

NURSES— WE'RE HERE FOR YOU, TOO.

TIED
TOGETHER
FOREVER

MAXIMIZING FAMILY-CENTERED CARE AT THE
END OF LIFE

Dear Coworker,

We are sorry that the baby you are caring for is dying. This is daunting and you may feel like you do not know what to do or say. We want to provide resources to help you be confident. This baby's family is feeling shocked, scared and sad. This is their time to be parents and you are capable of positively impacting their lives.

- Help parents slow down. Optimize uninterrupted time for parents to spend with their baby. Do not rush to complete tasks--handprints, foot molds, lock of hair can all wait. Provide comfortable seating for family or a quiet open room. Remove unnecessary medical equipment and silence monitors. Allow parents to take breaks for food or rest. Tell them that you will be close by and there is no need to hurry.
- Provide reassuring guidance. Everything feels weird and wrong. Tell parents that it is okay to be scared but also normal to hold, cuddle and take pictures of their baby, before and after they die. Parents say "no" to yes/no questions because it is easier and they cannot make a decision. Instead, say:
 - "I'll get supplies and I will help you give her a bath."
 - "You keep holding/bathing/changing her and I will take pictures of you together."
 - "Let's unwrap him, change his diaper and you can count his fingers and toes."
 - "Here (while handing mom her baby), you hold her while I change this blanket."
 - "Let's give him his first haircut and you can take a small lock of hair with you."
 - "After we give her a bath, I'll help you dress her and we will get you comfortable so you can snuggle."

There are certainly individual and cultural differences but almost universally, parents say that they wish they had more guidance, more cuddles, more time, more pictures, more everything. Parents who said no to holding, bathing or pictures almost universally wish that nurses had asked again later or in a different way or reminded them that this was their time to create memories with their child.

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- Encourage pictures (before and after extubation). Even one cell phone picture is better than nothing. If available, explain that the professional photographers at NILMDTS (Now I Lay Me Down To Sleep) are experienced. ***Please check to see if NILMDTS is an option in your area.** Other parents say pictures are their most prized possession.
- It is okay to show emotion. You are one of the few people who met this baby and that makes you incredibly special. Talk about baby by name. Ask if she looks like siblings. Comment on his dark curly hair, long fingers, cute nose, chubby feet, feistiness, or gentle nature. Show parents that you recognize their baby as a real person who is loved and missed. Tell them you will remember her.
- Delegate tasks to other nurses, social work, or chaplain. Nurses can get warm blankets, Kleenex or water, make scrapbook page or crib card, help with footprints. Social work can help with birth and death certificates, insurance, and funeral home arrangements. Chaplains can perform baptism or blessing, contact family's clergy and be a comforting presence.
- If family is unable or unwilling to participate even with lots of encouragement, write a note explaining that you bathed and dressed the baby, held them and told them they were loved.
- Prioritize creating a comfortable space for family to spend quality time alone with their baby.

THERE IS SOMETHING POWERFUL IN A SIMPLE “I AM SO SORRY. YOUR BABY IS BEAUTIFUL. [THEY] CAN FEEL HOW MUCH YOU LOVE [THEM].”

This was written by **Julie Trangsrud**, a NICU RN and baby loss mama. Julie's son, Bear, unexpectedly died at 39 weeks after a healthy pregnancy. Julie created a letter for nurses to help them better assist families dealing with the death of their baby. She knows it can be an intense and challenging experience. Her living boys are now four and eight. They talk openly about Bear and how much they love all three of their boys. Julie says motherhood is indescribably wonderful, often frustrating, and the stuff of dreams. She will always wish that her house was one boy crazier.