



RIGHTS OF PARENTS WHEN A BABY DIES: CHOICES OR MANDATES

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I remember the day when a young bereaved mother called to talk to me about the death of her baby at 17 weeks gestation. She was overcome by the intensity of her feelings and wanted to voice a concern about her care. At the time of her baby's death, she and her husband had decided not to see, hold, or name their baby, nor did they want to know the gender. They both thought that knowing the sex of the baby would add additional grief to their already broken hearts. She was upset by the bereavement counselor's follow-up phone call. In the conversation, the counselor told her, "We have the pictures of your son. Would you like us to keep them or would you be more comfortable coming in to see them?" The mother was so shocked by this. Her rights had been violated! Her choice had not been respected.

Recently, I had another mother call me whose baby died fifty years ago. She shared with me her haunting experience. Her stillborn baby girl was whisked away without her seeing her, not named and buried without family with six other babies. She was not given any choices and told me it took her 35 years to finally have the courage to name her baby in an official ceremony with her closest circle, but she is still hurting due to this horrific experience. She is so happy knowing that bereaved families of today have so many choices and opportunities to memorialize their precious babies; it comforts her to know they will have healing experiences.

I also have had a caregiver say to me, "I did not choose to see my baby who died at 16 weeks. I still do not understand why we give families all these options." This caregiver made her choice, but that does not mean it is the right choice for her patients. She has the responsibility to give her patients information and options, even if she disagrees with their decisions. The choices families make may not be our choices, and this can be disturbing and make us feel frustrated or guilty. Acknowledge your own feelings because they are very real, however, rest assured that if you have presented the options to the best of your ability and with compassion, the choices made will be the right ones for the bereaved families you serve at that moment.

In the twenty-nine years I have ministered to families who have experienced the death of their baby, I continue to be touched by the individuality of each death. Each footprint that is left on the hearts of the parents is unique and different from every other footprint. Therefore, the parents' reactions and choices will be different and varied. Caregivers can get into trouble when they assume each family will or will not want to see, hold, touch, name and bury their baby. Caregivers need to be careful not to force, but rather gently explain patients' options. Some caregivers even feel they have failed if the bereaved parents did not choose the options they felt would aid in their healing. There is no right or wrong choice. However, choices *are* influenced by the degree of information as well as the amount of time bereaved parents are given to make these important decisions. Remember, the most vital part of decision-making is affected by the way caregivers present options.

As caregivers, we can play a critical role in the healing process by laying the foundation for a positive grieving process. Realize how special you are and how much your patients and their families look to you

for compassion and guidance. Know it is an honor to share this devastating time with parents and their beloved baby. They will never forget your caring presence.

Rights of Parents

The term "rights" is not used as a mandate for the bereaved, or as a militant statement of demands. It is an affirmation for parents who wish to be involved with their baby, to make decisions based on informed consent, and to assume the parenting role in meaningful ways despite the tragic circumstances. As Sister Jane Marie Lamb, OSF so poignantly stated in her article "Parent's needs and rights when a baby dies," "Every minute is significant, every decision important for the future peace and healing of these parents." Many, however, are afraid to request anything our society might consider morbid, unusual, or weird. This document serves as a guideline for the possibilities and options available to parents and gives them "permission" to follow their parenting instincts within the limits of state, local, and hospital policies.

Before you have a conversation with the parents, acquire as much information about the patient and her significant other as possible. Review her chart and prenatal record and then talk to her primary caregivers. Also, ask the patient's caregiver if she and her support system have voiced any concerns. This better prepares one to obtain answers for these worries or fears when you enter the room.

It is important to use a checklist to enhance continuity of care plus an organized packet. Every staff person who cares for the patient and her family needs to document on this checklist, and it should be a permanent part of the patient's medical record. To stay organized, develop a bereavement packet that includes grief pamphlets or booklets and resources for the patient as well as the necessary forms and paperwork caregivers need to complete.

Before you walk into the room to begin presenting the options, try to have a quiet moment to yourself. This may help you to be focused and allow you to be present to each family and their needs. Introduce yourself and explain your role of caregiver to each of them. Express your sympathy by saying, "My heart goes out to you at this time. I am here to support you through this challenging time." You may touch their hand or arm. However, sometimes you may sense they are not comfortable with touching, so refrain from doing so in that instance. Encourage all persons in the room to sit down and pull up a chair close to the patient and ask if they would like to share their story with you; I have even simply stated, "Share with me what your baby has meant to you and your family." As the parents share their story, you may discover some very important details that help you to understand what the loss may mean to this mom/couple and their support system.

Before proceeding, ask the mom and her partner and/or support persons if they have any immediate questions or concerns. Sometimes this allows for a natural lead into the options; other times there are no questions, so begin talking about choices as gently as possible.

The Rights of Parents, Rights of Parents Whose Baby Dies Very Early in Pregnancy, Rights of Children When a Sibling Dies and Rights of the Baby are not meant to be hard and fast rules. Rather, they are meant to guide caregivers in ensuring that all parents grieving the death of a beloved baby are allowed to care for and make memories with their baby in ways that are best for their family. The following narratives describing each of the Rights of Parents and Baby give suggested ways to implement these rights when working with bereaved families.

1. To be given the opportunity to see, hold, touch, and bathe their baby at any time before and/or after death within reason. Instead of directly asking if they would like to see and hold their baby, ask, "Can you share with me your feelings about seeing the baby?" Many times, fears about the appearance of the baby will arise. Address those fears as honestly as possible, and assure them that you will prepare them for possibilities, i.e., skin tears, skin discoloration. Tell them that, as with all babies, they will see special family features of each of them. Let them know they can hold the baby or put the baby in a special basket and spend as much time with their baby as they need. Inform the parents that their

decision may change as time evolves, and they may feel different after the baby is born. They may choose to not see or spend time with their baby and that needs to be respected.

2. To have photographs of their baby taken. As caregivers, we know the time at the hospital or funeral home is the only opportunity to take pictures of the baby. If photography is not culturally accepted, still ask to be clear that this is not an option. For other families, ask, "How does it feel if we take pictures of the baby?" For some this may feel morbid and others are unsure. It is important to state you have a facility policy of taking some photographs. No one should be forced to take or to view the pictures, but they should be kept in a safe place for the parent should they ever want to see or have them. Explain the process of taking these special pictures, which include positioning the baby, special props, and clothing. It is important to take digital photos or 35mm pictures, and professional pictures. Most facilities have professional photography companies that provide well baby and also bereavement pictures. In addition, local communities may have trained volunteer bereavement photographers that provide beautiful pictures free of charge. Some families choose to take an active role and use their own camera and/or video recorder. Some wish to have family pictures taken. It is not uncommon, though, for parents to be uncomfortable and refuse to have any additional pictures taken; this should be accepted and not forced on the parents.

3. To be given as many mementos as possible. Explain that past bereaved families have expressed the need for mementos of their babies. Share with them the keepsakes you will provide, i.e. baby book, memory box, crib card, baby name bracelets, photos, lock of hair, permanent foot and hand prints, and records of weight and length. Parents find great comfort picking out an outfit that the hospital provides or using one they have brought from home. Any item the baby's skin touched means a great deal to the parent – such as a blanket or a prop from the picture. These items are all tangible evidence that the baby existed, and it has been found that these items aid in the parents' healing. Sometimes, the mementos may be overwhelming, and the family may decide they do not want them. If this is their choice, the mementos need to be kept in a secure place. Many times, the family decides at a later date that they want their baby's keepsakes.

4. To name their child and bond with him or her. Instead of directly saying, "Are you going to name this baby?" Gently ask, "Can you share with me the names you picked out during the pregnancy?" Ask the meaning of the names and how that decision came to be. This allows a very special conversation about this process and their connection to the baby. Then explore if they would like to use one of their chosen names. Sometimes, parents are very comfortable using the name they had originally chosen, and in other instances, they may need to explore another name. If they had not picked out a name, ask if they feel comfortable naming the baby. Frequently, you may hear an immediate "Yes" that the baby will be named. Other times, they may say no or exhibit some uncertainty about this option. Advise them that there is no pressure to name the baby--no one should be forced to make this decision quickly. Oftentimes, families may want to look at the baby or feel they need to ponder this option. Some may feel the need to peruse the many popular baby name books. There are some parents who leave the hospital without naming their baby and name their baby months and even years later. However, as soon as a name is chosen, begin to honor the baby by using his/her name in your conversations. Another way to honor the baby is to provide a naming ceremony, blessing, or baptism if the family desires.

5. To observe cultural and religious practices. When I was a new OB nurse, I was always concerned that I was not completely aware of each culture and religion and their beliefs. As years passed, I attempted to educate myself by reading and attending workshops. I gleaned valuable insights through this process. I am now more aware of different beliefs, but I have found that even individuals in the same faith or culture may have very different ideas. Therefore, when ministering to parents, invite them to share their individual beliefs, past traditions, and rituals regarding each choice with you. In the case of mixed faith relationships, an attempt should be made to find a middle ground. Typically, their minister, rabbi, or priest may perform rituals; however, they may not have a religious background or an established religious community. The hospital chaplain can provide support and rituals as well.

6. To be cared for by an empathetic staff. Many of the parents who contact me share that their healing was made easier through the sensitive, caring individuals who assisted them during their darkest hours. It

is imperative to continue to providing on-going education regarding perinatal loss to hospital staffs via conferences, workshops or bereavement dvds. Recent cuts in funding for education and time constraints have made this opportunity challenging. Many perinatal organizations now provide online courses and professional support.

7. To be with each other. With today's family-centered OB units, hopefully, it is a given that one's support system will be allowed to stay with the mother twenty four hours a day, plus be near during all procedures. This policy should include the father or partner of the mother and in the case of a single mom, her support person as well.

8. To be given time alone with the baby. After parents have had some time with the baby in your presence, explore if they would like time alone with their baby. Provide them with a bassinet or basket for the baby, items for bathing the baby, extra baby clothing, a rocking chair, CD player with soothing music, and a camera. Assure them that this is their time and no one will intrude. Always remind the parents you are available and that they can call you for support during this time if they choose. If the baby needs to be taken to the morgue, additional request(s) may be made later to see the baby again. These requests need to be honored. The baby should be brought back up to the nursing division, warmed on the baby warmer or placed in a warm blanket so parents can have additional time with their baby.

9. To be informed of the grieving process. Many times, parents are unable to process all the information given to them initially due to their feelings of shock. This may be the first time they have experienced a tragedy, and they may be overwhelmed by the intensity of the many feelings of grief. It may be challenging for them to read a large publication, so small vignettes or brochures that explain the grief process are easier for them to read and digest and should be included in their take-home packet. In addition, the mourning needs of siblings, grandparents, and other family members should also be addressed and acknowledged with appropriate resources made available for these needs.

10. To be given the option of donating their baby's cartilage, tissue and/or organs for transplant or donating the baby's body to science. In general, attention has been brought to the forefront about tissue and organ donation. This opportunity can only occur if a baby is of designated gestation and/or a live birth. Laws have been passed to explore these donor options after death. Facilities have trained organ donor representatives who have printed materials and the knowledge to explore these options. If the family has an interest in donating the baby's body to science, some research would need to be done at a local medical university to see if this is a possibility.

11. To request an autopsy or pathology exam and genetic testing. It is not uncommon for parents to be frightened by the prospect of any testing, and they may be unclear of the need or reason for an autopsy or pathology exam. It is vital that their physician(s) discuss these options and the possible reasoning and/or benefits for these procedures. Other concerns may be the cost involved or their lack of information regarding the procedures. Their fears and concerns of each option are points of discussion. Some do not want their baby to be subjected to any additional procedures while others feel it is important to search all possible avenues for answers. If possible, delay the autopsy until the family has spent the desired time with the baby. However, the baby can still be seen by the family after the autopsy at the hospital. Families need to be informed that the final results of an autopsy or genetic testing make take 6-8 weeks for the report.

12. To have information presented in understandable terminology. Everyone has the right to comprehend the material presented to him or her. It is imperative to speak in terms that parents will understand. Also, due to their state of mind, they may need to have the information repeated more than once. It is crucial to have an interpreter for non-English speaking persons or someone to sign for a deaf person.

13. To plan a farewell ritual, burial, or cremation. Instead of asking the family, "Are you going to have a funeral?" Simply state, "Share with me the traditions of your family regarding funerals and rituals." With this question, you often find out their past experiences, faith background, or spiritual needs in regards to death. Acknowledge how difficult planning a funeral might be for them since this could be the first time

young parents may be attending the funeral of someone in their immediate family, let alone planning one. Share with them your willingness to help them in addition to their clergy (if there is someone) or funeral director. If they do not have a religious affiliation, you may be their main resource. Encourage them to personalize the ceremony as much as they want to. Address their cultural and religious traditions in regards to the rituals. Also, provide them with printed information regarding area funeral homes/cemeteries along with options and costs. I have assisted many families through this challenging process, and I am always amazed at the individuality of each farewell ritual. It is vital to be aware of state and local regulations regarding burial, and if the parents' wishes are within regulations, they should be honored.

14. To receive information on support resources. A list of support resources should be given at the time of discharge. A follow-up phone call may need to be made before the farewell ritual to assist them with final decision making. Additional calls or emails should be made to check on the family at established intervals and at difficult times, such as due dates and anniversaries. If a support group is run by the institution, follow-up letters explaining the meeting and upcoming meeting dates and memorial services should be sent by the facilitator. In addition, the availability of other resources such as interactive perinatal loss websites, library books, and videos or newsletters should be noted.

Rights of the Baby

1. To be recognized. It is important to explore what this pregnancy meant to the family. The bonding process may begin very soon in the pregnancy; therefore, hopes and dreams for this baby may have already been established. If the family considers this pregnancy as a human being, this needs to be validated. Avoid insensitive terminology such as the "missed abortion," "fetal tissue," or "products of conception or fetal demise." Acknowledge the baby's presence by a birth or recognition-of-life certificate. Always use the baby's name when referring to the baby.

2. To be named. Explore the patient's and her partner's feelings regarding naming the baby. This may be too overwhelming and they may choose not to name the baby. This needs to be respected. If they are indecisive, let them know there are no time limits. Others have named their baby weeks, months, and even years later.

3. To be seen, touched, and held. In respect to the baby, he/she should be presented as a live baby would be presented--in a soft blanket and beautiful clothes. When families see their caregiver respect and cuddle the baby, they may find it easier to do so themselves. If the parents choose to not see, hold, or touch the baby, this should be abided by. However, they may be grateful if you held their baby even if they could not.

4. To have life ending acknowledged. A farewell ritual may be very helpful in acknowledging the short time this baby was here. Give parents information on the different styles of birth and death announcements available. Explain the many creative ways of memorializing their baby, from memory books and boxes, to tree plantings. Holiday memorial services and remembrance walks honor these precious babies in the years to come.

5. To be put to rest with dignity. Burial or cremation options should be explained to all families regardless of gestation of pregnancy. All states have strict regulations for proper care of baby's remains over twenty weeks gestation in which a baby must be buried or cremated. There are no state regulations for babies that are delivered or miscarried prior to twenty weeks gestation; thus the remains in some medical institutions are considered medical waste. However, many facilities have established policies and have collaborated with funeral homes and cemeteries to respectfully care for the remains of babies under twenty weeks gestation. Some even have a quarterly group burial and remembrance service families can attend. Some states have laws that mandate that the patient experiencing early loss be informed of the hospital disposition policy and also are given the right of private disposition. If there is a hospital disposition option, a minimum thirty day waiting period for burial/cremation allows families to reconsider their decisions. Invitations should be extended to families to attend the group burial or memorial service.

Parents have the right to know where their baby is buried, and a memorial headstone at the group burial site is comforting. Burial cradles for tiny babies less than twenty weeks are available for a dignified burial.

Nurses and other caregivers who support families experiencing the death of a baby play a pivotal role in ensuring the baby and other family members are treated respectfully. By implementing the Rights of Parents into the care provided at the time of the loss and in the following months, you will validate the important role each baby has in his or her family as well as assist parents in creating memories they will treasure for a lifetime.

The Rights of *Parents and Babies* were originally revised and enhanced by Sr. Jane Marie Lamb, OSF and Foundress of Share, from a document developed by the Perinatal Bereavement Team at Women's College in Toronto, Canada. The Rights were updated in 2008 by the National Share Office Staff. The Rights of the Parents and the Baby can be used as guidelines for institutions and as a handout for parents.

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