

## Multiple Birth Loss and the Hospital Caregiver

Jean A. Kollantai and Lisa M. Fleischer  
Center for Loss In Multiple Birth (CLIMB), Inc.

- *After infertility, parents give birth to a baby at 28 weeks whose twin has died in-utero at 14 weeks.*
- *Identical twins are born near term and apparently healthy; later in the day, one is diagnosed with congenital anomalies and a life expectancy of weeks to months.*
- *Triplets are born at 32 weeks; all seem to be doing well, then at 2 weeks one dies from NEC.*
- *Twins are born at 26 weeks, after weeks of complications from twin transfusion syndrome; one baby has died soon after birth, and the outlook for the other is very uncertain.*
- *Two babies are born at 32 weeks, with one having been diagnosed earlier with anencephaly; the previous year, the parents lost their first set of twins to prematurity, and a triplet baby was reabsorbed earlier in this pregnancy.*
- *Triplets are born at 23 weeks; one dies at birth, another a few hours later, and then the third, for whom there had been some hope.*
- *A 24-week surviving twin dies at 4 months old, a few days before being scheduled to go home.*
- *An 8+ pound twin is in the NICU after a prolapsed cord on the due date; his sister is fine. The parents are making the decision whether to remove life support.*
- *A quadruplet baby who had gone home at 6 months is rehospitalized with pneumonia and is not expected to live; one of the quads died at birth, one at two weeks old, and the fourth is at home.*

The death of one or more, both or all twins, triplets or higher multiples is sadly a fact of life in all hospitals with neonatal intensive care units (NICU's), as the above scenarios show; sudden multiple birth loss also occurs at non-NICU hospitals. With the increase in multiple conceptions from fertility technology--and given the risks for multiples, even twins--this is not likely to change. The sheer number of babies and of the complications that can occur create an almost unlimited array of scenarios that can take place over hours to months or longer, often with first-time parents who have already endured very stressful circumstances to conceive, high-risk pregnancies, or traumatic births (or all of these).

The experiences of many parents have shown that there are common points which are extremely important in all situations. When they are understood, this understanding can be applied sensitively and with confidence to each specific, often unique situation. These are some of the more important points:

- ***It is essential to acknowledge all the multiples, no matter how many have died and how many have lived, or the timing of the death, even if months before.*** Especially with the prevalence of ultrasonography, parents are typically bonded to each baby from early pregnancy, and to "our twins" or more. *Parental needs cannot be effectively addressed without recognizing them as the parents of all their babies, regardless of other circumstances.* Triplets are three babies who have each died, not one collective baby. A healthy surviving baby is still one of the twins; and as one person put it, "Two out of three is bad when it's your baby who died."

- ***The presence of surviving (often tenuously) babies and the overwhelming nature of the loss of both or all the babies can create confusion and uncertainty among the staff which must be recognized; in parents, a similar confusion and uncertainty must be acknowledged.*** Parents may often have difficulty focusing on more than one aspect of their situation--it's very difficult to focus on all of it when it is so complicated and with so much going on with each baby. Parents may not be able to express their overwhelming grief. It is crucial for staff to empathize with the entire situation, and not to judge parents for their preoccupation with a living or a dead multiple(s). Staff should play an even more active role in helping parents create memories which will facilitate their healthy grieving when they are able to get to it. Parents themselves may try to rationalize that "it was meant to be," or "after infertility we should just be grateful to have one or two," but staff must understand that this too is part of the grieving process, and express that it is a hard experience and process.

- ***All the considerations which are nowadays considered important when a single baby dies are equally important in multiple birth loss, as well as some other, "twin-specific" issues.*** The fact that there is more than one baby and complicated circumstances make it crucial to have tangible mementos of each baby so that parents can later reconstruct and process the reality of what has happened and facilitate healthy grieving (and healthy parenting of any surviving or subsequent children). For many parents, this will be their first experience of having children, and for some, their last, after many years of hopes and dreams. For all, these are "my twins" and "my triplets" or more, and they do not expect to have this experience in the future.

Given these points, there are some important specifics:

- ***An opportunity to see and hold each baby is essential. Each baby should be seen and held for as long as desired and more than once if desired, regardless of the condition of the baby or the mother, or of any survivors.*** This should be natural and expected, not something parents are asked about doing in a way that encourages them to say no. If one or more babies does not look "normal", the importance this can be realistically but gently explained--remembering that almost all parents focus on the beauty of their child, not the imperfections, and that what they imagine is usually much worse than what is. Not seeing the premature, stillborn twin while the other baby is critical in the unit will be deeply regretted later, regardless of the outcome with the other twin, and will not "spare" the parents or help them "focus on the living baby." Bathing the baby has also been very much appreciated.

- Most parents would give the world later for ***an opportunity to have held their babies together, or to have even seen them together.*** After months of multiple pregnancy, this will be their only chance to do so, ever. If at all possible, arrangements should be made so this can happen, prior to and/or after the death. At the very least have them side-by-side in the NICU if one or more cannot be removed from isolettes. When a baby is still alive but dying, most parents do wish to hold the baby while it dies. Those who do not often later come to regret it deeply. When a twin or triplet has died earlier in the day, it is important to bring the baby or babies back so the parents can be with both/all of them. When there are survivors, geography can sometimes be a factor but it is still possible and important to get everyone together. After the parents had made the decision to remove a triplet from life support, one hospital arranged for the surviving babies to be transported over to the second hospital so the parents could have them all together for the first and last time. The parents knew that the survivors had had an opportunity to be with their brother while it was still possible. Photos of such an event are also invaluable in later helping any survivors to understand concretely the story of their birth and the loss of their sibling(s).

- ***The issue of whether to delay burial of one or more multiples when the outcome with the other multiples is uncertain, is a difficult one.*** Delaying burial does create some opportunities and also offers what many have described as their only source of comfort: knowing that their twins or triplets were buried together. Some parents will feel the need not to wait, since they have "paid the price" and consider it unthinkable that the other would die; others acknowledge the possibility but want to "think positive." If the burial is not to be delayed, seeing and photographing the babies together is all the more important, regardless of circumstances.

- ***Photos of each and all babies are essential.*** Families should be encouraged to bring their cameras and video cameras, with the hospital still assuming responsibility for taking photos (that will be saved and claimed later if necessary. Many have been lost and a system for this is essential.) The baby or babies should be washed and dressed or wrapped in items chosen by the parents. It is very important that the photos show the baby's features--and that there be photos of both or all together, and being held not only by the parents but also by any other family members. Many have appreciated having their babies' hands touching, especially when both have died.

- ***Crib cards, and labeling of survivors are important.*** Many parents are very offended when "Twin A" suddenly becomes "Baby X". Others are hurt at seeing "Twin A" without an "B". What is important is to ask what the parents prefer. Most parents are very hurt when, just hours after the death of a triplet, everyone is calling the survivors "twins", or similarly, acting as if a twin who died never existed. Survivors can be referred to as a surviving twin, surviving triplets, etc. Any acknowledgment that a baby is actually a twin or triplet is usually deeply appreciated by the parents.

- ***Assessing zygosity:*** Zygosity is often assumed, or assumed not to be important, but it is very important for parents to know later in order to help them assess the probable causes and risks in a subsequent pregnancy. It helps parents know how to "picture" their babies, and also impacts on issues in raising a survivor. If there is any question as to zygosity of same-sex twins, testing should be done to the extent necessary, as it will usually not be possible later

- ***The importance of baptism, or other ceremonies.*** Many parents have deeply appreciated the opportunity for baptism when both twins or all triplets have died, feeling that the ceremony was one of the few things they could do for their children. Those with surviving babies have deeply appreciated having a service that combines a baptism for the living baby or babies with a memorial for the baby or babies who died. Some have been able to arrange a service at home. Parents may not think of these ceremonies as an "okay" option unless suggested and encouraged by the hospital staff.

- ***Mementos.*** All other mementos--locks of hair, footprints and handprints, caps, crib cards, fetal death certificates, seashells that were used for each baby's water at the baptism, blankets, ID bracelets are valued and their obtaining them must not be overlooked even when there is a crisis with another baby, or when there are multiple survivors going home.

- **Burial.** Most parents who lose both or all babies find comfort in their being buried together, though some have reasons for doing it otherwise. It is essential that the burial be at a time when the mother is able help plan and attend it, and that there are no conflicts with surgery for another baby or other demands. Videotaping is highly recommended.

- **Birth announcements.** These are a tangible way of honoring both or all the babies and letting others know what has happened and what support is needed. CLIMB has examples available to share of announcements parents have created for many types of multiple birth loss situations.

- **Siblings.** Even the youngest siblings are often very involved with the pregnancy and "my twins", and have been sad and angry later if they did not have an opportunity to see and say hello and goodbye to the baby or babies who died. This contact also helps siblings in processing the reality of going home with fewer or no babies. No matter how overwhelming the situation may seem to adults, it is important to make these opportunities available to children in the family as well. Later, it has a great impact on how naturally the loss can be talked about within the family, and the ways in which the baby or babies can be remembered.

Other realities faced by many parents are:

- **"Twin Encounters."** Parents have found themselves and their tiny survivor surrounded over the weeks in the unit by 4, 5 or more sets of twins who are expected to go home. This is normally extremely painful, especially when relatives are visiting and fussing over the sets of twins. Sometimes, parents who mention that their baby is a surviving twin are treated "like I have a disease" by the families. The same situation often occurs with triplets. It is imperative that staff recognize the difficulties of this situation and consider the parents' feelings, and provide for physical separation to the extent possible. As one person said, "I was lucky all of the nurses would listen as I cried over Colin's death. They all cared about us. They moved Erin when I said how uncomfortable I was, sitting next to boy/girl twins about the same gestational age as mine, both of them going home." Many parents not given this opportunity or at least the acknowledgment by staff often find it nearly impossible to visit. As well they receive an institutional message that their grief is not real or respected. As with many things, it is a good idea to ask the parents what they would like to do. It is also very important that staff to avoid making comments to others within hearing of bereaved parents such as: "You're a real mother, taking care of two!"

A related reality concerns the association of certain places with the death of the other baby or babies. Parents expected to pump milk for a survivor or spend several days caring for their survivor in preparation for homecoming in the same room where they held their other baby or babies at the time of death, often find this an agonizing experience.

- **Physical separation of parents and babies.** In the days following the birth, it is not uncommon for the father to be at one hospital (hours or more away) with the sicker baby, while the other baby is another facility, and the mother recovering (or ill) in another. Fathers are often faced with making critical decisions alone, or facing the death of a baby alone, while at the same time worrying about the mother and other baby or babies. Fathers may be "commuting" with little rest or food, and often responsible for older children as well. Mothers are often separated from their husbands and not able to see their surviving babies at a time when they need this contact most. Mothers should be in the same facility with at least one of the babies if at all possible. Fathers who are alone or commuting need the maximum support and involvement from staff, which can also mean facilitating the involvement of extended family or friends.

- **Decisions are not easier to make.** The decision to discontinue life support for a twin, for example, is not made "easier" by the presence of a healthy survivor, which, in fact, creates additional, wrenching issues. No decision is easy to make when the parents are exhausted from relating to the realities and crises of multiple babies. It is important to facilitate parents' pulling in all their resources--their pediatrician, clergy, and family members--when there are decisions to be made, and to assist them in making the time and focus to really think such decisions through.

- **The feeling of separate babies.** Parents often feel that they had two or more babies at once, not twins or triplets or more, because there are so many separate realities and physical separations. Anything that can be done to assist the parents in seeing and holding both or all the babies at once before and after any deaths is valuable for this reason as well. When one or more babies is hospitalized for a long period of time, anything that can be done to "integrate" the family is also extremely valuable. One mother's healthy survivor had her own little crib in the NICU for her first six months, so that her mother could be with the dying twin as well as care for the healthy one and be with both her twins. It is very important to facilitate parents' spending time with a baby who is terminal, even if it means their being away from the survivor(s) for that amount of time. However, when both or all babies are very premature or sick, it is important to keep the amount of time spent with each relatively equal--it is not uncommon for a "better"

one to die and a sicker one to pull through, leaving regrets that little time was spent with one who did die, and creating bonding difficulties with the survivor(s).

- ***The "limbo" situation and fear for any survivors.*** Many parents simply do not know for quite some time whether one or more of the multiples will live or die, and what the ultimate situation will be. Many fear for their survivor(s) possibly being handicapped. Even the parents of the healthiest survivors fear what may happen, now that they have seen that baby's twin die. It is important to realize that the overwhelming nature of the experience creates very real issues and difficulties with bonding with any living babies. One of the most basic issues is: "the more I love the one(s) who is living, the more painful will be the loss of the other(s), and the more fear there will be for this one too". It is important to recognize this while supporting attempts to bond (i.e., nursing).

- ***The meaning of homecoming.*** For those who have lost both or all babies, their own homecoming is the recognition of that fact, and the final leaving of the place where people saw and perhaps knew their babies. "The silence was deafening," after homecoming is a typical reaction. For those who are going home to a survivor after other(s) had died in the unit, the realities are in some ways similar. For those who are bringing home one or more survivors, it is essential to realize that homecoming will not be the happy, "lucky" day that it may be for those bringing home a singleton baby. It is the full recognition that one or more of the multiples has died, and having to cope with that outside the "safe," knowing world of the hospital. For many it means caring for a tiny, fragile baby (perhaps as a first-time parent), and for some, two or more tiny survivors--while also grieving for the baby or babies who died and for "my twins" or multiples, and the loss of the experience that should have been.

We have found that whatever has not yet been processed tends to surface at this time or as soon as there is a more "normal" situation with any survivors. It is a time of full grief, guilt, anger or blame, marital strains, difficulties with relatives and friends, feelings of vulnerability, confusion--just at the time when everyone is expecting the parents to be "over it" and acting normally. We have also found that the more parents are supported in their grieving process before homecoming, the more joyous a time it can be for those with survivors--and the less traumatic for those who have no survivors.

One mother whose triplets all died, after years of infertility and an IVF pregnancy that proved to be traumatic, appreciated most the hospital social worker's expectation to see and talk with her every day, not only throughout her hospital stay, but regularly for weeks after she was released and until the social worker knew that the mother was in good hands with another counselor. This caring and continuity made all the difference. It is also very helpful for staff to make themselves available later when parents are able to go back to the hospital, review records, and talk to people who knew the babies, in order to reconstruct the experience as a whole and find answers to remaining questions.

## **Summary**

Multi-babies mean multi-realities. A baby may need major surgery on the day that his twin brother is being buried. A father may be in a Level III NICU with the sicker baby hundreds of miles away from the mother and the other sick twin. A mother may be giving birth to the third triplet while the first is dying. A family may be making a decision about terminating life support at the same time they are preparing to bring another baby home. Another may still be in the unit. It is essential to remember that parents who are experiencing multi-realities will respond and react to any one aspect of them differently from a parent for whom that event (a surgery, a death, a homecoming or other event) is the only reality. By always acknowledging the whole situation and being there with parents in a caring way, staff can help parents who are dealing simultaneously with experiences that would be considered overwhelming if a family were to experience them separately over a period of several years. Parents have truly appreciated staff who have asserted themselves and expected to be involved, at a time when the parents could not even ask for help and didn't dare expect understanding. When some "twin-specific" suggestions and encouragement are added, the family has the best possible groundwork for being able to later process and heal from their experience, and decrease the mental health risks to any surviving or subsequent children, as well as to themselves.

**Center for Loss in Multiple Birth (CLIMB), Inc. © 1993-2003**  
**P.O. Box 91377, Anchorage AK 99509-907-222-5321**  
**climb@pobox.alaska.net**