

YOUR TREATMENT TOOLKIT

Primary Brain Tumor (Glioma)
Radiotherapy Supportive Care Guide

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Evidence-based protocols from NCCN, ASTRO, American Brain Tumor Association,
and recent clinical trials (STUPP, MGMT methylation studies)

Welcome to Treatment

A primary brain tumor diagnosis is serious, but modern radiation therapy combined with chemotherapy offers meaningful survival benefit. This guide outlines evidence-based strategies to manage treatment side effects and optimize your quality of life during and after therapy.

Your Treatment Plan

Standard regimen: 6 weeks of external beam radiation therapy (60 Gy in 30 fractions) with concurrent daily temozolomide (TMZ), followed by adjuvant TMZ cycles. **Hypofractionated regimen:** 40 Gy in 15 fractions for elderly patients or poor performance status.

Phase	Timeframe	What to Expect
Week 1	Setup	Imaging, planning. Begin anti-seizure meds, steroids, TMZ. Minimal symptoms.
Weeks 2–3	Ramp Up	Radiation side effects begin. Fatigue, steroid effects emerge.
Weeks 4–6	Peak	Worst fatigue, cognitive changes, steroid effects. Focus on compliance.
Weeks 1–4 post-RT	Recovery	Side effects may worsen briefly, then slowly improve over months.

The Golden Rules

1. Take Temozolomide Exactly as Directed

This chemotherapy is essential to your survival. Take it at bedtime on an empty stomach, with anti-nausea medication. Blood counts will be monitored weekly during radiation.

2. Steroids: Take Them, Taper Them

Dexamethasone controls brain swelling (edema). Never stop abruptly — it must be tapered. Follow your oncologist's dosing exactly.

3. No Driving — Seizure Risk

Brain tumors carry seizure risk. Even if you don't have seizures yet, your neurologist will restrict driving for safety. Your health is worth the inconvenience.

4. Protect Your Immune System

TMZ + radiation suppresses white blood cells and lymphocytes. Avoid sick people, report fever immediately, and take PJP prophylaxis (Bactrim) as prescribed until your counts recover.

Section 1 — Temozolomide (TMZ) Chemotherapy

*Temozolomide is **the** most important part of your treatment. The STUPP trial (Stupp et al., NEJM 2005) showed it improves 5-year survival from 10% to 27% when combined with radiation.*

How It Works

TMZ is an oral chemotherapy taken daily during radiation (75 mg/m²), then in monthly cycles after (150–200 mg/m² for 5 days every 28 days). It damages DNA in cancer cells, preventing them from dividing.

How to Take It

1. **Timing:** Take at bedtime on an empty stomach. Wait 2 hours after your last meal. This improves absorption and reduces nausea.
2. **Anti-nausea:** Many people tolerate TMZ best at bedtime on an empty stomach. If your team prescribes an anti-nausea medication (such as ondansetron), take it exactly as directed before TMZ.
3. **Blood count monitoring:** Weekly labs during radiation, before each adjuvant cycle. CBC (complete blood count) tells us your white cells, red cells, and platelets.
4. **PJP prophylaxis:** You will be prescribed Bactrim (trimethoprim-sulfamethoxazole) to prevent *Pneumocystis jirovecii* pneumonia. Take as directed during the concurrent TMZ + RT phase and continue until your blood counts recover — your team will tell you exactly when it is safe to stop.

Side Effects

- **Nausea:** Usually mild if you take Zofran prophylactically and TMZ at bedtime. Ginger chews, peppermint tea, and small frequent meals help.
- **Fatigue:** Very common. This is expected and does not mean you should skip your dose.
- **Low blood counts (myelosuppression):** TMZ typically causes a mild to moderate drop in white blood cells and platelets. Nadir (lowest point) is usually day 21–28. Severe drops requiring dose delays are uncommon with TMZ.
- **Liver function:** Rarely, TMZ affects liver enzymes. We will monitor liver function tests.

When to Report Symptoms

- **Fever over 100.4°F:** Do NOT take Tylenol and wait. Call immediately.
- **Easy bruising, bleeding, or nosebleeds:** Sign of low platelets.
- **Mouth sores (oral mucositis):** Uncommon with TMZ but possible.
- **Uncontrolled nausea:** We have stronger anti-nausea options available.

Section 2 — Steroids (Dexamethasone)

Brain swelling (edema) is common with tumors and radiation. Dexamethasone controls swelling and prevents increased intracranial pressure. **This is essential medication — do not skip or reduce it without consulting your oncologist.**

Why You Need It

Brain tumors and radiation cause fluid buildup in surrounding tissue. Steroids reduce this swelling. Without them, intracranial pressure can rise, causing headaches, vomiting, weakness, or worse.

How to Take It

1. **Dose schedule:** Your dose will be individualized. Never adjust on your own.
2. **Timing:** Take early in the morning (6–8 AM) to minimize insomnia.
3. **Food:** Take with food to minimize stomach upset.
4. **Tapering:** Steroids are usually tapered down over weeks as brain swelling resolves. Your team will provide a tapering schedule. **NEVER stop abruptly** — this can cause adrenal insufficiency.

Side Effects (Expect These)

- **Increased appetite:** Steroids dramatically increase hunger. Choose nutritious foods.
- **Insomnia:** Steroids are stimulating. Take them early in the day.
- **Mood changes:** Irritability, anxiety, or euphoria. Usually reversible.
- **Moon face and weight gain:** Fluid retention + appetite. Will reverse with tapering.
- **Blood sugar changes:** If diabetic, monitor closely. We may adjust diabetes medications.
- **Muscle weakness and bone loss:** Long-term steroids cause these. We monitor and mitigate.
- **Increased infection risk:** Steroids suppress immune function. Avoid sick people.

Management Tips

- Low-sodium diet minimizes fluid retention and swelling.
- Regular blood glucose monitoring if diabetic.
- Calcium and vitamin D supplementation for bone health.
- Follow your oncologist's tapering schedule precisely.

Section 3 — Seizure Management

Brain tumors increase seizure risk, especially cortical (surface) tumors and low-grade gliomas. Anti-seizure medication is typically prescribed if you have had a seizure or around the time of surgery. Your neurologist will decide whether you need it based on your specific situation.

Common Anti-Seizure Medications

- **Levetiracetam (Keppra):** First-line. Possible side effects include irritability, agitation, anxiety, aggression, or mood changes (sometimes called behavioral side effects). Report these to your team — alternative medications are available. Does NOT require blood level monitoring.
- **Lacosamide (Vimpat):** Newer option, better tolerated by some patients.
- **Valproic acid (Depakote):** Older agent, effective but requires blood level monitoring and carries more side effects.

Important Notes

- **Do NOT stop suddenly.** Abruptly stopping anti-seizure meds increases seizure risk. Only your neurologist decides when to discontinue.
- **Medication interactions:** Some seizure meds interact with other drugs. Always inform all your doctors (primary care, neuro-oncology, neurology) of all medications.
- **Driving restrictions:** State laws vary, but typically you cannot drive if you have had a seizure. Your neurologist will advise when it is safe (usually 6+ months seizure-free).

If You Have a Seizure

1. Stay calm. Do not panic.
2. If convulsing >5 minutes, call 911.
3. Lay the person on their side to keep airway clear.
4. Do NOT restrain or put anything in their mouth.
5. After the seizure, let them rest and call their neurologist and oncologist.

Section 4 — Fatigue & Cognitive Changes

*Fatigue and cognitive changes are often the **hardest side effects** of brain tumor treatment. They are very real, not “in your head,” and they improve over time.*

Fatigue

The combination of radiation + TMZ + steroids + the tumor itself causes profound fatigue. Most patients report severe fatigue weeks 4–6 and for weeks after treatment ends, gradually improving over 2–4 months.

- **Expect it.** This is **not** laziness or depression (though depression can co-exist).
- **Pace yourself.** Work with your employer on a temporary reduced schedule or leave.
- **Exercise helps.** Even 10–20 minutes of gentle walking reduces fatigue if you can manage it.
- **Sleep hygiene:** Keep regular sleep schedule. Limit screens before bed.
- **Nutritional support:** Adequate protein and calories support energy.

Cognitive Changes (“Chemo Brain” / “Radiation Brain”)

Many patients experience memory problems, concentration difficulties, slow processing, or word-finding difficulties. This can feel terrifying — like losing yourself. Be reassured: most cognitive effects improve significantly over 3–6 months after treatment.

- **Short-term memory:** Difficulty remembering recent conversations, appointments, names.
- **Concentration:** Hard to focus, easy distraction, difficulty reading or following meetings.
- **Processing speed:** Thinking feels “slower.” Decisions take longer.
- **Word-finding:** You know what you want to say but can’t retrieve the word.

Cognitive Strategies

1. **External memory aids:** Lists, calendars, phone reminders. Keep them visible.
2. **Routines:** Keeping a consistent daily schedule reduces cognitive load.
3. **Simplified schedules:** Make fewer decisions per day. Batch similar tasks.
4. **Occupational therapy:** Ask your team for referral to neuro-cognitive rehabilitation.
5. **Brain exercises:** Crosswords, puzzles, reading may help with recovery (limited evidence).

Critical: Driving Safety

Do NOT drive if cognitively impaired or on seizure precautions. Cognitive slowing increases accident risk. Arrange alternative transportation (family, Uber, public transit, medical transport).

Work & School

Many patients need temporary leave during and after treatment. Work with your employer on FMLA accommodation if eligible. Some patients can work part-time; others need full leave. This is OK.

Section 5 — Skin & Scalp Care

Scalp skin in the radiation field will become red, itchy, and may peel. Hair loss occurs in the treatment field and may be permanent.

Expected Skin Reaction

- Weeks 1–2: Skin turns pink, itching begins.
- Weeks 3–4: Redness intensifies, dry desquamation (peeling).
- Weeks 5+: May progress to moist desquamation (raw, weepy areas).

Scalp Care Protocol

1. **Gentle washing:** Use baby shampoo or Cetaphil. Pat dry gently. No hair dryer.
2. **Moisturize liberally:** Aquaphor or CeraVe cream, 2–3 times daily.
3. **NO scratching:** Itching is maddening, but scratching causes infection. Apply moisturizer instead.
4. **Soft headwear:** Loose cotton hats only. No tight scalp coverings.

5. **SPF 45+ sunscreen or hat:** Treated scalp is permanently sun-sensitive.

Hair Loss

Hair loss begins weeks 2–3 in the radiation field. Complete loss takes weeks to months. Hair may regrow (often thinner) after 3–6 months, but regrowth is not guaranteed.

- If significant hair loss is distressing, a wig may help. Cranial prosthetics are often covered by insurance.
- Scarves, hats, and head coverings are another option.

When Skin Breaks Down

If your scalp becomes raw or weepy: tell your nurse immediately. We may prescribe silver sulfadiazine cream, hydrogel dressings, or other wound care.

Section 6 — Immune System & Infection Prevention

TMZ + radiation cause lymphopenia (low lymphocytes), suppressing your immune system for months. This is temporary but requires vigilance to prevent serious infections.

PJP Prophylaxis (Critical)

You will be prescribed Bactrim (trimethoprim-sulfamethoxazole) to prevent *Pneumocystis jirovecii* pneumonia (PJP). This is **essential**. Continue it until your blood counts recover — your team will tell you exactly when it is safe to stop based on your lab results, not a fixed calendar date.

- **Typical dose:** Double-strength tablet (800/160 mg) once or twice daily.
- **Side effects:** Mild nausea, rash (report immediately if rash develops).
- **Drug interactions:** Tell all your doctors you are on Bactrim.

Infection Prevention Strategies

1. **Hand hygiene:** Wash frequently, especially after public places or before meals.
2. **Avoid sick contacts:** No visits from people with colds, flu, or infections.
3. **Food safety:** Avoid raw/undercooked meat, unpasteurized dairy, raw vegetables (if CD4 <50, which is rare with TMZ). Ask your oncologist.
4. **No live vaccines:** Flu shot (inactivated, not nasal) is OK. Ask before any vaccines.
5. **Oral care:** Brush teeth gently, use soft toothbrush. Report mouth sores.

Fever: The Red Flag

Fever over 100.4°F during TMZ is a medical emergency. Do NOT take Tylenol and wait. Call immediately or go to the ED. You may have a neutropenic infection requiring IV antibiotics.

Section 7 — Nutrition & Weight

Steroids increase appetite dramatically. TMZ causes nausea. Fatigue makes cooking impossible. Planned nutrition prevents malnutrition during treatment.

Steroid Appetite & Weight

Expect significant appetite increase, often within days of starting dexamethasone. This is **not** loss of willpower — steroids increase hunger hormones.

- **Choose wisely:** High-protein, lower-sugar options. Greek yogurt, nuts, eggs, lean meats.
- **Limit salt and sweets:** Both worsen steroid side effects.
- **Hydration:** 8+ cups of water daily minimum. Steroids worsen dehydration.

Nausea from TMZ

Nausea is usually mild if you take TMZ at bedtime on empty stomach and take Zofran beforehand. Ginger chews, peppermint tea, and small frequent meals help.

- **Avoid:** Strong food smells, fatty foods, high-fiber foods (if diarrhea develops).
- **Try:** Soft, bland foods: crackers, broth, rice, applesauce, yogurt.

Weight Monitoring

Weigh yourself weekly (same day, same time). Most patients **gain** weight on steroids. This is expected. Do **not** severely restrict calories — your body needs nutrition. Report significant changes (10+ pounds in a week) to your team.

Nutritional Shakes

If you cannot eat full meals due to nausea or fatigue:

- **Boost VHC:** 530 calories, 22g protein per 8 oz. Highest calorie option.
- **Ensure Max Protein:** 30g protein, only 150 calories. Good if not losing weight.
- **Fairlife Core Power:** 42g protein, tastes better to some patients.

Avoid supplements without asking: Grapefruit juice and high-dose antioxidants can interfere with seizure meds and chemotherapy. A standard multivitamin is OK — ask your team.

Section 8 — Emotional Support & Planning

Primary brain tumor diagnosis is life-altering. Fear, sadness, anger, and loss are **completely normal** — not weakness.

For You

- **Acknowledge your feelings.** A cancer diagnosis and 6+ weeks of treatment is genuinely hard.
- **Talk to your team:** Nurse, social worker, chaplain, psychologist. They are here.
- **Support groups:** American Brain Tumor Association, National Brain Tumor Society offer groups.
- **Therapy/counseling:** If anxiety or depression develops, we can prescribe medication or refer you.
- **Advance directives:** It is wise to establish a healthcare proxy and advance directive early. This gives you control over your care decisions if things change.
- **Family meetings:** Bring close family together to discuss care plans, fears, and expectations.

For Caregivers & Family

Caring for someone with a brain tumor is emotionally and physically exhausting. Caregiver burnout is real.

- **Batch-cook and freeze meals** before treatment starts. Weeks 4–6 are hardest.
- **Help with logistics:** Drive to appointments, manage medications, handle appointments.
- **Cognitive reminders:** Help with memory (lists, calendars) without being patronizing.
- **Emotional support:** Listen without fixing. Your presence is enough.
- **Respite care:** Ask social work about respite care options to give yourself breaks.
- **Take care of yourself:** Your health matters too. Use support groups, therapy.

Red Flags: When to Call Us

Contact your team IMMEDIATELY if you experience any of the following:

Symptom	Why It Matters
Fever over 100.4°F	Possible neutropenic infection — URGENT
New or worsening headache with vomiting	Increased intracranial pressure
New seizure or status epilepticus (>5 min)	Call 911 if lasting >5 minutes
New weakness, numbness, or speech difficulty	Possible tumor progression
Confusion, personality change, or extreme mood swings	Needs urgent evaluation
Vision changes or eye pain	Needs evaluation
Difficulty walking, loss of balance	Needs evaluation
Easy bruising, nosebleeds, blood in stool	Low platelets — call us
Severe nausea/vomiting preventing food intake	Dehydration risk
New rash (especially if on Bactrim)	Possible drug reaction

Long-Term Follow-Up

Treatment ending is not the end of your care. Brain tumor surveillance is lifelong.

MRI Surveillance

After treatment, you will have MRIs every 2–3 months while on adjuvant TMZ, then per your oncologist’s plan (typically every 3–4 months initially, expanding over time if stable). Pseudoprogression (apparent worsening on imaging at 2–3 months) often reflects treatment effect, not true progression. Your team will interpret this.

Blood Count Monitoring

CBC (complete blood count) before each TMZ cycle to monitor for myelosuppression.

Cognitive Rehabilitation

Occupational therapy and neuro-cognitive rehabilitation can help with memory, concentration, and processing speed. Recovery typically continues for 6–12 months post-treatment.

Seizure Management

Anti-seizure medications are continued per your neurologist's plan. Long-term use is common. Driving restrictions persist until cleared by neurology.

Endocrine Monitoring

Radiation to the brain can affect pituitary function (growth hormone, cortisol, thyroid, reproductive hormones). Annual screening and monitoring are recommended.

Thyroid Function

If your thyroid is in the radiation field, TSH will be monitored periodically. Hypothyroidism can develop weeks to years after treatment.

Quality of Life

Report cognitive changes, fatigue, mood changes, headaches, or other long-term effects to your team. Many are treatable.

Tumor Treating Fields (TTFIELDS / Optune)

Some patients are offered Tumor Treating Fields (Optune) after radiation. This device delivers low-intensity electrical fields to the scalp that interfere with tumor cell division. In the EF-14 trial, TTFIELDS combined with TMZ improved both progression-free and overall survival compared to TMZ alone. The main supportive-care consideration is scalp skin irritation from the arrays, which is usually mild to moderate. Your neuro-oncologist will discuss whether TTFIELDS is right for you.

MGMT Methylation

Your team may mention MGMT methylation status. This is a tumor biomarker: if your tumor has MGMT methylation, it tends to respond better to temozolomide and is associated with a better prognosis. It does not change your day-to-day supportive care, but patients commonly ask about it and it helps your team make treatment decisions.

Pseudoprogression

After chemoradiation, MRI can sometimes look worse even when the tumor is not truly growing. This is called **pseudoprogression**. It is seen in about 20–30% of patients overall, and among scans that look newly progressive, roughly 36% prove to be pseudoprogression rather than true tumor growth. Most cases occur in the first few months after treatment, though the window can extend beyond 3 months. It can be hard to distinguish from real progression — advanced imaging (MR perfusion, MR spectroscopy, PET) and careful clinical monitoring help your team make the right call. **Do not panic if**

your first post-treatment MRI shows changes.

Recommended Products

Below are commonly recommended products. These are suggestions, not endorsements — equivalent brands work fine.

Category	Product	Cost	Link
Chemotherapy	Pill organizer (daily TMZ)	~\$8	amazon.com/s?k=pill+organizer
Anti-nausea	Ginger chews (natural)	~\$8	amazon.com/s?k=Ginger+Chews
Scalp Care	Baby shampoo (Cetaphil)	~\$5	amazon.com/s?k=Cetaphil+Baby+Shampoo
Scalp Care	Aquaphor ointment	~\$12	amazon.com/s?k=Aquaphor+Healing+Ointment
Scalp Care	SPF 50 hat or visor	~\$15	amazon.com/s?k=spf+hat
Infection Prevention	Hand sanitizer	~\$5	amazon.com/s?k=hand+sanitizer
Infection Prevention	Digital thermometer	~\$10	amazon.com/s?k=digital+thermometer
Fatigue	Comfortable walking shoes	~\$50	
Nutrition	Boost VHC (530 cal/8oz)	~\$55/27 pk	amazon.com/s?k=Boost+VHC+Very+High+Calorie
Nutrition	Ensure Max Protein	~\$28/12 pk	amazon.com/s?k=Ensure+Max+Protein+30g

Prescriptions (TMZ, Dexamethasone, anti-seizure meds, Bactrim, Zofran) will be sent to your pharmacy by your care team.

Important Contact Information

Main Line Health — Radiation Oncology

100 East Lancaster Ave · Rosengarten Bldg, Basement · Wynnewood, PA 19096

1078 West Baltimore Pike · Health Center 1, Ground Floor · Media, PA 19063

Phone

Appointment Line: 1.866.CALL.MLH (1.866.225.5654)

If you are experiencing a life-threatening emergency, call 911.

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My Treatment Journal

A place to notice patterns, remember questions, and track what helps.

You do not need to fill this out perfectly. Even a few notes can help you see patterns, remember what worked, and tell your care team what is actually happening at home.

This Week

Week of / goals / anything I especially want help with

Daily Check-In

Day / Date	Energy (0-10)	Pain (0-10)	Eating / Drinking	Sleep	Main note
Mon					
Tue					
Wed					
Thu					
Fri					
Sat					
Sun					

Symptoms I Want to Watch

<input type="checkbox"/> Headache	<input type="checkbox"/> Nausea	<input type="checkbox"/> Steroid effects
<input type="checkbox"/> Seizure concerns	<input type="checkbox"/> Fatigue	<input type="checkbox"/> Memory / concentration
<input type="checkbox"/> Other: _____		

What I Tried / What Helped

Use this page to test small changes and keep track of what helps, what does not, and what you want to ask about next.

Problem or symptom	What I tried	Did it help?	Next step / question

Examples: taking pain medicine before meals, changing skin care timing, drinking earlier in the day, using a humidifier, adjusting fiber, walking after treatment, or asking for a refill.

Questions for My Care Team

Bring this page to visits. Small questions are worth writing down, especially when treatment days start to run together.

Symptoms or side effects I want to mention

Medication, refill, or product questions

Eating, drinking, bowel, bladder, skin, sleep, or activity questions

Logistics: appointments, transportation, work, family, forms

One thing I keep forgetting to ask
