



## **Advice To Parents Who Have To Say Good-bye To Their Cherubs**

*CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support  
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- Tell your baby that it's ok to go- studies show even newborns seem to die more peacefully when hearing those words.
- Take as many mementos as you can- hand and foot prints, plaster castings of hands and feet, lock of hair, clothing, blankets, ID bracelets, pictures, video, blankets, diapers, etc. Keep fabrics in air tight containers with acid-free tissue paper- years later you can smell your baby's scent.
- Hold your baby even after he/she has gone- we've never had a parent say "I wish I hadn't held my baby after he died". We can't count the parents who've said the opposite.
- Take your time. Rock your baby, hold your baby, sing to your baby.
- All hospitals have chaplains who can perform christenings, even after the baby has gone.
- "Do not allow anyone to rush you. Take as much time as one needs to say good byes. I spent about 45 minutes with Ryan before they let us take him to pathology, which is against hospital rules, but we broke the rule. I regret that I didn't hold him more. Also, this sounded weird to me, but the nurse told me about it the day before Ryan died. She told me we'd unhook all the tubes and wires, bathe him, put baby lotion all over, comb his hair (cut a lock of it too!) dress him, wrap him in a blanket and hold him. Take pictures and say our good-byes and explain why God was taking him from us. That part I couldn't figure out to explain--still can't! I kept all the stuff the hospital used on Ryan--scissors, pacifiers, diapers, his toys, clothes, the sign on his bed. For 29 days, he collected quite a bit of stuff. It's all in an air tight box and known as Ryan's box." Cindy Mohr
- "Continue pumping until after the funeral- hugs can be very painful when you're engorged". Rhonda Montague
- "A homeopathic remedy to dry up breastmilk is to put cold cabbage leaves in your bra and change as they become wilted (strange I know, but it helped, after I quit being stubborn and tried it.) If your cherub passed at birth, or shortly after, your milk will probably come in the day of the funeral. This was the worst day of my life, as I was in so much physical pain, and so numb emotionally. I would even go so far, as to print in the funeral bulletin, "We know how much you want to hug us, but please refrain from hugging the recently delivered mother", or something like that". Amy Rademaker
- I am making a "shadow -box" with Thomas' Mementos. His little hat and socks and bracelets and some cards, ect. are put into a special "frame" which I will hang on a special wall. This way I can Look at Thomas' memories everyday without opening a box, and it is such a nice decor too. I also had one made for my older son Michael, and he enjoys to look at it too." Gabi Frietag
- In our case, it wasn't a sudden at-birth death, but after 3 weeks of intensive care. I would suggest having as many visitors as possible-- the more people who actually meet your baby before they leave, the better. Makes them more real, helps affirm they were really here! We celebrated his life with a full on funeral, reception back at our house, etc. These events were important, for us and well as friends and family. Many told me it gave them a chance to really focus on what had happened. It has been good for me to gather everything about Fletcher's short life together. I made an album of sorts and have a huge box for all the cards that came in. Now it's all together to take out and "visit" when I'm in the mood. There are many books on infant loss. I related to some of the material, and not to a lot of it. Same with other infant loss sites/boards on the Web. Something for everyone, I suppose. It was helpful to look around and check everything out. It has helped me to reach out to others who have suffered a similar loss. I'm in a support group with wonderful women who all had late or during labor still births. Mine was the only one "here" for aw hile, but it hasn't really made a difference in the way we have connected. But truly, the 2 women I met through Cherubs have been the best relationships of all. We give each other strength and support regularly." Laurie Stusser-McNeil
- "Hold your precious baby and tell them everything you want them to know, without holding back. Let them know how much you love them and will miss them forever. Take pictures, so you have them. You may want to see them later. Give them a bath, dress them and then have all families members close to you say goodbye. It is important for everyone to say goodbye. This will always be a cherished, yet painful memory that you will reflect on". Brenda Slavin
- "Take as many pictures and mementos and possible. Make sure that siblings are involved, or that you record things so that future siblings can see what you experienced." Amy Rademaker
- "When my son passed away we opted to do things a bit differently. We released 6 Sesame Street balloons (1 for each year he was here) and 100 red, yellow and blue balloons (1 for each year he should have been here).". Dawn Torrence
- "We asked for donations to CHERUBS in lieu of flowers". Dawn Torrence
- "I designed and printed the funeral programs myself - I didn't want some sad, impersonal booklet written by a stranger. I wanted it to reflect him. It was bright, had cherubs and Sesame Street characters. Letters to him from me and his dad. A poem written by a friend and member". Dawn Torrence
- "His dad and I both wrote letters to him that were read by his Godparents at the funeral". Dawn Torrence
- "I wish had never touched him in the casket. It took me years to get over that, feeling him cold and hard. I held him after he died and I would have rather had that memory". Dawn Torrence
- "We found a casket with cherubs on it. There are casket discount stores out there (I didn't know this at the time)". Dawn Torrence
- "I wish we had all worn bright colors instead of black, but I didn't think of that either. His Godmother wore a bright yellow dress and it couldn't have been more appropriate - Shane would've loved it.
- "We buried him with letters from us, toys, a Bible". Dawn Torrence
- "His headstone has a cherub logo character on it, Big Bird, Elmo, a truck... symbols that were him.
- "On his headstone there is also a Bible verse that if you look it up, it reads. "He flew on the wings of a cherub, Yeah he did fly like the wind" There wasn't room enough and it was too expensive to have all that letter so it was easier to put the verse and chapter info". Dawn Torrence
- "Shane is buried on my parents property in Virginia - their county had no cemetery laws at the time. We didn't have a family cemetery. Now we do". Dawn Torrence
- "After Gabe passed away in the hospital I couldn't bear the thought of planning his funeral, it was all too much for me and my husband and his parents did most of the work for me so there wasn't a whole lot of unique things about the funeral, but it was nice to have. We buried him with pictures of all of us and some toys." Corin Nava

- "After spending so much money in the hospital and not working the cost of the funeral alone was going to be an added stress we couldn't deal with. Fortunately a local funeral home did everything free of charge. There are some funeral homes who will wave their costs and fees for infant funerals as a way to give back to the community. It allowed us to have a proper funeral for our son." Corin Nava
- "Once we got home from the hospital after losing our daughter, we had family members taking care of the funeral. One thing that never enters your mind is what is will mom where to the service. I remember family and friends asking me what would you like to where. Honest 1st thing on my mine was like.. " are you nuts! " I know now they where being very kind and thoughtful. It's just so much is coming at you so fast while you are still in a total state of shock and numbness. The other part is that I had had an emergency c-section and then had to be driven home over 4 hours away so I was very swollen. It takes some time for your body to get back to normal after the C-section. Anyway, where I'm getting at is that maybe you can add something in the reference guide for grieving parents to have someone help the mom have or pick out something to wear to the funeral. That alone can become such an overwhelming task." Freedom Green
- "I also would've liked a list of poses for our pictures. I did get alot of pics in our 6 days but there are some I just never thought of doing. Looking back, I wish I had laid down next to him and got a pic but it is too late now. That would've been nice to have...a list of different poses, regardless if baby makes it or not. Also would've been nice to know how important dressing him after he passed was...I didn't and now wish I had. I wish I stayed back and did the hand and footprint but I didn't. I wish I had someone taking pics of all these things but I didn't. I was in shock. My world had ended and I just didn't know..." Theresa Wellman
- "Now I Lay Me Down To Sleep organization taking photos and something that I wish I would have thought of was to bring a outfit with me for the baby everytime I was there" Kim Richards
- "One thing the nurse did for my husband since I was not able to see our daughter for so long was she let him cut locks of her hair. She has so many wonderful curls. I would of never in a million years thought of this. I'm so happy we did this. My husband later gave me a wonderful locket that I keep her hair in with a tiny pink bow tied to it and in the other side a picture of her. I love, love, love, love this." Freedom Green
- "Ask the hospital to give you all his/ her stuff that they used while in NICU. It will be hard at first to deal with but later on you will be so happy you have all of these items. Like the little beds they have the babies sleeping in". Freedom Green
- "The hospital we stayed at allowed us to give our daughter her 1st bath and diaper change after she had passed. We then dressed her and wrapped her up in a blanket that was given to us as a gift. We where allowed to rock her and hold her for as long as we needed. They gave us a private spot to do so in the NICU. All family from both sides was aloud to spend time with her. They also allowed my mom to bring her up to my room one time before they took her away. I will never forget that moment". Freedom Green
- "One thing we did when Joel left us was to have him come home the night before his funeral. It raised lots of eyebrows here from older family members but we felt it was important for Joel to spend sometime here.The coffin was closed. My other children ranging from 2- 18 at the time said they thought it was a wonderful thing to do. It also meant that seeing his coffin wasn't a shock to them on the funeral day. Its lovely knowing that he came home and spent a night here. The children ( and David and I ) all wrote letters to put in his coffin too and the children also all gave something that was special to them too". Debbie Blakeley
- "In the state of Michigan, you can actually take a deceased baby home for up to 30 days, but it must be properly buried after that time". Amy Rademaker
- "Send out birth announcements, I found a saying in a book and modified it to my liking. ...I had a regular birth announcement company do the printing etc". Amy Rademaker