Steroids
(prednisone, prednisolone or dexamethasone)
Side effects and what to expect

What are steroids?
Steroids are used to treat many conditions. Your providers will decide how much of the steroid you will take and how often. Steroids can be life saving, but have some common side effects that affect your body and your emotions. Some side effects can be difficult to deal with, but it helps to know what to expect.

Different people may have different side effects. Side effects depend on:
• How long you take the steroid
• How often you take it
• How big a dose you take

This flyer tells you about the some of the physical, nutritional and emotional side effects you may have while taking a steroid. Ask your healthcare team if you have questions. Your provider will watch you carefully for side effects and will help you to deal with them.

When will the side effects stop?
The side effects of steroids stop when you stop taking them. Even as you take less, the side effects will get a little better. Some of the side effects may not happen at all if you take a steroid every other day instead of every day. Your provider will decide how much you need. Your health is first priority. It is very important to follow your provider’s instructions when you take your steroid.

It is also very important not to stop taking a steroid suddenly. This can harm your body. Instead, steroids must be taken a little less over time (tapered) slowly. This way, your body can adjust to making it on its own again.

Effects on your body
Steroids can affect your muscles, bones, stomach, skin, eyes and other things. It can cause problems with how your body processes food, too. For all of these reasons, it is important to talk to your provider and to your dietitian. They can help you take care of yourself and eat well to lessen side effects.

Infections
Steroids weaken your immune system. A normal immune system tries to fight off foreign invaders (like bacteria and other tissue it does not recognize). Weakening this normal defense may affect how well you can fight infection caused by viruses, bacteria and fungus. So it is a lot easier to get sick when you are taking a steroid. It is very important to let your team know right away if you have a fever, cough or cold symptoms or a sore that is not healing.

Your healthcare team may need to check you for signs of infection using blood tests and other kinds of tests.
Muscle pain or weakness and muscle loss
Your arms and legs may ache when you have been taking steroids for a while. Walking, gentle exercise and rest will help. You may see a physical therapist who can show you how to stretch and exercise without hurting yourself. Your provider may also give you medicine to help the pain.
Taking steroids can also lead to muscle loss. Regular physical activity and eating foods that are high in protein can help prevent muscle loss and weakness.

Changes in skin
You may see changes in your skin while you are taking steroids. The color of your skin may change or look patchy or blotchy. You may notice that your skin looks thinner than usual, and some people also get stretch marks. Steroids can cause your skin to break out, and some people can have acne while taking it.
Keep your skin clean by bathing or showering every day. Please check with your care team if your skin breaks out or if you get sores or rashes. Also check with them before using any creams or ointments on your skin.

Slower growth and delayed puberty
Steroids change your body so it makes less of the hormones that make you grow. As a result, you may be shorter and smaller than others your age. Your provider will watch how you grow and may order blood tests to measure your growth hormone. Your provider may also give you extra growth hormone to help you catch up.
You might also have a delay in the start of puberty, and girls may notice changes in their period.

Cataracts
Some people who have been taking steroids for a long time can develop cataracts, a condition of the eyes. A film or clouding covers the lens of the eye, which makes your vision blurry. Your provider will check your eyes when you have clinic appointments. Please tell your provider if you are having blurry or double vision or any problems seeing. Cataracts can be removed by laser or surgery.

Weakening of the bones
Steroids can weaken bones, especially around the joints (hips, knees and shoulders). This can make your bones more likely to break (fracture) and can cause wear and tear in your joints.
People who take high doses of steroids for a long time (many months to years) can have problems with their bones becoming so thin the bone does not get the nutrients it needs and dies. This is called avascular necrosis (AVN). If this is a problem for you, you may need surgery to repair or replace the bone or joint. Your provider may check your bones from time to time using X-rays and other tests.
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Keeping too much fluid and salt in your body
Steroids can make your face, legs and ankles look swollen or puffy. This is caused by your body holding on to extra water and salt (sodium).

High blood pressure
Many people who take steroids can have high blood pressure. Your healthcare team will check your blood pressure while you are taking steroids, and your provider may give you medicine to lower your blood pressure. Eating well (like eating low-salt foods), gentle exercise, relaxation and rest can help.

Increases in blood sugar
Taking steroids can make the sugar (glucose) in your blood high, especially if you also need IV nutrition (parenteral nutrition or PN). Signs that your sugar levels are high include:
• Feeling more thirsty than usual
• Peeing (passing urine) more often than usual
• Blurry vision
• Feeling dizzy or tired
Your healthcare team may check your blood sugar with your other lab tests. If you have high blood sugar, you may need to avoid foods that have lots of sugar, like candy and soda.

Side effects related to eating
Some of the effects of steroids are related to what you eat. While you are taking it, it is important to pay attention to what foods and drinks you have. Your provider and dietitian can talk with you about these. For more detailed information about what to eat while on steroids, see the Seattle Children’s flyer, “What to Eat While Taking Steroids” (http://www.seattlechildrens.org/pdf/PE615.pdf).

Hunger and weight gain
You may feel more hungry than usual while on a steroid. Most people who take steroids gain weight. Some may develop a fatty area below the back of the neck called a “buffalo hump.” These changes are normal and will go away as you take less steroids.

Upset stomach
Steroids can give you an upset stomach. You may get heartburn, nausea or indigestion. Talk with your provider or dietitian if this is a problem for you.

Tips for eating while on steroids
• If you are hungry, eat healthy snacks and avoid too much extra sugar (especially if you have high blood sugar). Exercise gently each day and avoid eating at unusual times during the day or night.
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- Eat plenty of foods with calcium to keep bones strong
- Avoid eating salty foods to avoid puffiness
- Avoid foods that are high in fat or acid
- Eat foods that are high in protein

**Emotional side effects**

Steroids can affect more than just your body. It can affect your mind, too. You might have feelings and emotions that you are not used to. You might have other problems, like having trouble sleeping. Talk with your care team about any emotional or sleep-related side effects you have.

**Trouble sleeping**

You may have problems sleeping while taking steroids. It can make you feel “wired” or hyper like you drank too much caffeine. You might find it hard to sleep at night, or you might wake up several times in the night. Sometimes changing the times, you take your steroid can help. It is always very important to talk with your provider before making any changes to your medicines.

Rest is important. Even just relaxing with soft music and being still and quiet can help with being tired, even if you cannot sleep. Your provider may also give you medicine to help you sleep.

**Mood swings**

Mood swings can be sudden and extreme. You may feel very happy one minute and very sad the next, and not know why. You may become angry and feel frustrated more easily than before. It is important to talk about your feelings with someone you trust and feel comfortable with. Remember that many people who take steroids feel like this.

Some people who take steroids have euphoria (you-FOR-e-uh). This is a feeling of great happiness and excitement, like how you might feel if you won the lottery. Some people have euphoria one minute then feelings of sadness the next minute.

This feeling may affect sleep and the ability to rest well. It is important not to get too tired. Take breaks and rest often, and pay attention to what you are feeling from day to day. Keeping a journal, and reading back over good and bad days may help. If you are feeling so euphoric that you are unable to rest well, please talk with your care team.

**Confusion**

You may feel unable to pay attention. This can affect reading and schoolwork, or even just talking and answering questions. You may feel mixed up or confused about things. Having a regular daily routine and writing down the things you need to do and remember can be very helpful.
To Learn More

- Cancer Care Unit
  206-987-2032
- Ask your child’s healthcare provider
- www.seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your child’s nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

Anxiety and panic

Signs of anxiety include restlessness, a lot of worrying about things that probably will not happen, and not being able to pay attention or remain focused on a task.

Sometimes the stress can get extreme and lead to panic attacks. Panic attacks are short times of intense fear and anxiety, which often include quick heartbeats, shortness of breath, chest pain, dizziness or stomach problems. Please talk with your provider if you are having any of these signs.

Some things that may help lower your stress are:

- Getting enough rest (at least 8 hours a day)
- Meditation (sitting quietly with your thoughts)
- Talking about your feelings with someone you trust
- Listening to gentle music
- Reading
- Massage
- Taking a warm bath
- Going for walks
- Regular exercise that you are used to doing

Depression

Steroids can cause signs of depression, and dealing with a serious illness already causes a roller coaster of feelings. Feeling sad and helpless during this time is typical. If you have depression, it can make you feel empty, hopeless, negative or restless. In addition to the effects that steroids can have, depression can cause you to:

- Lose interest in hobbies or interests
- Feel unable to focus or concentrate
- Have trouble sleeping, or sleep much more than usual
- Lose your appetite or overeat

Talking about your feelings with someone who listens well (parents, friends, a child life specialist, a social worker, a nurse, a doctor, a volunteer or a psychologist), or sharing your experiences with someone who has also been through something similar can really help.

If you are having these feelings, or thoughts about hurting yourself, please talk with your care team right away. It is important to get professional help when you need it. Counseling or medicine might help manage your depression.