

## ***The Death of Your Higher Multiple Baby***

For parents and families who have experienced the death of one or more of a set of triplets, quadruplets, quintuplets or higher multiples during pregnancy, at birth, or in infancy, with one or more survivors



### **The Loss**

If you have experienced the death of one or more of your supertwins—triplets, quads, quints or more, also called higher order multiples, or HOMs—with one or more survivors, we are very sorry. You are not alone. Because of fertility technology, triplet and other higher order multiple conceptions and births have gone from being quite rare to something that occurs much more often—yet the risks are still very great. Though the popular media and others tend to focus on the "miracles" and the very rare mega-"successes" of 6 or 7 which imply that somehow every mother can do this if she wants to enough and make it look like triplets or quads are supposed to be easy, the sad truth is that in having three, four or five or more babies at the same time, there is so much that can occur. While the most prevalent cause of loss is prematurity, it is also true that anything that can affect any one baby is 3 times as likely to come up in a set of triplets, 4 times in a set of quads: we've known many families who have lost a triplet or quad to stillbirth in the 3rd trimester, from congenital problems, SIDS, or illness or accident in infancy. And there are the multiple-related conditions: many have lost one or more of their babies to Twin Transfusion Syndrome, or being monoamniotic. There are very high risks that can become a heartbreaking reality for parents no matter how much they love and want their children and try to do and *do* everything right. Whether the babies came after months or years of trying and fertility technology, or whether they were amazingly spontaneous, it is incredibly difficult to have such a special "gift", then have to experience the reality of the death of a baby or babies while also becoming the parent of and caring for a baby or babies who are part of the same set and often has special care needs and issues from prematurity. No matter how many babies have lived and how many have not, loss in supertwins is an incredibly difficult journey into some pretty uncharted territory. It is one that parents could never have imagined as being what it would be like to be a parent, or a parent again, and the more so after the kind of bonding that takes place through ultrasounds. This kind of loss situation been mostly unrecognized and unsupported, and we hope to share here some of what our members over the years have felt was important in hopes of helping to change that.

### **After the Loss**

The circumstances around the death of a higher multiple(s) are likely to be complicated and hectic, because there is more than one baby, the timing of the death before or after birth, and the fact that the other baby or babies are likely to be in the neonatal intensive care unit. Mothers may be ill after a traumatic pregnancy or delivery, and babies may even be in different hospitals, with the mother and father separated so that one could be at each. But no matter what, there are

some things that are very important to do—and they are even more important to do because these are multiples, and because there is a surviving baby or babies, so that over time the family can begin to process their entire experience and begin to cope, heal and relate in a healthy way to their survivor or survivors about their co-multiple(s) who died.

- seeing, touching, holding the baby or babies who died, even when the death was in-utero before birth. This validates the reality that there really were triplets (or more), and makes it possible to begin the grieving process for that baby or babies while creating memories that will be appreciated later. There is no reason to settle for a few foggy moments in the delivery room—parents need and should have as much time as they desire over the coming days to spend with the baby(s) who died, as many times as they wish, as well as later at the funeral home. Though it is difficult, many parents have deeply appreciated being able to see and hold all the babies together, even if it meant transporting a healthier survivor from another hospital, or putting isolettes together before or after one or more has died. Some of these decisions may be difficult when the baby(s) who has died does not look “normal”, but it’s important to remember that babies do not have to be perfect for their parents to need to see and honor them—and that parents tend to imagine worse than what the reality is and then focus on the beauty of what they do see. It’s also very important for grandparents, siblings of any age, and other relatives and friends to have an opportunity to say hello and goodbye. One mother said, “After an entire triplet pregnancy and loving and wanting all of them so much, there was no way I was going to miss what was now my only chance to hold all of them together, and I’m so grateful I did. My triplets and my son who died are real to my family, also, because they met him too.”

- photos of the baby who died, and the babies together. A photo of the baby(s) who died, and one of all the babies together, and the parents holding them together are treasured mementoes later, and also “worth a thousand words” when talking to young survivors about their birth. It’s preferable that parents bring their own camera (35 mm film, and consider using black and white as well) and have it processed in a shop that does it onsite, or a digital camera; and if the hospital offers to take photos, claim them promptly as these are sometimes lost. Videotaping can also provide some precious mementoes, as well as obtaining copies of ultrasound videos. Professional photography may also be arranged. Besides photos, other important mementoes are locks of hair, foot- and handprints, blankets, caps, crib cards and id bracelets.

- If two or more of the babies are the same gender, they may be "identical" (monozygotic, monochorionic) even if they don't look alike (and even if they were conceived through fertility technology). Many parents have found it important for medical and emotional reasons to definitely know whether their babies were "identical" or fraternal. This can be determined in a number of ways, and it is important for parents to discuss this with their physician as soon as possible.

- This varies according to state and country, but if the baby who died was more than a certain number of weeks’ gestation, parents will be responsible for burial or cremation; if the baby or babies was less than that, the hospital is responsible and parents who wish to see the baby(s) and make arrangements need to speak up soon and often. For parents who are making arrangements, it’s really important to be able to look back later and feel that they did everything they would have wanted to honor that baby. So even though there is pressure from the situation to hurry—parents have been grateful to have that opportunity and those memories. If another baby(s) is in critical condition, parents have sometimes worked with a funeral home to wait with

the arrangements for the baby who died to know what their needs and wishes will truly be and avoid the possibility of a second funeral.

- Many parents have combined a baptism for the survivor(s) with a memorial for the baby(s) who died, or honored all of them in another ceremony or ritual. This can still be done weeks or months later, as can sending birth announcements that include all the babies—CLIMB has examples available of announcements that parents have done. For parents who have lost a multiple(s) to miscarriage or reduction, these can be opportunities to name and honor that baby(s).
- Surviving triplets are still triplets, surviving quads are still quads. It's important for parents' wishes about how their surviving child or children are referred to by hospital staff, relatives and friends be known and respected. It's difficult for parents who have a single survivor be treated as if he was a single baby—and parents of more than one survivor of triplets, quads or quintos almost always say that their #1 difficult issue is their babies being called twins (or triplets or quads). How parents relate to all of this changes over time. At the beginning, it's painful to see Baby B and Baby C without Baby A, but it's important to let staff know that is what is preferred instead of relabeling the survivors Baby A and Baby B (for example), if that would be even more painful. Also, it is difficult to see intact sets of the same number of babies (for example, living triplets) and important for parents and NICU staff to limit this kind of exposure as much as possible and acknowledge the loss.

## Homecoming

Joy and deep sadness...loving and grieving...bonding and letting go...all the realities of being a parent—and all the realities of being a bereaved parent: these and more fill the days, weeks and months after the death of a multiple baby(s). Some very opposite experiences, which are difficult enough done separately, are all wrapped up in one package now: “my triplets” (or higher). Parents who bring home a sole survivor of supertwins usually are dealing with the needs of a very premature baby; those who bring home more are dealing with all the realities of baby multiples, plus the likelihood of special needs from prematurity—all combined with bereavement. Most parents find that they don't actively begin to grieve and seek support until after things become a little more “normal” with the health of the survivor(s). (This can be complicated because that's just when others think the parents should be fine.) This is why the mementoes and experiences at the time of the birth are so important, as parents begin to try to process their experience as a whole mentally, emotionally, and spiritually. If parents didn't have those opportunities, then it's important to find creative ways to meet their needs (for example, having a portrait of the babies together done from polaroids or from someone's memory). Many parents have benefited greatly from infant loss support groups, and counseling—they may be hard to get to, but the reward is an uninterrupted hour to focus on the baby or babies who died. It offers the opportunity to not be around people who try to say, “at least...”. We've found that participation in grieving and in support helps to reduce anxiety and depression later on, and really helps to lay the groundwork for talking comfortably with the survivor(s) as they grow. It also helps with decisions about subsequent pregnancy and parenting, something which may come back on the table just when parents thought that they would be past needing to try.

As one mother, whose triplet son died when the babies were 6 weeks old in the NICU, has said,

“I finally decided I needed to move on in my grieving. I was very motivated after reading a story by a mom who lost one of her babies more than 15 years ago and she was finally dealing with it. I didn't want to have this grief looming in my heart and mind for that long! Through my

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employer I sought professional help with the goal of just talking about it and not going on any depression medication. I'm a talker (in case you can't tell!) and my husband wasn't. I just needed someone to listen to my every 'crazy' thought of guilt and what if's. Luckily I found a great doctor and after about another 18 months of seeing him, reading CLIMB, and going to a support group at the hospital—I started to REALLY move in my grief. I'd say after a year I was doing much better—getting through all those 'firsts' were tough. By the time the kids were 2 years old and their health was good :-) I felt I could finally be 'selfish' and deal with my grief over Owen. By the time the survivors were 3, I was feeling inner peace and a smile whenever I thought of him. That was progress! It's still hard around their birthday and then 6 weeks later on Owen's day—but that is understandable. The survivors have known that they are surviving triplets and not twins since Day 1 and after a little struggle with some family members not to call them twins — it's now second nature to not call them twins. If someone tries to call them twins at school or church, the kids always correct them. They have a strong bond with their angel brother. They made sure we all sang Happy Birthday to Owen after we sang to them. We always include a white rose in our family pictures to represent Owen. The kids love looking in his small trunk of items from his isolette and pictures. They sometimes show sadness in missing him. I sometimes struggled with trying to explain these difficult things (like death of a baby and where is Owen now) to such young kids but they really seem to 'just get it'. We never really planned anything it just kind of happened—not sure if that is a good 'plan' or if we are just lucky so far. It will be interesting to see if the survivors change their interest in Owen or start letting folks call them twins as they get older and less innocent. I'll always leave that up to them—though to me they will always be TRIPLETS.”

## **Remembering**

Parents have found many ways to remember their supertwin baby or babies and to include them in their family for the rest of their lives. CLIMB's website has more information about this and other aspects of higher order multiple birth loss. It is important for each family to find ways that are meaningful to them. Few of us ever forget “our triplets” or higher multiples, but with time and support, our baby's memory is part of life.