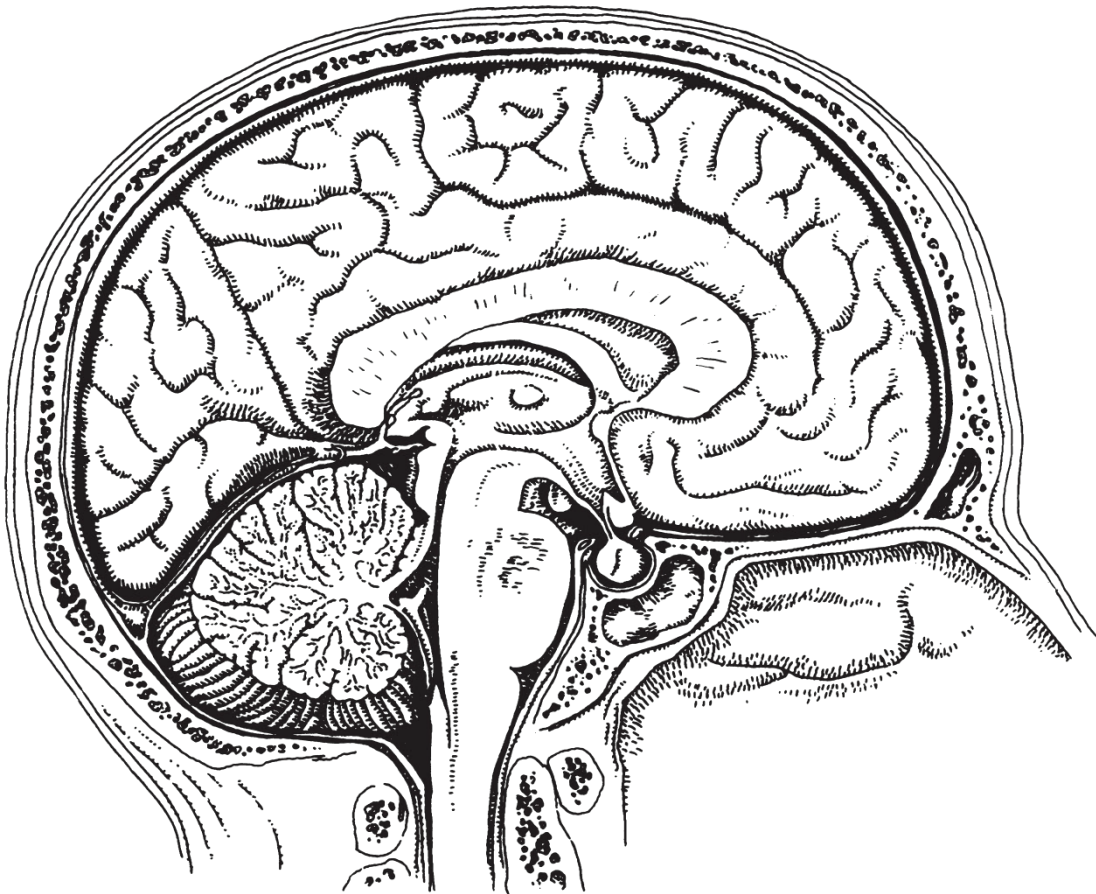
Download the templates  
and tools at [www.curethekids.org/  
starolio-templates](http://www.curethekids.org/starolio-templates).  
Make copies as needed.

# Templates and Tools



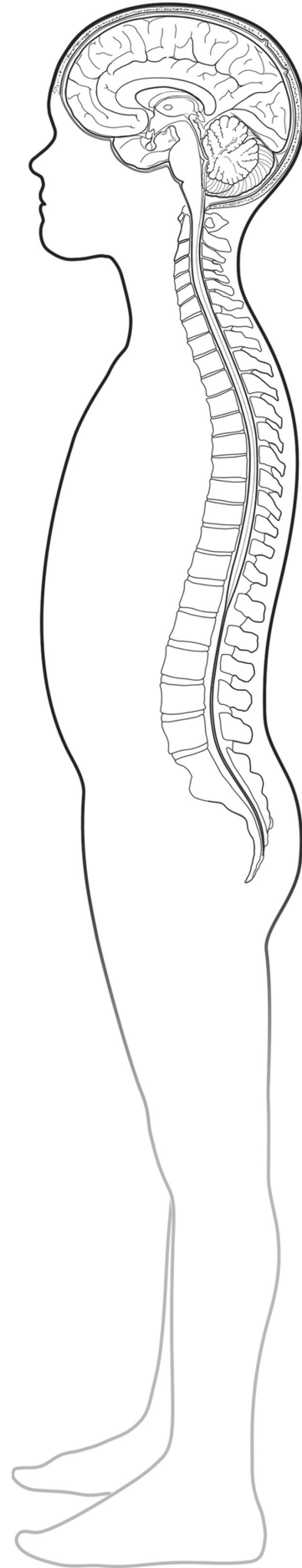
Use these pictures to help you understand your child's diagnosis and treatment. You can ask your doctor to draw the location of your child's tumor and the targeted areas for treatment such as radiation or surgery. You may wish to show the drawings to curious family and friends.

# Brain Cross Section



# Brain and Spine Cross Section

NOTES:



# Healthcare Team Contact Information

Use this form to keep track of the contact information for every healthcare team member you meet. Ask them for business cards which you can keep in this notebook. Make copies of this page so you can reuse it.

Healthcare team member name	
Specialty	
Date of first visit	
Hospital	
Address	
Phone / fax	
Email	
Website	
Best way to contact	

## Notes

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# Calendar Page

You can use this blank calendar page to write down appointments, track chemotherapy and blood transfusions, note when prescriptions need to be refilled, etc. Make copies of this page so you can reuse it.

<b>MONTH:</b>	<b>Saturday</b>					
	<b>Friday</b>					
	<b>Thursday</b>					
	<b>Wednesday</b>					
	<b>Tuesday</b>					
	<b>Monday</b>					
	<b>Sunday</b>					

# Parent-School Communication

**A student in your school has been diagnosed with a brain or spinal cord tumor. The child may have side effects from the treatment they receive and may have special needs at school.**

Please give a copy of this form to all staff members who work with this child, such as teachers, teacher assistants, nurses, office workers, and coaches, to help them understand these needs and to help the student if difficulties occur.

Student Name: \_\_\_\_\_

Grade and Teacher: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Type of Treatment Child is Receiving: \_\_\_\_\_

\_\_\_\_\_

Parent/Caregiver Name: \_\_\_\_\_

Phone #: \_\_\_\_\_

Specific Concerns (may include medical, physical, emotional, and educational concerns):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How the school can help:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Parent signature: \_\_\_\_\_ Date: \_\_\_\_\_

# How to ask the school for extra help for your child

You can use this letter to ask your school for special education services for your child. Adjust it to fit your situation. Asking for special education services does not limit your child's potential. Instead, it asks for a team at the school to work with you to make a plan to help your child succeed in school and learn all they can after they've had a brain tumor.

Dear Special Education Director,

Our son, [your child's name], date of birth \_\_\_\_/\_\_\_\_/\_\_\_\_, who is a \_\_\_\_-year-old, \_\_\_\_ grade student at \_\_\_\_\_ School, was diagnosed with a \_\_\_\_\_ brain tumor on \_\_\_\_/\_\_\_\_/\_\_\_\_. He has had surgery to remove most of the tumor, and is now going through chemotherapy and radiation. Our doctor told us that [your child's name] may struggle with physical, learning and social/emotional problems as a result of the tumor and treatment, and may need accommodations and/or special education services.

We ask that the school hold a Student Study Team/School Guidance Team for us to figure out if [your child's name] needs extra help in school through either a 504 Accommodation Plan or Special Education Supports and Services under the IDEA (Individuals with Disabilities Education Act). It would be helpful to pick a key staff member to talk with us and help with this process. Please send us the correct release forms so that we may give our permission for the school to exchange information with [your child's name]'s doctors who will provide you with the most useful medical records.

We have been told that a student who has a brain injury from a tumor and treatment has very unique needs, and needs at least one school team member who knows about brain tumors/treatment and the effects they can have on how a student learns.

We look forward to getting a written letter from you within a short period of time letting us know the steps the school district will take to make sure our son is considered for the right support and services.

Sincerely,

[signature of parent(s) or legal guardian(s)]



# Comparing 504 Plans and IEPs (Individualized Education Plans)

	504 Plan	IEP
<b>What is it?</b>	A written plan under <b>Section 504 of the Rehabilitation Act of 1973</b> , a civil rights law that allows students with certain disabilities to have accommodations in a regular classroom setting.	A more involved legal document under the <b>Individuals with Disabilities Education Act (IDEA)</b> that makes sure students with disabilities get special education services from their school if they need them.
<b>Who is it for?</b>	Students who have a physical or mental impairment that limits one or more major life activities (for example, learning, working, speaking) and have documents to prove it.	Students ages 3-21 who qualify to receive special education services after they are assessed by a team at the school. A student must have a disability that is within one or more of 13 specific categories listed in the IDEA.
<b>Does the plan include accommodations or modifications?</b>	504 Plans include <i>accommodations</i> (see box below for examples).	IEPs include <b>both</b> <i>accommodations</i> <b>and</b> <i>modifications</i> (see box below for examples).
<b>What kinds of help can a student get?</b>	Education in regular classrooms, education in regular classes with support services, or special education and related services: extra time to finish assignments and tests, a seat at the front of the class, audio recordings of textbooks, copies of notes, a short school day.	The accommodations in the box to the left of this one, plus special education teachers or other specialists, test support, alternate seating, changes to the curriculum like reducing the amount of homework, assistive technology, partial school day, smaller class size, speech and occupational therapy, counseling, and nursing services.
<b>How does a student get this help?</b>	A parent or school staff asks for a meeting. A 504 team will meet with the family and discuss the student's needs. A plan for accommodations will then be made.	A parent or school staff ask for an evaluation. After parents give permission, a team evaluates the student. An IEP team (including parents and student) meet to write an Individualized Education Plan.

# Medicines Taken

Your healthcare team can help you complete this form.  
 Make copies of this page so you can reuse it.

Name of medicine	Prescribing doctor	Why this medicine is being given	Dose	Time	How taken (pill, shot, liquid, IV)	How often	Side effects	Date started	Date completed
Example: Amoxicillin	A. Jones		250 mg	9 am	Pill	Twice a day	None	1/6/---	1/6/---

# Hospital Admissions

Keep track of your child’s hospital stays with this form.  
Make copies of this page so you can reuse it.

<b>Date</b>	
<b>Name of hospital</b>	
<b>Reason for admission</b>	
<b>Procedures performed</b>	
<b>Test results</b>	
<b>Treatments/drugs given</b>	
<b>Notes/comments</b>	

# Appointment Summary

Prepare yourself for every appointment by filling out this form. The form can also be used to summarize your appointment. Make copies of this page so you can reuse it.

<b>Appointment date &amp; time</b>	
<b>Doctor's name</b>	
<b>Address</b>	
<b>Phone/email</b>	
<b>Referred by</b>	
<b>Reason for appointment</b>	
<b>Concerns/symptoms</b>	
<b>Things to bring to appointment (medical records, insurance card, etc.)</b>	
<b>Questions for doctor</b>	

**Answers:**

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# Appointment Summary

Treatment/medication(s) prescribed or changed:

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Test results:

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Next steps:

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Next appointment date & time:

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NOTES:

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# Tests and Procedures Performed

List all MRIs, CAT scans, EEGs, and procedures.  
Make copies of this page so you can reuse it.

Date	Test/Procedure	Hospital and Doctor	Results or Reactions	Out/inpatient

# Surgeries Performed

List all surgeries.

Make copies of this page so you can reuse it.

Date	Surgery	Hospital and Doctor	Results or Reactions	Out/inpatient

# Weight/Height Monitoring

You can track your child's weight and height with this chart.  
Make copies of the page so you can reuse it.

Date	Weight	Height	Notes



# Symptom and Pain Monitoring

You can monitor your child’s symptoms, including pain, by using this chart and the pain scale below. Show it to your child’s doctors and ask them if they think it would be helpful or if they have another scale for you to use.

## PAIN INTENSITY SCALE

<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
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No pain ..... Worst pain imaginable

Date	Time pain medication taken	Pain rating before medicine 1-10	Pain rating after medicine 1-10	Medicine & Dose	Other relief methods

# Blood Count Tracker

Use this log to keep track of your child’s blood test results.  
Make copies of this page so you can reuse it.

<b>Date:</b>					
<b>Red Blood Cell Count (RBC)</b>					
<b>White Blood Cell Count (WBC)</b>					
<b>Hemoglobin (Hgb)</b>					
<b>Platelets</b>					
<b>Absolute Neutrophil Count (ANC)</b>					

# Blood/Platelet Transfusion Tracking

Use this log to keep track of your child's blood/platelet transfusions.  
Make copies of this page so you can reuse it.

Date	Time	Number of units	Red blood cells	Platelets	Notes

# Daily Food, Fluid and Supplements

Use this log to write down what your child eats and drinks, including any supplements your child takes such as vitamins. Bring this log to appointments to share with your child’s healthcare team. Make copies of this page so you can reuse it.

<b>DATE:</b>					
Liquids		Solids		Feeding tube	
Time	Volume	Time	Amount	Time	Volume
Total:		Total:		Total:	

<b>DATE:</b>					
Liquids		Solids		Feeding tube	
Time	Volume	Time	Amount	Time	Volume
Total:		Total:		Total:	

# Summary of Treatment

Use this form to track your child's treatment over time.  
The healthcare team can help you complete it.  
Make a copy of this template so you can reuse it.

**Date of diagnosis:**

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**Type of tumor (include any pathology specifics or further details):**

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**Surgery dates (include type of surgery):**

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**Does patient have a central line (include type and date(s) placed)?**

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**VP shunt (or other type of shunt, include date(s) placed):**

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**Radiation dates:**

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**Chemotherapies/biologics (include drugs, doses and dates):**

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**Other treatments or procedures and their dates:**

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**Significant treatment complications:**

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**Date of last ophthalmology visit:**

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**Date of last endocrine visit:**

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**Date of last audiogram:**

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# Health Insurance Interaction

Keep track of your conversations with your health insurance company with this log. Make copies of this page so you can reuse it.

<b>Date and time</b>	
<b>Name of person you spoke to</b>	
<b>Phone number</b>	
<b>Reason for call</b>	
<b>Notes</b>	
<b>Follow-up</b>	

# Phone Calls

Use this log to keep track of important phone numbers and phone conversations. Make copies of this page so you can reuse it.

Date	Time	Name	Phone #	Purpose of call	Follow-up needed?	Notes



# Weekly Activities

Write your normal daily and weekly activities and share this with a friend who can take the lead in getting others to help. Make copies of this page so you can reuse it.

Notes														
Volunteer contact information														
Volunteer name														
Activity (car pool, sports, dinner, etc.)														
Day/Time														

# Other Families I've Met

Use this template to list the names of other families you meet in clinic, at events or in support groups. Make copies of this template so you can reuse it.

Notes														
Email / website or blog														
Phone number														
Name(s)														

# Gift Tracking Sheet

Use this gift tracking sheet to send thank you notes for gifts or food your family receives. Make copies of this template so you can reuse it.

Notes														
Thank you sent?														
From														
Gift received														
Date														