A Guide to Follow-up Care After Cancer Treatment

This information is not designed for bone marrow transplant families
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Families experience a range of emotions at the end of their child’s cancer treatment. Children and their family members may want to celebrate the end of treatment, enjoying less frequent visits to Children’s Hospital of Philadelphia (CHOP). Families have told us that this time also brings feelings of uncertainty about life after cancer treatment. You may have questions about what to expect now that treatment has finished, and you may worry about how to create a “new normal” given the changes your family has gone through since your child’s cancer diagnosis. We hope this guide will help you and your family with the transition from treatment to survivorship, and that by providing answers to frequently asked questions, we will help you feel better prepared for this next phase of your child’s care. Remember that your oncology team is always here to answer questions and provide support.
Important Contact Information

Physicians

Pediatrician ________________________________ Phone ________________________________

Oncology care provider ________________________________ Phone ________________________________

Oncology phone nurse: 215-590-2299, 7 days a week, 8:30 a.m. – 5 p.m.
The phone nurse is still a resource who you can call with any questions.

Oncology fellow on call: 215-590-1000, after 5 p.m.
Call the fellow in case of an emergency during hours when the phone nurse is not available.

Oncology Clinic appointments
215-590-3025

Cancer Survivorship Office
Claire Carlson, RN 215-590-0432

Psychosocial Services Program
Lamia Barakat, PhD 267-426-8135

Your social worker ________________________________ Phone ________________________________

Registered dietitians
Karen Smith, RD, LDN 267-426-6560
Nancy Sacks, MS, RD, LDN 267-426-5613
Life After Treatment: Psychosocial Considerations

Cancer changes life in both positive and negative ways. Your child, as well as other members of your family, may feel that the cancer experience has given them a new perspective on life. At the same time, your child and others in the family may have trouble returning to school or other social events and activities. Some children and family members may have difficulty readjusting to spending time with family and friends. Fear of cancer coming back may make it difficult to move on with life. We encourage you to ask your pediatrician, oncology care provider, social worker or child life specialist any questions you have about your child’s or family’s adjustment after cancer.

Adjustments After the Cancer Experience
Most children make the adjustment to life after cancer treatment. While children may have a few worries about their health or have strong reactions to returning to the hospital or having blood drawn, many children do not have significant cancer-related psychological effects. Parents often have more worries than their children. On the other hand, many children and parents also report positive changes in how they view life, their relationships and the future as a result of their cancer experience. Contact your oncology care provider if you feel your child is having difficulty adapting. If needed, your oncology provider can refer you to a psychologist.

Returning to School
It is very important that children and teenagers return to their usual activities, including school, as quickly as possible after treatment ends. However, some children struggle to create a routine that includes school and other activities. Even if children don’t want to go to school or claim to feel sick, it is best for them to attend school and engage in other regular activities each day. Speak with a CHOP Cancer Center neuropsychologist, social worker or your oncology care provider if you are concerned. Your child may need additional support to return to school, catch up on schoolwork, reconnect with friends and feel successful in school.

Learning Skills After Cancer Treatment
While some treatments bring the possibility of future learning problems, such as with memory and attention in brain tumor survivors, most children are not expected to have long-term learning problems after cancer treatment. For some children, missing many school days during cancer treatment can make the first year back to school more challenging as they work to catch up on what they missed while receiving treatment. If you have any concerns about your child’s learning, we can arrange an appointment with a neuropsychologist in the Cancer Center, who will gather information from you, your child and your child’s school to identify the problems and make recommendations for helping your child be successful in school. Your oncology care provider can give you information about how to have your child’s learning needs evaluated, and your social worker can assist you with getting special education services or accommodations if needed.
Life After Treatment: General Health Behaviors

Diet After Treatment
Cancer treatment can affect children’s nutrition and diet. After treatment, children may crave or refuse certain foods. They may experience weight gain, weight loss, nausea or mouth pain. The goal now is for your child to return to normal, healthy eating. Talk to your oncology care team if you would like to meet with a registered dietitian for guidance. The dietitian can assist you and your child if your child is having difficulty with gaining, maintaining or losing weight, for healthy meal planning, or other nutrition issues.

Infection Prevention
Daily hygiene is important for everyone, and good hand washing is the best way to prevent infection in both healthy and immunosuppressed people. Good dental hygiene is also very important, especially if your child had radiation to the head and neck area. Your child should brush their teeth twice a day with a soft toothbrush and fluoride toothpaste. Schedule dentist visits for routine care every six months. If you notice white patches or thrush in your child's mouth, call your pediatrician.

Sun Protection
Children who stay on Bactrim will be more sensitive to the sun. Also, in general, children who have had chemotherapy may be more sensitive to the sun than children who have not had chemotherapy. Sunscreen (SPF 30 or higher) is recommended and should be reapplied every two hours. When children’s hair is growing back, they should wear a hat when out in the sun. All children, especially children who have been treatment for cancer, should not go to a tanning salon.

Physical Activity After Treatment
Generally, all sports and activities are allowed, and you do not need to limit your child's activities. Daily exercise or movement is important for health and should be encouraged. For children with one kidney, a kidney guard is recommended for use during contact sports or during activities that could potentially damage the remaining kidney. For children who have had brain or spine surgery, please discuss safety concerns with your neurosurgeon. If your child has low vision or is blind, protective glasses will be necessary when participating in sports. Heavy weight lifting is not recommended for children who have received chemotherapy medicines called anthracyclines (Adriamycin, Daunomycin, Idarubicin) in high doses. We recommend strength training with low weights and increased repetitions. If your child is interested in weight lifting and received anthracyclines, check with your oncology care provider before beginning any program.

Swimming
Children can engage in swimming activities, as long as the central line has been removed and your oncology care provider says it’s OK. Children with a history of seizures, however, should not swim in open water, such as the ocean. Children should always have one-on-one supervision from an adult when swimming or bathing.

Hair
Hair will usually grow back when treatment has ended. It may grow back a slightly different color or texture than before treatment. However, if your child had radiation to the head, hair may not fully grow back at the radiation sites.
Frequently Asked Questions About: Fever

Q: Who do I call if my child has a fever or becomes ill? Should I call the pediatrician or the phone nurse?
A: In the first few weeks after the end of treatment, your child’s blood counts may still be low, and your child may still have a central line. If this is the case, you MUST call the phone nurse or the oncology fellow on call. Once your child has normal blood counts and the central line has been removed, fevers and minor illnesses should be handled as they would be for any child, and you can call your pediatrician. The pediatrician can contact your oncology care provider if needed.

Q: Can I give Tylenol (acetaminophen) if my child has a fever? Can I give Tylenol if my child has minor pain?
A: If your child does not have a central line and blood counts have recovered after the last treatment, you can give Tylenol when your child has a fever. It is also OK to give Tylenol for pain. Follow the dosing instructions on the label.

Q: Can I give my child ibuprofen (Advil/Motrin) now that treatment is finished?
A: Once your child’s platelet count has recovered from the last course of chemo, it is safe to give ibuprofen.

Q: How long will my child be at a higher risk for infection?
A: It will take several weeks for your child’s blood counts to return to normal from the last course of chemotherapy, and several months for the immune system to recover. Children are at risk for pneumocystis pneumonia for about three months after chemotherapy is completed. Your child will need to continue to take co-trimoxazole (Bactrim) during this time.

Q: Should we continue to avoid crowded places or limit visitors?
A: Once your child’s blood counts have recovered from the last course of chemotherapy, we encourage a return to normal activities. Your child can be in crowded places and can be around any visitors. Remember, good hand washing is still very important to prevent everyone from getting sick.
Frequently Asked Questions About: Illness

Q: How long after completion of treatment is my child still at risk from the varicella virus (chicken pox and shingles)? What should I do if my child is exposed to someone who has the chicken pox or shingles?
A: Children who have been off treatment for three months or more do not require treatment for chicken pox and can be followed by your pediatrician. If the exposure happens prior to being off treatment for three months, call the oncology phone nurse. Your child may need to take medication to help prevent infection from the varicella virus.

Q: What should I do if my child complains of nausea or is vomiting?
A: Call the oncology phone nurse if your child has a ventriculoperitoneal (VP) shunt, as vomiting may be a sign of shunt malfunction. Otherwise, if your child complains of nausea or is vomiting, offer small amounts of water, tea, ginger ale or flat soda. Do not offer milk, citrus juices or solid foods until your child can keep clear liquids down. If vomiting is constant, lasts longer than 24 hours, or you are concerned about dehydration, call your pediatrician.

Q: What should I do if my child has diarrhea?
A: If your child has diarrhea, give clear liquids. Gradually add other liquids (avoid milk products), then bland foods (bananas, rice, chicken, applesauce and toast), and then a full diet as tolerated. Call your pediatrician if diarrhea lasts for more than 24 hours.

Q: What if my child has a nosebleed? Who should I call?
A: If the nosebleed does not stop after holding pressure for five minutes or if your child is having frequent nosebleeds, call the oncology phone nurse.

Q: What if I notice bruising or petechiae?
A: If you notice unusual or unexplained bruising or petechiae, call the oncology phone nurse.

Q: What should I do if my child complains of a headache?
A: If your child had a brain tumor and complains of a headache, call the oncology phone nurse. For all other patients, encourage drinking liquids for hydration. Tylenol is OK to give for minor pain.

Q: What should I do if my child has a seizure?
A: Call the oncology phone nurse or oncology fellow on call.

Q: My child has a VP shunt. How will I know if it is not working?
A: Warning signs of shunt malfunction include headaches, vomiting, fatigue, irritability, swelling or redness along the shunt tract, decreased school performance, periods of confusion, and/or seizures. Your child may have only one or two symptoms at a time. Call the oncology team if you notice one or more of these signs in your child. If your child becomes very ill (severe headache, extreme fatigue, continuous vomiting), seek medical attention immediately. Do not push or put pressure on the shunt.
Frequently Asked Questions About: Immunizations

Q: When we restart immunizations, do we start all over, or pick up where we left off?  
A: Your child will pick up where immunizations were stopped. Chemotherapy does not usually destroy the protection that comes from immunizations received before your child was diagnosed with cancer. Most children are able to begin catching up on missed immunizations around six months after treatment ends. Your oncology care provider will determine the exact date. Only children who have received a bone marrow transplant start from the beginning.

Q: What about the vaccine for meningitis or the MMR shot? Are there special considerations for these immunizations?  
A: Re-immunization can occur six months after completing treatment. At that point, your child can be caught up on all vaccines.

Q: Is it safe for other members of my family to get immunizations?  
A: Yes, all family members should get immunizations as scheduled. There are no restrictions on immunizations for family members.

Q: What about the immunization for the varicella virus (chicken pox and shingles)? Is it safe for my child and other family members to receive this?  
A: The varicella vaccine is safe for all patients except patients who had a bone marrow transplant.

Q: Should my child continue to receive a flu shot each year?  
A: Yes, your child and all family members should receive a flu shot each year. Children who are off treatment can receive the flu shot at the pediatrician’s office.
Oncology Follow-up and Survivorship Care

About Your Child’s Health Now
Once your child’s blood counts have recovered, we encourage you to call your pediatrician first with your questions. We know this may be uncomfortable for you, but your pediatrician can handle most health issues and will determine if your question is better answered by the oncology team.

The Plan for Oncology Follow Up
Once treatment ends, you will be given a roadmap that will list follow-up visits. Visits will range from once per month to once every three months for the first year. Please make every effort to follow the recommendations for follow-up care.

Secondary Medicaid
If you are a Pennsylvania resident who accessed Medicaid as secondary insurance during your child’s cancer, we strongly recommend that you continue to renew the insurance as required on an annual basis.

The Cancer Survivorship Program
Your oncology care provider will follow your child for about three to five years after treatment. You will then transition to the Cancer Survivorship Program, where the focus is helping your family navigate life after cancer, including both the physical and emotional issues some families face. The Cancer Survivorship Program guides patients through a schedule of follow-up appointments and routine screening tests, provides ongoing education about long-term effects of cancer treatment and referrals to specialists as needed, and helps older patients transition to adult care when ready.
Patient family education materials provide educational information to help individuals and families. You should not rely on this information as professional medical advice or to replace any relationship with your physician or healthcare provider.
Every day, teams at Children's Hospital of Philadelphia make breakthroughs that transform children's lives. Since our founding in 1855 as the nation’s first children's hospital, we have made extraordinary discoveries, trained generations of leaders, and advocated for children everywhere. Our pediatric research program, one of the largest in the country, has set a new standard for scientific innovation around the world. As a nonprofit charitable organization, we rely on the generous support of donors who are inspired by our work — and our mission.