



Turning to End of Life

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 NB family. Because this handbook is intended for the entire NB community, we concluded it should acknowledge the struggle of parents coping with their child's last illness. Thus, this chapter is our attempt to support those facing the most challenging thing imaginable.

Like every stage of a family's NB 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 NB 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.

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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.”

How do I make the most of my child's time?

“This will depend on your child’s condition. Some children are still able to go places and do things with reasonable comfort. Do the things they want to do. Take a lot of movies of your child, take pictures, make hand prints, tape record their voice, touch them all the time, smell them, take a lock of their hair. Do as many things as a family as you can even if it is just sitting and watching TV. “

“I wish that someone had told me from the very beginning to take a million pictures, videos, recordings, etc. I don't know how you tell someone that from the beginning, but there has to be a way. Rather than waiting until near the end of life to record your child’s voice etc, because we are not all given that opportunity in the end. . . .”

“Let them do whatever they feel like doing and want to do. Take tons of pictures and videos, take a lock of hair if they have any. Get their hand and foot print. Just spend every moment with your dying child.”

“It is such a difficult situation and decision when hearing the word hospice. For so long you believe in the hope for a cure for your child. You have to maintain hope but transition the focus of hope for precious quality time spent with your child and hope for a peaceful passing. Make each moment of each day count and create positive family memories that you will treasure in the days and years to come. One thing I am so thankful that we did was to get many family photographs taken. Even though you have probably taken more pictures that you can count of your child, make sure that you have photographs that capture your family unity and love.”

How do I talk to my child with neuroblastoma?

“This can be difficult. Some parents are afraid to tell their child they are dying. And it depends on the age of the child. With many older children, you have to tell them it is okay to stop fighting and they can now rest. I think some of the children want to know that you will be okay once they are gone. They worry about you since you are so sad and you cry a lot. Some parents can’t say anything to their child about dying. If the child is very young, they would not understand what dying is. I don’t think there is a right or wrong way to do this. Some say speak honestly about it. I couldn’t tell my son he was dying. I just couldn’t.”

“No matter the age and developmental level, always listen to your child, whether verbal or nonverbal, and be open to discussing your child’s illness and how they are feeling. I felt with my four year old daughter that she knew more about her prognosis and what was happening than I did at times. Surround them with your love and emotional support. Be sensitive to their needs, questions they may have and stories they may tell you. Many children may talk about angels or heaven and I believe it is so important to be open to exploring their visions or ideas and to respond sensitively. My daughter spoke often about her fairy friends that were helping her, loved her, and would show her heaven and bring her back again. I truly believe my daughter’s words and I treasure the discussions we had about the fairies. They brought a sense of comfort to both her and me and I believe with all my heart that my daughter was telling me about the fairies to reassure me that everything was going to be okay. Maintaining open communication with your child can provide them with a sense of trust and confidence through which they can express their feelings and thoughts.”

What do I tell the siblings of my NB child?

"I think it is important to be honest with the brothers & sisters and tell them the truth so they can prepare themselves too. This will depend on the age(s) of the siblings."

How to I get the support I need from family, friends & others?

"If anyone offers to help, let them. If you don't want a lot of visitors have a person designated to kick everyone out if need be. Take it easy on yourself and your other children. Let friends take your other kids out for a while to give you and them a break."

"Support from family and friends runs all across the board. Some are very helpful and are there all the times that you need them. And others will only stay around for a little while before they get tired of it and move on with their lives. They expect you to do the same. Seek counseling if you have to. It is difficult to get siblings to go for counseling depending on their age(s)."

What do I need to know about the dying process (since no one is telling me about this)?

"This will depend on where the disease has spread to I think. In our case it took a while before the major organs were affected. The urine will slowly turn an orange/brown color from the liver starting to fail. The darker it is the worse the liver is getting. The child will have difficulty urinating due to the morphine or other narcotics. The child's breathing will get more labored. They will sleep more. The pain may intensify causing the need for more morphine or other painkillers. The child may get delusional from the spread of the disease and/or the narcotics. The actual act of dying itself is very peaceful. The heart stops and that is all."

"Thankfully for our son it was very peaceful. He just closed his eyes and was gone five minutes later."

"Unfortunately some children do not have a "peaceful" ending. Some lose their sight, experience seizures, vomit blood, or have respiratory distress syndrome that can last a short time or a version that stretches out over a day or more, which is very, very hard to hear and watch. There are other very difficult scenarios. One possibility is to speak at length about what is to come with a physician or hospice nurse who knows the child's specific situation. Of course, they don't know everything, but an educated guess about what may happen can be better than having nothing else to go on. One mom told me her hospice nurse warned her to have dark colored towels so her pre-teen daughter would not be scared when she began to vomit blood. The mother was so very glad she was told that, because it helped so much in their situation."

What do I need to know about planning and making final arrangements?

"Many parents will make final arrangements prior to their child's death. This is so, so hard! It is an unnatural act. But they may plan a celebration rather than a sad ceremony."

"My husband and I had made the decision shortly after we were told our son's diagnosis that we would have him cremated if in fact he died. I am glad that we made that decision then. It gave us the knowledge that the decision was made ... "

"We didn't make any arrangements until after our son had died. I wish we had planned earlier, then I would have remembered everything I had wanted to do (like have a balloon release)."

“I was fortunate in that my son's memorial was recorded. I have listened to it once since then. I am glad, because I remember so little.”

“Although we made our son DNR in the hospital, once we got him home we did not have the necessary paperwork in place to keep the local paramedics from trying to intervene if they were called in. Due to this, I waited several hours after he died before we called the oncologist to tell them that he had died and what time. The oncologist was good to us to simply sign the death certificate for the time that I reported. Due to certain laws, etc, the paramedics had to be called anyway to state that there did not appear to be any child abuse, etc. That is certainly something I would never have thought of then, but of course now it makes sense ... I remember this huge fireman walking into our bedroom. The doorway and ceiling is only 6 foot at that one point, and he was muscular and filled the doorway. I told him, “Don't you touch him. It is too late now.” I think that fireman actually knew that in that moment it would be over my dead body before he laid a hand on my son. He wisely agreed...”

“I remember that some ladies at my church organized a meal for the extended family that came in from out of town. Stuff like this helps so much as entertaining all of the extended family and friends is simply beyond one's capability.”

“I had let my primary care physician know that I expected I would need some medicinal help after my son died. I most certainly did. Although I was already on an antidepressant before we learned he had relapsed, the day he died I became a non-functioning human. I took Xanax after his body was taken from me, and it helped me keep from losing my mind. I literally felt as though I would lose my mind. It is more difficult than can be put into words. I know some people can cope, but I could only get through each day waiting for time to pass until I could begin to cope. It is a very, very long and difficult process ...”

How do I let go? What is my role in releasing my child to a journey I have not experienced?

“I didn't let go until he stopped breathing and his heart stopped. I knew the day he died that he was going to die that day. I got up that morning and I felt God tell me that was the day. He slept most of his last day. He woke up right before he died and told me again that he loved me forever and made me promise again that I would be ok. I told him I would and how much I loved him too. I told him to go to God when he was ready and five minutes later he was gone. I felt his soul leave his body and felt him watching us cry from above.”

“At the funeral home if your child is small enough for you to hold and you want to hold your child, then DO IT! The funeral director we had laid our son in my lap and I slept in the funeral home holding him all night the night before his funeral. It gave me some closure.”

“Although I kept my son with me for several hours after he died, I have read about other parents keeping their son or daughter with them for a day, and then even going to the funeral home and spending more time with their son or daughter's body to say goodbye in their time as they needed. I find that few people realize they have choices that they can make, but in that state it is very, very hard to make those choices. My husband carried my son from my lap in a chair in our bedroom to a stretcher the funeral home brought into our house. I wish I had had my husband carry his body all of the way to the waiting van. It is not something I tear myself up over, but had we been thinking, we would have done that. The gentleman that took his body out on the stretcher asked us if we wanted to wait before he covered up his face and head. I told him to wait, and we all watched from our porch as they took his body to the van, and then covered his face and body.”

“Watching your child endure so much and decline in the end and the helplessness knowing there is nothing more you can do to save your child is the most painful experience a parent can ever go through. The one thing that you can do is let your child know the wonderful impact that they have had on so many peoples lives. Let them know how very proud of them you are and that they are so brave. Let

them know how much you love them and will forever and ever. What a good brother or sister, daughter or son, granddaughter or grandson, cousin, niece or nephew they are. Let them know what a good mother or father they have been to their pets or favorite doll or stuffed animal. No matter how difficult, promise them that you will be okay and that is okay for them to go."

What thoughts do you have about the time ahead without our children?

"In the coming days and years remember your promise you made to your child, "I will be okay" and live by that promise for your child...they will want you to."

"In my own way, by my posts on NB Angels and now on Angel On My Shoulder, I keep a journal of sorts that I print out and put in my scrapbooks. Shortly after my son died I asked people to write to me about memories they had of him, and one lady had saved every email update I had ever sent out. I am really glad to have all of those updates now. Time is a thief, and I write down as many specific memories of my son that I can."

"The isolation you feel, after your child dies, is beyond words. So many people give you unsolicited advice ("you should go back to work", "you should move on") that you isolate yourself just to get away from these people. These people tend to be those that you love even, and so the isolation becomes even worse. People mean well, but you learn to stay away from them. Life takes on new perspectives in that you are no longer capable of putting the time and energy into people who talk to hear themselves talk without having any real clue. There occasionally is a wise person who will ask you how you feel, and then after you give them the words that shut them up, will quietly ask you, "Ok, how do you really feel?", and then actually listen. These are precious people who tend be older and wiser souls despite their young physical age, and they are few and far between. Mostly, they tend to be other parents who had a child die. So the lists like NB Angels and Angel On My Shoulder are a support system where we can say the things we can't say anywhere else."

"A quote I really like is 'the measurement of one's life is their enduring impact.' All of our children will be remembered forever until we meet again."

Please contact info@cncfhope.org with any comments