

Getting through Chemotherapy

Chemotherapy – or “chemo,” as it is so often called -- is what many of us associate with cancer treatment. The notion that your child must experience the thing you may have seen portrayed so graphically in movies or accounts from friends can be agonizing. Unfortunately, depending on the risk assignment of your child’s NB at diagnosis, chemotherapy will likely be the first step in standard therapy for your child. Chemotherapy *does* cause significant side effects as it is killing the cancer, but experienced health care professionals will carefully monitor your child during all aspects of NB chemo.

Although your child will be in very good hands, you may wish to know more about what to expect and how you can help keep your child as comfortable as possible. The focus of this chapter is the potential short-term side effects of chemotherapy and coping strategies that have helped other NB parents during their children’s chemotherapy treatments. (Please use the e-mail link at the end of this section to send comments about coping strategies that *you* have found helpful during your child’s chemotherapy.) Although we hope it will be useful, please keep in mind that each child’s situation is unique, and you should always address all of your questions and concerns about your child’s specific situation to your medical team.

Chemotherapeutic agents are medications that destroy rapidly dividing cancer cells by targeting different phases in the cancer cell’s life cycle. (**See “Overview of Treatment for High Risk NB.”**) Since various agents attack the cancer cell differently, they are commonly given in combination for maximum beneficial effect. *Combination chemotherapy* decreases the possibility of the cancer’s survival and lessens its ability to grow.

The manner in which the chemotherapy is prescribed for your child will be based on a clinical trial, a protocol or an institution’s previous medical experience with NB. Your child will probably start on a regimen of *induction chemotherapy*, chemo that is given to shrink the tumor before surgical resection (removal). The child will then move on to *adjuvant chemotherapy*, a term used for chemo given to a child who is considered to have minimal evidence of disease after surgery.

At this time, most institutions administer induction chemo in-patient for high-risk NB and out-patient for low- and intermediate-risk NB. An exception to this rule includes Memorial Sloan-Kettering Cancer Center where most children do chemo in the Pediatric Day Hospital and are discharged with backpacks of IV fluids and/or medication infusing through portable pumps. It may sound daunting at first, but if your hospital utilizes this approach, rest assured that you will be trained in simple and time-tested procedures to make everything go smoothly during any at-home infusions.

The most common method of administering chemotherapy is intravenously. However, it can also be delivered by mouth, subcutaneously, intramuscularly, into a body cavity, or into the cerebrospinal fluid. The dose of chemotherapy will be determined by your child’s body surface area or weight. Before every round of chemo your child’s weight will be recorded in kilograms and height in centimeters in order to determine your child’s body surface area (in square meters, or “m²”).

After the chemotherapy consent is signed, the hospital pharmacist will prepare your child’s specific chemotherapy dose. First, premedications (often referred to as “premeds”) will be administered. They are commonly anti-emetics (anti-nausea medications). Then, typically, a specially trained nurse will administer the intravenous (IV) chemo agents by IV pumps into your child’s central

catheter. You will probably watch anxiously the first round of the liquid medication dripping into your child's body. You may imagine it searching out and destroying the cancer. You might look to your child for some type of reaction, but he or she will probably continue watching TV, putting a puzzle together or chattering away. It will likely be an anti-climatic moment.

Along with the IV chemo, your child will receive carefully calculated intravenous fluids also. A lot of hydration can sometimes mitigate the toxic affects of some chemotherapeutic agents. These extra fluids may cause your child to urinate frequently during chemo and wake during the night. Even young children who have been toilet-trained for several years may have to wear "pull ups" or diapers due to the excessive amts of fluid. Any infant/child in diapers should be changed frequently, (even during the night), as this urine and chemo eliminated is irritating to the skin.

Usually blood work (CBC and chemistries) and a urine sample will be tested each day prior to chemo initiation and your child's urine output will be measured (from urinating in a hat or weighing wet-diapers.)

Potential Side Effects of Chemotherapy

Once you understand that chemotherapy is designed to kill rapidly dividing cancer cells, you realize that it can also attack other rapidly dividing cells within your child's body. Your child's hair, skin, nails, gastrointestinal tract and bone marrow will be under assault. This hit on your child's non-cancer cells is what leads to the most common side effects of chemotherapy your child will likely experience.

Each specific type of chemotherapy, its purpose and its potential side effects will be explained by a member of your child's oncology team. (For example, doxorubicin and cisplatin generally cause nausea; cyclophosphamide can sometimes cause bladder bleeding; vincristine can cause loss of reflexes. Some side effects happen soon after the chemo is initiated and some are delayed- days, weeks and even years after the chemo is given. The most common short-term side effects are discussed below, along with various strategies that have helped some NB families cope with them. (As noted, please use the e-mail link at the end of this section to send comments about coping strategies that *you* have found helpful during your child's chemotherapy.)

Gastrointestinal (GI) Tract Issues

Nausea, Vomiting and Diarrhea

During the first round of chemotherapy, nausea and vomiting often start within the first 12 hours and usually sooner with future rounds, depending on the agents used. These symptoms can occur because of the effect of chemotherapy on the GI tract and/or on the vomiting center of the brain. Each child's medication regimen is individualized and child-specific. You will need to work closely with your child's oncology team to determine which medications help ease your child's nausea and vomiting. It is good to keep your own notes on all the medications and write down how well they worked or didn't work (**see "Keeping Records"**). And keep in mind that it's best to have medications administered before the symptoms become pronounced. Also, if your child vomits chemo that was taken orally, it is imperative that you inform the oncology team immediately.

There are some dietary considerations that may be helpful to ward off nausea and vomiting. Most parents have found it helpful to encourage, but not force, the child to eat, and to avoid greasy, spicy, strong- smelling food. Cold food is commonly tolerated better than hot food. Try having your child drink, wait a about a half an hour, and then eat. High protein, high calorie foods--like shakes, high fat yogurts, and breakfast meals--are ideal. Some chemotherapy cause a metallic taste, and your child may ask for a favorite food and then reject it because it tastes wrong.

Food intake should not become a source of stress for your child. As parents we often obsess about every morsel of food our NB child consumes, but our children should not feel our stress. It's better to follow your child's lead. Some children develop strong cravings during chemotherapy and they commonly experience changes in taste. They intuitively know what their body may tolerate. Giving your child the power to make dietary decisions gives them a sense of control. And remember, anxiety can also cause nausea and vomiting.

Your child may experience diarrhea because chemo can damage the cells that line the intestinal wall. If this occurs it is usually advisable to avoid fatty foods. If your child can tolerate it, and it falls within his or her dietary restrictions (see "**Surviving Neutropenia**"), try foods naturally low in fiber and high in potassium like bananas and potatoes. Notify your health care team if your child's diarrhea is severe or if it occurs multiple times in one day.

Constipation

Chemotherapy can also cause constipation, as it affects the intestinal nerves, slowing "peristalsis," the movement of food and wastes through the intestines. Pain medications and some tumor locations can also cause constipation. Encourage your child to drink fluids, especially apple juice, and eat high fiber foods like whole grain breads and cereals. Fruits and vegetables are beneficial if they can be tolerated and are allowed. Exercise can also encourage bowel regularity. You need to keep track of your child's bowel movements and inform the health care team if your child's bowel habits slow and constipation begins to develop. Medications such as stool softeners and laxatives may be prescribed (or available as over-the-counter drugs) to assist regularity. It often requires some trial and error to determine the lowest effective dose—too much can cause diarrhea.

Mucositis

Sores in the mouth and anywhere in the gastrointestinal (GI) tract, or "mucositis," can be a result of the chemotherapy destroying the mucus membranes. Mucositis occurs as a result of cell death caused by chemotherapy or radiation. This causes the mucosal lining of the mouth to slough off and then become red, inflamed, and ulcerated.

Oral mucositis can be severely painful, depending on the extent of the tissue damage, and can result in trouble speaking, eating, or even opening the mouth. These ulcers can also become infected. Make sure your child maintains good oral hygiene, and brushes with a soft toothbrush or sponge brush and rinses with water or water mixed with baking soda after each meal. A "swish and swallow" preparation and/or a "rinse and spit" mouthwash will usually be provided to assist in oral care. Different institutions have their own preferred mixtures. Just make sure no products contain alcohol, as this will almost surely cause a stinging pain. Try soft foods and avoid citrus, spicy, and hot foods. Popsicles, jello, sodas, ice cream, yogurt and shakes can be helpful.

For pain control, mild cases can be treated with home remedies such as ice pops, water ice, or ice chips. Some older children may find sore throat lozenges help. Topical pain relievers, including lidocaine, benzocaine, dyclonine hydrochloride, chlorhexidine gluconate, and ulcerease, are often prescribed for severe mucositis, but it is hard to obtain an effective coating of all areas and the pain relief provided is usually brief. A medication called Magic Mouthwash, which is a mix of lidocaine, diphenhydramine, and Maalox, is sometimes prescribed for mucositis patients. Some say that Magic Mouthwash has not been proven effective and that the Maalox further dries the tissue, which can add to complications, so that it is best to use lidocaine alone in a swish and spit method. If a narcotic is used for pain control, remember to watch for constipation. Severe cases of pain with mucositis may require a hospital admission if IV pain administration is needed.

Because the mucous is present in the stomach and intestines, mucositis can also cause very gelatinous diarrhea. A diaper rash type paste, “Butt Paste,” is often provided for rectal area skin.

Nutrition

Your child’s weight and nutritional status will be monitored closely. During severe cases of mucositis and/or nausea, vomiting and diarrhea, a child may be unable to eat or drink any significant amount. Your child’s weight, hydration, and nutritional status will be monitored closely. If there are signs of malnutrition and dehydration, your child’s oncologist may order supplementary nutrition. This should not be seen as a failure for parents or the healthcare team, but as what is needed to help your child fight cancer.

Your child’s oncologist will explain alternative feeding methods if they are needed. “Enteral” feedings are liquid feedings that are delivered by a tube--either a naso-gastric tube (a tube that is passed through the nose to the stomach referred to as NG-tube) or a gastric tube (a tube that is passed through the abdominal wall into the stomach referred to as G-tube.) Intravenous fluids can be administered to improve hydration. “Parenteral” feedings are carefully calculated nutritional intravenous feedings that are administered through your child’s central line, bypassing the gastrointestinal tract. There are two types of parenteral nutrition: Total Parenteral Nutrition (TPN) or Partial Parenteral Nutrition (PPN). [Some good info is included on the use and pros and cons of parental and enteral feedings here—

<http://www.cancer.gov/cancertopics/pdq/supportivecare/nutrition/Patient/page4>
ie effect on organs such as liver etc]

Problems with Skin and Hair

Dry, flaky skin is common with chemotherapy. Mild soap, skin moisturizers, lip balm and sunscreen are a must for good skin care. Skin cracks and fissures need to be avoided, as they are potential places of entry for infection.

Special attention to diaper skin area is necessary for parents with infants and toddlers. The medications, in combination with the high amounts of IV fluids, make it nearly impossible to avoid diaper rash burns on the skin unless you are well-prepared to aggressively use preventative measures. Heavy barrier creams are needed as are more frequent diaper changes due to the extra fluids. Prevention goes a long way toward avoiding a rash and subsequent increased risk for infection.

Your child’s hair follicles will be damaged by the chemo. This includes scalp hair, eyelashes, and eyebrows, as well as axillary (armpit) and pubic hair for teens. Hair loss or “alopecia” can occur gradually over weeks or months or it may happen suddenly. It is important that you explain to your child BEFORE hair loss begins, that the hair will come out, that it won’t hurt, and that it will grow back. If your child would like a wig, it should be selected as early as possible, for matching purposes. Some parents and children opt to cut the hair or shave it, so the loss doesn’t seem as dramatic. Regardless, when the strands start to fall, so may the tears--yours and your child’s.

Although initially upsetting, hair all over the pillowcase, on the couch, and attached to the clothes eventually becomes an annoyance. Having a handy lint remover is helpful. Scarves, hats, and sunscreen should be used to protect the scalp.

Having a child going bald really brings home the reality that your child has cancer; there’s no denying it anymore. At first you and your balding child may feel uncomfortable in public. But in time, your child will transition to acceptance and you to a feeling of parental pride in your child’s strength during cancer treatment. It is not uncommon to see bald fathers in the cancer clinic, who

have decided to keep their heads shaved during their children's cancer treatment, to say to the child and to the world --bald truly is beautiful!

Bone Marrow Suppression

Chemotherapy can suppress the bone marrow's ability to produce blood cells. This will affect your child in different ways.

Your child's white blood cell level may decline. Since white blood cells are needed to fight infection, this decline can put your child at high risk for potentially serious infections. A "colony stimulating factor" medication injected subcutaneously (i.e., by shots) may be prescribed in order to stimulate the bone marrow into white blood cell production. When the white blood cells that fight bacteria, the "neutrophils," get dangerously low, it is called "neutropenia". There is a lot of information about neutropenia and precautions that need to be followed during this condition. If your child is neutropenic and develops a temperature of 100.4 or any worrisome symptoms, the oncologist should be called immediately. Depending on your child's white blood cell level, hospital admission for observation and IV antibiotics is common to prevent sepsis (bacterial in the blood). (See "**Surviving Neutropenia.**")

In order to prevent a serious life-threatening infection called "pneumocystis carinii" pneumonia (PCP), various antibiotics are prescribed as a precautionary measure -- trimethoprim-sulfamethoxazole (Bactrim), dapsone, and/or pentamidine. (See "**Surviving Neutropenia.**")

Chemotherapy can also suppress your child's red blood cells and hemoglobin, causing "anemia." With anemia your child may seem pale, tired, irritable, have a shortened attention span and can get dizzy. When the hemoglobin level drops below a certain number (typically below 8), or there are worrisome symptoms such as mentioned above, your child will likely receive a transfusion of packed red blood cells at a dose of 10 milliliters per kilogram. (See "**Blood Transfusions.**")

Platelets, which are needed for clot formation and bleeding prevention, are also affected by chemotherapy. A drop in platelets to less than 100,000mm³ (also referred to as platelets of 100,000, 100K, or just 100) is called "thrombocytopenia." If your child's platelets are low and you notice any signs of bleeding--nosebleeds, "petechiae" (spatters of pinpoint, flat, red spots on your child's skin caused by broken capillary blood vessels), bruising on your child's extremities, blood in stools or urine (some bloody stools are actually black), bleeding from gums, or bleeding from intravenous access sites- you need to contact your child's health care team immediately.

When your child is thrombocytopenic, there are bleeding precautions that need to be followed. These include having your child avoid contact sports like soccer, bicycling and the trampoline and having them always use safety equipment like helmets, side-rails, car seats. Constipation needs to be avoided so stool softeners are often recommended. Emery boards should be used to keep fingernails and toenails trim and smooth; nail clippers and scissors should be avoided. In order to prevent oral trauma, extra soft toothbrushes or tooth sponges are preferred. For the adolescent patient who insists on shaving, electric razors are safer than a razor blade.

During chemotherapy and thrombocytopenia, children should not have rectal temperatures, suppositories or enemas due to the risk of injury, infection and bleeding. They should not receive non-steroidal anti-inflammatory (i.e. ibuprofen) or aspirin-containing medications (e.g., Pepto-Bismol) due to bleeding precautions and the potential for Reye's syndrome.

If your child's platelets are substantially low, invasive procedures (i.e., surgery, bone marrow biopsy, urinary catheterization) may be delayed or performed with great caution.

Platelet transfusions are usually administered when the platelet level is significantly low (<20,000/mm³, or platelets of 20,000, 20K, or just 20), your child is experiencing bleeding symptoms, or in preparation for surgery, a procedure or a platelet-depleting medication administration. (See **“Blood Transfusions.”**)

Delayed Side Effects

Chemotherapy can also affect your child’s organs and body systems (i.e. heart, kidneys, liver, hearing, future reproductive function and growth). Your child will be continuously monitored for these effects on an individual basis, throughout his or her NB treatment and thereafter. See **“Living with Long-term Survivorship Issues.”**

Summary

Chemotherapy is an important aspect of the current treatment regimen for many children with NB. We parents should have basic information about each chemotherapeutic agent, their potential side effects, and the corresponding medication that our children can receive to combat these side effects. We need to know the dose of any such medication, how to give it, and any special instructions.

Keeping careful records of all drug names, dose administered, dates given, and any reactions is very important for reference during and after treatment.

Make sure that you completely understand when to notify your child’s oncology health care team during chemotherapy, know the best manner to communicate with them at any hour of the day or night, and have all relevant phone numbers, pagers, e-mail addresses, and emergency services.

Before long, your child’s first round of chemo will be completed. With the knowledge and experience gained, as a family you will feel more ready to begin the second round, and will quickly become “pros.” Having a child who is receiving chemo is certainly a challenge, but together as a family you will conquer each hurdle so that the medications can rid your child of cancer.

Sources

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Please contact info@cncfhope.org with any comments