# **COGNITIVE HEALTH GUIDE** FOR BRAIN TUMOR PATIENTS & CAREGIVERS

Advocate. Educate. Connect.

Powered by Head for the Cure Foundation\*

INS FOR CURE



# TABLE OF **Contents**

About	2
What is Occupational Therapy?	3
Exploring Occupational Therapy Settings	5
How Brain Tumors Affect Function: A Lobe-by-Lobe Overview	6
Frontal Lobe	7
Parietal Lobe	8
Temporal Lobe	9
Occipital Lobe	10
Cerebellum	11
Brainstem	12
Healthy Habits for Recovery	14
Goal Setting	15
Printable Goal Setting Worksheet	16
Understanding Mindfulness	17
Printable Mindfulness Worksheet	18
Working Memory and Attention Strategies	19
Printable Landing Pad	21
Planning and Organization Strategies	22
Printable Prioritization Worksheet	24
Problem-Solving Strategies	25
Printable Problem-Solving Worksheet	26
Questions to Ask Your Healthcare Team	28
Notes	31
References	37

Contact Information located on the back cover.



Brains For the Cure, a program of Head for the Cure, is deeply committed to making a positive impact on the lives of individuals and families affected by brain tumors. We understand the challenges and complexities that come with a brain tumor diagnosis, and we strive to provide comprehensive support, resources, and advocacy for patients, caregivers, and healthcare professionals.

Advocate, Educate, Connect,

Powered by Head for the Cure Foundation'

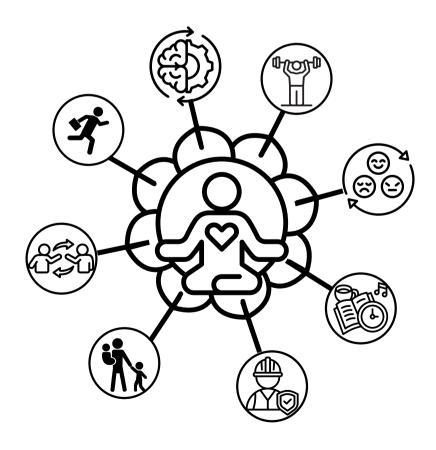
S FOR CURE

My name is Ally Ponticello, and I've partnered with Head for the Cure to create this guide because I understand how challenging a brain tumor diagnosis can be. As the daughter of a glioblastoma survivor, I've experienced the sudden changes and uncertainties that come with this journey. Brain tumors affect many areas of daily life, including cognition—the thinking skills you rely on to process information, make decisions, and navigate routines.

As an occupational therapy (OT) student, I created this guide to share my knowledge of OT and to make cognitive support strategies accessible to those impacted by brain tumors. Inside, you'll find interactive worksheets and cognitive strategies designed to support your cognitive skills. This guide is filled with practical tools, insights, and resources to encourage you to actively engage in recovery and reconnect with the activities that bring meaning and fulfillment to your life.

# WHAT IS OCCUPATIONAL THERAPY?

Occupational therapy (OT) helps brain tumor patients with the tasks they need or want to do to get through each day when faced with physical, cognitive, or emotional changes. OT takes a big-picture view of a person's life, focusing on the areas that make daily activities difficult. For example, OT might include exercises to strengthen your upper body so that you can get dressed independently or lift your child. It can also help with cognitive skills like memory and attention, making it easier to keep track of appointments or manage a busy day. OT can also provide education and training on adaptive equipment, like shower chairs or dressing hooks, to make everyday tasks safer and help you stay independent. Whether your goal is to be more comfortable at home or get back to work, OT is there to support you throughout your recovery, helping you maintain the quality of life that's important to you.



Imagine a healthcare approach that doesn't just treat symptoms but embraces the whole person body, mind, and spirit. That's the magic of occupational therapy... it's a journey of discovery, empowerment, and growth that touches every aspect of a person's life.

# EXPLORING OCCUPATIONAL THERAPY SETTINGS



#### **Acute Care**

In acute care, OT helps address immediate needs after a health event, focusing on basic self-care tasks (ADLs) like dressing and bathing. Therapists manage symptoms like pain and weakness, ensuring safety while planning for ongoing rehabilitation.



#### **Inpatient Rehab**

In inpatient rehab, OT provides intensive therapy to regain independence in both basic and instrumental daily activities (ADLs/IADLs). This includes improving motor skills, cognition, and adapting to challenges, with the goal of returning home or transitioning to a less intensive setting.



### **Outpatient Rehab**

In outpatient rehab, OT supports managing ongoing challenges with less frequent sessions, focusing on IADLs like work tasks, home management, and community mobility. Therapy aims to maintain progress and help individuals adapt while living independently at home.



#### **Home Health**

In home health, OT takes place in the person's home, focusing on modifying the environment for safety and ease of access. Therapists work with patients and caregivers to enhance participation in daily tasks (ADLs/IADLs) and improve independence and comfort.

#### **Community Services**

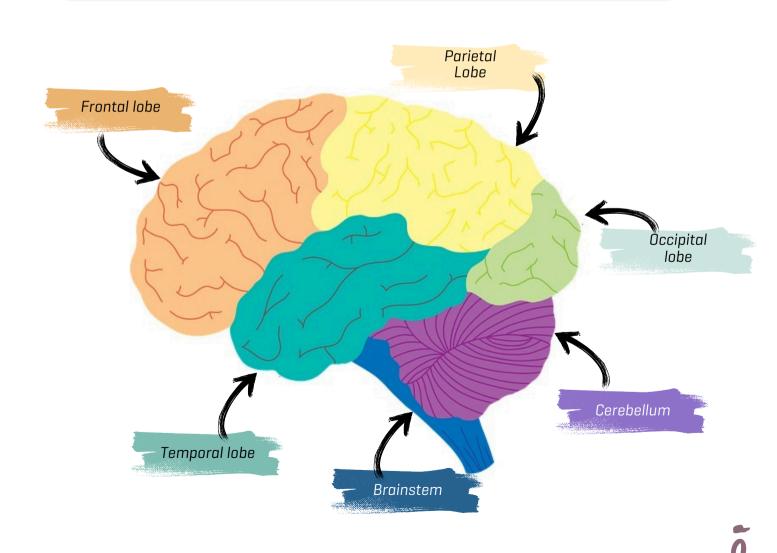
In community based settings, OT helps individuals reconnect with their community by supporting engagement in hobbies, work, and social activities. Therapists assist with vocational training, accessing community resources, and building social skills.

#### **Palliative Care**

In palliative care, OT enhances comfort and quality of life by helping manage symptoms and focusing on meaningful daily activities (ADLs/IADLs). Therapists prioritize maintaining dignity and supporting activities that reflect the individual's values.

# How Brain Tumors Affect Function: A Lobe-by-Lobe Overview

Facing a brain tumor diagnosis can feel like you're expected to become a neuroscientist overnight. This section aims to simplify that learning curve by breaking down the functions of the regions of the brain—the frontal, parietal, temporal, occipital, cerebellum, and brain stem—and explaining how a tumor in each area may affect those functions. Understanding this can help you and your loved ones better prepare for changes, participate in treatment decisions, and support the healing process.



### **Frontal lobe**

#### Region of the Brain

**Frontal** 

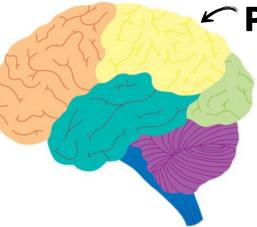
Lobe

### Function

- Manages voluntary movements and speech.
- Influences personality and emotions.
- Controls
   executive
   functions such
   as impulse
   control,
   attention span,
   planning,
   organization,
   problem-solving,
   and short-term
   memory.

- <u>Personality Changes</u>: You might act differently, becoming irritable or socially inappropriate.
- <u>Changes in Thinking</u>: Trouble planning, organizing, or making decisions.
- <u>Changes in Short-term Memory</u>: Trouble remembering recent events or new information.
- <u>Changes in Attention</u>: Trouble focusing, being easily distracted, or having a hard time staying on task.
- <u>Changes in Movement</u>: Weakness or paralysis on one side of your body.
- <u>Changes in Speech</u>: Difficulty speaking or language (aphasia).
- <u>Changes in Impulse Control:</u> Acting impulsively without thinking of consequences.
- <u>Changes in Emotions</u>: Mood changes like depression or lack of motivation.

**`Parietal Lobe** 



#### Region of the Brain

#### Function

- Processes touch, pain, and temperature.
- Helps you understand
   where your body
   is in relation to
   objects around
   you (commonly
   referred to as
   proprioception).

understanding

and processing

spoken language

written and

as well as

numbers.

visual

• Plays a role in

processing such

as determining

the length and

around you.

depth of objects

symbols and

Involved in

Parietal Lobe  <u>Changes in Sensory Processing</u>: Diminished sensation of hot and cold temperatures or sharp and dull objects, tingling or burning, numbness., or difficulty locating where on the body a sensation is coming from (localization).

- <u>Left Side Neglect</u>: Loss of awareness of one side of the body (most commonly the left side). Unable to see, feel, or hear sensations from affected side of the body, as if that side of the body no longer exists.
- <u>Changes in Hand-Eye Coordination</u>: Difficulty accurately reaching for an object even when looking right at it (optic ataxia), difficulty buttoning shirts or bringing a fork to your mouth.
- <u>Changes in Balance:</u> Decreased balance may occur due to decreased proprioception or understanding of where your body is in space,
- <u>Changes in Understanding Spoken Language</u>: Difficulty following conversations or comprehending what others say.
- <u>Changes in Reading Comprehension</u>: Reading words or sentences may become challenging.
- <u>Changes in Writing Ability</u>: Struggling to write words correctly or express thoughts in writing.
- <u>Changes in Math Skills</u>: Finding it harder to perform simple calculations or understand numbers.
- <u>Changes in Interpreting Symbols</u>: Difficulty understanding common signs or symbols.



### **Temporal lobe**

## Region of the Brain

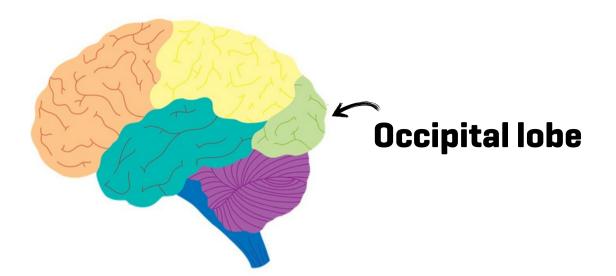
Temporal

Lobe

#### Functions

- Helps you hear and interpret sounds and noises.
- Essential for creating and retrieving memories.
- Assists in comprehending spoken and written language.
- Involved in processing emotions and emotional memories.
- Helps identify and make sense of visual information to recognize objects and faces.

- <u>Changes in Hearing</u>: Difficulty hearing or interpreting sounds.
- <u>Changes in Memory</u>: Trouble forming new memories or recalling past events.
- <u>Changes in Understanding Language</u>: Difficulty understanding what others are saying.
- <u>Changes in Emotional Responses</u>: Mood swings, increased anxiety, or altered emotional reactions.
- <u>Changes in Recognition</u>: Difficulty recognizing familiar faces or objects.
- <u>Changes in Seizure Activity</u>: Increased likelihood of focal seizures.
- <u>Changes in Smell or Taste</u>: Altered sense of smell or taste.



## Region of the Brain

**Occipital** 

Lobe

### Functions

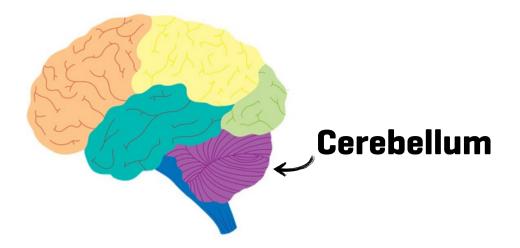
#### Processes visual information.

- Helps recognize colors, shapes, and movement.
- Aids in distance and depth perception

• <u>Changes in Distance and Depth Perception</u>: Difficulty judging how far away objects are or how large they are, which can lead to bumping into things or misreaching.

- <u>Changes in Object and Face Recognition</u>: Difficulty recognizing familiar objects or faces; you might not recognize people you know or common items.
- <u>Changes in Vision</u>: Complete loss of vision, loss of vision in certain areas of your sight; blind spots or missing parts in what you see.
- <u>Changes in Visual Perception</u>: Overall difficulty making sense of visual information, leading to confusion or misinterpretation of what you're looking at.





#### Region of the Brain

Cerebellum

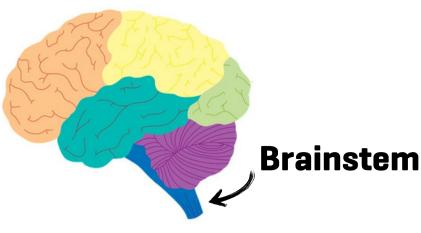
#### Functions

#### Controls balance and coordination.

- Helps with smooth and precise movements.
- Involved in learning new motor skills.

- <u>Changes in Coordination</u>: Difficulty coordinating movements, leading to clumsiness or unsteady walking (ataxia).
- <u>Changes in Balance</u>: Problems maintaining balance, causing frequent stumbling or falls.
- <u>Changes in Fine Motor Skills</u>: Trouble with tasks that require precise hand movements, like writing or buttoning a shirt.
- <u>Changes in Muscle Control</u>: Loss of smooth muscle movements, resulting in jerky or shaky motions.
- <u>Changes in Speech</u>: Slurred or slow speech due to lack of muscle coordination (dysarthria).
- <u>Changes in Eye Movements</u>: Involuntary eye movements or difficulty controlling eye motion (nystagmus).
- <u>Changes in Muscle Tone</u>: Reduced muscle tone, making limbs feel weak or floppy (hypotonia).
- <u>Tremors</u>: Shaking or tremors that occur when attempting precise movements (intention tremor).
- <u>Changes in Learning New Movements</u>: Difficulty acquiring new motor skills or adapting movements.





#### Region of the Brain

**Brainstem** 

#### **Functions**

- Regulates lifesustaining activities like breathing, heart rate, and blood pressure.
- Oversees

   alertness and
   sleep-wake
   cycles.
- Helps with swallowing food and managing digestion.
- Assists in keeping balance and coordinating movements.
- Contains nerves that control facial movements, hearing, taste, and eye movements.

**Possible Effects of Tumor** 

- <u>Changes in Vital Signs</u>: Difficulty breathing or irregular breathing patterns. Irregular heartbeat or trouble regulating blood pressure.
- <u>Changes in Consciousness</u>: Feeling very sleepy, hard to wake up, or even loss of consciousness.
- <u>Changes in Swallowing</u>: Trouble swallowing food or liquids safely.
- <u>Changes in Balance and Coordination</u>: Unsteady movements, difficulty walking, or frequent falls.
- <u>Changes in Movement and Sensation</u>: Weakness or paralysis in arms or legs; numbness or loss of feeling.
- <u>Changes in Facial Movements and Sensations</u>: Difficulty moving facial muscles or altered facial sensations.
- <u>Changes in Speech</u>: Slurred speech or difficulty speaking clearly.
- <u>Changes in Eye Movements</u>: Uncontrolled or abnormal eye movements; difficulty focusing.
- <u>Changes in Sleep Patterns</u>: Problems with sleeping too much or too little; disrupted sleep cycles.
- <u>Changes in Hearing and Taste</u>: Hearing loss or changes in the sense of taste.

**1**12

# **Starting Rehabilitation at Home**

Rehabilitation can begin in the comfort of your own home, even before receiving formal rehab services. This allows you to start addressing cognitive symptoms and daily challenges at your own pace. From an occupational therapy perspective, the goal is to promote independence and improve quality of life by incorporating therapeutic strategies into daily routines.

This section provides practical tips, tricks, handouts, and worksheets designed to support you and your loved ones through your journey of recovery. The focus is on promoting cognitive functions such as memory, attention, and problemsolving skills, in order to improve participation in daily activities. By using these resources, you and your loved ones can work on setting achievable goals and integrating adaptive strategies into everyday activities.



# **The 4 Keys to a Healthy Lifestyle**



712

#### 1. Sleep

Quality sleep helps you stay alert and think clearly. Try sticking to a consistent bedtime and avoiding screens an hour before bed to improve your rest.

#### 2. Nutrition

A balanced diet can help you stay focused and energized. Eating regular meals with a mix of fruits, vegetables, whole grains, and proteins can provide the nutrients your body and brain need.

#### 3. Exercise

Exercise improves blood flow and delivers oxygen to the brain, helping your body heal. Taking a 10-minute walk or doing simple stretches like touching your toes can make a big difference.

#### **4. Managing Stress**

High stress levels can affect your health, so it's important to find ways to relax. Deep breathing exercises or spending a few minutes journaling can help you unwind.

# **Goal Setting**



Setting clear goals is an important part of the recovery process. Goals help us focus on what matters most and allow us to track progress over time. Whether you're working to improve memory, stay physically active, or manage daily tasks more easily, having clear goals provides direction. Writing down specific goals and seeing your progress can build motivation and a sense of accomplishment.

### **Identify Priorities**

As you set goals, think about the areas of daily life where you'd like a bit more support or improvement. Here are some examples:

- Managing fatigue and finding ways to conserve energy
- Keeping track of medications or medical information
- Regaining independence with everyday activities like cooking or shopping

Choose one or two priorities that feel most meaningful to you to focus on as you set your goals.

### **SMART Goals**

Once you've chosen your priorities, let's create a goal using the SMART format to make sure it's clear and achievable.

For each goal, consider the following questions:

- Specific: What exactly do you want to accomplish?
- <u>Measurable</u>: How will you know you've achieved it?
- Achievable: What steps can you take to make it happen?
- <u>Relevant:</u> Why is this goal important to you?
- <u>Time-bound</u>: By when would you like to achieve it?



# **Goal Setting & Tracking**

Example SMART Goal	I will practice deep breathing exercises for five minutes each morning for the next three weeks to help manage stress.
My SMART Goal	

Step #	Description of Step	Target Completion Date	Notes/Reflection
1			



# **Exploring Mindfulness**

#### What is Mindfulness?

Mindfulness involves being fully aware of what you're thinking, feeling, and sensing. This helps you stay more connected to important activities and improves your ability to manage emotions and understand yourself better.

#### The Benefits of Mindful Practices

- Promotes attention and awareness
- Promotes emotional regulation skills
- Promotes a balanced lifestyle
- Promotes quality of life

### **Tips for Practicing Mindfulness**

- <u>Start small & stick to it</u>: Add quick mindful practices into your daily routine.
- <u>Use resources</u>: Check out apps or online videos for guidance.
- <u>Be patient</u>: It takes time for mindfulness to feel natural and progress happens gradually.



### **Mindful Practices To Try!**

- <u>Mindful Occupations</u>: Spend 5-10 minutes on a routine task, like showering. Pay attention to the warmth of the water, the sounds, and the scents. Notice your body's movements. If you get distracted, gently return your focus to the task.
- Mindful Journaling: Pick a specific time every day, in the morning when you wake up or right before bed, to write down your thoughts and feelings as they come to you. Don't judge them; just let them flow. Feel free to add sketches or doodles.



# Mindfulness Reflection Questions

After practicing mindfulness, taking a moment to reflect can make your experience more meaningful and impactful. The questions below are designed to help you explore your feelings, thoughts, and body sensations during your practice. So, take a moment to reflect on the following questions to deepen your experience and appreciate the progress you've made.

What emotions did I experience during this activity, and how did they change over time?

1

2

3

4

5

6

7

8

- What specific thoughts or distractions interrupted my focus, and how did I address them?
- What physical sensations did I notice in my body while practicing mindfulness?
- How did this activity impact my mood or outlook on a current situation?
- What insights about myself or my feelings did I gain through this practice?
- In what ways did I practice self-compassion or forgiveness during this activity?
- How can I apply the lessons learned from this experience to my daily life?

What intentions can I set for my next mindful practice to enhance my awareness and well-being?



# **Working Memory and Attention Strategies**

Memory and attention challenges can be a frustrating part of life after a brain tumor, but they don't have to define your journey. These challenges can make it harder to stay organized, focus, or remember important tasks. Working memory, which helps you store and recall information in the moment, and attention, which keeps you focused, are essential for managing everyday tasks. When these skills are disrupted, life may feel more complicated—but there is hope. This section provides practical strategies and tools to help you tackle these challenges, regain independence, and approach each day with confidence.

Here are some memory and attention strategies to try at home:

#### • Break Down Tasks Into Steps:

 Breaking down complex tasks into simple, step-by-step instructions makes them easier to remember. For example, making a cup of tea can be divided into steps: boil water, place a tea bag in the cup, pour water, and so on. Writing out these steps on a checklist reinforces memory and task completion.

#### • Use Memory Aids and Visual Reminders:

- <u>Visual Reminders</u>: Set up reminders like sticky notes, calendars, or visual cues for important tasks, such as taking medication. Designate a "landing pad" area where essential items like keys, phone, and wallet can always be placed. (See page 21 for a printable landing pad)
- <u>Daily Planner</u>: Use a small notebook or a designated section in a planner for daily to-dos and reminders helps reinforce memory.
- Engage in Cognitive Stimulation Activities:
  - <u>Memory Games</u>: Try activities that engage your brain, such as puzzles, card games, or reading. These activities help stimulate cognitive function, improve focus, and encourage memory retention.
  - <u>Creative Hobbies</u>: Engaging in hobbies like drawing, writing, or crafting not only supports cognitive stimulation but also provides a fulfilling routine.

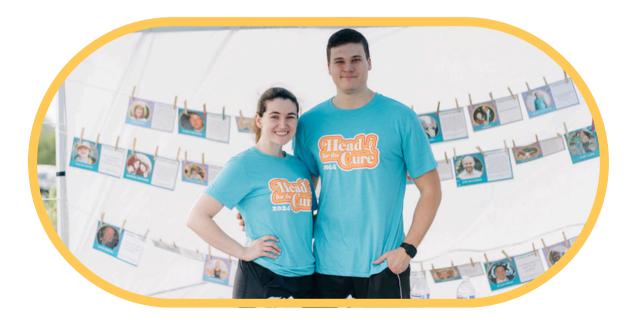
### **Working Memory and Attention Strategies**

#### • Practice Memory Strategy Training

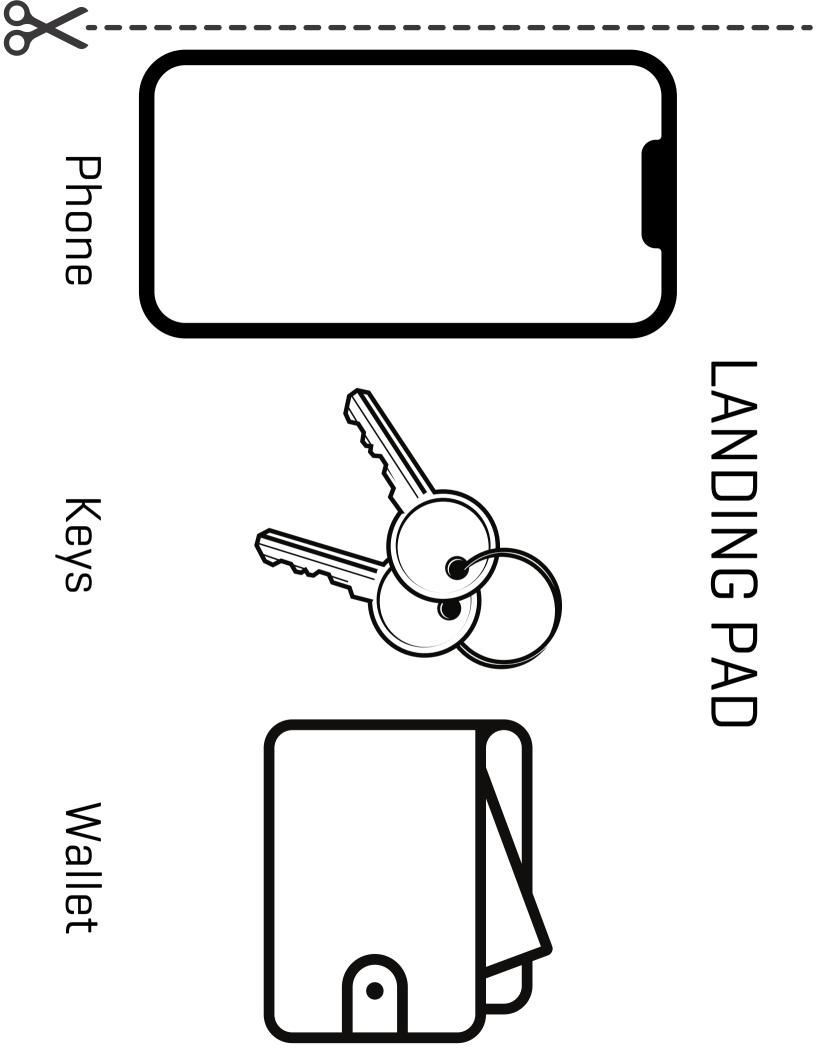
- <u>Visualization and Association</u>: Techniques like visualizing steps or associating new information with familiar objects can help strengthen memory. For example, picture yourself placing your keys in the same spot every time you come home.
- <u>Use Repetition</u>: Repeat key information, names, or steps to reinforce memory. Reviewing important points multiple times a day aids in long-term recall.

#### • Modify the Environment:

- <u>Organize for Accessibility</u>: Arrange frequently used items in visible and easy-to-reach places. Using labels, color-coding, or organizing items by category can provide helpful cues.
- <u>Utilize Technology</u>: Voice assistants, phone reminders, or reminder apps can help manage tasks and appointments, offering consistent memory support.







# **Planning and Organization Strategies**

Planning and organizing your day can feel overwhelming after a brain tumor diagnosis, but it's important to remember—you're not alone, and there are ways to make it easier. Changes in the brain may affect these higher-level cognitive skills, turning once-simple tasks into new challenges. However, with the right strategies and tools, it's possible to navigate these difficulties, regain independence, and build confidence. This guide offers practical, easy-to-use techniques to help you plan, organize, and prioritize tasks effectively, empowering you to take charge of your daily life.

#### Definitions

- <u>Planning</u>: Choosing how to effectively complete a task, listing the steps required, and deciding what is needed to complete the task.
- <u>Organization</u>: Arranging steps logically and gathering needed materials for easy execution.
- <u>Prioritization</u>: Ordering tasks by importance and deadlines.

#### **Strategies for Success**

- <u>Prioritize Tasks</u>: Identify tasks that are most important and complete them first.
- <u>Break Tasks into Small Steps</u>: Focus on one step at a time to avoid feeling overwhelmed.
- <u>Create Routine</u>: Establishing consistent times for daily activities makes it easier to follow through.
- <u>Use Visual Aids</u>: Calendars, planners, and checklists help keep track of tasks and important dates.
- <u>Set Reminders</u>: Use alarms or phone reminders throughout the day to take your medication on time or arrive early to doctors visits.
- <u>Minimize Distractions</u>: Limit background noise or visual clutter to improve focus.



### **Planning and Organization Strategies**

#### Strategies for Success (Cont.)

- <u>Implement Cognitive Strategies</u>: Engage in activities that challenge your thinking. Examples include:
  - <u>Card Games</u>: Play games like Uno or Solitaire that require changing strategies based on different situations.
  - <u>Puzzles</u>: Solve jigsaw puzzles or logic puzzles that challenge you to think in new ways and adapt to changing conditions.
  - <u>Cooking with a Plan</u>: Find a recipe you enjoy, gather the ingredients and tools needed, and follow the steps of the recipe. Starting with simpler recipes builds confidence, leading to more complex dishes over time.
- <u>Ask for Support</u>: Don't hesitate to ask for help. Friends or caregivers can help organize activities, provide reminders, or assist with parts of a task you don't feel confident doing on your own.

#### **Tips for Caregivers**

- Be patient. Instead of taking over a task when a loved one becomes frustrated, encourage them to use the strategies they've learned to promote independence.
- Provide gentle reminders. If you notice your loved one skip a step in a task, kindly remind them of the correct order. If this happens often, consider creating a visual aid (or find one online) that outlines the task step-by-step and place it where they can easily see it.
- Encourage the use of simple tools like sticky notes, calendars, or phone reminders.
- Participate in activities <u>together</u> to help reinforce these strategies and build their confidence.
- Provide a calm, organized space to help your loved one stay on track with tasks and routines.



### **Planning and Organization: Prioritize**

Cut out the task cards below and prioritize them using the chart on the following page. Missing a task? Fill in blank cards with your tasks. If you run out of cards, consider utilizing sticky notes.



### **Planning and Organization: Prioritize**

High Priority	Low Priority	Can Delegate

# **Problem-Solving Strategies**

Problem-solving is a skill we use every day, whether it's deciding what to cook for dinner, fixing a broken item at home, or figuring out how to fit errands into your schedule. After a brain tumor and its treatments, these tasks might feel more challenging. These changes can impact your ability to analyze situations, come up with solutions, and make decisions, making even simple problems harder to navigate. But with the right strategies, you can find new ways to manage these challenges and feel more confident in tackling your daily tasks.

#### **Strategies for Success**

- <u>Set Clear Goals and Steps (Goal-Plan-Do-Review</u>): Break tasks into simple steps. Start by identifying the problem, set a clear goal, plan how to accomplish it, do the steps, and then review how it went. This approach helps you evaluate your actions and build problem-solving skills over time.
- <u>Use Visual Reminders and Checklists</u>: Use tools like sticky notes, alarms, or written lists to guide each part of a task. These reminders can help you stay on track and complete tasks more independently.
- <u>Try Trial and Error</u>: Don't be afraid to try different approaches until something works. Mistakes are learning opportunities that can make you more resilient and better prepared for future challenges.
- <u>Practice Flexible Thinking</u>: Be open to new solutions if your first idea doesn't work. Ask yourself, "What else can I try?" This mindset helps you handle unexpected situations with confidence.
- <u>Collaborate with Others</u>: Work through problems with family members or therapists. Talking things through in a supportive environment can help you test solutions, gain confidence, and feel more independent.



### **Problem-Solving Strategies**

#### **Step 1: Identify and Define the problem**

- State and describe the problem as clearly as possible
- Set realistic and achievable goals for solving the problem

Goals for Problem

#### **Step 2: Create Potential Solutions**

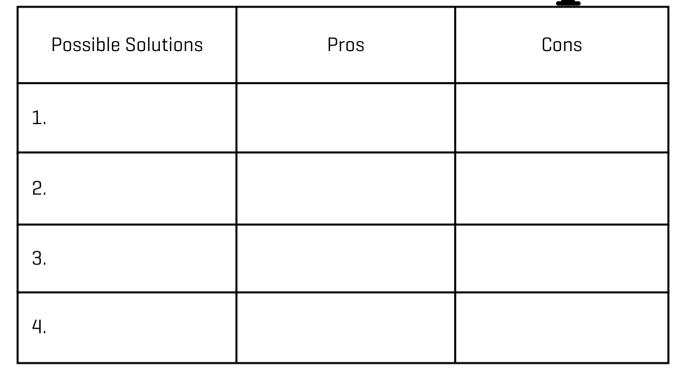
- List any and all possible solutions
- Eliminate solutions that aren't practical or favorable
- List remaining solutions in order of preference

List All Possible Solutions	Pick the Best Solutions 🦙
	1.
	2.
	З.
	4.

### **Problem-solving Strategies**

#### **Step 3: Evaluate Potential Solutions**

- List the top 3-4 solutions
- Weigh the pros and cons of each solution



#### **Step 4: Create an Action Plan**

- Pick the top solution
- List out the steps to the solution, who will complete them, and when they'll be completed



Action Steps	Who	When

#### **Step 5: Implement Action Plan**

- Implement the solution as planned
- Evaluate the solution. Did you achieve your goal? What could you have done differently?







# QUESTIONS TO ASK

When faced with a brain tumor diagnosis, it's essential to ask key questions to gain clarity in your next steps. We encourage you to take these questions to your healthcare team as they can provide personalized and unique answers to address your specific diagnosis.



Fostering an open and communicative relationship between you and your care team is crucial for achieving the best possible outcome.



Advocating for yourself may be necessary to obtain the answers you desire.



Deciding ahead of time how you want to navigate knowing your prognosis vs. not knowing your prognosis is critical in framing the conversations you have with your healthcare team.

### **TUMOR SPECIFIC QUESTIONS**

- What is my official diagnosis?
- What information can you provide about my brain tumor?
- How do you anticipate my brain tumor will progress?
- Is my tumor operable?
- What is the likelihood of recurrence?
- How does the grade and stage of my tumor affect my prognosis?
- Is my tumor considered slow or fast-growing?
- What is my prognosis?

### **TREATMENT SPECIFIC QUESTIONS**

- What treatment options are available?
- Is there a timeline for starting treatment? Do I have the option to wait?
- How much time do I have to decide on my treatment plan?
- What is the standard treatment for my tumor vs. clinical trials?
- Will insurance cover this treatment?
- How will this treatment be administered (oral or IV)?
- Are there alternative treatment options? Nontraditional treatment?
- How do you assess the effectiveness of the chosen treatment?
- What are the common short-term and long-term side effects of my recommended treatment? How can I manage these?
- How often do you recommend gettMRI's?
- Can I maintain work and other activities, including driving, during treatment?



### **QUESTIONS FOR YOUR NEUROSURGEON**

- Where is the tumor located and what is the size?
- What are the potential risks with tumor removal?
- How might surgery affect my memory, cognitive abilities, physical movement or speech?
- What are the benefits to surgery?
- How long will surgery last?
- Why is surgery your recommendation?
- How many brain tumor patients with my tumor type do you treat each year?
- Are there other treatment options available based on my current condition?
- What happens if I do not have the operation?
- What is your experience in completing this operation?

### **GENERAL QUESTIONS FOR HEALTHCARE TEAM**

- How many patients with my type of brain tumor do you treat annually?
- Which specialists constitute my healthcare team? (neurooncologist, neurosurgeon, radiation oncologist, nurse, social worker, nutritionist, physical therapist)
- What are the roles of each specialist?
- How will communication occur among these specialists regarding my treatment?
- In the event of hospitalization, will you be my doctor?
- What can I expect during recovery?
- Where do you recommend I get more information about my diagnosis?

### **QUESTIONS FOR YOUR OCCUPATIONAL THERAPIST**

- What strategies can you provide to help me regain independence in activities like dressing, cooking, or working?
- Can you explain how we will work on memory, attention, or other cognitive difficulties I might face?
- What can I do to improve my fine motor skills between therapy sessions?
- Are there any recommended assistive devices or adaptive equipment to help me complete daily tasks?
- What support can you offer if I want to return to my job or manage other responsibilities like caregiving or parenting?

### **QUESTIONS FOR YOUR PHYSICAL THERAPIST**

- What signs and symptoms should I be on the alert for in case of recurrence?
- What balance exercises are recommended that can be completed safely at home?
- What exercise parameters should I work within (blood pressure, heart rate, RPE)?
- Are there any recommended assistive devices or adaptive equipment to help make me safer at home?
- How often should I exercise or be physically active?
- How will I know if I'm overdoing it?

NOTES	Appointment Type:		Date :
QUESTIONS?		UPDATES:	
		O OF DATES.	
			Ō

NOTES	Appointment Type:	Date :	
QUESTIONS?	Ð	UPDATES :	
			5
			~34

NOTES	Appointment Type:		Date :
QUESTIONS?		UPDATES :	
			2
		· · · · · · · · · · · · · · · · · · ·	

NOTES	Appointment Type:		Date :
QUESTIONS?	Ĕ	UPDATES :	
			5

#### References

American Brain Tumor Association. (n.d.). Living with a brain tumor. https://www.abta.org/about-brain-tumors/living-with-a-brain-tumor/

Azulay, J., & Mott, T. (2016). Using Mindfulness Attention Meditation (MAP) with a Mixed Brain injury Population to Enhance Awareness and Improve Emotional Regulation. Journal of Psychology and Clinical Psychiatry, 6(5). https://doi.org/10.15406/jpcpy.2016.06.00372

Cleveland Clinic. (2021, June 21). Brainstem: Overview, Function & Anatomy. Cleveland Clinic. https://my.clevelandclinic.org/health/body/21598-brainstem

Cleveland Clinic. (2022a, July 7). Cerebellum: What It Is, Function & Anatomy. Cleveland Clinic; Cleveland Clinic. https://my.clevelandclinic.org/health/body/23418-cerebellum

Cleveland Clinic. (2022b, December 5). Frontal lobe: What it is, function, location & damage. Cleveland Clinic. https://my.clevelandclinic.org/health/body/24501-frontal-lobe

Cleveland Clinic. (2022c, December 5). Occipital Lobe: Function, Location & Conditions. Cleveland Clinic; Cleveland Clinic. https://my.clevelandclinic.org/health/body/24498-occipital-lobe

Cleveland Clinic. (2023a, January 8). Parietal Lobe: What It Is, Function, Location & Damage. Cleveland Clinic. https://my.clevelandclinic.org/health/body/24628-parietal-lobe

Cleveland Clinic. (2023b, January 8). Temporal Lobe: What It Is, Function, Location & Damage. Cleveland Clinic. https://my.clevelandclinic.org/health/body/16799-temporal-lobe

John Hopkins Medicine. (2024). Brain Anatomy and How the Brain Works. Johns Hopkins Medicine; Johns Hopkins Medicine. https://www.hopkinsmedicine.org/health/conditions-and-diseases/anatomy-of-the-brain

The OT Toolbox. (n.d.). Organization activities for kids. https://www.theottoolbox.com/organization-activities-for-kids/ Tools to Grow, Inc. (n.d.).

Piet, J., Würtzen, H., & Zachariae, R. (2012). The effect of mindfulness-based therapy on symptoms of anxiety and depression in adult cancer patients and survivors: A systematic review and meta-analysis. Journal of Consulting and Clinical Psychology, 80(6), 1007–1020. https://doi.org/10.1037/a0028329

Planning and organizing resources. https://www.toolstogrowot.com University of Washington Medical Center. (2008). Initiation, planning, organization, and brain injury. https://www.washington.edu

Using Memory Strategies After Brain Injury. (2017). Acquired Brain Injury Outreach Service.





#### Advocate. Educate. Connect. BRAINS FOR CURE Powered by Head for the Cure Foundation'



info@headforthecure.org



www.brainsforthecure.org



@BrainsForTheCure

Personalized Guidance and Resources for Every Step of Your Brain Tumor Journey JOIN YOUR PATH TO HOPE

