

✓ Tips

Advice

Guide for Parents of Children with Cancer

Resources

Info



Ontario Parents Advocating for Children with Cancer

www.opacc.org

OPACC's Guide for Parents of Children with Cancer ("Parent Guide") has been developed by parents for parents. After all, who can better address the questions and concerns that parents of children with cancer may have than those who have been there themselves?

Our complete Parent Guide, as well as a companion guide for your friends and family, can be found as an electronic resource on our website at www.opacc.org. In this rapidly changing world, OPACC decided that an on-line guide would be the best and easiest way to ensure that the information we provide is current, fresh, up-to-date and inclusive while making editing, updating and adding links within them faster and easier. We encourage you to access OPACC and the Parent Guide from whatever device you feel most comfortable with...and to always know that your input and feedback are welcome. This guide is for you and its future accuracy and information will be done together with and by you!

A childhood cancer diagnosis more often than not comes to us out of left field, the very last thing we ever expected to hear. Once the initial shock begins to wear off, and we realize that this is the new reality we find ourselves in, the questions begin to bubble to the surface. Those questions and our unfamiliarity are myriad. For treatment related questions, it is our medical teams to which we can turn. As an organization whose main focus is parent and family support, OPACC www.opacc.org always wants to provide answers and direction where we can. Through our various programs, we strive to give parents the answers they are looking for.

Over the many years since my own daughter's cancer diagnosis, I have done my best to navigate the system for myself and others. Peer-to-peer support with its mutual safe sharing is vital! As Parent Liaison, I had what I called my "serendipity list," those informational things you wanted to know more about, but which you often only stumbled upon as if by accident. We knew that parents were searching for a one-stop place to look for answers - answers that OPACC strives to provide in a variety of ways. This project came about through the committed efforts of many, but most especially, thanks go to Heather Stewart, an amazing OPACC mom, who organized her thoughts and put pen to paper on our behalf. From beginning to end, this project took a number of years and was written while her own daughter has been in treatment. I enjoyed working with Heather as a sounding board, source of information, collaboration, editing and encouragement to bring this document forward to OPACC's Board and to see this finished product to completion.

Many thanks to the many people who helped make this happen, including our readers, Barb Johnson, Sarah Mueller for her always amazing graphic designs and to Sarai Porretta, OPACC's Administrative Coordinator whose help and abilities make OPACC run smoothly every day. The document you will see today is truly reflective, not just of one family's childhood cancer journey, but also of all the families we are privileged to meet and work with on a daily basis. Please treat it as the work in progress it is meant to be so that our links stay current, relevant and informative. We encourage you to please send your feedback and suggestions, including new additions and improvements to: info@opacc.org

With sincere good wishes,
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What Cancer Can't Do

It cannot cripple love

It cannot shatter hope

It cannot corrode faith

It cannot destroy peace

It cannot kill friendship

It cannot suppress memories

It cannot silence courage

It cannot steal eternal life

IT CANNOT CONQUER THE SPIRIT

~Author Unknown

Right now, you are sitting there in a fog. You have just been given the worst news a parent can hear – your child has cancer. While the type may be different, we have been exactly where you are. Just remember, we are parents first and foremost. This disease does not define our child or us, nor does it limit us.

This guide is not about the disease itself or the specifics of treatment for your child. Throughout the last 5 years, I have walked this path and personally and through friends' experiences I have learned a lot about cancer, treatments, protocols, counts and other words that may still seem foreign or unfamiliar to you. Believe me, you will become very comfortable with terms, procedures and other information you would have never thought possible.

There is a lot of information to know, retain and remember. This guide is to help you record, organize and get some sort of control back into your life. Personally, I had paper everywhere and found it very difficult to be and stay organized. In my former life (before cancer), I was very organized and kept track of a lot of things, but with the stress and anxiety from the diagnosis, I couldn't get under control at all. My husband and I quickly divided our roles. I was the cancer parent and he managed home and working. Since I did the majority of the hospital duties, I carried another stressor, which was: "what if something happened to me and I could not go to the hospital, who would know what is going on?" This guide will also help to remove those concerns as it can be a permanent and ongoing record of your child's diagnosis, treatment and health.

This guide does not provide medical information nor cancer-specific treatments, but can be a place for you to record all those pieces of information and the details.

Throughout this guide, you will learn of resources available to you and services available to your child and your family.

We wish we could tell you that it will be okay, but we cannot. It will be bumpy, scary and exhausting.

We hope knowing so many others have done it will help you stay strong and believe your child and you can do it too. Remember, no matter what: NEVER EVER GIVE UP (NEGU)!

Each section of this guide will deal with a specific topic or issue that will arise during your child's cancer journey. We strongly recommend that you get a separate journal for yourself to record your thoughts/emotions/information on a daily or regular basis. We also strongly suggest, if your child is old enough, to ensure he/she also has a journal to record anything that is important to them and to help them voice their emotions and questions.

~ Heather Stewart

CONTACT INFORMATION

The following are the main numbers you will need for SickKids. Please insert names and numbers specific to your child's medical team.

Clinic	416-813-5859 *4 (you can speak to the receptionist between the hours of 9am and 4pm)
SickKids	416-813-1500 (8A the floor)
8D Day clinic	416-813-
Oncologist – Dr.	416-813-
Nurse Practitioner	416-813
Clinic Nurse	416-813-
Social Worker	416-813-
Interlink Nurse	416-813-

Satellite Hospital

Your satellite hospital is:

Nurse to contact at your satellite is:

Contact number during regular hours is:

After hours contact number is:

(Speak with the charge nurse)

Alternate Satellite –

When you are at your cottage or family member's home your satellite is:

Nurse to contact at this satellite is:

Contact number during regular hours is:

After hours contact number is:

(Speak with the charge nurse)

Note: If this second location is a regular place for your child and family to go (i.e. cottage or family member's home), we recommend you take a quick visit with your child to this satellite so they know your child and you and then should you be required to go there it isn't unfamiliar.

Medications – Home Care

Depending on your child's diagnosis, you may be required to give medications at home. A SickKids oncology pharmacist will sit and explain exactly what needs to be done. Do not be afraid to ask questions, even the same question, repeatedly until you are comfortable with the information. If you do not speak English as a first language and are unclear of the information you are being given, be sure to ask for an interpreter to help you.

Giving a child medicine can be scary, so always ask and, if in doubt when you are at home, don't hesitate to call the on-call oncologist. The doctors and nurses are always there to help you with any issues that may arise. We know one big question is what to do when the child vomits after taking oral medication - do you repeat it? The answer is very drug-specific so you need to call to ask for advice when or if that ever happens.

Homecare is available through Community Care Access Centres (www.healthcareathome.ca) in some instances to assist you with your child's care. Make sure to ask about it and use it. Homecare nurses are sent to your home who will give the medical care to your child and train you to do the care yourself. Do not feel pressured to assume the homecare duties until you are comfortable and able to manage those duties. Your comfort must be both physical and emotional. For example, some people are personally scared of needles; if that is the case then giving your child a needle may not be realistic. For a while after diagnosis, a lot of parents are too overwhelmed emotionally to take on more. There are lots of reasons for you to not do the homecare yourself and you are more than in your rights to say you cannot take it over from the nurses. You may find, however, you want to take over some of your child's care as it allows you to be out of the home and not tied to the homecare nurse's schedule.

During all meetings when receiving instructions regarding medication or care, or immediately after the meetings, make notes of all the procedures and the "how to" of what needs to be done so that you have the information when you get home to reference what you were told. Given our emotional state, we often forget details - writing it down helps remove that risk. Given your unique family situation, you may want a neutral person to attend the meetings with you to help ensure that you can remember all the information.

Always remember, no matter what, if you are in doubt about anything call the hospital and speak to the oncologist on-call or the pharmacist.

If your child is to take medications DO NOT stop giving it for any reason except a doctor's instructions. These medications are given to help your child fight and stay as healthy as possible.

Appointments

During this period of unbelievable stress, you will have to remember numerous things, like appointments. Depending on your child, you may have various appointments with various departments at SickKids or at your satellite hospital. Trying to keep dates and times straight is hard enough at regular times!

If you find you just can't remember things like appointments, perhaps having a friend or family member come with you to appointments will help you by making notes and remembering dates.

If you use an electronic device to organize your appointments, it is important to keep a handwritten copy in case something happens to your device. It is also good to have a hardcopy in case someone else needs to help you or fill in should you get ill.

Counts

As we said at the beginning of this guide, you will learn terms that you never thought you would need to learn. One of the important words is "counts." Generally, they refer to your child's complete blood count (CBC) – which is the hemoglobin (red blood cells to carry oxygen), platelets (blood clotting cells) and white blood cells/neutrophils (infection fighting cells).

Regardless of the type of cancer your child has, their counts will be very important for very different reasons. It is important throughout your child's journey to record the counts so you can remember them and understand what they mean for treatment and for your child.

Every time your child has bloodwork done, you should receive (make sure you get!) a copy of the CBC. You can punch holes in the pages and add them in your OPACC Parent Binder for ease of reference. If you keep them in order by date done, you will be able to access them quickly and easily. If you highlight the date of the CBC, you will know which one is most recent.

In addition to a CBC, counts can also refer to a more comprehensive blood panel including electrolytes and other organ function tests. When these tests are done, you should receive (make sure you ask for and receive!) a copy of the reports for your reference and understanding. You should keep copies of these reports in your OPACC Parent Binder, too.

Protocols

When a child is diagnosed with cancer, their oncologist - after considering a variety of factors - makes the decision of what treatment to be given to the child. The schedule of treatment as well as the types of drugs given is found in a "Protocol."

Your child can be on various protocols at the same time for different reasons and issues. It is important to obtain and keep a copy of the protocols in your OPACC Parent Binder for ease of reference. You will need to sign a consent to treatment, at which time you will receive a copy of the protocol.

The protocols give a detailed outline of the treatment and the schedule that your child is going to receive. Once things have "settled down" a little, it is important for you to read the protocol to make sure you are familiar with the schedule, medications and plan of care for your child. We strongly recommend that you allow your families to read the protocols too. It will help them know what is happening without you trying to explain everything. Having family know about the protocol will also ensure that someone else knows what is happening should you need someone to help you.

The protocols are also important when you are researching or talking to other cancer parents, you can refer to it so others know what you are talking about without having to go into much detail.

Research by Parents

One of the best pieces of advice we were given when our child was diagnosed was DO NOT go online to randomly research the cancer, treatment or other questions you might have.

In this age of technology, we are overwhelmed by information. Despite the unbelievable benefits of the Internet, there are a lot of disadvantages. There is no regulation of what is put on the Internet. Not all "official" sites are actually official and not all people are who they say they are.

It is our recommendation that you ask your child's oncologist, nurse or social worker for specific and approved places to go online to do research. They are very knowledgeable about what is out there and where you can go to learn more and get answers to your questions.

One place that is a great source of support are online groups for parents of children with various forms of cancer. We strongly recommend that you speak with other parents dealing with the same cancer to find out specific groups. OPACC has a Facebook page that you can join to help you start your information journey: www.facebook.com/OPACC

Please remember no matter what anyone says, every child is different, so every battle and journey is different. While chatting with other parents can be of great help, it can also cause a great deal of anxiety. It is important not to get overwhelmed by other parents' opinions or experiences. Your child's doctor is a professional with expertise in treating your child's cancer.

Do not let other parents scare you, but rather take their opinions and discuss them with your child's oncologist.

You can list here some websites that you have found useful to do research and educate yourself about your child's cancer (to be completed with the help of your child's health care team):

Admissions

This is exactly what it means – your child being admitted to the hospital. There are various reasons why your child might be admitted. As you have already experienced, your child will be admitted during the time of diagnosis.

Depending on the cancer, your child may be admitted for all their treatment. The treatment may be required to be given over several days or extended periods of time which requires your child to stay in the hospital. The protocol will outline what the schedule is for your child's admissions. These are important, as they will help you to organize your home life and care for your other children during the admission.

During treatment, your child may be admitted for fever/neutropenia. You are now asking what does "fever/neutropenia" mean? The chemotherapy your child receives will suppress their immune system which will make them more vulnerable to illnesses. While at home, should your child develop a fever, you will need to contact your medical team for next steps. If your child is neutropenic – which means they have a neutrophil count of below .5 - they may be admitted until they are 48 hours fever-free or they are no longer neutropenic. As you have probably already experienced, children have fevers at the most inconvenient times, mostly during the middle of the night.

There are other times that your child may need to be admitted, like if they have procedures like surgery.

One of the biggest supports you can receive from your family and friends is to be able to count on them to take your other children so that you can be with your child in the hospital.

It is fine when an admission is planned and you have time to pack for yourself and your child, but there will be times when admissions are not planned and you have no time to get organized. We strongly recommend that once you are home after diagnosis, you keep a bag for yourself and your child always packed (just like when you or your partner were pregnant).

Packing

We were going to write a separate heading for this but it fits here and is a good reference for every parent.

In order to ensure you have everything you need should you have to make a middle of the night run to the hospital, having a bag packed all the time makes life a little less stressful, which always helps.

We are not going to do an exhaustive list but here are a few key ones:

- clothing for you and your child;
- toiletry and personal items, including your own medications etc.;
- special items i.e. blankets, stuffed animals;
- extra phone charger;
- your OPACC Parent Binder for information;

- cash for unexpected expenses (coffee/chocolate bars etc)
- your own book/magazines
- other:

Diagnosis on family, kids and relationships

Having a child with cancer is probably the worst stress a family/marriage/relationship can have placed on it. Your relationship will be tested in ways you can't begin to imagine. When you consider the famous phrase "in good times and bad, and in sickness and in health" little did you realize it would be referring to your child.

With the stress, lack of sleep and emotional toll that the diagnosis brings, you and your spouse will be tapped out in ways you would have thought unbelievable. It is so very important that you talk to each other. Keep communicating and not just about the cancer, although that will dominate your conversations. Be kind to each other and cut each other some slack. Things that used to seem so very important will not even cross your mind. Also be kind to your friends and extended family, as you will need them and their support during this journey.

You need to lean on each other but also remember each of you may cope with the news and stress in very different ways.

Your team may include a social worker, who is a great source of information and services that are available to you and your spouse, to provide you with people who can help you cope and make the necessary adjustments.

There are also psychologists available at the hospital for parents and families to help adjust to the new reality of your life. The hospital also runs a support program for siblings of children with cancer. These are accessible through any member of your child's medical team.

It is important to advise your family doctor about your child's diagnosis to ensure that you can get any medical support you may require to help you cope. Also, if your doctor knows what is going on, should you require any medical help with illness, your doctor can assist you faster and easier without having to wait.

If you have a religious affiliation, it is so very important that you tell your religious leader of the situation. They have access and training to valuable resources that can help and support you during this unbelievably trying time.

Friends

We have also written a companion guide for friends. It was written by friends who provided unbelievable support during a child's journey with cancer. Your friends will be so vital to your physical and emotional health during this journey! One of the biggest issues that we face as parents is that we don't know what to tell friends or how to tell them what we need. No matter what you think you can do on your own, you will need your friends and they want to help you. Also you must realize that you may find your friendships change and those people who you considered your best friends don't provide the support that you expected while other people step in to become more valuable friends during this turbulent journey.

During our child's journey, we learned of a person who was battling cancer herself and, since she needed a lot of help and so many wanted to help her, she developed a patient registry that allowed friends, acquaintances and total strangers to see what needed to be done and to help in whatever way they could. OPACC has a registry of things that you and your family can use to list all the ways people can help. We recommend that you appoint a family member or really close friend to be the administrator of that registry so that you don't need to be involved or making the decisions: www.opacc.org (select "Family Wishlist" under the "Resources" section)

We all think we can do everything on our own and don't need to ask for or require help. Believe me, you will need help and you shouldn't ever feel badly for asking for help or receiving the help of others.

School

If your child attends school full-time prior to diagnosis, it is important that you or a family member notify the Principal at your child's school as soon as possible about the circumstances. This will prevent you receiving calls from the school for lack of attendance, as well as ensuring that the school is aware of what is happening so that when your child returns to school they understand what is happening. If you need any help dealing with your child's school, there is an Interlink nurse at SickKids who can assist you with this issue. You can also check on OPACC's website for an example of a useful document from Candlelighters Simcoe Parents of Children with Cancer on their School Support Program: www.opacc.org (select "Education" under the "Resources" section).

While this may seem like the last thing on your mind, encouraging your school-aged children to keep up with their class is a great way to help them feel more normal and be more hopeful about their lives.

If your child is school-aged (Grade 1 and up), your child is entitled to be schooled by a professional teacher while inpatient at SickKids. Of course, your child's ability to participate and willingness to work are other factors to be determined by you and your child.

Once you have returned home, your child may be able to attend school either on a full-time or part-time basis. The decision to return to school is to be discussed with your child's health care team and ultimately you, as the parent, make the decision.

The Principal at your child's school is a valuable resource to assist you in making the decision about returning to school as well as options. Depending on your child's health, they may be entitled to homeschooling which is a certain number of hours per week for a teacher to come into your home to teach your child. The Principal, together with the Interlink nurse, can discuss this option with you and help you decide if it's right for your child and for you.

There are also teachers in your child's school who are called Special Education Resource Teachers (SERTs). These teachers are there to assist students who, for a variety of reasons, cannot participate in the regular stream classroom. These teachers are excellent liaisons as they can meet with you and your child and discuss both the child's wishes as well as the needs your

child may have due to treatment, physical limitations or support for the child to “catch up” with the work missed during treatment.

Together the Interlink Nurse, the SERTs, and the Principal at your child’s school can assist you with ensuring your child’s education is continued in whatever form possible.

Another consideration is to notify the Principal of the school where your other children attend (if not the same). It is important for the sibling’s school to know what is happening to ensure your other child(ren) get the support they need, as well as should you be late for pickup or forget lunch etc., they understand the circumstances and can provide the assistance.

Please remember that everyone, and we mean *everyone*, wants to help and that includes your children’s school - you just need to let them know and try not to worry about being indebted. The schools want to make all your children as comfortable as possible. They are trained to help students, so try to rely on them and their expertise in dealing with education. They may have options you haven’t considered or even knew existed.

Communication

One pressure you will get from extended friends and family is keeping them updated. We know that is the last thing on your mind, but you will have lots of people asking you what is going on, how is your child doing, etc. You may choose not to inform people except your immediate family. Also, depending on your child’s age, your child may not want you to share details about what is happening. While we respect that decision, we want you to be aware of how to get the information out there without having to write to each person individually. There are a variety of vehicles you can use, but of course they revolve around the computer/Internet. There may be more technologically advanced parents who can come up with other ideas, but the main ones used by most parents are Caring Bridge www.caringbridge.org , creating a Facebook page (i.e. “Prayers for (child)” or get creative with the name), writing a blog (an online diary) or creating an e-mail group so that you can write one e-mail and send it to everyone in the group with one button. Another idea is a phone chain in which you can put a person (either close friend or family member) in charge and you tell them and they phone a few people who in turn phone a few people as a way to get information out to extended family and friends.

There are advantages to each option. You don’t have to decide this right away, but just so you have some information when you start getting pressure to keep people informed. We know that when you are sitting there right after diagnosis you really don’t care about anything; but once treatment starts and you have some time on your hands as you sit in a hospital room or waiting room, one of these options might appeal to you. Certainly this is not an exhaustive list of options.

You should consider when writing a blog, e-mail or message how much do you want everyone to know. Certain people, immediate family and close friends, may be given more information than extended family and friends/acquaintances. You must consider how much your child will want others to know. Some children do not want any personal details shared with anyone, so it is important to respect the child’s preferences. Another item to consider is that, while sharing your most personal feelings may feel great and cathartic at the time, once on the Internet those

comments will never be removed. So the post you wrote after a long and exhausting day, when you were lying on that little bed sobbing, may not be something you want others to see when you have had some sleep and are feeling a little calmer. Just remember nothing is private once put on the Internet. This is just a personal thought for you to consider.

Forms

You will be inundated with forms. You will come to be able to fill them out in your sleep (which sometimes you may feel like you are doing!).

This section is not to help you complete the forms, but rather to make you aware of what aside from actual medical forms you should remember to complete as you start and continue on this journey.

E.I. Claim

As of June 2013, a parent or guardian of a child with a life threatening illness is entitled to claim employment insurance. If either you or your partner are required to stop work due to your child's illness and/or medical care, you can make a claim. Again, all forms are online together with an explanation of entitlement. To avoid the risk or misstating entitlement we are providing the website for you to go to learn and make your application. A member of your child's health care team should be able to assist you with completing these forms: www.servicecanada.gc.ca/ei

Canadian Cancer Society

When you are taking your child to and from the hospital for treatment, tests and check-ups, you may be able to submit a claim to the Canadian Cancer Society (in your area) to assist you with the cost of that travel. Here is the link to the Canadian Cancer Society home page: www.cancer.ca and type in "local cancer society" under search in the top right corner of the home page to find the local addresses.

POGO

The Pediatric Oncology Group of Ontario (POGO) is an organization that assists families whose children have cancer. There is a daily payment for each day a child is at hospital for treatment, test or checkup. The rates are different whether your child is inpatient or outpatient. POGO also offers assistance with childcare for your other children who require care while you are at the hospital with your sick child. There is an annual maximum to the daycare costs. POGO can also assist you with hotels should you be requiring one due to treatment or tests. This office is located in SickKids in the Black Wing on the second floor. A volunteer can help you find this office. Please visit their website for more information: www.pogo.ca

Disability Claims

Depending on your child's cancer and other related issues, you may be entitled to make an application for disability benefits. This application would result in your child being declared disabled. You will be entitled to receive a monthly payment and make annual deductions in your income tax return. This application requires your child's oncologist to complete and sign the forms. It is your oncologist's decision if you should be making this application for your child. It is your child's social worker who you should speak with about this application process.

There are other organizations in the community that may be able to help you with expenses and services. The following is a list of organizations you may wish to contact or ask a family member to contact for you:

- Easter Seals (www.easterseals.ca)
- Kiwanis Service Clubs (www.kiwanis.org)
- Shriners Service Clubs (www.shrinersinternational.org)
- Rotary Service Clubs (www.rotary.org)
- Optimist Clubs (www.optimist.org)
- Childhood Cancer Canada Foundation (www.childhoodcancer.ca)

Receipts

We strongly recommend that you keep all receipts you obtain for food, parking and other related expenses. At the end of the first year of your child's treatment, you can consult an accountant or tax specialist to assist you with completing your return to ensure you claim everything you are entitled to. While you may not be required to produce the receipts, it is better to have them than have your claim be denied because you don't have receipts.

Accommodations

If you do not live close to the Hospital for Sick Children, you may be entitled to use the accommodation at Ronald McDonald House in Toronto (www.rmhtoronto.org) for long-term housing or obtaining a night at a local hotel. You should consult with your social worker or go on your own to make the application for this housing.

As mentioned earlier, POGO can also assist you with hotel for a night accommodations. The circumstances for assisting are provided by POGO.

Also, hotels in the vicinity of the Hospital for Sick Children offer slightly lower rates for families of patients.

Other Services Available

In the hospital

When you and your child are in the hospital, there are many services available to help you and support you during the long exhausting days.

There are Parent Liaisons from OPACC (www.opacc.org) who are available most days of the week to visit, to help you find information or just to sit and listen when you need it. They have walked in your shoes, being parents of children with cancer. They do know how you feel and can understand the stress and anxiety you are experiencing. They also run a parent drop-in on Monday mornings and Tuesday nights for parents to come have a coffee and snack and a chance to chat.

There are lots of people who can come and give you a break from being in the hospital room with your child. There are volunteers who have been trained and screened who can come and play, sit or chat with your child so you can get a coffee and some fresh air.

There are also Child Life Specialists. These people are employees of Sick Kids, and they are trained to help children understand any medical procedures they are going to experience, but also they are valuable resources for activities for your child and support for you during the tough days.

There are places for your child and you to go to get out of the room if permitted. On the 9th floor is the Starlight Room. There your child can go on computers, play videogames, do arts and crafts and even get outside if the weather cooperates. The specific days and times it is open are posted on the floor or the Child Life specialist can get that information for you. Another place to go is Marnie's Lounge on the 4th Floor. Again, videogames, computers, pool table, crafts and even baking time. The schedule for Marnie's Lounge along with any special events will be available from the Child Life Specialist on your floor.

Across the hall from Marnie's Lounge, there are laundry facilities that are free to the parents. So while your child is occupied in Marnie's or with a volunteer, you can go down and clean some clothes or that special blanket that needs to be refreshed. OPACC provides free detergent pods for this.

Also available are Camp Ooch staff from Ooch on the 8th Floor. Camp Oochigeas (www.ooch.org) is a camp for kids with cancer. There is a northern site in the Muskokas where your child can attend camp for up to two weeks per summer. There is also a Downtown Toronto location where they run evening and weekend programs. Camp Ooch also runs a day camp for younger children. Ask your nurse or the Child Life Specialist to introduce you and your child to someone from Ooch and they can tell you all the options there are for your child to participate.

Out of Hospital

As discussed above, your child is entitled to attend Camp Oochigeas either at residential camp, day camp or Downtown site depending on age and other factors.

In addition to Camp Oochigeas, your child is entitled (depending on age) to attend Camp Trillium (www.camptrillium.com) and Camp Quality (www.campquality.com). Your Child Life Specialist is able to get the contact information for both of these organizations for you.

In addition to camps, there are other services available in various communities. In the Durham Region, there is Hearth Place (www.hearthplace.org) in Oshawa. In Peel/Halton Regions, there is Wellspring (www.wellspring.ca). In Simcoe County, there is Candlelighters Simcoe Parents of Children with Cancer (www.candlelighterssimcoe.ca). The Parent Liaison from OPACC can provide you with contact information for all of these places, as well as other services which may be available in your community, such as established parent support groups in areas like Kitchener-Waterloo, Newmarket, and Hamilton. These places offer counselling, parent support groups and various forms of therapy for your child, the siblings and families to help you cope and adjust to your new reality.

Definitions

CBC stands for a complete blood count which includes hemoglobin (red blood cells), platelets and white blood cells – typically this is called a child's counts and these numbers are different for each cancer and affect treatment differently. It is important to understand from your child's health care team what the counts mean for your child and what the team wants them to be, which is dependent on the type of cancer your child has.

Chemotherapy is chemicals given to a child to kill the cancer cells in the body. It is not a specific drug but may include a variety of drugs which will be different for various forms of cancer. Your child's protocol should outline the drugs to be given.

Hemoglobin is the red blood cells which are the cells that carry oxygen and nutrients to the body as well as carry carbon dioxide out of the body.

Neutropenic is when your child's white blood count (neutrophils) is below .5, which puts your child at an elevated risk of infection as their body cannot fight typical illnesses. When your child is neutropenic they will be prone to fevers which will result in a hospital visit and most likely an admission. The chemotherapy given to your child typically has the side effect of making your child neutropenic.

Platelets are the portion of the blood that allows it to clot (stop bleeding) and heal up a wound.

Protocol is the schedule of treatment that a child is going to be given. The protocol will outline the medications to be used, the timing of those medications, as well as the side effects and risks of those side effects.

Radiation is another form of treatment and does not include drugs but rather radiation beams sent from a machine to a targeted area in the child's body to kill the cancer cells.

White Blood Cells are the portion of the blood that fights infections in the body. A portion of the white blood cells are called neutrophils and they are like baby white blood cells which indicate that the bone marrow is working properly.