

TAKING IL-2 AND MANAGING ITS SIDE EFFECTS



how to safely take and manage
this experimental hiv therapy

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When you're prescribed IL-2 therapy, it's important that your doctor or nurse teach you how to inject the drug and how to store, prepare and safely dispose of the syringes. Moreover, there are a number of tips for preventing and managing its side effects.

At a minimum, you should not begin IL-2 without having on hand plenty of liquids that contain electrolytes (Gatorade, chicken soup, etc.) as well as filled prescriptions for antihistamines and ibuprofen. *(NOTE: Some antihistamines have serious interactions with commonly used anti-HIV drugs. Be sure to discuss the best choice with your doctor and/or pharmacist.)* Finally, before starting therapy, talk to your doctor and pharmacist about other drugs that you're taking, including non-prescription over-the-counter drugs. Some of these may cause adverse effects when taken with IL-2.

Preparing and storing syringes

Sometimes pharmacies supply IL-2 in pre-filled syringes. Other times, you may need to mix a powdered form of IL-2 with special sterile water and then prepare your own syringe. The water and syringes should only be used once. If you prepare your own syringes, ask your doctor or pharmacist for written instructions to keep on hand.



A few things to be aware of:

- ▶ *Never* freeze IL-2 (in powdered form, vials or syringes). Store IL-2 in your refrigerator, *not* your freezer.
- ▶ If you carry IL-2 with you, put it in a container that keeps it cool, like a small cooler or lunch bag with ice or an ice pack.
- ▶ Prepare the syringe just before the injection and do not shake the vial.
- ▶ IL-2 should look clear and colorless. Sometimes it has a slight yellowish tint. If your syringe or vial of IL-2 is cloudy, has particles floating in it, or is colored other than slightly yellow, *do not use it*.
- ▶ Keep new and used syringes out of the reach of children.
- ▶ Used syringes should be disposed of in special biohazard containers.

Fatigue, feeling tired

During the five-day course:

- ▶ Plan your days to include rest periods. Change your normal routine as needed—don't exercise or run errands.
- ▶ If you work, plan to go home immediately after and rest—rent movies, watch TV or simply lay around.
- ▶ To avoid losing time from work, start your course three days before your weekend. The worst side effects will more likely fall on those scheduled days off.

Flu-like symptoms include fever, chills, sweats, joint pain, muscle aches and other flu-like effects.

These often worsen throughout the five-day course and will subside almost immediately after it's done. Fever, joint pain, and muscle aches generally do not occur until two to four hours after an injection.

- ▶ Be prepared. If you feel feverish, lay down and stay down. This means preparing for your five-day course. Make meals in advance or have frozen foods on hand. Keep a supply of drugs on hand to manage side effects. In general, make sure you have everything you're likely to need for five days because you may not feel like shopping.
- ▶ Take ibuprofen (600mg every six hours) or acetaminophen (650mg every 4–6 hours, starting one hour before IL-2 dose) throughout the five days. Keep an icepack or cool cloth on hand to lower fever as necessary. (A package of frozen vegetables works fine.)
- ▶ Drink lots of liquids high in electrolytes, not just water! This includes sports drinks like Gatorade and other "salty liquids" like chicken soup, vegetable juice (V-8 Juice), Pedialyte, etc. Start taking more of these types of liquids a day or so before beginning a five-day course.



- ▶ As electrolyte imbalances may be a problem, consider taking oral magnesium and calcium supplements.
- ▶ Shakes or chills may start within a half hour to an hour of an IL-2 injection. Keep warm with blankets, heavier clothing or a space heater. Antihistamines (diphenhydramine, Benadryl, 25–50mg, as needed) may be used to prevent or treat mild-to-moderate chills. If they're severe, the narcotics meperidine (Demerol, Mepergan) or morphine (Duramorph, MS Contin, MSir, Oramorph, Roxanol) may be warranted.

Nausea, vomiting, diarrhea or loss of appetite. Nausea and vomiting can occur within 2–3 days after starting therapy.

- ▶ For nausea or loss of appetite, consider eating more frequent meals of small amounts of soft, bland foods like mashed potatoes, rice and cooked cereals. Avoid spicy, greasy or sweet foods. Also consider using dronabinol (Marinol) or natural alternatives like medical marijuana.
- ▶ For diarrhea, try the BRAT diet (bananas, rice, apple sauce and toast) or have bulking laxatives on hand.
- ▶ Therapies that may help prevent or manage diarrhea include dipheoxylate/atropine (Lomotil) or loperamide (Imodium), two tablets with each loose stool, not to exceed eight per day. Codeine or tincture of opium may be needed if less aggressive approaches are unsuccessful. Avoid caffeine in coffee, teas and sodas and avoid alcohol.
- ▶ Anti-nausea drugs, like prochlorperazine (Compazine) 5–10mg every 4–8 hours, as needed, with lorazepam (Ativan) 1mg every six hours, as needed may help prevent or treat nausea.

To prevent or manage skin rash, redness, itching and peeling

- ▶ Use mild unscented water or oil-based lotions or creams (like Aveeno) liberally and frequently to keep skin moist and prevent peeling. Don't use lotions that contain alcohol. Use lotions a few days before and throughout the five-day course.

IL-2 side effects

- › Take lukewarm, not hot, baths or showers.
- › Use mild, unscented soap (such as Basis) or non-soap cleansers (such as Nutribiotic unscented non-soap).
- › Oatmeal soaps and baths may relieve red, itchy skin.
- › Pat, don't rub, your skin with a towel to dry off.
- › Avoid being in the sun. Wear hats and cover up while in the sun. Use sunscreen with a 15 or higher SPF rating.
- › Keep antihistamines on hand to help prevent or treat skin conditions.



Dizziness, lightheadedness, large changes in blood pressure

- › You can prevent changes in blood pressure by being careful when you move from a laying to standing position. If you are lying down, first sit up and make sure you're not dizzy, then move to standing position.
- › If possible, keep a chair in or near the shower or bath.
- › Hot water may make skin conditions worse. It also lowers blood pressure. Avoid hot showers/baths while taking IL-2.

Changes in sleep patterns, insomnia

- › Changes in sleep patterns may be related to IL-2 therapy. Antihistamines can cause drowsiness and a warm glass of milk may help.



To manage lumps under the skin at the injection site

- › For lumps or nodules, bring IL-2 to room temperature for 15 minutes before injection. Icing the injection area five minutes before and after shots helps decrease lumps. Also, gently rubbing the area for 3–5 minutes after injection may help. Nodules may take weeks or months to disappear.

Mouth sores, tenderness or discomfort

- › Rinse your mouth frequently with lukewarm water or saline rinses.
- › Avoid hot or spicy foods, and acidic fruits and juices. Eat soft foods that require little chewing.
- › Suck on sugar-free candy to help with dryness and soreness.
- › Use a very soft toothbrush and brush gently.
- › “Suspension” solutions that include anesthetics, antihistamines and antacids may relieve oral pain and discomfort (2% solution of kaolin pectate, Xylocaine and Benadryl).
- › If you use mouthwash, be sure it's alcohol-free.

Anxiety, depression

- › For anxiety, lorazepam (Ativan) 1mg daily or mild sleeping pills like flurazepam (Dalmane) may be useful.
- › Shortly following a five-day course, IL-2 users report mild depression. Being aware that this may be drug-related seems to help, as well as talking to others who use IL-2. In rare cases, attempted suicide and suicide have been documented and associated with IL-2 use. Shore up emotional support networks to help you.

Dry eyes

- › If you experience dry eyes, try using artificial tears.

Injecting IL-2

Ask your doctor, a nurse or a physician's assistant to teach you how to inject IL-2 the first time you use it. After your first lesson, the following suggestions may help remind you of how to do it.

Before injecting IL-2, remove it from the refrigerator or your carrying container and allow the syringe/preparation to warm to room temperature (about 15 minutes). Wash your hands thoroughly and then wipe the area where you'll inject the IL-2 with an alcohol pad or swab. Allow the skin to dry before you inject.

Change the site each time and do not inject IL-2 into an area that's red or has lumps from an earlier injection. Do not inject it near or on areas where you have scars, bruises, or moles. Sites for injecting IL-2 are the stomach (but not within an inch of the belly button), the middle part of the outer thighs (hand width below hip and above knee), and the outer part of the upper arms.

With one hand, use your thumb and fingers to pinch or fold the cleaned skin where you'll inject the IL-2. With the other hand, insert the prepared needle at about a 60° angle into the fold of skin with a short, quick movement and then push down on the plunger. Let go of the fold of skin while you push down on the plunger.

Remember that you are injecting IL-2 under the skin, not into a vein and not into muscle. Some people put an ice pack (or a bag of frozen vegetables) on the skin before and after injection, and then massage the area for three to five minutes afterwards to help reduce lumps and skin reactions.

Safely dispose of your needles

Your doctor or study personnel should supply you with a hazardous material/sharps disposal container and tell you how to get rid of it. You should not throw used or unused syringes in the trash because the needles can easily pierce the bag and stick other people. Discard syringes, needles, needle caps and other blood exposed items (gauze pad, etc.) in the container. **Do not** place needle caps back on the needle. Just put them in the special container.

Call your doctor if ...

If you have signs of serious side effects as noted below, contact your doctor immediately.

- You notice that you are making less than normal amount of urine or if you stop urinating altogether;
- You have shortness of breath;
- You have fever over 102°F that doesn't go away with over-the-counter drugs;
- You experience major changes in mental status, like confusion;
- You faint; or
- You have major swelling in your face, neck and/or feet.



the bottom line on taking IL-2

- › Avoid alcohol for a few days before and during each five-day course.
- › Drink liquids that have electrolytes (Gatorade, Pedialyte, chicken soup, vegetable juices, etc.) a few days before and throughout each course.
- › Use non-scented skin creams and moisturizers a few days before and throughout therapy.
- › Take ibuprofen or acetaminophen throughout each five-day course.
- › Prepare meals beforehand and plan to rest through the five days.

Have the following on hand to manage side effects:

- › Ibuprofen or acetaminophen
- › Antihistamine (diphenhydramine, Benadryl, etc.)
- › Dipheoxylate/atropine (Lomotil) or loperamide (Imodium)
- › Dronabinol (Marinol), prochlorperazine (Compazine) and lorazepam (Ativan)
- › 2% solution of kaolin pectate, Xylocaine and Benadryl
- › Soft, bland foods
- › Sugar-free candy
- › Liquids with electrolytes (Gatorade, chicken soup, etc.)
- › Ice pack or cool cloth
- › Soft toothbrush
- › Magnesium and calcium supplements
- › Mild unscented soap or non-soap skin cleanser
- › Mild unscented water or oil-based skin lotions or creams
- › Artificial tears
- › Meperidine or morphine (only for severe shakes or chills)