

No parents should ever have to face the end of their child's life. The mere thought defies the natural order and is unbearable to each of us. Unfortunately, some children do lose the battle. Still, they and their families always remain a part of our neuroblastoma family. Because we focus on meeting the needs of the entire neuroblastoma community, we acknowledge the heart-wrenching struggle of parents coping with their child's last illness. The information found here is our attempt to support those facing the most challenging thing imaginable.

Like every stage of a family's neuroblastoma journey, the issues that arise at end of life vary depending on the child's disease and many other factors. Below are questions that have presented themselves to some parents, along with thoughts and guidance on these topics from neuroblastoma angel parents. The statements below should not be taken as definitive--there simply are no "right" or "wrong" answers when one is facing the loss of a child. What follows are merely the very personal reflections of individual angel parents.

Despite the painful memories this topic evokes, these angel parents have lovingly shared their thoughts and insights, in the hope that they might allay another parent's particular concern, answer a troubling question, or merely let a parent know that others have had these experiences. We are very grateful for their courage, generosity and willingness to help others.

This is a work in progress, and we welcome assistance and any suggestions for improving it.

How do I know when it is the time to stop treatment? To stop transfusions?

"A lot will depend on how far the disease has spread; whether the major organs are involved; how much treatment the child has had already; what are the child's blood counts; will the child qualify for any clinical trials; how old is the child (may sound like a strange reason); can you travel to other parts of the country; financial situation for the family; religious beliefs; whether the child is responding to any treatment; whether the child is having severe pain; and many other things. A thought I had was -- is it better to have my child die of disease or from treatment, i.e., what is the best quality of life for the end of life."

“This is a very tough and difficult question and there is no correct answer to it. I think a parent will always think that, if I stop treatment, then I haven’t done all I’m supposed to do for my child. ‘A good parent doesn’t give up!’ At least that is the thought you will probably grapple with in your head.”

“An older child may want to have a say in whether or not they want to continue with treatment. If the treatment will make them throw up or feel worse than they already are, they may not want to have more.”

“I think most parents will go as far as they can with some sort of treatment until weeks or even days before the child’s life ends.”

“When to stop transfusion is a difficult question. One of the biggest fears a parent may have is having their child bleed to death because of low platelets, so they will continue with transfusions for as long as they can. One thing to keep in mind and to discuss with your doctor and hospice nurse is whether or not transfusions will be effective. Depending on the extent of disease in the body, additional fluids such as red blood or platelets may actually cause even more harm, as the body may not be able to process it properly and they may basically cause the child to ‘drown’.”

“When to stop transfusions? For us this was the easy decision. If the doctors couldn’t save him, then why put him through having to go to the hospital every other day for transfusions. We kept him at home where he was happy. He was only 3 years old, but he told us he was tired of the hospital and going to the doctor’s all the time.”

What do I consider in choosing whether to have my child on hospice at home or in the hospital?

“This may depend on a few factors: one may be your comfort level in helping your child at home with the medicines, such as morphine or other narcotics for pain control, and your comfort level in working with the morphine pump when the hospice nurse is not there. The other factor may be how sick your child is and where the disease has spread.

If your child is still somewhat mobile and wanting to do things or go places, then your child can be cared for at home under the guidance of the hospice nurse. If the disease has spread to areas where your child needs special care and you feel more comfortable with having someone with you every minute, then the hospital may be a better place for you and your child. However, if you are at home then you can be more of a family, and not have to worry about traveling to and from the hospital if you want to bring other family members to visit. You may all be more comfortable at home.”

“For us the hospital was just not an option. The hospital couldn't save him, so why make him be in a place he didn't like to be. He was home where he was most comfortable and had all of his toys and could do whatever he wanted to do.”

“It is important to know that hospice can be available not only in the hospital setting, but also in specialized hospice centers and in the home. Some hospitals allow a child to remain in the current hospital room and transfer to hospice care with the appropriate hospital physicians and supportive staff coming to the child's room. Some families welcome the ability to remain in a room that they already know with familiar staff still available to them. Some hospitals require a move to a different floor, with transfer of care to physicians and staff that provide hospice care. In some cases this transfer of care may be to a different organization that provides hospice care for that hospital. Some families find this preferable because all care transitions completely towards supporting the child without the distractions of other families who are still fighting cancer. Hospice can also be transferred to the home setting, which can be the choice for some families who want their son or daughter to have all the comforts of home. In this setting, hospice provides the necessary medical devices and hospice staff comes to the home in order to provide care for the child.”

What sort of care is available for my child on hospice? What do I need to know about hospice to get the best care?

“Hospice does not have the goal of prolonging life, nor does hospice have the goal of hastening death. In order to be considered for hospice, a child must have a life expectancy of less than 6 months. The focus for the child transitions from treatment for the purposes of a cure to providing treatments that facilitate quality of life through pain control and supportive care. . . . most hospice providers will state that their primary goal is to provide comfort, peace, and dignity with the primary goal of pain control.”

“It is important to learn what you can of the hospice organizations available to you, how they define hospice, and the point at which they limit their interventions.”

“Parents should find out if the specific hospice organization regularly deals with children. Too many parents find out after the fact that their hospice provider only cares for children on an "occasional" basis. Pain control for children and other special issues of children are difficult for hospice professionals to understand if they don't work with children on a somewhat regular basis.”

“The ability of the hospice to provide staff that can communicate and give the explanations you need, in order to understand what your child is going through, is vital to achieving the best care you can for your

child. Hospice representatives should be willing and able to meet with and speak with you. . . . Unless the oncologist is able to write orders for and in conjunction with that specific hospice organization, ask your questions specifically of an individual employed by the hospice organization you are considering and who will be one of the employees implementing your child's care. Be sure to write your questions and the answers down, because as you have already learned, it is frequently difficult to remember all of the details later. This is a time of great stress, and your ability to remember the easiest of things will be challenged.”

“Once care is transferred to hospice, treatments like red blood cells transfusions and platelet transfusions may or may not be able to be carried out depending upon the scope of practice of the specific hospice organization. Depending on the length of time since the last round of chemo this may or may not be a concern. Other treatments such as TPN nutrition may be able to be continued, or may need to be discontinued. Possibly nutrition may need to be administered via a nasogastric tube, jejunostomy tube, or G-tube if already in place. The determination of these types of decisions can be limited by the hospice's scope of practice. For some, it can ultimately be a source of relief that certain options are no longer available, as each intervention can have its risks and these risks can become more difficult to handle as a child becomes increasingly debilitated.”

“Hospice care is covered differently depending upon whether your child's care is covered by private insurance provided by employers or individual policies, state-

provided insurance, Medicaid, or in some cases on a charitable basis. Good social workers, caseworkers, and hospice social workers will be able to make this transition smooth. Unfortunately, wrong information can make a very difficult time even more difficult, and sometimes questions must be asked more than once and of more than one person in order to get the help needed even when one legally qualifies for it.”

“ . . . it is nearly impossible to think of all situations and make all possible preparations. As you have learned throughout the time in treatment, you do the best you can with all that you are given and can find.”

How can I most effectively manage my child's pain?

“Hospice is nationally recognized as the expert on pain control, particularly for cancer patients. . . . the types of medications used for the purposes of pain control, the amounts used, and the frequency with which they can be used are based on how much medication has been used in the past, how much is currently in use, and how much (possibly several medications in conjunction with each other) may need to be used in order to effectively achieve pain control. Depending on the child’s age and ability to communicate, the child and the parents are asked about symptoms, effects from the medications, and

the level of medication at which the pain is controlled and, if possible, still allows the child to interact with her or his parents, family, and friends.”

“If you have a good pediatric hospice service they will be around whenever you need them. Ask them any question you can think of. Make sure they are used to giving children narcotics, as some services are reluctant to do so and that is not what you want. Always talk with the hospice nurse and coordinate pain control between him/her and your oncologist. You want to maintain a good quality of life for your child with as little pain as possible. If your child is having “break through” pain you may have to up the regular dose of pain meds so as not to have too many boluses in between the regularly scheduled infusion. Use more than one drug if you have to in order to get the pain under control. Bone pain is very severe and can come on very suddenly and last for a long time until you can get the dosing right. Be aware that a drug-induced coma may be the only solution to keep your child from suffering with severe pain. Every child

is different, and some do not have any pain and can succumb to the disease quickly and peacefully.”

“I did everything myself but adjust the morphine pump. The hospice nurse came once a day to check on him, but we did the rest.”

Please contact info@cncfhope.org with any comments