



## **Advocating for Your Child**

### **From the frying pan into the fire—becoming an Advocate for your child**

If having a child with cancer isn't bad enough, parents of children with neuroblastoma must quickly become experts in navigating a dizzying array of medical tests and treatments—making decisions about which path to take without having much time to process or even learn about any options. So we become advocates for our children, politely getting them the treatment, dignity, and the control they deserve as they battle this disease.

### **Getting people to help you advocate for your child**

It can be a good idea to bring an extra adult helper/listener with you to meetings with doctors or other providers. It is helpful to have a second person to help you remember details, take notes, and ask questions when you will be hearing a large amount of medical information. If you don't have a family member or close friend available, ask the social worker at the hospital.

### **Advocacy in the early rounds—knowing what to ask!**

Few of us had any chance to really evaluate different protocols before our children are started on chemo. In many ways there aren't huge differences between the various protocols in terms of the up-front chemotherapy, but there are more differences as treatment progress. There are differences, changes are made over time, and some treatments may be leading the curve more than others. Remember you have a right to ask questions, and the right to a night to "sleep on" a decision. See **"Patient's Rights and Responsibilities"** and **"Questions for Your Doctors"** sections for more on this topic.

### **Advocating for your child during treatment and procedures**

Most clinics and hospitals where you will be treated specialize in pediatric care, and most are staffed with kind, caring professionals. Yet, there will still be many small ways in which you can advocate for your child to give them (if they are old enough to talk and have an opinion) and yourself a bit of control in what is often a frustrating and anxiety-ridden experience. All kids seem to develop little preferences—for example: one boy had to have orange flavoring for CT contrast, one girl didn't want anyone to touch her when she threw up, another preferred to have his G-CSF shots given "fast." Tune into your child's preferences, and step in and ask the nurses and doctors to respect and honor those small requests.

Some issues are a bit more involved and may require more knowledge, but the truth is there are some options patients and parents have but must be requested. This is especially challenging, because you may not know when to ask. For example, one child didn't respond well to the Dilaudid pain medication given during 3F8 treatments, and was eventually switched to morphine which had fewer side effects for her. But in this case, if the parent had been significantly frustrated and had not asked the nurses about alternatives, the child would have remained on Dilaudid because it was a standard part of the protocol. Other concerns might be making sure that protective measures are being taken to reduce damage caused by some of the chemotherapy agents. There are advances in protecting hearing, reducing heart damage, and reducing secondary cancer risks that may be worth considering while subjecting our children to the harsh chemotherapy that will potentially save their lives. This type of advocacy is difficult, and some of these issues are better addressed in other

sections of the handbook dealing with specific treatments, but underscore the importance of advocating for your child in medical areas as well as those areas where parents can truly have more control.

### **Advocating for your child to be treated as a human being**

Again, most medical professionals are extremely kind and child-focused, however everyone seems to have an encounter where that is not the case. You can and should advocate for you child to be treated in a way that is respectful. Even very small children should be talked to directly by medical personnel, and not only through the parent. If someone is talking to or interacting with your child in a way that makes you or your child uncomfortable, you have a responsibility to say something and step in to correct the problem. That being said, advocating for your child is not the same thing as starting a yelling match, throwing a fit, or otherwise threatening the person who you feel is acting in an inappropriate manner with your child. Asking them to stop for a moment, step in the hall, or even a gentle reminder will usually correct those kinds of issues. Frequently, it is just a matter of medical professionals doing their job in a bit too much of a hurry.

### **Advocating for quality of life issues**

Balancing quality of life with getting the needed treatment is an ongoing issue. Here, we are specifically referring to the ways you can continue life as “normally” as possible during treatment—school, activities, and routine medical appointments.

**School** can sometimes be a difficult challenge for kids and parents. Even for parents of preschoolers, where academic concerns are less the issue, it can be hard to know when to send the child back into the normal world. This is made even more difficult when the people at the school balk at having a child with cancer in the classroom. It is helpful to talk with a school principal or administrator, the teachers, and the school nurse to establish how to make everything work for your child, while reducing their worries. Some may be concerned about spreading contagious illness to your child—a valid concern no doubt! Suggest that children in the class be taught about hand washing, better ways to cover coughs and sneezes, and other general germ-spreading behaviors. In one girl’s case, her class and school became so supportive of keeping the school germ-free for her that the school actually had one of the lowest rates of illness ever that year! It is up to the parents, however, to help pave the way for these win-win situations. For older children, especially those in larger school districts, there may be policies against wearing hats or bandanas in the school, so be sure to talk about this with the school.

If your child is school age, there can be concerns about not losing too much ground academically, as well as concerns about truancy laws if the child is not in attendance. It is important to be in contact with your child’s school. Some schools will make things difficult, and it is important to insist that your child has a right to be in school. If the school is unwilling and your child needs some accommodations to make school work out, ask about a 504 plan (a legal document based on the Americans with Disabilities Act). The bottom line is that most of our children do best when their life can return as much as possible to normal activities. They benefit from social time with others their own age, and parents can benefit from a little time off as caregivers. Call in social workers, nurses, and doctors for support in talking to school staff about your child’s situation—many will come and speak to a class to help make the transition back to the classroom smoother.

**Activities** like sports, dance class, art classes, and all the other things our children love are often easy to drop in all the chaos that cancer treatment can become. But, these activities can be really great outlets for children in treatment, a chance for them to feel more like themselves again. It is okay to ask that your child be able to participate, even if he or she can’t participate as fully. Make sure to talk to the coach or instructor about any physical limitations or restrictions your child may have. If your doctor has told you not to participate, ask why, there may be ways to compromise.

**Routine medical appointments** for blood work, transfusions, and even chemotherapy can often be adjusted to allow for life to continue at least somewhat normally. As an advocate for your child, you can ask for a specific time for an appointment and have a reasonable expectation that you will be seen more or less on time. You can ask to have a transfusion after your child gets out of school. You may even be able to schedule some chemotherapy so that it allows for your child to have the weekend to recover and to be back at school. Or maybe, it is more important to have him feeling good for a birthday party on Saturday, so you push to have a transfusion a little earlier than usual. Ask, suggest, think about what is best for your child.

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