

Congratulations on your discharge from IPOP!

This booklet has some important facts that will help you take care of yourself after treatment.

Remember, even though your new immune system is working and you can fight infections, your body's immune system (infection fighting system) has not finished healing. That takes time. You should follow these guidelines for the next 6 months. You may, however, need to follow these guidelines for a longer time period. They will help protect you as your immune system heals.

I. Going home to your Doctor

Before you leave IPOP, make an appointment to see your home doctor within 7 days.

Remember this is the time to bring up any little thing. It may be important. Your research nurse will set up follow up appointments in the outpatient department over the next year and longer as needed. Please be sure to visit everyone on your follow up appointment schedule whether you know the name or not.

II. Your immune system and life after Treatment

A. Immune system function

- The chemotherapy you got during your treatment "wiped out" your healthy immune system cells that fight infection.
- This puts you at risk for bacterial, fungal, and viral infections.
- You are most at risk for infection during the first three months after your treatment.
- Usually your immune system works much better beginning six months after treatment.
- Because some parts of your immune system take longer to get back to normal, there will be certain kinds of infections that you'll be especially at risk for getting. This booklet will explain these to you.

B. Preventing infection

Hand washing:

- Hand washing, especially in public places, is the best way to prevent infection.
- Helpful Hint: Keep a soapless hand gel in your pocket, your purse or in your car for times when you can't get to a sink! (Avoid hand gels with alcohol, they can be very drying to your skin)
- Use your own hand towel to dry your hands (not the family one) or use paper towels

You should wash your hands:

- Before eating or preparing food
- After touching pets or animals
- After gardening or touching plants or soil
- After going outdoors
- Before and after touching a wound or cut
- After changing diapers
- After holding infants & children
- After shaking hands
- Before and after going to the bathroom
- After touching items that might have had contact with human or animal stool/waste

Masks:

- Wearing a mask is another way to prevent infection.
- Masks help screen out infection and remind you and others that your immune system is still healing.
- We recommend that you wear an N95 Respirator mask in hospitals, doctors' offices, near construction, and any crowded place for six months after treatment.
- Change your mask every week or if it gets moist or dirty.
- Try to go to the grocery store, movies, restaurant, etc., when it isn't crowded. Take a mask with you just in case. Remember a lot of people go out even though they are sick.

Family and Friends:

- Avoid people (including family and friends) with any infections, including colds, flu, chicken pox, measles, and mumps.
- Be extra careful around infants and children because they are more likely to have infections without feeling or looking sick.
- Wash your hands well after holding infants or children, and after changing diapers.
- Teach your friends, family and school or daycare teachers that it is very important to keep your children healthy so that you can stay healthy.
- Remind other parents that you and your children should not be around people who are sick or have a contagious (catching) infection.
- Other parents can help by not letting their "sick" child visit with yours.

What to do if your child gets sick:

- Keep your personal hygiene products (toothbrush, facecloth, etc.) separate
- Wash your hands after contact with a sick child or any secretions from that child (used tissue, etc.)
- Teach your child to wash their hands or use hand gel after coughing or sneezing
- If possible, have family or friends help by looking after your sick child for you.

Returning to the Workplace:

- We suggest that you do not go back to work or school until six to eight weeks after your treatment to give your immune system time to recover.
- Being out of work or school for a long time may be hard for you. If you can, try to work at home or work "off hours" when work areas tend to be less crowded.
- Working part-time may be easier for you. Talk with your doctor if you have to go back to work or school before six to eight weeks after treatment.
- Some workplaces may be safer than others. Talk with your doctor about your workplace.

Immunizations:

- Antibodies are things that your immune system makes to help you not get sick.
- You make these antibodies after you get your childhood "shots" or immunizations (another word for immunization is vaccine).
- Your antibodies have now been wiped out by the high doses of chemotherapy you got.
- You will need to get your childhood "shots" (or immunizations) again.
- Right now, your new immune system is not ready to make antibodies, so "shots", wouldn't work.
- Never get a "live" vaccine (or shot) for the first two years after treatment. These vaccines are made with very small, living doses of the illness they prevent. They can make you sick!
- Examples of live vaccines are: Smallpox, chicken pox, MMR (measles, mumps & rubella)
- Avoid contact with anyone who has had the smallpox vaccine for at least one month.

Your children's immunizations:

- It is important that children keep getting their "shots".
- Make sure that the child does not get the "live" Polio vaccine by mouth (oral), the "killed" polio vaccine shot is safe.
- If a child has had a live vaccine, avoid contact with that child for one month.

Flu shots:

- Get a flu shot every fall beginning 6 months after your treatment. It may not work yet but it won't hurt you.
- Flu shots are given in the early fall. It is important to get it before flu season starts because it takes about 2 weeks before it starts working.
- Your caregivers and household members should also get a shot in the fall.

Remember: You cannot get the flu from the flu shot!

C. Taking care of Yourself after Treatment

Fatigue:

- Your energy levels will slowly increase.
- Sometimes it takes up to a year (or longer) to get your "old" energy back.
- Expect to have some good days and some bad days.
- Slowly increase your exercise. Walking is a great exercise. This helps to keep you physically and mentally active.

Nutrition:

- Your appetite will get better as your sense of taste and smell get better.
- Wash all fresh fruits and vegetables well under running water.
- Prepare raw meat and vegetables on separate surfaces or cutting boards.
- Wash your hands after touching raw meat and fish.
- Cook meats & fish completely (160 degrees F in center).
- Refrigerate leftovers as soon as possible; do not let them sit at room temperature.

Mouth care:

- Your mouth should be better or getting better.
- Your taste buds and dryness should be getting better but it can take a couple of months. However, some medications may continue to cause dryness.
- If you have any new sores, blisters, thick white patches, or mouth pain.
- Let your doctor know about anything new or changes in your mouth that you notice. You may need treatment.

Going to the Dentist:

- After your 6 month visit, you should be able to start normal dental care.
- Check with your doctor first.
- You may need to take antibiotics before any dental appointments for up to one year after treatment.
- Your doctor should know about any major dental problems.
- Make sure your dentist knows about your treatment.

Skin care:

- You can use mild moisturizers after your treatment to help with dry skin. If you have very dry skin, petroleum jelly works well and is safe and cheap.
- Try using soaps that have moisturizers.
- Your skin is more sensitive after chemotherapy, and while taking certain medications.
- Wear sunscreen with SPF of at least 15.
- Cover your skin with clothing to help prevent sunburn
- Don't forget the top of your head! Wear a wide brim hat.
- Don't over heat. You may not be able to regulate your body temperature as well.

Eyes:

- Report any changes in your vision to your doctor. Wait 3 to 6 months before changing your eyeglass prescription.

Contact lenses:

- Talk with your doctor before starting to use your contact lenses again.

Gardening:

- You can garden and cut grass if you wear a mask and garden gloves.
- Soil and plants contain bacteria and fungus that can be harmful to you.
- Wash your hands thoroughly after touching plants or soil.

Pets:

- Contact with common household pets is safe, but avoid face "kisses" (licking) with animals.
- Do not clean up any waste/feces.
- Wash your hands thoroughly after touching your pets.

If bitten or scratched:

- Clean small wounds very well with hydrogen peroxide, apply antibiotic ointment and cover with bandage.
- Change bandage every day and check for signs of infection (redness, swelling, drainage/pus, painful, hot).
- If you have signs of infection call your doctor.
- For large cuts and bites, clean area but also call your doctor right away.
- It is important to keep your pets clean and healthy to decrease your risk of infection. Maintain their regular veterinary appointments and immunizations (remember to make sure that they are "killed" vaccines and not "live").
- Contact with barnyard animals should be avoided.
- Pets you shouldn't have contact with: birds, ducks, reptiles, exotic animals.

Swimming:

- Do not swim if you still have your catheter.
- Do not swim in lakes or rivers as they generally have much higher bacteria content.
- Public pools are required by law to keep chemical levels high enough to kill most harmful bacteria but private pools are not. Harmful bacteria can still be present in both private and public pools.
- Avoid hot tubs and whirlpools for 6 months.

Travel:

- Traveling in an airplane puts you at risk for infection because you are in a close, crowded area with people who may be sick.
- Avoid developing countries.

Sexuality:

- Wait to resume sexual activity with penetration until your platelet count is 20K (20,000) or higher to prevent bleeding.
- Your Absolute Neutrophil Count (ANC) should be over 250 before resuming sexual intimacy.
- Intimate contact increases your risk for infection. Sexual contact puts you at risk for sexually transmitted diseases (STDs).
- Limit the number of sexual partners and use a condom during the first six months after your treatment.
- A condom helps to prevent you from getting an STD from a partner with an STD.
- Your interest in sex and physical ability to engage in sexual activity may be changed due to your emotions, current medications, energy levels, or the effect of the chemotherapy. Remember, this is temporary!
- High dose chemotherapy can cause early menopause. You may be able to get hormone therapy.
- Women having hot flashes or other menopausal symptoms should be seen by a gynecologist.

Infertility:

- Infertility means you are not able to conceive (make) a child.
- Infertility is very likely after the high doses of chemotherapy you had for your treatment. Your sperm or eggs may be damaged from the treatment.
- However, there may be a small chance that you are fertile and could have a baby or father a baby after your treatment.
- For females, your body may not be healthy enough to carry a baby.
- You should take steps to prevent pregnancy if that is a concern for you. Talk with your oncologist about the risk of having a baby or fathering a baby after therapy.

D. Medications**Iron supplements:**

- Check with your doctor before taking any vitamins that have Iron!
- Every time you get a blood transfusion you get a lot of iron that your body stores. Too much Iron can be harmful.

Aspirin containing products:

- Continue to avoid any aspirin containing medicines until your platelet count is regularly over 100,000 (100K).

Other:

- Check with your doctor before taking any herbal supplements.

III. Your Blood Counts

Many patients' white blood cells will grow back before their red blood cells and platelets. It can take weeks to months for red blood cell and platelet counts to return to normal. Some patients, though, won't need any more transfusions after discharge.

- Your discharge packet will have your blood product information for your doctor.
- It includes your transfusion history, any transfusion reactions you may have had, and what, if any, pre-medications you need.
- If you need any blood transfusions during your 1st 6 months after treatment, the blood products need to be irradiated.
- Irradiation prevents the donated blood from causing a graft versus host reaction.

A. Blood Type

- Know your blood type.

B. Erythropoietin (Procrit, Epogen)

- People often need blood transfusions after treatment.
- Erythropoietin can help if you need to be transfused 2 or more units of blood a week and your other blood counts (platelets & WBC) have recovered.
- Talk with your doctor to see if you should get this drug.

C. White Blood Cell (WBC) growth factors

- There may be times when your WBC drops. This can happen for many different reasons including infection & side effects from medicines.
- Your doctor may give you growth factor (e.g. Neupogen) to help raise your WBC.

IV. Late complications & what your doctor needs to know from you

A. Lungs

Interstitial pneumonia: Is swelling of the lungs that cause a stiffening of the lungs, shortness of breath and difficulty breathing. It may be due to an infection or as a result of your treatment. You are most at risk between 1 to 3 months after treatment.

Call your doctor for:

- Increasing shortness of breath, difficulty breathing and cough.
- A fever (you may or may not have one)

One cause of interstitial pneumonia is: Pneumocystis Carinii (PCP).

PCP Prevention:

- Take an antibiotic called Bactrim (sulfa drug) for at least 6 months after treatment.

- If you are allergic to or can't take Bactrim you must take something else (usually Dapsone or Pentamidine).

It is very important that you take this medicine because PCP can be life threatening.

PCP Treatment:

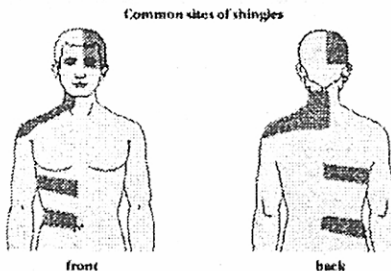
- You will need IV medications and may need to go to the hospital for treatment.

B. Varicella Zoster Virus (VZV)

- Varicella Zoster is the virus that causes Chicken Pox. Most people only get chicken pox once. That's because your immune system makes antibodies to prevent another chicken pox infection.
- Once you've had chicken pox (varicella zoster virus or VZV) you will always have an inactive "sleeping" form of the virus. In times of stress, old age, critical illness or immunosuppression the "sleeping" virus may "wake up" and cause an illness called shingles.
- About 10-20% of patients come down with some form of Chicken Pox.
- The time of highest risk is from 2-8 months after treatment. HiCy patients have a high risk of more severe or even life-threatening illness from VZV.

Prevention:

- Avoid being around anyone who seems to have a contagious (catching) illness (cough, fever, rash).
- Signs of Chicken Pox are fever and an itchy rash that looks like red bumps. Some of them will be filled with pus or fluid. The rash is usually in several places on the body.
- Shingles may have a similar rash but it may be on just one area of the body or it may be on more than one area of the body.



- All close family and friends should be aware that HiCy patients shouldn't be around anyone with known or suspected Chicken Pox or Shingles.
- A person will be contagious for 24-48 hours before any symptoms appear.

Example: If you are with your niece on Sunday and her mother calls you Monday evening to tell you that your niece has just come down with Chicken Pox then you need to call your doctor right away because you have been exposed to someone with Chicken Pox.

- It is very important that you **call your doctor right away.**
- There is a medicine you can get to protect you but you have to get it within 96 hours (or 4 days) of the contact.
- The medicine is called Varicella Zoster Immune Globulin or VZIG.
- It is a one-time shot that your doctor will have to get for you.

Treatment for Varicella Zoster Virus:

Sometimes very mild cases can be treated with oral medicines but you may need to be given IV medicines in the hospital.

C. Sinuses

- Sinusitis and upper respiratory infections can be common.
- The symptoms can be subtle and a fever may be the only symptom.
- Sinusitis can usually be treated with oral antibiotics.
- Don't ignore any symptoms you may have (fever, pain, drainage, congestion, stuffiness). Call your doctor.

D. High Blood pressure

- If you had blood pressure medicines stopped, do not restart taking them unless your doctor tells you to.

E. Hearing Loss

- You may have changes in your hearing from some of the medicines you may have had during your treatment.

F. Relapse

- If your doctor thinks or knows that you have relapsed, please ask them to talk to your Hopkins doctor to discuss any possible options for treatment that may be available.

IV. Some other things you may experience:

A. Electrolyte (Potassium & Magnesium) replacement or supplement

- Some medicines that you take can make your body "waste" or get rid of Potassium and Magnesium.
- You may need to take extra Potassium or Magnesium to keep your levels up.
- You can try and eat foods that are high in potassium and or magnesium but you still may need to take pills to keep your levels up.