Treatment with High-Dose Interleukin 2

PATIENT/FAMILY INFORMATION

Oncology 6/18/09
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Introduction

Welcome to Nebraska Cancer Specialists. This booklet will provide you and your family information about your treatment with Interleukin 2.

- It will review some basic information about your immune system.
- It will explain how Interleukin 2 affects your immune system and why that effect can be used to treat your cancer.
- It will review how your Interleukin 2 treatment will be given.
- It will review what kind of side effects you may experience during and after your treatment and how you may deal with those side effects.

Your participation in your own care during your Interleukin 2 treatment is critical. It is important that you read over this booklet completely and discuss any questions or concerns you may have with your physician.

It is important that you and your family understand that treatment with Interleukin 2 can be extremely difficult physically and emotionally. Your doctor and nurses will work closely with you to monitor your progress and to help you deal with the side effects of this treatment. Please feel free to ask any questions you or your family may have. Telephone numbers are listed in the back of this book should you have questions after you are dismissed from the hospital.

Before you could even be considered for treatment with Interleukin 2:

- **You have to have a specific type of cancer.** Interleukin 2 is not a treatment for all types of cancer. You also have to have a very specific “cell type” with your cancer for Interleukin 2 to be effective.

- **The extent of your disease (how advanced is your cancer) has to be evaluated.** If your disease is too advanced, you will not respond well to this treatment.

- **The status of your overall health has to be considered.** If you are too weak to tolerate the treatment and treatment side effects, this treatment will not be considered.

- **The status of your heart, lungs, and kidneys has to be evaluated.** These organs can be strongly affected by the treatment and must be able to tolerate it before the treatment can be considered.

- **And finally, insurance coverage has to be assured.** This is a very expensive treatment, and it is important to you and your family that insurance covers these expenses.
Your Immune System

The immune system is a collection of organs, specialized cells, and substances that protect your body from “foreign invaders” such as “germs” (bacteria, viruses, parasites). Bacteria, viruses, and parasites have substances or proteins on their outer surface. When these “germs” enter the body, the immune system will recognize these proteins as “foreign” and go into action. This reaction of the immune system is called an “immune response.”

Cancer cells can also be recognized by the immune system as “foreign.” As normal cells change and become cancer cells, they start to produce different proteins on their outer surface. Just like the proteins on the surface of a germ, the immune system can recognize the proteins on the surface of a cancer cell and it will stimulate an immune response. This response is usually not as strong as one produced by a germ, probably because the difference between a normal cell and a cancer cell is not as obvious as that of a germ.

An “immune response” is a very coordinated process that uses many types of specialized cells and substances. Most of the cells of the immune system are lymphocytes. Several types of lymphocytes work together to destroy “foreign invaders.”

- **B cells / B lymphocytes** – transform into Plasma Cells and produce antibodies. These antibodies attach to the proteins on the surface of a germ and destroy it.

- **T cells / T lymphocytes** – there are 2 types of T cells:
  - **Killer T cells** recognize unwanted cells in the body and produce substances that will kill those cells. The “unwanted cells” can be germs or cancer cells.
  - **Helper T cells** help B cells and Killer T cells work better.

- **Interleukin 2** – is an immune system “messenger.” It is a substance that stimulates the immune system to activate T cells.

How Interleukin 2 Therapy Works

As part of the immune response, your body produces Interleukin 2 naturally. But Interleukin 2 can also be manufactured outside of the body. This is called “Recombinant Interleukin 2.”

When you receive recombinant Interleukin 2, it does not attack the cancer cells itself. The Interleukin 2 stimulates the immune system to produce and “activate” T cells. It is these T cells that will attack and destroy the cancer cells. Large doses of Interleukin 2 are given so that large numbers of T cells will be produced.
“Getting Ready”

As listed in the introduction, before Interleukin 2 can be offered as a treatment for you, many things need to be checked:

- Has the cancer spread into your lymph nodes?
- What other symptoms is your cancer causing?
- Has the cancer spread to your bone? Your lungs? Anywhere else?
- What cell-type is your cancer?
- How is your thyroid doing?

Once it has been determined that Interleukin 2 is a reasonable treatment option, an even more in-depth evaluation needs to be done to be sure you can tolerate the treatment and to help your doctor anticipate any possible complications during your treatment:

- **Pulmonary Function Test (PFT)** – to check how well your lungs are working
- **Dobutamine Stress Echo (DSE)** – to check how well your heart is working
- **CT/MRI of the head** – to check for possible cancer and any risk of seizures
- **Lab work** – to check how well your kidneys, liver, and thyroid are working and how easily your blood makes blood clots

**BEFORE YOU ARE ADMITTED TO THE HOSPITAL:**

You need to have a good, dependable IV. You will be scheduled to have a PICC line (Peripherally Inserted Central Catheter) placed. A PICC is a long IV catheter that is placed into a large vein in your arm. This long catheter goes all the way to the top of your heart. The PICC will be used to give you Interleukin 2. It will also be used to draw your lab work and give you any additional IV fluids or IV medications you may need while you are receiving your treatment.

- You and a care partner (family member) may need to take care of the PICC when you are out of the hospital. You will be responsible for cleaning, dressing and flushing the PICC.
- The PICC will be inserted at the location where you will be hospitalized.
- After the catheter is placed, a chest x-ray will be done to make sure it is in the right place.
- You and your care partner will be taught how to clean, dress, and flush your PICC, if necessary.
- You will receive a booklet on PICC care.
- If you are taking medication to lower your blood pressure, you may be asked to stop taking this medication before coming into the hospital, usually for one day prior.
How High-Dose Interleukin 2 is Given

**THE TREATMENT SCHEDULE:**

Each hospital stay is approximately 5-7 days depending on how well you tolerate the high-dose Interleukin 2 (IL-2).

- Each hospital stay is called a **cycle**.
- Two cycles make up one course.
- 7-10 days after the last dose of IL-2 given in cycle 1, you will be re-admitted to the hospital for cycle 2.
- At the end of cycle 2, you will have completed **1 course**.

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During your course(s) of IL-2 you are NOT to receive or use any STEROIDS! You should not take any steroid pills, receive any steroids in your IV and you should not use any steroid cream. Even over-the-counter steroid creams you might have at home should NOT be used.
WHEN YOU ARE ADMITTED TO THE HOSPITAL:

- You will have a small clip put on a finger to monitor the oxygen in your blood.
- The nursing staff will be checking your temperature and blood pressure at least every 4 hours and before each dose of IL-2.
- You may be placed on a cardiac monitor so the nurses can monitor your heart. The cardiac monitor patches and wires will remain on your chest continuously.
- Your weight will be checked every morning.
- The nursing staff will need to measure your urine every time you go to the bathroom.
- Your lab work will be checked every morning and evening. The lab will be drawn from your PICC.

WHEN YOU RECEIVE YOUR INTERLEUKIN 2:

- You will be scheduled to receive a dose of Interleukin 2 every 8 hours to a maximum of 14 doses.
- The nurse will evaluate you before each dose
  - Temperature, pulse, blood pressure, and oxygen level will be checked
  - The nurse will listen to your lungs to see that they are clear
  - You will be evaluated for any other side effects (rash, swelling, etc.)
- The physician will be called to give approval prior to each dose.
- The IL-2 is given through the PICC over 15 minutes.

**Your dose of IL-2 may be held if you are found to have:**
- An excessively rapid heart rate
- Fluid in your lungs
- Had a seizure, become confused or start to hallucinate
- A substantial change in kidney or liver function

**Any missed doses will NOT be “made up.”**
Possible Side Effects of High-Dose Interleukin 2

As Interleukin 2 therapy progresses, side effects may make you feel increasingly uncomfortable. These symptoms are common:

“FLU-LIKE” SYMPTOMS:

- Fever, chills
- Muscle aches
- Fatigue/weakness
- Nausea/vomiting/loss of appetite
- Diarrhea

SKIN EFFECTS:

- Rash
- Redness/itchiness
- Peeling skin

HEART/LUNG EFFECTS:

- Fast/racing heart
- Irregular heart beats
- Dizziness/fainting spells/lightheadedness
- “Capillary leak syndrome”:
  - Low blood pressure
  - Swelling of the face, neck, hands and feet or weight gain
  - Cough
  - Shortness of breath/difficulty breathing

KIDNEY EFFECTS: (CAN ALSO BE PART OF CAPILLARY LEAK SYNDROME)

- Drop in the amount of urine output
- Urine becomes dark and may smell
- No urine output
NERVOUS SYSTEM EFFECTS:

- Anxiety
- Changes in thinking or mood
- Confusion
- Hallucinations
- Difficulty concentrating
- Trouble sleeping

Managing Side Effects

“FLU-LIKE” SYMPTOMS:

**Fever/Chills/Muscle Aches**

- Keep yourself warm, wear warm clothing, use warmed blankets.
- Drink plenty of fluid.
- If you start to chill, your nurse can give you medication to stop this chilling.
- You may receive medication to reduce discomfort.

**Fatigue/Weakness**

- Conserve energy – sit rather than stand for daily activities when possible.
- Balance activities with periods of rest.
- Take only SHORT NAPS! – no longer than 20 minutes at a time.
- Avoid too much caffeine – no caffeine after noon.
- Read the teaching sheet “Managing Cancer-Treatment Related Fatigue.”

**Nausea/Vomiting/Loss of Appetite/Diarrhea**

- Many symptoms can be controlled with medication.
- Let your nurse know if your nausea/vomiting is not controlled with medication.
- Let your nurse know the number and kinds of stools you are having.
- Drink plenty of fluids – let your nurse know if you are unable to drink or eat.
- Eat smaller amounts but eat more frequently.
- It is expected that you will lose your appetite for a few days. This improves quickly after the IL-2 is completed/stopped but if you would like, we can call the dietician to speak with you and your family.
SKIN EFFECTS

**Rash/Redness/Itchiness/Peeling**
- Your health care provider can give you special creams, lotions, and soaps to manage skin problems.
- You may notice peeling or flaking of the skin on your hands and feet.
- Your hair and nails may become very dry.
- You may receive medication to reduce itching and discomfort.
- Make sure shower water is not too hot.
- Avoid sunburn while you are receiving Interleukin 2 therapy.

HEART/LUNG/KIDNEY EFFECTS:

These are some of the most serious and severe side effects of Interleukin 2. IL-2 can cause “Capillary leak syndrome.” In Capillary leak syndrome, fluid leaks out of the blood vessels (veins and arteries) – not blood but fluid. This fluid builds up in body tissues. This leaking fluid causes many of the heart, lung, and kidney side effects.

- Fluid leaks into the body tissues which causes them to swell. You may see swelling (edema) in your face, neck, hands, and feet.
  - Edema can cause your weight to go up quickly. You must be weighed every day.
  - This edema can make delicate skin even more susceptible to damage and infection. Be careful to avoid injury.
  - Remove all rings before starting IL-2 therapy.

- Fluid leaving your veins and arteries can cause your blood pressure to drop and your heart to race or beat irregularly.
  - Change position slowly. A drop in blood pressure can make you feel very dizzy and lightheaded if you stand up too quickly.
  - You may need to receive medications and IV fluids to support your blood pressure.
  - You may need to be on a cardiac monitor so the health care team can watch for any unusual heart activity.

- Fluid leaving your veins and arteries can go into the tissues of the lungs. This can cause you to have coughing, shortness of breath, or difficulty breathing.
  - Your nurses and doctors will be checking your lungs regularly.
  - You may have to limit activity if you find it difficult to breath.
  - You may need to receive medications to get rid of excess fluid in the lungs.
  - You may need to be on oxygen for a period of time.
• Less fluid in your veins and arteries means less fluid can be filtered through your kidneys.
  o Your urine may turn darker and have a stronger odor.
  o You may make less urine.
  o You may stop making urine.
  o You may need to receive IV fluids and other medications to keep your kidneys working properly.

NERVOUS SYSTEM EFFECTS

Family members need to be aware of these side effects. They know you and your personality the best and may be the first to notice changes in mood or thinking. Sometimes the emotional changes caused by the IL-2 make you want to quit taking it, but please talk with your family and healthcare team.

You or your family members should tell the health care team if they notice changes in your ability to concentrate or follow a conversation. Be sure to report any increases in anxiety or if you are having trouble sleeping, or begin to have vivid dreams or hallucinations.

“What’s Next?”

AFTER YOU GO HOME FROM THE HOSPITAL

When your lab work has stabilized and you are feeling better, you will be discharged from the hospital.

• Most people start to feel better quickly after the IL-2 is finished/stopped.

• Depending on your lab work results at discharge, you may need additional lab work done once you are home.

• After you have completed one course of IL-2 (2 cycles), the PICC will be removed.

• There will be a 4-5 week break where no therapy will be given.

• After the 4-5 week break, you will come back to the clinic. Lab work and scans will be done to evaluate what kind of response you had from the IL2 treatment.

• Future treatments will depend on how well you respond to and tolerate the IL-2 treatment.
TO HELP YOU RECOVER FROM YOUR INTERLEUKIN 2 THERAPY:

- **Food and fluids**
  - Gradually increase your food intake.
  - Drink about 8-12 full glasses of fluid each day.
  - Follow the advice of the dietician in making food/fluid selections.

- **Fatigue**
  - Gradually increase your exercise.
  - Take breaks frequently but not long naps.
  - When your energy is limited, set priorities!

- **Skin changes**
  - Continue to use the skin products suggested by your health care providers while you were in the hospital.
  - Follow the skin care routines until all signs of dryness are gone.
  - Take prescribed medication to control itching and rash.
  - WEAR SUN SCREEN whenever you are outside.

- **PICC Care**
  - You and/or your family member will be responsible for the home care of your PICC.
    - Observe the exit site every day and report any redness or drainage.
    - Flush each line of the PICC every day with saline if instructed to do so.
    - Change the dressing at least once a week and whenever it becomes damaged, soiled, or gets water underneath.
    - Change the caps on the line at least once a week.
    - Take the antibiotic ordered by your doctor the whole time you have the PICC line.

- **General Safety**
  - Let your family know if you continue to have vivid dreams so they are aware of the need to keep you safe as you sleep.
  - Do not drive for at least 2 weeks after treatment.
When to Call

You need to call your health care provider:

- If you are unable to drink for 24 hours or eat for 48 hours
- If nausea is not relieved with medication
- If you develop a fever or chills
- If you develop any difficulty breathing
- If you develop chest pain or feel a racing or irregular heart beat
- If skin problems become worse despite following skin care routines
- If you have more than 5 liquid stools in one day
- If your PICC does not feel the same, look the same, or act the same

Who to Call

Call the office that you are seen at:

**Methodist: (402) 354-8124**

**Bergan-Mercy: (402) 393-3110**
Managing Cancer-Treatment Related Fatigue

Fatigue is a feeling of tiredness that can keep you from doing the things you normally do or want to do. It is the most common side effect of cancer treatments. Factors such as cancer itself, low blood counts, nutritional problems, and sleep problems can contribute to fatigue, although the exact cause is not known.

SIGNS OF FATIGUE:

- You feel weary or exhausted. It may be physical, emotional, and/or mental exhaustion.
- Your body, especially your arms and legs, may feel heavy.
- You have less desire to do normal activities like eating or shopping.
- You may find it hard to concentrate or think clearly.

WHAT YOU CAN DO TO MANAGE YOUR FATIGUE:

- **Rest and Sleep**
  Rest and sleep are important, but don’t overdo it. Too much rest can decrease your energy level. In other words, the more you rest, the more tired you will feel. Avoid stimulants such as alcohol and/or caffeine before going to sleep. Practice going to bed at the same time each night. Create an environment conducive to sleep. If you have trouble sleeping, talk to your doctor or nurse.

- **Activity**
  Stay as active as you can. Regular exercise like walking several times a week may help. Pace yourself and avoid rushing through an activity. Decide which activities are important and perform them when your energy level is high.

- **Nutrition**
  Drink plenty of liquids. Eat as well as you can, and eat nutritious foods. Eat frequent small meals rather than three large meals.

- **Energy Conservation**
  You can do more by spreading your activities throughout the day. Take rest breaks between activities. Learn to delegate. Let other help you with meals, housework, or errands. Do not force yourself to do more than you can manage. Practice good body mechanics.

- **Energy Restoration**
  Do activities that you enjoy and make you feel good. Many people enjoy nature activities such as bird watching or gardening. Try listening to music, or visiting with friends and family, or looking at pleasant pictures. Try to do these activities at least three times per week. Learn relaxation techniques.
BERGAN MERCY MEDICAL BUILDING
7710 Mercy Road, Suite 122
393-3110

METHODIST ESTABROOK CANCER CENTER
8303 Dodge Street, Suite 250
354-8124

WEST DODGE MEDICAL PLAZA
515 N. 162nd Avenue, Suite 102
455-8010

MIDWEST CANCER CENTER LEGACY
17201 Wright Street, Suite 200
334-4773

MIDWEST CANCER CENTER PAPILLION
611 Fenwick Drive
593-3141

nebraskacancer.com