

AMERICAN BRAIN TUMOR ASSOCIATION

Steroids



American
Brain Tumor
Association®

Providing and pursuing answers®

ABOUT THE AMERICAN BRAIN TUMOR ASSOCIATION

Founded in 1973, the American Brain Tumor Association (ABTA) was the first national nonprofit organization dedicated solely to brain tumor research. The ABTA has since expanded our mission and now provides comprehensive resources to support the complex needs of brain tumor patients and caregivers, across all ages and tumor types, as well as the critical funding of research in the pursuit of breakthroughs in brain tumor diagnoses, treatments and care.

To learn more, visit **abta.org**.

We gratefully acknowledge Jeffrey Raizer, MD, director of Medical Neuro-Oncology at Northwestern Memorial Hospital, Professor of Neurology at Northwestern University/Feinberg School of Medicine and co-director of the Northwestern Brain Tumor Institute, for his review of this edition of this publication.

This publication is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician(s), utilizing your specific medical information. Inclusion in this publication is not a recommendation of any product, treatment, physician or hospital.

Steroids

INTRODUCTION

Steroids are naturally occurring substances. In brain tumor treatment, steroids are used to reduce the brain swelling, or cerebral edema, sometimes caused by the tumor or its treatment. The steroids given to brain tumor patients are corticosteroids – hormones produced by the adrenal glands. They are not the same as the anabolic steroids used by athletes to build muscle.

Dexamethasone (Decadron™) and prednisone are some corticosteroid drugs. These steroids can temporarily improve neurological symptoms by reducing brain swelling but in most cases do not directly treat the tumor. Because steroids are hormones, their long-term use requires close monitoring. This publication will review why steroids are given, potential side effects, how to manage the effects of steroids and a few guidelines for their safe use.

WHEN ARE STEROIDS GIVEN?

Steroids may be prescribed when a brain mass is seen on an MRI or CT scan of the brain, around the time of surgery or radiation, or sometimes with chemotherapy. Steroids are used for short-term symptom control

although they may occasionally be continued for a period of weeks or months.

Steroids can also be used for other reasons. They can improve appetite, prevent nausea and vomiting from chemotherapy, reduce pain and prevent allergic reactions to some chemotherapies.

ABOUT CEREBRAL EDEMA

Cerebral edema is the accumulation of fluids in the tissue around a brain tumor. It is a common occurrence in people who have a brain tumor. Edema happens when the blood brain barrier (a protective barrier) becomes leaky and fluid collects in the surrounding tissue. Edema can also occur following surgery or radiation therapy.

Edema can lead to increased pressure in the brain as the swelling increases, it can cause headaches, drowsiness, difficulty walking or increased weakness. Often the edema actually causes more symptoms than the tumor itself.

DO STEROIDS TREAT TUMOR CELLS?

In the case of most brain tumors, steroids are not prescribed to eliminate cancer cells. One exception is lymphoma involving the brain or spinal cord (primary central nervous system lymphoma or PCNSL). If this type of tumor is suspected, steroids are not usually used until after the diagnosis is confirmed by biopsy or removal of the tumor. Please note that even in lymphoma steroids are not typically a long-term cure for this tumor.

HOW ARE STEROIDS TAKEN?

Steroids are usually administered intravenously (IV) or by mouth (orally). It may take 24–48 hours before you begin to see the effects of the medication, but the change is often remarkable. The dose used is dependent on how much swelling is seen on the MRI or CT scan of the brain.

To protect your stomach, take your steroids with food or milk. Your doctor may also prescribe a medication to further protect your stomach.

As with all medicines, the goal is to use lowest, most effective dose of medication. This may mean the dose is adjusted up or down to find the best dose for you. The goal for the steroids is to use the lowest dose to control symptoms or lead to CT or MRI changes. You and your family can be helpful by keeping your doctor aware of the way you react to steroids.

When your doctor feels you no longer require steroids, you will be given instructions for slowly stopping (tapering off) the drug. Do not abruptly stop taking your steroids. A gradual reduction of steroid dose allows your body to begin producing its own steroids again. This gradual tapering avoids a problem known as adrenal crisis, which is caused by insufficient levels of the hormone cortisol. Lowering steroid levels too quickly can also cause a rebound increase in brain swelling and return of symptoms and sometimes joint pain.

SIDE EFFECTS

Steroids can cause a wide range of unwanted effects. The most common side effects include increased appetite, weight gain, increased blood sugar levels (especially if you have diabetes), gastrointestinal problems (like stomach ulcers), frequent urination, insomnia and mood changes like irritability or mania, muscle weakness, susceptibility

to infections like pneumonia, thinning of the skin, and acne. Steroids can interact with other medications, either increasing or decreasing the levels in your blood, which can alter their effectiveness or increase their side effects. Other, more serious side effects can occur, although they are less common.

The benefits of steroid use almost always outweigh their potential side effects when they are prescribed. If you have any questions about balancing risks and benefits, please talk with your doctor.

MANAGING COMMON SIDE EFFECTS

Weight Gain and Increased Blood Sugar Levels

Steroids increase the appetite and often cause weight gain. They can also cause the redistribution of fat in an unusual pattern – puffy cheeks or a small hump at the top of your back (“cushingoid features”). Fat is redistributed more on the abdomen and less in the extremities. Stretch marks are also common as is bruising.

- Steroids cause gradual weight gain. If you gain more than three to five pounds in one week, please call your doctor. A sudden, large weight increase can signal medical problems that should be reported to your health care team. Monitoring food intake can help prevent un-wanted weight gain.
- Ask your doctor for a referral to a licensed registered dietician experienced in treating cancer patients. A healthy eating plan may slow weight gain and provide the nutrients important to your healing.
- Exercise can minimize weight gain caused by steroids.

Steroids may affect your blood sugar level, especially if you are diabetic. Some patients need medications to help control elevated blood sugars. If you are experiencing increased thirst and urination, contact your physician as this is a sign of elevated blood sugar levels.

Lastly, it's important for you to stay adequately hydrated. Keep your kidneys and bowels in good shape by drinking six to eight glasses of non-caffeinated liquid per day.

Gastrointestinal Problems

Steroids can cause stomach irritation or bleeding in the bowels.

- Take your medication with food, milk or an antacid that your doctor prescribes for you.
- Call your doctor if you have abdominal pain, run a temperature, are constipated or notice any blood in your stool after a bowel movement.
- Avoid the use of non-steroidal anti-inflammatory drugs (Advil™/ Motrin™/ibuprofen or Aleve™/naproxen) and aspirin unless directed by your doctor.

Insomnia and Mood Changes

Sleep disturbances are a very common side effect.

- Ask your doctor if your dosage can be adjusted so you take more medication in the morning and less after dinner. (Don't make this change on your own.)
- Healthful sleeping habits may be of help. These include avoiding bright light in the evening hours, avoiding caffeine in the afternoon and evening, establishing a regular nighttime routine, and observing a consistent bedtime.
- Medication may be prescribed to help you sleep.

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- Steroids are also known to cause changes in mood, including depression, mood swings, irritability or (rarely) psychosis.
 - Let your doctor know how you are feeling. Medications may relieve some of these symptoms and can be particularly helpful if you are required to be on steroids for a long period of time.
 - It is also helpful to discuss these effects with your family so they know what to expect and can be supportive.

Muscle Weakness

Steroids often cause weakness in the muscles of the legs, arms, neck and chest. The most common symptom of muscle wasting from steroids is difficulty getting up from a chair or toilet or difficulty climbing the stairs. If the chest muscles are affected, you may experience difficulty taking deep breaths.

- Exercise is important to keep your muscles as strong as possible.
- Ask your doctor about exercises that may help strengthen your muscles, or for a referral for physical therapy.
- Let your physician know about any muscle or joint pain you experience.

Infections

Steroids can impair your body's ability to fight infections and can mask the beginning of an infection in your body by preventing a fever.

- Be alert to anything that just doesn't seem right, especially if you develop a fever, chills or body aches. An increase in temperature may be the first – or only – sign something is amiss.
- Look at your tongue and inside your mouth each time you brush your teeth – people on steroids are especially prone to yeast infections, or “thrush,” in their mouth. If you notice a thick white coating on your tongue or white spots on the roof of your mouth and back of your throat, make your nurse or doctor aware. A medication can be prescribed to treat this.
- Some people are prone to developing a certain type of pneumonia after they have been on steroids for a prolonged period. Notify your doctor if you have any breathing difficulties. Your doctor may choose to start an antibiotic for this reason.
- Ask your physician if you should receive the influenza, shingles or pneumonia vaccines.
- Be careful to follow the health precautions used by people at higher risk for infection. Wash all fresh fruits and vegetables carefully. Wash your hands frequently. Cook meat and poultry until well done. Use gardening gloves when working outside. Avoid large crowds and close contact with people who may be sick.

CALL YOUR DOCTOR IF ...

- You develop a fever (temperature higher than 100.0°F), even if you feel well otherwise.
- You see any blood in your stool after a bowel movement.

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- You have stomach pain.
 - You gain more than three to five pounds in one week.
 - You develop a rash or sores in the mouth.
 - You are drinking and urinating a lot.
 - You are falling.
 - Chest pains or difficulty breathing may signal a medical emergency. Call for emergency help.

AMERICAN BRAIN TUMOR ASSOCIATION INFORMATION, RESOURCES AND SUPPORT

Brochures

Educational brochures are available on our website or can be requested in hard copy format for free by calling the ABTA. Most brochures are available in Spanish.

General Information

About Brain Tumors: A Primer for Patients and Caregivers
Brain Tumor Dictionary
Brain Tumors: A Handbook for the Newly Diagnosed
Caregiver Handbook

Tumor Types

Ependymoma
Glioblastoma & High-Grade Astrocytoma
Medulloblastoma
Meningioma
Metastatic
Oligodendroglioma
Pituitary

Treatment

Chemotherapy
Clinical Trials
Conventional Radiation
Proton Therapy
Stereotactic Radiosurgery
Steroids
Surgery

Additional Resources

Neuropsychiatric Symptoms
Questions to Ask Your Doctor – Primary Brain Tumors
Questions to Ask Your Doctor – Metastatic Brain Tumors
Seizure First Aid

AMERICAN BRAIN TUMOR ASSOCIATION INFORMATION, RESOURCES AND SUPPORT

Information

ABTA WEBSITE | ABTA.ORG

Offers more than 200 pages of information, programs, support services and resources, including: brain tumor treatment center and support group locators, caregiver resources, research updates and tumor type and treatment information across all ages and tumor types.

Education & Support

- **ABTA Educational Meetings & Webinars**
In-person and virtual educational meetings led by nationally-recognized medical professionals.
- **ABTA Patient & Caregiver Mentor Support Program**
Connect with a trained patient or caregiver mentor to help navigate a brain tumor diagnosis.
- **ABTA Connections Community**
An online support and discussion community of more than 25,000 members.
- **ABTA CareLine**
For personalized information and resources, call 800-886-ABTA (2282) or email info@abta.org to connect with a CareLine staff member.
- **ABTA Financial Assistance Program, Glenn Garcelon Fund**
Offers limited financial assistance for patients diagnosed with a primary benign or malignant brain or spine tumors.

Get Involved

- Join an ABTA fundraising event.
- Donate by visiting abta.org/donate.
- Share your story

Contact The ABTA

CareLine: 800-886-ABTA (2282)

Email: info@abta.org

Website: abta.org

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AMERICAN BRAIN TUMOR ASSOCIATION

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