

Special Issues with Stem Cell Transplants

Putting a child through a stem cell transplant (SCT) is one of the hardest decisions parents have to make during a child's treatment for high-risk neuroblastoma. Transplant can be a relatively smooth (albeit never "easy") experience for some children, but extremely difficult and even life-threatening for others. This section is not intended to offer guidance in making this very personal medical decision—but aims instead to provide tips for coping with the transplant experience for those undergoing it.

Various transplant protocols

First, some background. Currently the majority of children with high-risk NB in the US are treated on the COG Phase III trial that randomizes children to one or two (tandem) transplants ([COG-ANBL0532](#)). Other hospitals treat children according to other protocols, which are not randomized and may include a single, double, or triple transplant; an allogeneic (donor) transplant; or *no* transplant (MSKCC in NYC). Parents may also decline to enroll their child on the Phase III ANBL0532 randomizing single vs tandem transplant and opt for single only. The current transplant "options" are thus complex and varied. For a brief discussion of current transplant trials and the history of phase III trials leading to the "standard" use of transplants, see **Chapter 2, Overview of High-Risk Treatment**.

Because a stem cell transplant for NB does not usually involve the use of marrow or stem cells from a donor (although there are exceptions to this), it is more accurately thought of as a "rescue" -- the child's own previously-harvested stem cells are infused (in the same fashion as a blood transfusion) after high-dose chemotherapy causing so much damage to the bone marrow that the child must be "rescued." The "transplant" term is prevalent because the cancer center's "transplant" team cares for the children undergoing this treatment and the often long and difficult period while the bone marrow rejuvenates. Occasionally you will see the term "stem cell rescue" or SCR used.

Preparing for transplant

Once it has been determined your child will undergo transplant, you may be confused and nervous. After all, even though the stem cell transplant will involve "familiar" chemotherapy, the anticipated aftermath of prolonged low counts and severe side effects indicates a more challenging experience lies ahead for your child and your whole family. We hope this section will help allay your anxiety, by giving you an overview of the special precautions and lifestyle changes you may face during transplant. It is a lot easier to plan how to cope with the known challenge than the nerve-wracking unknown!

During your child's transplant, your child will be hospitalized probably for much longer than any other time during treatment. You will be spending a significant amount of time away from home, which can be uncomfortable and frustrating. If you have other children, or if you or your spouse must continue working during this time, your family may be split up for some time. Your child will spend several weeks in an inpatient isolation room, which requires much preparation and compliance with many hospital guidelines and restrictions. In addition, there will be several medications to keep track of before, during, and after his/her isolation period. You'll want to figure out ways to keep you and your child busy, as well as keep in touch with family and friends. And

after isolation, returning home will also require some specific preparation. The information below will help you with these as well as other aspects of your child's transplant.

Home away from home

Probably one of the most difficult emotional aspects of the transplant process is all of the time you will spend away from home if you don't live near the hospital. Your transplant social worker or other hospital coordinator will help you arrange for housing if you live far away. During the weeks of outpatient transplant recovery most hospitals will require your child to be within a 30 minute drive (with traffic) from the hospital in case of fever or other medical issues. Although it's comforting to be close to your hospital, chances are you'll end up staying in a facility provided by your team, such as a Ronald McDonald House, local hotel, or temporary apartment. Some families are lucky enough to have friends or family near their hospital and able to accommodate them. Check with your child's transplant team before making any arrangements, as individual hospitals have various guidelines and preferences for where a child may stay during the transplant process. Such guidelines relate to disease-control issues and are imposed with your child's safety in mind.

Wherever you are, it isn't home of course. That said, there are many ways to make your surroundings feel more comfortable and familiar.

- Although lots of little knick-knacks can get dusty and are usually discouraged, bring a few favorite items from your child's room or your home.
- Consider laminating posters of your child's favorite characters or movies to put up in the transplant room. Laminate family photos (easier with a copy printed from your computer if you have digital photos). Laminated items are easy to clean and make a better choice than framed items (usually not allowed on the walls because of nail holes).
- If it is not provided, consider bringing a small lamp with a soft light. This can make any room more comfortable.
- Invest in a portable DVD player or CD player if the transplant room will not contain a TV. If you're staying for a couple of months, consider bringing a small TV if it is allowed (it may not be because of noise control).
- Bring your child's favorite towels, sheets, pillows, and blankets.
- Bring washable stuffed toys for your child's bed.
- Consider bringing an area rug or play mat for the floor to soften up the room. Make sure it is easily washable.
- If it isn't provided, bring a shower squeegee. You can get one of these at Target, Wal-Mart, or the like. It will help control mildew in the shower.
- Since food for caregivers is usually not allowed in individual rooms (to avoid germs), bring plenty of familiar snacks and foods to keep in the communal kitchen. Check with the medical team about any food since some are prohibited during transplant.

Preparing for isolation

Although your stem cell team will help you prepare, getting your child and yourself ready for inpatient isolation can be stressful and intimidating. Guidelines and rules for isolation stay can vary greatly from hospital to hospital; however, some suggestions and general information are provided below to help you get ready.

- Insist that you be allowed to inspect your child's isolation room before he/she is closed in. Check that every surface has been properly cleaned, sanitized, and repaired. Look in the corners, closets, etc. (Some hospitals go so far as to clean these rooms with toothbrushes and re-paint the walls and re-wax the floors between each patient.) Don't be afraid to point out any dirty or damaged areas of the room. Check that your child's bed is comfortable, safe, and clean. You don't want to have to break isolation to get your child a new bed or have something repaired later.
- All your child's clothing will need to be freshly washed and completely dried in a dryer (no air drying) and placed in plastic sealable bags. This is for germ control. Hefty and Glad make oversized bags that make the transport a little easier. Once you get to your child's room, these clothes will probably need to be removed from bags before entering the room.
- You will also need to be freshly showered and dressed in freshly laundered clothes when you arrive at the hospital. Some hospitals will require you to shower again before entering your child's room. Some will allow you to shower at home but ask that you not make any stops (gas station, grocery, etc) before arriving. If you do, you may be asked to shower again. Leaving the hospital may mean another shower (even if it is to just get a Starbucks). Remember, it's all for your child's safety.
- Your child's toys will probably need to be new or sanitized. Toys that can be completely submersed in water by either washing them in a sink or a washing machine can usually come in the room. Some hospitals will purchase new toys for children undergoing transplant, so check with your transplant coordinator before you run out to buy all new stuff.
- Remember to sanitize and wipe down anything you plan to bring into the room. If it can go in the washer, put it in the washer. If it can go in the dishwasher, put it in the dishwasher. If not, seriously consider whether you need it or not. Check with your team about electronics, as anything electronic or with batteries will probably need to be cleaned by the environmental department of your hospital or otherwise may not be allowed. (Think laptops, DVD players, portable game devices, etc.) Notebooks, books, and other paper materials will probably need to be new or cleared by your transplant team.
- Your child's meals will need to be specially prepared, and the hospital will have a special menu for your child. Make sure your child's meal comes wrapped in plastic. Check to see whether or not you can have a meal delivered for yourself as well, since you probably won't want to leave your child to get a bite. Also check before you order any takeout. Some foods may be prohibited altogether in your child's room.
- As noted above, try to surround yourselves with familiar things -- photos, posters, pillows, blankets, towels, etc. It may mean a little extra laundry for you, but it will help your child feel more comfortable. Rugs will probably not be allowed.
- Make sure you purchase new toiletry items for your child- and COMPLETELY discard the old ones -- don't save them at home for use after transplant, because your child's immune system will not be normal for a long time. These items include toothpaste, hand soap, toothbrush, nail clippers, lotion, deodorant, etc. Anything that has touched your child's skin, hair, mouth, nails, etc. should be replaced, unless it can be washed or totally submersed in water (like a comb).
- Bring a lot of straws and disposable cutlery for yourself, and don't share with your child from your plate!!! This is not a time to be environmentally conscious or conservative. Don't keep leftovers or leave food out for more than an hour. Don't save a napkin from your takeout bag that wasn't used. Germs are a totally different thing for your family now.
- Consider bringing your own Swiffer and pads. Bring lots of anti-bacterial wipes and go over the computer keyboard, phone, door handles, counter tops, bed trays, buttons, blood pressure cuff, bed frame, and thermometer handle several times a day. Although the room should still

be cleaned daily by the custodial staff, you may want to go over it yourself. The room CANNOT be too clean!

- As convenient as it may have been during your child's initial rounds of chemo, DO NOT share bathroom facilities with your child. Use the parent restroom outside your child's room when possible. If your child does not use the toilet, make sure you wipe the toilet/sink after every use.
- Be extremely selective about visitors, especially children. Your hospital will have special visiting policies during transplant, but be extra vigilant yourself. NO ONE (including you) should be in your child's room if not feeling well. Young children (even siblings) should not be in the room at all (as they are less likely to report not feeling well). The smaller number of people you allow in, the better. Your child can get sick very easily during this time.
- Insist that cleaning staff, food service staff, nursing assistants and any visitors entering your child's room wear gowns and/or masks. Anyone entering your child's room should ALWAYS wash their hands with soap and dry with a paper towel. If ANYONE coughs, sneezes, or snuffles in your child's room, insist that they leave immediately. Small germs can cause big problems during transplant.

Some medical issues during transplant

Drugs. Your child will probably be taking several different drugs before, during, and after his/her transplant. These drugs are primarily administered to prevent viral, bacterial, and fungal infections, which can of course be very dangerous to your child during this time. Some of them don't taste very good, so experiment if possible with your pharmacy's flavoring system. Choose something that generally tastes good to your child, or whatever is most likely to go in and not come right back out. Get into a routine for administering these drugs -- keep a schedule, checklist, calendar, or timer set, as each one is probably going to be administered at different times. Eventually you will be able to wean your child slowly off of each of these drugs as his or her counts begin to recover.

Nausea and fatigue. Not surprisingly, nausea and fatigue will be common for your child during transplant, as his or her body will be severely immune-suppressed. Expect lots of naps, easy fatigue even in low-activity situations, and overall crankiness while your child's counts are recovering.

Food. Make sure you are fully-informed by your child's medical team about food restrictions. The avoidance of fresh fruits or vegetables, deli meats, some breads, buffets, fast foods (unless freshly prepared), yogurt and some other dairy products, and tap water will be among the many restrictions for your child. Food also must be prepared in accordance with certain precautions, so make certain you understand all the requirements. Know what is safe and what is not. These restrictions are for your child's safety, and shouldn't be taken lightly. Some teams will refer to the rule "packaged, processed, frozen" as a guideline for foods for your child. As disgusting as it sounds, most of these foods are safe and should be the basis of your child's transplant diet. If you've been lucky enough to avoid an NG tube or TPN before now, you'll probably become familiar with one during transplant. Since most children don't eat or drink for several days or even weeks during this time, the provision of nutrition by IV infusion is likely. Both options have their pros and cons, so discuss both with your team so you can make the best decision for your child.

Skin. Shortly before your child's isolation, he/she will receive the final round of chemo. These high-dose chemos come with some added precautions to protect your child's skin and internal tissues that you probably have had to experience during induction chemo rounds. Again, discuss the requirements and side effects of these drugs with your team. Some of the protective precautions taken may include: use of a Foley catheter during the duration of the Cytoxan dose; 4-6 hour bathing intervals (round the clock) during and a couple of days after a Thiotepa dose; frequent mouth care with lidocaine or similar mouthwash to counteract mouth and GI sores that accompany several

drugs (ACT or lidocaine-free mouthwash helps for a young child that cannot spit yet, and offering frequent popsicles *before* onset of mouth sores help to reduce the incidence and pain); protective creams (also for the skin burns that can accompany Thiotepa- ask for the Remedy line if your hospital provides, otherwise ask other parents what they used). One cancer family concocted their own recipe -- equal parts Kaopectate, A&D ointment, and Aquaphor cream. Mix it all together in a big bowl, put it in a squeeze bottle (like a shampoo bottle), and rub on diaper area and any skin fold areas where irritation occurs. Keep away from the eyes, of course! Even if your child is out of diapers, his/her diaper area will be very irritated for some time. There are several creams that parents have found to work well during transplant. Dr. Smith's Diaper Cream, Flander's Diaper Ointment, or the homemade version mentioned are all standard choices. Be prepared to try lots of things until you find what works for your child.

Pain. Your child will most likely be on morphine or other pain control (either PC or continuous) at some point during the isolation period. This may seem extreme to us, but it really does help control the continuous irritation from mouth and GI sores, as well as the sometimes severe skin irritations. If your child is old enough, he or she may be able to control the dose, and the pump may be put on a continuous flow for some children. The doctors will slowly wean your child from the pump, and most children must clear the pump before leaving the hospital.

Complications. Talk to your child's team about the possibility of other medical complications that may occur and any symptoms to be aware of. Your child may experience changes in blood pressure, heart rate, temperature, water retention, consciousness, infections, or breathing ability. Although rare, VOD, respiratory distress requiring a ventilator, CMV, kidney failure, and other severe complications can happen. Know what to expect, but stay positive! Most children do not experience these severe complications.

Keeping your family together during transplant

It's hard to keep your family together during this difficult time, especially if you are traveling to a distant cancer center, if there are other children in the home, or if one or both parents still need to work. Having a support system is very important. Many times neighbors, relatives, and friends will take turns with your other children. As much as you would like to help them with their every day activities, it may not be the best solution at the time. Because there are so many disease-control issues with your transplant child, you want to try to minimize the number of people who come into contact with him or her during this time. As much as possible, your child's only contact other than the medical team should be you and your spouse. Many hospitals will also not allow young visitors when your child is in isolation. Keep this in mind, and be sure to talk with your team before bringing siblings to visit in the hospital.

While your child is staying at a facility, hotel, or friend's house near the hospital (either before or after isolation) consider bringing siblings to these places to visit and/or stay the night. Most of the time accommodations can be made, although not usually every day, when siblings want to visit.

Also think about trying a web-cam service to keep your child in touch with siblings, other family members, or friends. Someone at the hospital may be able to help you hook up this service, either on your own laptop or on one loaned by the hospital. This way your child can chat live with his or her family and friends. It works out great for Grandma, too!

Older siblings might enjoy keeping a journal or tape-recording themselves for your child to read or hear. If your child is old enough, he/she may want to journal back or tape-record a message back. Hearing familiar voices is also good for little ones, as they are very responsive to familiar voices.

Keeping yourself busy in the hospital

There are many things that you can do to keep your sanity while you're inpatient with your child. Although not always the case, some children sleep A LOT during transplant and may even be unconscious for periods of time. Although this may be scary for you and your child, it is generally normal and will pass. In the meantime, you'll have to find something to keep your mind busy. Since you probably won't want to come and go from the room very often (minimizing contact with germs), you should bring along lots of stuff to keep you occupied. Some suggestions are:

- Magazines, books, crossword puzzles
- Laptop computer with internet access (sometimes hospitals will loan one to you)
- Movies
- Sketch pad or journal
- Crochet, knitting, or scrapbooking
- Hand held game system (may sometimes be loaned by the hospital)
- Healthy munchie snacks (nuts, popcorn, etc.)
- A new address book to fill out
- Remember that your child's toys can also be therapeutic for you- coloring and crafting have actually been shown to reduce blood pressure and quiet the mind!

Keeping your child busy in the hospital

You will need to bring some things from home to keep your child busy and happy while in the hospital. Many hospitals that offer transplant procedures do a great job of making your child's room comfortable and homey, and provide toys and other items to help entertain the child. Ask to speak with a child life specialist or social worker BEFORE isolation to see what can be done to help your child's stay more enjoyable. Remember that he or she will be very tired and may not feel well enough to play or do any activities. This doesn't mean you shouldn't try! Each day, encourage your child to get out of bed if possible, read, interact with you, watch favorite videos, bathe and change clothes, eat or drink, and walk. There will be some days that your child will not be able to do any of these things, but daily encouragement and motivation will help your child recover. Here are some suggestions:

- Bring new board games or puzzles.
- Buy or rent new movies or movies your child has been wanting to see.
- Encourage play that gets your child moving and out of bed -- bubbles, window markers, floor activities, tents, ball pits, video games like Wii, anything that might encourage your child to move! Most hospitals are supportive about bringing whatever you think might help your child. Just make sure it is either new or properly sanitized first.
- Many hospitals will stock your child's room with age appropriate activities, new toys or games, and other favorites based on information you provide about your child. New things are always a nice distraction!
- Talk about the view with your child and encourage him or her to get up and look out the window. Even if you can only see a wall, sunlight and a busy alley can even be exciting.
- Keep a calendar of your child's activities and status each day. Display a large classroom calendar (you can get one at a teacher supply store, make one yourself from a poster board, or even ask the hospital for one) and keep track of your child's days inpatient. Encourage him/her to decorate it too.

- Remember to be happy and upbeat as much as possible around your child. Even on the toughest days, being positive can help your child feel better.

Preparing your home for your child's return

Preparing your home for transplant is a big job. Once again, check with your child's team as every hospital's guidelines are different, but here are some suggestions:

- At the very least, have all carpets in your home shampooed, steam-cleaned and sanitized. If you are financially able and your carpets are more than a few years old, you may want to consider replacing them. If you do this, don't forget to vacuum the floorboards before new carpet is laid. Usually the carpet-layers won't do that.
- Have your duct-work professionally cleaned if possible and change the filter in your furnace. Buy enough filters to change them every month for the next year, and if you're financially able, buy the really good ones.
- Have your home cleaned top to bottom. Whether this is done professionally or by you, family, and friends, be very picky about how your home is cleaned.
 1. Wash all draperies, throw rugs, throw blankets, pillows, sheets, and towels.
 2. Wash any stuffed animals.
 3. Vacuum or dust behind and under all furniture, including appliances.
 4. Clean out your refrigerator and freezer. If you have a door-front water dispenser, change the filter.
 5. Discard or give away any house plants. Ask your team if you're really attached. Some plants can just be moved to other rooms of the house.
 6. Put away or discard your portable humidifiers. You probably won't be able to use them in your home for at least 6 months.
 7. Wash out all cabinets (inside and outside) in the kitchen and bathrooms.
 8. Clean all blinds.
 9. Scour all bathrooms.
 10. Clean all light fixtures and fans.
 11. Vacuum or dust all ceiling corners and vent covers.
 12. Wash all windows and windowsills.
 13. Scrub floors and grout.
 14. Clean your child's toys with an alcohol/water solution. Add essential oil or lemon juice for a better smell!
 15. Dust, sweep, mop, clean, vacuum and scrub everything in sight! Again, your home CANNOT be too clean.
 16. Have your chimney swept.
- Don't forget to insist that everyone who enters your home be healthy. Anyone with a sore throat, cough, sneeze, or snuffle should not be near your child until it is okayed by your stem cell team. This includes grandma, siblings, and even you!
- Ask your transplant team about pets. Even the cleanest of pets carry germs, shed hair, and create bacteria in your home. Your team will be able to help you make the decision that is right for your family regarding your pets. At the very least, your pets should be regularly bathed and up to date on all immunizations.
- If you haven't yet established this rule, insist that anyone who enters your home remove their shoes at the door or in the garage. They should also immediately wash their hands with anti-bacterial soap. This includes service professionals, nurses, family members, friends. This should become the new normal for your home. Shoes and hands carry way too many germs.

- Do not put hand towels in your bathrooms for about six months. Although it may seem wasteful to use paper towels, this is again an easy way to stop the spread of germs in your home for your child. Bath towels should be washed after every use for at least a few months. Same with bath mats and washcloths.
- For at least six months, wash everything your child wears, even if it doesn't "appear" dirty. Don't "re-hang" anything your child has worn. Wash or clean favorite toys as often as possible.
- Replace your child's toothbrush every week or two for about six months.
- Buy anti-viral tissues (Kleenex makes them)
- Wipe down all kitchen and bathroom surfaces daily with anti-bacterial wipes for about three months.
- Never leave a snack or cup (especially milk) sitting out for more than an hour. Again, what is normal bacteria for us can harm your child after transplant. Also, don't save an uneaten portion from your child's plate or cup. Be wasteful!
- Finally, as cruel as it may sound, be careful about how you and others touch, kiss and hug your child for a while. Kisses on the mouth should be limited, and make sure that anyone who touches your child is healthy and has washed their hands. If your child touches someone or something that you're not sure about, break out the anti-bacterial wipes. Again, it is difficult to think about limiting something as essential as human contact, but unnecessary contact with germs will definitely affect your child's recovery.

Take a deep breath! This is a lot to digest! Yes, transplant is a challenging process, but it is also an important step in your child's full recovery and remission. Although you may be feeling overwhelmed by the idea of your child's transplant in the future, know that you can do it! Become fully informed about the necessary safety precautions, make a plan, and stick to it! Also, don't try to go it alone – now is the time to rely on your Neuroblastoma community and your family and friends to support you during a trying time.

Please contact info@cncfhope.org with any comments