

Guide for Newly Diagnosed Parents

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1. Introduction – From this OncoMom to you...

Hi there...

First of all – here is a big hug! You are now part of this group, even though I wish you weren't. You are not alone, there are many of us and we all stand together.

Look around you in the ward, all those moms have walked where you are now. They were new OncoMoms too. They will become your family.

Look at staff around you – the Doctors, Sisters, Nurses, (possibly students), cleaners. They will also become your family and will walk the toughest journey of your life with you. You won't get along with all of them but you and your child will form bonds with some of them, bonds that will carry you all.

I know you are scared. I know you are worried sick. I know you hurt for your child.

Deep breath.

Take it 5 minutes at a time. One procedure at a time. One blood test at a time. And don't do it alone. Talk to the other moms in the ward. Get help. Don't be ashamed to ask for emotional, physical or financial help.

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2. Emotional Tips

You've read this far. Well done. Keep going.

It's okay to not be okay. What you are going through is one of the hardest things a mother (or father) can experience.

Speak and act positively around your child. Your ability to cope will help them. That being said, never lie to them about the seriousness of their disease. You need them to trust you – don't break that because you think you are protecting them. Be factual and tell them what they need to hear. If you

are sad, don't be afraid to show your child. They need to know that this hurts you too. Remind them that even though you're sad or scared, it is not their fault. None of this is their (OR YOUR) fault!

You didn't cause your child's cancer... Repeat that to yourself.

If you find that you are not coping, ask the nurses about a psychologist. This does not make you weak or crazy. It means you are looking after yourself. It means that your wellbeing (and your child's) is more important than your pride. It means you're ok...

If your child is struggling (which they probably will) then a play therapist (or psychologist for older children) is a fantastic idea. Ask the nurses if they can recommend one.

Try and stay calm – everyone is doing their best to help your child. Even so, it will sometimes feel like that is not the case. Get all the facts, make sure you know what is really happening, and then if the situation doesn't get fixed, by all means, stand your ground. Protect your child but try not to second guess those who are providing medical care.

Part of being honest with your child is to not create unfair expectations. Injections hurt, blood draws hurt. Don't tell them it won't hurt. Explain why it is necessary and hold them. Tell them it's almost over. Be there. Help them be prepared – no one likes a surprise, especially one that hurts.

If at all possible allow your child to have some control wherever they can. Do not spoil them (you will struggle after treatment) but if they want to shave their head, let them. If they would prefer mashed potatoes instead of whole potatoes, give that. If they prefer a liquid medicine to a tablet (and it's available) try and get that for them. They give up so much control during treatment that gaining a little control means the world to them.

You are a warrior. Don't stop fighting or believing that your child will get through this.

Lastly, you will lose friends on this journey. There will be people from your "old life" who will not understand. They won't know what to say or how to cope with your child's diagnosis. That is ok. It is hard but it's ok. Because you will make new friends. Friends who have walked this journey, friends who really understand. Don't waste your energy on people who don't get it. This is not about them – it is about you and your child.

And your family. Don't forget that your husband (or wife) is also taking strain. Your other children might not understand where their sibling is. If necessary, a psychologist or play therapist can help with those "at home" too.

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3. Practical Advice

a. Food / Nutrition

It is more important now than ever, that your child eat healthy. It is also harder than ever to get them to do so. Never forget that you are doing your best. You are not a failure if you can't get your child to eat healthily.

In the beginning of treatment children often receive steroids. These increase the appetite so much that your child ends up eating more than you. Try offering healthier options but remember that your child's taste is also affected by chemo and they get cravings worse than a pregnant woman.

But soon the chemotherapy does its job and mouth sores develop. These mouth sores often extend all the way down, through the whole gastro-intestinal system, ending up at the bum, with terrible "bum rash". Frozen pots of yogurt with a spoon inserted in the foil are a great way to soothe a sore mouth. Ice lollies are also a great idea.

Try and limit the amount of sugar your child eats. Sometimes the only thing they are willing to eat is sweet and any food is better than no food, but try keep sugar to the minimum.

In many cases, children just don't want to eat. It hurts too much. If your doctor suggests a feeding tube (nasogastric tube) don't fight it. It is uncomfortable in the beginning but the relief of not having to worry if your child is getting enough nutrition is wonderful. It makes giving most oral medication easier too.

Another nutrition complication is nausea. Dry foods, like crackers or popcorn, with no strong smells are a good option.

Remember to get your child to drink lots of water. Both vomiting and diarrhoea can lead to dehydration which could be life-threatening.

Be creative with food. (But don't do more than you can. You can't afford to burn out!) Picnics outside or in the lounge are a good idea.

Avoid vitamin, mineral and herbal supplements during treatment. If you would like to use something, ask your doctor to be honest with you about whether there are any negative complications regarding using these products. The concern is an interference with treatment, but if there is no interference, then there should be no problem.

Do not be afraid to ask for a dietician to consult on your child's case. The oncologist deals with the cancer but a dietician can help with keeping your child strong enough to cope with chemotherapy. They can also prescribe supplements which won't interfere with treatment but will help with some of the side-effects of the chemotherapy.

Because of their lowered immunity to infection, our children should not eat biltong or droëwors (uncooked meat) as it could cause infection.

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b. Hospital Stays

All of you will experience a hospital stay, some only for a night or two, others for weeks at a time. Your hospital will become like a second home and there are some ways to make it easier.

Take with favourite toys or even a few posters to brighten up your room. A familiar environment is good for healing. You can also decorate their drip stand. Use balloons and maybe even a toy.

ALWAYS have a bag packed. I have a set of plastic drawers ready for if we needed to be admitted with all the things I needed. (At one point I lived out of the drawers regardless of whether we were at home or the hospital!)

In this bag you need clothes and pjs for you both, toiletries, medicines (and other medical supplies), snacks, slippers, toys or activities, something for you to do, (nappies if your child is still on them).

Take the notebook we gave you and keep track of medicines your child receives, when they have blood drawn, when they receive blood. This is important mainly to give yourself a feeling of control, but can be important if there is a new nurse that is unsure about something. It helps you keep track of what is happening and what your child is eating. It is a great referral tool for when you want to ask the doctor questions or if they ask you questions.

Pay attention to what the nurses do. They also get tired and sometimes forgetful. Keeping track of medicines will help you to help the nurses. Watch for problems with the IV machines and for air bubbles in the line. You are an extra pair of eyes and that helps a lot with looking out for your child. Check that your child's name is on the medicine being given to them.

During hospital stays you will hear many new words. Write them down and ask what they mean. Knowledge is power!

Ask for labels with your child's name on and put these on food you want to keep in the fridge.

While it is important to keep your child entertained and distracted during hospital stays, it is just as important for you to have something to do, especially while your child is sleeping, or watching a movie. Mostly, I suggest sleeping when your child sleeps, but that is not always practical. Try your hand at crochet or knitting. Adult colouring in books are also a good idea. (You can only Facebook or play games for so long.)

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c. Medicine / Hygiene

One of the first decisions you will have to make medically is that of whether to put in a port or a j-line. Your child needs to have one or the other. It means less pain and continuous IV access. Both get put in under general anaesthetic and provide easy access to a main vein for medicine. A port is under the skin and gets accessed by a needle at the beginning of a hospital stay. With a port a child can swim and shower but there is pain when accessed. A j-line extends outside the body and is not painful to access. A child with a j-line cannot swim or shower and must take care to not get the line wet. The decision is yours and your child's. Make it together.

Nausea plays a horrible role in treatment. Ask for Zofran tablets and how to administer them to help deal with nausea and vomiting. Always keep a large Ziploc bag with your child's name written on

with you. If they throw up in it, you can seal it and if need be show it to your doctor or nurse. (This sounds gross but is often an important diagnostic procedure.)

Oral hygiene is important, especially when your child has mouth sores. Keep their mouths clean with mouthwash, which will numb the sores and cleanse the mouth (if they are old enough). For younger children that can't gargle and spit, gauze swabs dipped in the mouth wash can be gently dabbed inside the mouth. Ask your doctor about Daktarin oral gel, andolex mouth spray and dynexan gel. If they suspect an infection in the mouth, Nystacid Oral suspension is a good idea.

Most chemotherapy (and other medications your child will receive) can cause diarrhoea. Combined with the sores from chemo can cause a very severe case of "nappy rash". For the diarrhoea ask for Tasectan Paed which you can mix into food and helps with general diarrhoea. (Please take note that doctors will not prescribe something to stop the diarrhoea if it is the result of an infection.) For the bum rash, you can use Antipeol bum cream or other zinc oxide based creams. Air out the bum as much as possible and keep it as clean as possible. If infection is suspected, then Nystacid ointment can be prescribed.

Some children develop rashes or eczema related side effects from treatment. Advantan fatty ointment is a good remedy for this.

Ask about using Zinplex junior (tastes like cream soda) to help your child's skin (both outside and inside). Also ask about glutamine for the same reason.

Hand washing is very important and there are disinfectant washes at the hospital that you can use. Some bacteria do not respond to the alcohol rub so ask your nurse about using these. For at home, you can get some of these disinfectant hand washes like the BioScrub they use in the hospital. Make sure it's main ingredient is chlorhexidine gluconate. This will fight most bacteria. There are also wipes available with this as ingredient. Ask your nurses for advice.

Face masks are also a good idea for your child while they walk through the hospital. And if you feel a bit under the weather, a face mask will be good for you too.

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d. Reasons to call the doctor or go to hospital

There are four main reasons to either call the ward, the doctor or just go straight to the hospital. Do not wait on ANY of these as your child's life could depend on it.

Firstly, if your child seems pale, dizzy, tired and has a headache. This is an indication of low red blood cells and your child needs a blood transfusion. A simple blood test will tell you what their hB count is and whether they need blood or not.

Secondly, if your child is bleeding – from their gums, nose, red urine, red or dark stools, wounds that bleed. This is a sign of a low platelet count which can also be tested with a simple blood test. They can receive platelets at the hospital to help with clotting and to prevent them from bleeding too much.

Number three is a temperature. You will become obsessed about your child's temperature and for good reason. Using a thermometer will become second nature. If your child's temperature goes over

38°C go to the hospital, even if the temperature comes down with Panado. This could be a sign of infection and your child will need extra help fighting it, which they will receive at hospital.

Lastly, if anything seems strange or out of place with your child, speak up. Ask, phone, be a pain until you get an answer that satisfies you. You are your doctor's first set of ears and eyes and they actually rely on you to pick up abnormalities or changes. Do not keep quiet, even if you think it is something small.

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4. Other

There are great resources out there for more information but be careful of google. Not everything you read on the internet is true or even appropriate. CHOC has a wonderful handbook for parents with a lot of information that is incredibly helpful.

You can also ask your doctor to refer you to websites or give you information for you to better understand diagnosis or treatment. It is your right to get all the information regarding your child and their treatment.

If your child is well enough to return to school during treatment, allow them to do so. But ask your doctor for advice about this, as infections are a constant threat.

People will want to know what is going on with your child and will continually want updates on their wellbeing. A Whatsapp group is a good idea for this and you can even delegate a friend or family member to run the group and post approved updates. (Make sure those on the group remember this is just for updates and not a discussion group, otherwise people tend to leave the group.)

Friends will want to help. Ask one person to coordinate meals for your home or a roster of care for other children. Allow people to help you but do not allow them to overwhelm you more than you already are.

Take it one step at a time.

One day at a time.

And remember, you are not alone.

Contact us if you need any help...

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