

## Prednisone

*The good, the bad, and the ugly—a guide to side effects*

### What is prednisone?

Prednisone (PRED-ni-son) is used to treat or prevent graft-versus-host-disease (GVHD) in bone marrow, cord blood and peripheral blood stem cell transplant patients. It has strong healing effects and is used to treat many other conditions. Your doctors will decide how much prednisone you take and how often, based on many important factors.

Prednisone can be life saving, but has some common, unpleasant side effects to your body and mind (emotions).

This information covers some of the physical and emotional side effects you may have while taking prednisone.

### What will the side effects be like?

The side effects of prednisone vary from person to person. The longer you are taking prednisone, the more often you take prednisone and the bigger the dose effects which side effects you may or may not have. Please talk to your doctor if you have questions. Your doctor will also be watching you carefully for side effects.

### When will it get better?

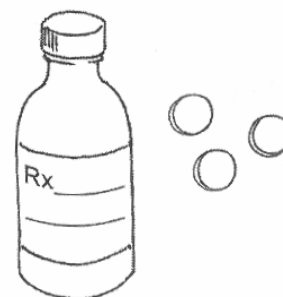
Remember most side effects of prednisone will decrease as you take less or taper off and stop taking the medicine. Some of the side effects of prednisone may not happen at all if you take it every other day instead of every day. Your doctor will make the complicated decision about how much you need.

**It is very important to follow your doctor's instructions when you take your prednisone.**

**You should never stop taking prednisone suddenly as this can harm your body.**

Prednisone must be reduced (tapered) slowly, so that your body can gradually take over making it on its own again.

Please talk with the transplant team about how to handle any of the physical or emotional side effects you may have.



**Physical side effects of taking prednisone can include:**

- More risk for infection
- High blood pressure
- Increases in blood sugar
- Keeping too much fluid and salt in your body
- Increased hunger and weight gain
- Muscle pain and weakness
- Rounding or filling out of the face
- Bone thinning
- Upset stomach
- Skin changes; color, thinning, acne
- Slower growth and delayed puberty
- Cataracts

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## More risk for infection

Prednisone helps treat or prevent GVHD by weakening the defensive power of your immune system. A normal immune system tries to fight off foreign invaders (like bacteria and other tissue it does not recognize). We want your new immune system (transplant) to accept your body, not fight it. However, weakening this normal defense may also effect how well you can fight infection caused by viruses, bacteria and fungus. In other words, you can catch things a lot easier when on prednisone. It is very important to let your doctor know immediately if you have a fever, cough or cold symptoms, unusual diarrhea or a sore that is not healing.

We may check you for signs of infection using blood tests, chest X-rays and other tests and your doctor may give you medicine to fight or prevent infection while you are taking prednisone (for example fluconazole, acyclovir and bactrim).

## High blood pressure

Many people who take prednisone, especially with cyclosporine or tacrolimus, can have high blood pressure. Your blood pressure will be checked while you are taking prednisone and your doctor may give you medicine to lower your blood pressure (for example, a medicine called amlodipine).

Eating foods with less salt will help. Please ask your dietitian for help choosing foods that are best for you. Gentle exercise, relaxation and rest also help.

## Increases in blood sugar

Taking prednisone can make the sugar (glucose) in your blood high, especially if you also need IV nutrition (hyper alimentation or HA).

Signs that your sugar levels are high include:

- Feeling more thirsty than usual
- Passing urine (peeing) more often
- Blurry vision
- Feeling dizzy or tired

We will check your blood sugar with your other lab tests. Some people need to use insulin, a medicine that helps lower blood sugar and check their blood sugar more often. If you have high blood sugar, you may need to avoid foods that have lots of sugar like candy and soda. Your dietitian will help you choose which foods are right for you.

## Keeping too much fluid and salt in your body

Prednisone can make your face, legs and ankles look swollen or puffy. This is caused by your body holding on to extra water and sodium (salt). It will help if you avoid foods that are high in salt (i.e. potato chips) and not add salt to your food. Your dietitian will help you choose foods that are low in salt, as well as help you decide how much fluid you need to drink.

## Increased hunger and weight gain

You may feel more hungry than usual while on prednisone. You may want foods at unusual times of the day and night. Try to eat healthy foods and snacks, avoid foods that are high in salt and sugar and try to exercise gently each day. Your dietitian can help you choose which foods are best for you.



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Most people who take prednisone 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 prednisone.

### Muscle pain and weakness

Your arms and legs may ache when you have been taking prednisone 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 doctor may also give you medicine to help the pain.

### Rounding, or filling out of the face

This is a common side effect of prednisone. You may notice that your face looks rounder, with bigger cheeks. This is because you are retaining water and sodium and will go away as you take less prednisone.

### Bone thinning

Prednisone can weaken bones, especially around the joints (hips, knees and shoulders). This can increase your risk for fractures (bone breaks) and cause wear and tear in your joints.

People who take high doses of prednisone for a long time (many months to years) can have problems with their bones becoming so thin the bone doesn't get the nutrients it needs and dies. This is called avascular necrosis (AVN). Sometimes surgery to repair or replace the bone or joint is needed. Your doctor will check your bones from time to time using X-rays and a special kind of scan called a dexa-scan.

Your doctor may decide to give you a medicine to help make your bones stronger. It is also important to eat foods that are high in calcium like broccoli and dairy products.

### Upset stomach

Prednisone can give you an upset stomach. You may get:

- Heartburn
- Nausea
- Indigestion



It may help to avoid foods that are high in fat or acid. Please talk with your doctor and dietitian if you are having an upset stomach. Your doctor may give you medicine to help lower your stomach acid.

### Changes in skin: color, thinning, acne

You may see changes in your skin while you are taking prednisone. 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.

Prednisone can cause your skin to breakout, and some people can have acne while taking it.

Keep your skin clean by bathing or showering every day. Please check with your nurse or doctor if you have any breakout, sores or rashes and before using any creams or ointments on your skin.

### Slower growth and delayed puberty

Prednisone, as well as the chemotherapy and radiation you may have had before your transplant, can decrease hormones that make you grow. As a result, you may be shorter and smaller than others your age. People who take prednisone every other day, instead of every day will usually make enough growth hormone to grow normally. Your doctor will watch how you grow and may order blood tests to measure your growth hormone. Your doctor may also give you extra growth hormone to help you catch up.

Children taking prednisone can also have a delay in the start of puberty, and girls may notice changes in their period.

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## Cataracts

Some people who have been taking prednisone for years can develop cataracts. Cataracts are a condition of the eyes, where a film or clouding covers the lens of the eye, making vision blurry. Your doctor will check your eyes when you have clinic appointments. Please tell your doctor if you are having blurred, double vision or any problems seeing. Cataracts can be removed by laser or surgery.

## Emotional side effects of taking prednisone can include:

- Trouble with sleeping
- Mood swings
- Confusion
- Anxiety/panic
- Euphoria  
(great happiness)
- Depression/withdrawal



## Trouble with sleeping

You may have problems sleeping while taking prednisone. It can make you feel “wired” like you drank too much caffeine. You might find it hard to sleep at night or wake up several times in the night. Sometimes changing the times you take your prednisone can help; **always** talk with your nurse or doctor before making any changes to your medicines. Rest is important. Even just relaxing with soft music and being still and quiet, even if not sleeping, can help with being tired. Your doctor 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 prednisone feel like this.

## 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.

## Anxiety/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 doctor 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

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## Euphoria (You-for-ee-a)

Euphoria 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 doctor or nurse.

## Depression/Withdrawal

Dealing with a serious illness causes a roller coaster of feelings. You may have feelings of helplessness and sadness during transplant and so can the people who care for you. Depression can make you feel empty, hopeless, negative, or restless. You may 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.

Prednisone can also cause signs of depression. Talking about your feelings with someone who listens (parents, friends, child life, social worker, nurse, doctor, volunteer, psychologist), or sharing your experiences with someone who has also been through transplant can really help.

If you are having these feelings, or thoughts about hurting yourself please talk with your nurse or doctor at once. It is important to get professional help when needed. Counseling and/or medicine may help manage your depression.

### FOR MORE INFORMATION

- Seattle Cancer Care Alliance, (206) 987-2032
- Your Child's Health Care Provider

*Children's will make this information available in alternate formats upon request. Please call Marketing Communications at (206) 987-5205.*

*This handout has been reviewed by clinical staff at Children's Hospital. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's health care provider.*