



FOCUSING ON TREATMENT

Steroids



American Brain Tumor Association

A Word About ABTA

Founded in 1973, the not-for-profit **American Brain Tumor Association** has a proud history of funding research, providing patient services, and educating people about brain tumors. Our mission is to eliminate brain tumors through research and meet the needs of brain tumor patients and their families.

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Introduction

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

Dexamethasone (Decadron) and prednisone are corticosteroid drugs. These steroids can temporarily relieve brain tumor symptoms, improve neurological symptoms, promote a feeling of well-being, and increase your appetite. Because steroids are hormones, their long-term use requires close monitoring. In this publication we’ll share why steroids are given, how to manage the effects of steroids, and a few guidelines for their safe use.

About Edema

Edema is the accumulation of fluids in the tissue around a tumor – it is a common occurrence in people who have a brain tumor. Edema happens when the blood brain barrier, an invisible protection around the brain, is disrupted by the tumor. Small blood vessels around the tumor can then leak fluids which collect in the surrounding tissue. Edema can also occur following surgery, radiation, or other treatment for a brain tumor.

Edema can lead to increased pressure within the brain which, in turn, can cause headaches and drowsiness. Sometimes the edema actually causes more symptoms than the tumor itself. Steroids are medications used to reduce edema.

When Are Steroids Given?

Steroids may be prescribed before, during, or after surgery. They may be started at the time of diagnosis if edema is seen on MRI scan, or if swelling is causing pressure on the brain. Steroids may be used to control edema caused by surgery. In this situation, they may be started just prior to surgery or during the procedure. If swelling occurs following surgery, as it sometimes does, steroids can be given at that time. If you were on steroids prior to surgery, your dose might be adjusted after surgery if increased swelling causes an increase in your symptoms.

Steroids are also used to treat edema caused by radiation therapy. Steroids may be started prior to radiation, or at the time of treatment. The steroids are continued until the brain appears to have healed from the acute effects of the therapy.

For people with a recurrent tumor, or those with a metastatic brain tumor (which spread to the brain from a cancer elsewhere in the body), steroids can help improve quality of

life by reducing symptoms. When used in this way, steroids may increase a person's alertness, ability to be mobile, or perhaps increase their ability to communicate and interact with others.

Do Steroids Treat Tumor Cells?

Steroids are not intended to be a “cytotoxic” or cell-killing therapy. Their purpose is to reduce swelling, not cure the tumor. However, some researchers do believe steroids have some toxic effect on tumor cells. If true, this effect is probably not great enough to kill significant numbers of tumor cells or to make steroids an effective “stand-alone” therapy.

One particular tumor that is very sensitive to steroids is primary central nervous system lymphoma (PCNSL). If this type of tumor is suspected, steroids should not be used until after the diagnosis is made. There are other diseases that respond to steroids, and a pathology reading may be more difficult if the lymphoma was pre-treated with steroids. PCNSL can markedly decrease in size on scans taken immediately following the use of these drugs. Rather than controlling edema, steroids destroy lymphoma tumor cells, but they are not a long-term cure for this tumor.

How Are Steroids Taken?

Although steroids can be started through an intravenous (IV) line or by injection into a muscle (IM), most people with a brain tumor take their steroids by mouth – also called “orally.” The pills come in doses that range from 0.25 mg to 6 mg tablets, taken between two and four times a day. Your doctor will determine the starting dose of steroid based on your MRI scan and your symptoms. It will take 24-48 hours before you begin to see the effects of the medication, but the change is often remarkable. The dose may need to be adjusted – either increased or decreased slightly – depending on how your body reacts to them.

To protect your stomach, take your steroids with food or milk. Your doctor may also prescribe an antacid to be taken daily.

If your doctor prescribes the long-term use of steroids, don’t be disappointed if your steroid dose needs to be increased over time. The goal, of course, will be to find the lowest, most effective dose of medication that keeps your neurological symptoms at a minimum. With time, however, that “most effective dose” may need to be adjusted. The need to increase your medication does not automatically mean your tumor is growing, and it does not mean you’ve made errors in taking your medication.

You and your family can be of great help in this process by keeping your doctor aware of the way your body reacts to the steroids. If at

any point the side effects become difficult to manage, please share your concerns with your nurse or doctor.

When your doctor feels you no longer require steroids, you will be given instructions for slowly stopping the drug. **Do not abruptly stop taking your steroids.** The “tapering” process slowly decreases your steroid dose. Your body needs this period of time to again begin producing its own steroids, and to avoid an emergency medical crisis. Lowering steroid levels too quickly can also cause a “rebound” increase in swelling.

Side Effects

Steroids can have several positive side effects. They can markedly decrease symptoms, give one an overall sense of well-being, temporarily increase thought and functioning abilities, and increase your appetite.

Steroids can also cause a wide range of effects that must be carefully monitored by your doctor. The most common side-effects are: weight gain; thinning of the skin; gastrointestinal upset; muscle weakness in your thighs, shoulders, and neck; susceptibility to infections; “masking” or hiding a fever; mood swings; insomnia; pneumonia; and increased blood sugar levels (especially if you have diabetes.) Steroids can interact with some seizure medications, either increasing or lowering their levels in your blood, which can alter their effectiveness. Other, more serious side-effects can occur, although they are less common.

The benefits of steroid use almost always outweigh their potential side effects. 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

After a few months of steroid use, you may begin to notice a significant weight gain. This is not the “fatty” weight of overeating – it is your body processing and storing food in a different way. You may notice your face looks puffy or moon-like, and you’ve developed a small hump on your back, just below the neck, called a “buffalo hump.” You may notice stretch marks across your abdomen as it increases in size, while your upper arms and legs seem to become thinner. These changes are due to your body storing more fat on the trunk of your body and less in your extremities. While this is an unavoidable effect of steroids, there are several things you can do to help manage this change in your body.

Firstly, steroid weight gain gradually increases. If you gain more than 5 pounds in one week, please call your doctor. A sudden, large weight increase can signal medical problems that should be reported to your healthcare team.

Secondly, ask your doctor for a referral to a licensed registered dietician experienced in treating people on steroids. This may be a

dietician who regularly works with cancer patients, or a dietician experienced in treating people with pituitary disorders. Either can be of help in outlining a healthy eating plan that will provide the nutrients important to your healing, yet limit those which your body has difficulty with right now. Since nutritional needs vary from person to person, a professional is your best resource for this help.

Steroids may affect your blood sugar level, especially if you are diabetic. If your sugar levels increase, you may be referred to both an endocrinologist and a dietician. In some cases medication may need to be started or your existing medication may need to be adjusted.

Thirdly, it's important that your body maintain its ability to flush waste out of your system. Keep your kidneys and bowels in good shape – don't stop drinking water. It's a natural reaction to try to avoid adding liquids to your body right now, but that will only compound the problem.

GASTROINTESTINAL PROBLEMS

Steroids can cause an upset stomach. Be sure to take your medication with food, milk, or an antacid that your doctor prescribes for you. Call your doctor if you have stomach pains, run a temperature, are constipated, or notice any blood in your bowel movement. Avoid the use of non-steroidal anti-inflammatory drugs (NSAIDs such as Advil, Motrin, Aleve) and aspirin unless directed by your doctor.

While you are on steroids, it is especially important that you have regular bowel movements. If you become constipated, or experience diarrhea, call your healthcare team.

INSOMNIA

Sleep disturbances are a possible side effect of changing hormone levels. If you have difficulty sleeping, 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, such as avoiding bright light, caffeine and sugar as bedtime approaches, and a regular nighttime routine may be of help.

DEPRESSION/MOOD CHANGES

While taking steroids, you might experience depression, mood swings, irritability, or agitation. These symptoms are due to the steroid's effect on the natural hormone balance in your body, and can be treated. Let your doctor know how you are feeling. Medications may relieve some of these symptoms and can be particularly helpful if you remain 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 sometimes cause weakness in the muscles of the legs, arms, neck and chest. Leg weakness may be most noticeable when you get up from a sitting position and try to use the large muscles in your thighs. If leg weakness is a problem, ask for assistance when using the bathroom or getting up from a chair. Walk with another person who can get help should you stumble, or try an assistive device – such as a cane or walker. If the chest muscles are affected, you may experience difficulty breathing or pain when taking deep breaths – especially if you have a history of asthma, emphysema, or smoking. Please be sure your doctor is aware of your past medical history. Ask your doctor about exercises that may help strengthen your muscles, or for a referral for physical therapy.

INFECTIONS

Steroids have a tricky way of “masking,” or hiding, the beginning of an infection in your body. Be alert to anything that just doesn’t seem right. An increase in temperature may be the first – or only – sign something is amiss. Because of that, some people on steroids take their temperature at the same time every day, regardless of how they feel. This is an easy way to keep a baseline check on your good health. Additionally, look at your tongue 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, make your nurse or doctor aware.

Some people are prone to developing a certain type of pneumonia after they have been on steroids for awhile. Your doctor may start you on an antibiotic to prevent this from happening. Bactrim is a drug commonly used for this purpose, but please let your doctor know if you are allergic to sulfa-based drugs.

While you are on steroids, follow the health precautions used by people at higher risk for infection. Wash all fresh fruits and vegetables carefully. Wear gloves when using a kitchen knife. Cook meat and poultry until well done. Use gardening gloves when working outside. Avoid crowds and, in general, avoid sick people.

Call Your Doctor If....

- You are running a temperature – even if you feel well otherwise.
- You see any blood in your bowel movements.
- You have stomach pain.
- You gain more than 5 pounds in one week.
- You develop a rash.
- You are drinking and urinating a lot.
- You are falling.
- **Chest pains or difficulty breathing may signal a medical emergency. Call for emergency help.**

The Next Steps

We hope that the information in this publication helps you understand how these drugs work, and provides the knowledge you need to be more comfortable caring for yourself or your family member while they are on steroids. As we stated, the goal of steroid treatment will be to use the minimal amount of medication necessary, and to wean you from the medication as soon as practical.

Regardless of where you are in your treatment, your task is becoming well again. Make appointments for your follow-up doctor visits or scans and mark them on your calendar. Find a support group if you'd like to meet others with brain tumors. See friends. Learn about your tumor. Our web site – www.abta.org – offers extensive brain tumor information, treatment and research updates, and patient/family stories. The thread that runs through each of our services and programs is hope. Become involved – join us in some way, to make sure there is a cure, and ultimately, a way to prevent brain tumors.

We hope that the information in this pamphlet helps you communicate better with the people who are caring for you. Our purpose is not to provide answers; rather, we encourage you to ask questions.

Questions I Want to Ask

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Publications & Services

BUILDING KNOWLEDGE

A Brain Tumor – Sharing Hope
Tumor del Cerebro – Compartiendo la Esperanza
Dictionary for Brain Tumor Patients
Living with a Brain Tumor
A Primer of Brain Tumors

FOCUSING ON TUMORS

Ependymoma
Glioblastoma Multiforme and Anaplastic Astrocytoma
Medulloblastoma
Meningioma
Metastatic Brain Tumors
Oligodendroglioma and Oligoastrocytoma
Pituitary Tumors

FOCUSING ON TREATMENT

Chemotherapy
Radiation Therapy: A Basic Guide
Stereotactic Radiosurgery
Steroids
Surgery
Physician Resource List: Physicians Offering Clinical Trials for Brain Tumors

FOR & ABOUT CHILDREN

Alex's Journey: The Story of a Child with a Brain Tumor
(Video or Booklet)
Education Packet *(Parent or Teacher)*
When Your Child Returns to School

SUPPORT RESOURCES

Bibliography
Care Options
Emergency Alert Wallet Cards
Employment Information
End-of-Life Care
Financial Aid Resources
Health Insurance Resources
Housing During Treatment Resources
Net-Working Links
Scholarship & Educational Financial Aid Resources
Social Security Disability Resources
Spanish-Language Resources
Transportation Assistance Resources
Wig and Head Covering Resources
Wish Fulfillment Resources

NEWSLETTER

MessageLine Newsletter
Sharing Knowledge, Sharing Hope e-News

FOCUSING ON SUPPORT

Connections – A Pen Pal Program: Information
Listing of Brain Tumor Support Groups
Listing of Bereavement (Grief) Support Groups
Organizing and Facilitating Support Groups
Resources for Online Support
TLC (Tips for Living and Coping) e-bulletin

Single copies of these publications are available free of charge.



American Brain Tumor Association



Sharing knowledge. Sharing hope.



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