

YOUR TREATMENT TOOLKIT

Brain Metastases (SRS & WBRT)
Supportive Care Guide

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Evidence-based protocols from NCCN, ASTRO, and recent clinical trials

Welcome

Brain metastases diagnosis is serious, but you have **two modern, effective treatment options**: stereotactic radiosurgery (SRS) for focused tumors, or whole-brain radiotherapy (WBRT) for multiple lesions.

This guide explains what to expect, how to manage side effects, and why following your care plan matters. **Read it. Keep it. Reference it throughout treatment.**

The Treatment Timeline

Treatment	Duration	What to Expect
SRS	1–5 days	Highly focused. Usually 1–5 outpatient treatments. Minimal side effects.
WBRT	10–15 days	Treats entire brain over 2–3 weeks. More side effects, but effective for multiple tumors.
Side effects peak	Weeks 2–4	Steroids manage swelling. Cognitive and fatigue issues may develop.
Recovery	Months 1–6	Slow improvement. Continue medications. Monitor with MRI.

The Golden Rules

1. Take Your Steroids Exactly as Prescribed

Dexamethasone controls brain swelling (edema) around the tumor and from radiation. **Do NOT stop suddenly.** Sudden withdrawal can cause adrenal crisis (a medical emergency). Taper only as your doctor directs.

2. Do NOT Drive Until Cleared

Seizure risk is real. Your oncologist will tell you when driving is safe. This is about your safety and others' safety.

3. Report Neurologic Changes Immediately

New headache, weakness, vision changes, confusion, or seizures = call NOW. Do not wait. These may signal tumor progression, bleeding, or dangerous swelling.

4. Be Patient with Cognitive Changes

Memory and thinking may be slower, especially after WBRT. This is the disease and treatment, not you failing. Write things down. Use reminders. Be kind to yourself.

Section 1 — Steroids (Dexamethasone): Your Most Important Medication

WHY: Reduces brain swelling (edema) around tumors and from radiation damage. This is the core medication for brain metastases treatment.

Your Steroid Prescription

If brain swelling is causing symptoms, dexamethasone is often started at 4 to 8 mg per day. Higher doses (such as 16 mg per day) may be used for severe headache, vomiting, weakness, or other signs of high pressure in the brain. There is no single standard taper; your team will lower it as quickly as your symptoms allow. After longer courses, it must not be stopped suddenly because your natural cortisol system can be suppressed.

Why Sudden Withdrawal is Dangerous

Your body becomes dependent on steroids to regulate cortisol and other hormones. Stopping suddenly can trigger **adrenal crisis** — a medical emergency with symptoms like severe weakness, confusion, and dangerously low blood pressure.

Common Steroid Side Effects (Expected and Manageable)

Increased appetite & weight gain

Take with food, choose low-sodium and low-sugar options, monitor daily weight

Insomnia

Take your morning dose with breakfast. Avoid doses after 2 PM. Discuss sleep aids with your team.

Mood changes (irritability, anxiety, euphoria, or depression)

Report changes to your nurse. We can adjust the dose. This is medication-related, not “you.”

Elevated blood sugar

If diabetic or pre-diabetic: monitor glucose closely. May need insulin adjustment. Tell your team immediately if readings are high.

Stomach irritation

Always take with food. Your doctor may prescribe a PPI (proton pump inhibitor) if you are at higher risk for stomach irritation (e.g., high-dose steroids, history of ulcers, or concurrent NSAIDs).

Facial swelling (“moon face”)

Temporary. Resolves after taper. Low-sodium diet helps minimize swelling.

Muscle weakness (especially legs)

Gentle physical activity helps. Report severe weakness — may need dose adjustment.

Increased infection risk

Avoid crowds during severe immune suppression. Wash hands frequently. Report fever immediately.

Tips for Managing Steroid Side Effects

1. **Always take with food.** Never on an empty stomach.
2. **Timing matters.** Take your first dose with breakfast, avoid doses after 2 PM if insomnia is an issue.
3. **Monitor blood sugar** if you are diabetic. Keep a log.
4. **Low-sodium, low-sugar diet** to minimize weight gain and facial swelling.
5. **Report mood changes** to your team — we can adjust the dose or add anti-anxiety medication if needed.
6. **Gentle exercise** (walking 20 minutes daily) helps prevent weight gain and improves mood.

Section 2 — Seizure Precautions

Brain metastases can increase seizure risk. However, **anti-seizure medication is not routinely started just because brain metastases are present.** It is usually prescribed if you have had a seizure or in specific neurosurgical situations. Your neurologist and oncologist will decide if you need it.

Anti-Seizure Medication

If prescribed anti-seizure medication (levetiracetam/Keppra, lacosamide, or others), **take as directed.** **Do NOT skip doses.** Missing doses increases seizure risk. If levetiracetam causes irritability, agitation, or mood changes, tell your team — we can switch to lacosamide or another medication.

Seizure Safety Rules

- **Do NOT drive** until your oncologist clears you. Seizures can occur without warning.
- **Do NOT swim alone or take baths alone.** Shower with the door unlocked.
- **Avoid heights and ladders** — a seizure at height is dangerous.
- **Do NOT operate heavy machinery.**
- **Tell family and friends:** If you have a seizure, turn you on your side, protect your head, time the seizure, and call 911 if it lasts more than 5 minutes.

If You Have a Seizure

It does not necessarily mean treatment failed. Call your team immediately. We will evaluate for swelling, medication adjustment, or other causes.

Section 3 — SRS: What to Expect

Stereotactic radiosurgery is **highly focused radiation** targeting individual tumors. It is precise, typically outpatient, and has fewer side effects than WBRT. SRS is often preferred when the overall amount of brain disease is limited and performance status is good. In selected patients, this may include more than 4 metastases; the decision depends on total tumor volume, location, symptoms, and overall prognosis.

During Treatment

- Typically **1–5 treatments** (often just 1 session)
- A rigid **mask or frame** holds your head still (can feel claustrophobic — tell your team)
- Each session: **30–60 minutes** on the table (most is planning; actual radiation is 10–20 min)
- No pain during treatment. You will not feel the radiation.

After Each SRS Treatment

- **Mild headache** is common — Tylenol usually sufficient
- You can drive home (unless sedated). Return to normal activities the next day.
- **No pain, nausea, or fatigue** in most cases

Radiation Effect Timeline

The tumor effect develops over weeks to months. The tumor may initially *swell* before shrinking (this is normal). This is called “radiation necrosis phase” — swelling that peaks at 6–12 weeks, then gradually improves.

- **Weeks 1–4:** Minimal symptoms. Tumor may appear slightly larger on MRI (swelling).
- **Weeks 6–12:** Peak swelling possible. Steroids manage symptoms.
- **Months 3+:** Tumor shrinks. Swelling resolves.

Follow-Up MRI

You will have follow-up MRI typically **6–8 weeks after SRS** to assess tumor response. More scans may follow every 2–3 months initially.

Section 4 — WBRT: What to Expect

Whole-brain radiotherapy treats the **entire brain** to address known tumors and microscopic disease. It is more effective for multiple metastases but has more side effects.

During Treatment

- Typically **10–15 daily treatments** (2–3 weeks of weekday radiation)
- Each session: **15–30 minutes** on the table

- Mild fatigue may develop after a few treatments

Acute Side Effects During WBRT

- **Fatigue** (builds over treatment, peaks after therapy ends, may persist weeks)
- **Hair loss** (begins weeks 2–3, may be patchy or complete)
- **Scalp irritation** (redness, tenderness)
- **Nausea** (especially first few treatments — take Zofran 30 min before if prescribed)
- **Ear congestion / hearing changes** (if ears in treatment field)
- **Headache** (usually mild, steroids help)

Delayed Side Effects: Cognitive Impact

These may develop weeks to months after WBRT. They are dose-dependent. Higher doses = higher risk. Ask your team about the dose and your personal risk.

- **Short-term memory difficulty:** Trouble remembering recent conversations or events
- **Concentration problems:** Hard to focus on reading or complex tasks
- **Word-finding difficulty:** Knowing what you mean but struggling to say it
- **Slower processing:** Needing more time to think through problems

Hippocampal-Avoidant WBRT + Memantine

When whole-brain radiation is needed, **hippocampal-avoidant WBRT (HA-WBRT) combined with memantine** is now the preferred approach when feasible. In the NRG CC001 trial, this combination reduced the risk of cognitive failure (HR 0.74, P=.016): at 4 months, executive function decline was 23% vs 40%, and at 6 months, memory decline was 16% vs 33% compared to standard WBRT. Memantine is typically started within 3 days of treatment and titrated to 10 mg twice daily over 4 weeks, then continued for 24 weeks. **Ask your team if HA-WBRT applies to you.**

Section 5 — Headache & Pain Management

Headaches are **very common** in brain metastases. They come from edema, tumor mass effect, or radiation inflammation.

Headache Management

1. **Tylenol (acetaminophen):** First-line for mild to moderate headache. 500–1000 mg every 6 hours.
2. **Steroids (Dexamethasone):** Your primary headache control. Works on edema-related pain.
3. **Elevate your head of bed 30°** to reduce intracranial pressure, especially at night.
4. **Avoid NSAIDs (ibuprofen)** unless approved — can interact with some medications and increase bleeding risk.

Red Flag Headaches — Call Immediately

- **“Worst headache of my life”** — sudden, severe, different from usual
- **Headache with vomiting** — may indicate increased intracranial pressure
- **Headache with new neurologic symptoms** (weakness, vision changes, confusion)
- **Progressively worsening headache** despite steroids and pain medication

Section 6 — Fatigue & Cognitive Support

Fatigue is **very common**, especially after WBRT. It is not laziness — it is a real side effect from radiation and steroids.

Managing Fatigue

1. **Gentle physical activity:** Even 15–20 minutes of walking daily helps.
2. **Rest strategically:** Naps are OK (limit to 30 min) but do not interfere with nighttime sleep.
3. **Keep a routine:** Regular sleep/wake times improve overall energy.
4. **Nutrition:** Adequate protein and hydration support energy.

Cognitive Support Strategies

If you experience memory or concentration issues, these tools help:

- **Write everything down:** Lists, calendars, phone reminders
- **Establish routines:** Keys always in same place, pill organizer, set phone alarms
- **Brain games & puzzles:** Crosswords, Sudoku, reading may help maintain sharpness
- **Occupational therapy:** Ask your team for referral to cognitive rehabilitation
- **Memantine (Namenda):** Prescribed during/after WBRT to help delay cognitive decline. In RTOG 0614, it delayed time to cognitive decline, though the primary memory endpoint narrowly missed significance due to patient attrition

Section 7 — Hair Loss (WBRT Patients)

Hair loss is **expected with WBRT**, not a sign of problems. Onset and extent depend on the dose.

Timeline

- **Weeks 2–3:** Hair loss begins
- **Weeks 4–6:** May become patchy or complete depending on dose
- **Months 3–6 after WBRT:** Hair often begins regrowing
- **Higher doses:** Regrowth may be thinner or slower; some permanent thinning possible

Scalp Care

- **Gentle shampoo:** Use mild, sulfate-free options

- **Soft pillowcase:** Silk or satin reduces friction
- **Sunscreen or hat:** Scalp gets sunburned easily
- **Avoid heat styling:** No blow dryers, flat irons

Wigs, Scarves, Hats

Many patients find these helpful for appearance and comfort.

- **Wigs:** Insurance may cover under “cranial prosthesis” — use this term when filing claims
- **Scarves & wraps:** Colorful options available online
- **Hats:** Especially wide-brimmed for sun protection

Section 8 — Nutrition & Daily Life

Steroids increase appetite and can increase blood sugar. Being intentional about nutrition helps manage weight gain and supports healing.

Eating Well on Steroids

- **Low-sodium diet:** Reduces steroid-related swelling (moon face, weight gain)
- **Low-sugar choices:** Especially important if diabetic
- **Protein:** Supports tissue healing and immune function
- **Hydration:** Drink water throughout the day

Fall Prevention

Steroids can cause muscle weakness. Combined with potential dizziness or cognitive changes, fall risk increases.

- **Remove tripping hazards:** Cords, rugs, clutter
- **Nightlights:** In hallways and bathroom
- **Non-slip mats:** Bathroom
- **Grab bars:** Near toilet and shower
- **Sturdy shoes:** Not slippers

Avoiding Drug Interactions

If on anti-seizure medication: Avoid grapefruit and grapefruit juice — they interfere with medication levels.

Section 9 — Emotional Support

Brain metastases diagnosis is frightening. The threat to memory and independence is emotionally heavy. **This is real, and you are not alone.**

For You

- **Talk to your team:** Nurse, social worker, chaplain are here for this.
- **Support groups:** Join one for brain cancer or metastatic cancer patients.
- **Mental health care:** Therapy or psychiatry if anxiety/depression develops.
- **Cognitive changes:** Not “you failing.” This is the disease and treatment.
- **You are NOT radioactive.** Safe to be close to family, partners, children, pets.

For Caregivers

Caregiving for someone with brain metastases is emotionally and physically demanding.

- **Take care of yourself:** Caregiver burnout is real. Ask about respite care.
- **Help with medications:** Pill organizer, reminders, steroid taper tracking.
- **Cognitive support:** Help with calendars, memory aids, complex decisions.
- **Monitor for seizures:** Know what to do. Keep phone nearby.

Advance Care Planning

Brain metastases diagnosis is a good time to discuss goals of care with your family and team. Consider advance directives, healthcare power of attorney, and your values for treatment intensity.

Section 10 — Red Flags: When to Call Us

Call us immediately if you experience any of the following:

Symptom	Why It Matters
Sudden severe headache	Possible hemorrhage — EMERGENCY
New seizure	Call 911 if >5 min. Then call us.
New weakness/numbness (arm, leg, face)	Possible tumor progression or stroke
Sudden vision changes or double vision	Needs urgent evaluation
Confusion or personality change	Possible swelling or progression
Persistent vomiting	May indicate increased intracranial pressure
Fever over 100.4°F	Steroids mask infection signs
Difficulty walking or balance problems	Needs evaluation
Uncontrolled pain	We can adjust medications

Section 11 — Long-Term Follow-Up

Treatment is not the end. These are lifelong monitoring priorities.

MRI Surveillance

You will need regular brain MRIs to assess tumor response and watch for recurrence. Typical schedule: every 2–3 months initially, then every 3–6 months.

Steroid Taper Management

Your dexamethasone dose will be slowly tapered. **Never stop or reduce on your own.** Work with your team on a tapering schedule. Sudden changes cause problems.

Endocrine Monitoring (After WBRT)

WBRT can damage the pituitary gland. Your doctor may check thyroid, cortisol, and growth hormone function with blood tests.

Cognitive Assessment

If you received WBRT, your team may offer formal cognitive testing (neuropsychology) to track memory and attention.

Seizure Medication Management

If on anti-seizure medication, continue as prescribed. Do not stop without your doctor's approval.

Radiation Necrosis vs. Recurrence

MRI changes can be confusing. Swelling after SRS or WBRT peaks at 6–12 weeks, then slowly improves. Advanced imaging (PET, MR perfusion) helps distinguish tumor regrowth from radiation necrosis. If swelling is caused by radiation necrosis rather than active tumor, doctors may use steroids and sometimes bevacizumab (Avastin) to reduce edema. Ask your team.

Immunotherapy + SRS

If you are receiving immunotherapy (checkpoint inhibitors such as nivolumab or pembrolizumab), SRS can generally be given safely alongside single-agent immunotherapy. However, **dual-checkpoint therapy** (e.g., nivolumab + ipilimumab) appears to increase the risk of symptomatic radiation necrosis, especially when given concurrently with SRS. Your team will coordinate timing carefully. Report any new or worsening headaches, confusion, or neurologic changes promptly.

Recommended Products

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

Category	Product	Cost	Link
Steroids	Pill Organizer (7-day)	~\$8	amazon.com/s?k=pill+organizer
Blood Sugar	Glucose Monitor (if diabetic)	~\$20	amazon.com/s?k=blood+glucose+monitor
Scalp Care	Gentle Shampoo (SLS-free)	~\$10	amazon.com/s?k=sulfate+free+shampoo
Scalp Care	Silk Pillowcase	~\$20	amazon.com/s?k=Silk+Pillowcase
Scalp Care	Wide-Brim Hat (sun protection)	~\$15	amazon.com/s?k=wide+brim+hat
Cognitive	Whiteboard/Notebook & markers	~\$10	amazon.com/s?k=whiteboard+eraser
Cognitive	Pill Reminder App	Free	search app store
Nausea	Ginger Chews	~\$8	amazon.com/s?k=ginger+chews
Fall Prevention	Non-Slip Bath Mat	~\$15	amazon.com/s?k=non+slip+bath+mat

Category	Product	Cost	Link
Fall Prevention	LED Nightlights	~\$10	amazon.com/s?k=led+nightlights
Seizure Safety	Medical Alert Bracelet	~\$15	medicalalert.org

Prescriptions (dexamethasone, anti-seizure medications, Zofran, memantine) 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
