

## Steroids and Brain Edema (Brain Swelling)

The purpose of this handout is to discuss the use of steroids to treat brain swelling or brain edema.

### What is brain edema?

Brain edema is “extra fluid” within the tissues of the brain. This fluid can occur as a result of tumor cell growth, tumor cell death, or as a side effect of treatment. Since the skull is a rigid “container” with no extra room, this fluid causes pressure on the brain, blood vessels, and nerves. This causes you to have symptoms.

### What are the symptoms of brain edema?

- Increased or severe headaches that are not relieved by Tylenol®.
- Headaches that occur daily or several times a day, even if relieved by Tylenol®
- Headaches with nausea and vomiting
- Nausea or vomiting.
- Any change in strength or feeling (numbness or tingling)
- Clumsiness or coordination problems of a hand or leg
- Vision, hearing or speech changes or troubles
- Trouble with balance, walking or dizziness
- New onset of confusion
- New or worse seizures

### What are steroids?

Steroids are hormones produced by the adrenal glands that are used to reduce brain swelling. The steroids used to treat brain tumors are not the same as those used by athletes. The most common steroid is dexamethasone (Decadron®). Prednisone may also be used.

### When are steroids used?

Steroids are used when you are having symptoms of brain edema:

- Before, during, or after surgery.
- During or after radiation therapy.
- During or after chemotherapy.
- When edema is noted on an MRI scan, even if you are not having symptoms.

### How are steroids given?

Steroids can be given through an IV, into a muscle (IM), or as a pill (oral). Most brain tumor patients will take their steroids as a pill. Your doctor will order your dose based either on your symptoms or the amount of edema present on the MRI scan. We will adjust the dose up or down based on how your body responds.

Steroids should always be taken with food to protect your stomach. Your doctor may also prescribe a medicine (Famotidine® or Pepcid®) to protect your stomach. Steroids can also affect the normal bacteria in your mouth, making you more likely to have a yeast infection called “thrush”. Your doctor may also prescribe a medicine to prevent the yeast infection. Over time your doctor will try to decrease your steroid dose. Sometimes this is very easy to do, and other times it is a very slow process. Your steroids dose may need to be increased along the way. The brain is very sensitive to edema. Your doctor will work on finding the lowest dose of steroids needed to reduce the symptoms of brain edema.

**Never stop your steroids without talking to your doctor.** Steroids must be decreased slowly over time or “tapered.” The longer you are on the steroids, the slower this taper will occur.

**What are the side effects of steroids, and how do I manage them?**

Although steroids cause a range of side effects, the benefits outweigh the side effects. If you have questions about using steroids, please talk with your doctor or nurse.

**Weight gain and increased hunger.** After a few weeks or months on steroids, many people notice weight gain and a fullness or puffiness in their face or neck and the upper part of their back.

Although steroids increase appetite, the weight gain most people see is due to the way the body processes and stores fats. To deal with weight gain, avoid empty calories such as candy, cookies, sweets, and sodas. Try to eat fruits and vegetables.

If you have questions or concerns about your diet, talk with your doctor or nurse, or ask to speak with a dietician.

**Stomach upset/ulcers.** Since steroids can increase the acid in your stomach, steroids should always be taken with food. Your doctor may prescribe a medicine to protect your stomach. Avoid non-steroidal anti-inflammatory drugs (NSAIDs, Motrin<sup>®</sup>, Advil<sup>®</sup>, Aleve<sup>®</sup>, and aspirin).

If you have stomach pains, notice blood in your stool, or become constipated, call your doctor.

**Increased blood sugar levels.** If you have diabetes, steroids can increase blood sugar levels. Call your diabetes doctor to have your blood sugar levels followed more closely. Your doctor may need to adjust your diabetes medicines while taking steroids. You may also need to watch your diet more closely.

If you do not have diabetes, your body often adjusts to the increased blood sugar levels. If you notice you are drinking and urinating a lot, call your doctor. This may be an early sign of increased blood sugar levels.

**Muscle weakness in thighs, hips, and shoulders.** Muscle weakness from steroids can be seen when you try to get out of a chair, up from the toilet, climb a set of stairs, or walk a long distance. Steroids weaken the large muscles of the hips, thighs, and shoulders.

Safety should always be a concern. You should walk with others if there is a risk of stumbling or falling. You may want to install grab bars in the bathroom near the toilet or tub. If you need a walker, cane, or wheelchair, please discuss this with your doctor or nurse.

Your nurse can give you a copy of exercises for your hip and thigh muscles. Some people are able to do these exercises at home and maintain leg strength, while others may need the help of physical therapy (PT) or occupational therapy (OT). These services may be covered by your insurance plan. Discuss these issues with your health care team.

**Increased risk of infections.** Steroids can “mask” the early signs of an infection. Be alert for subtle signs of infections, especially in the mouth.

You can notice a yeast infection in your mouth called “thrush.” Your doctor may prescribe medicines to help prevent thrush. Even if you take the medicines as you were told, you can still get thrush. If you notice a “white” coating on your tongue, food has a foul or metallic taste, or you notice bad breath, call your doctor.

Good oral care is vital. Look at your tongue each time you brush your teeth.

**Insomnia or trouble sleeping.** Trouble sleeping is a common side effect of steroids. Some people combat this by taking their steroids earlier in the day. If you are taking steroids four times a day, you may not be able to do this. If sleeping is an issue for you, discuss this with your doctor.

**Depression, mood changes, or agitation.** While taking steroids, you may have any or all these symptoms due to the effect on hormone levels.

Discuss these symptoms with your doctor. Sometimes, the steroid can be changed or other medicines can be prescribed to deal with these symptoms.

**Thinning of skin or changes in your skin.** You may notice the skin appears “thinner,” stretch marks on the abdomen, or small red “dots” on the arms. Avoid exposure to sun. Avoid activities where the skin may get rubbed or torn.

## **Medicines**

Talk with your health care team about all of the medicines you take. Include over-the-counter drugs, herbals, and vitamins on your list of medicines. Avoid non-steroidal anti-inflammatory drugs (NSAIDs, Motrin<sup>®</sup>, Advil<sup>®</sup>, Aleve<sup>®</sup>, and aspirin) while taking steroids.

You can safely use Tylenol<sup>®</sup> or Extra Strength Tylenol<sup>®</sup> for pain when you are on steroids.