



Finding a new “normal”

by Jean Kollantai

Almost 17 years ago, after her full-term twin son Andrew died at birth, Jean Kollantai founded the Center for Loss in Multiple Inc. (CLIMB). Nearly every day since then she has listened to detailed stories of twin, triplet or higher-order pregnancies and births. While the majority of multiple pregnancies have a good outcome, many of the stories she hears involve the loss of one or more of the babies and sometimes of handicapped survivors. She offers, from her point of view, advice on reducing the risk of loss and supporting those who suffer loss in a multiple-birth pregnancy. E-mail her at climb@pobox.alaska.net. Visit www.climb-support.org for more information. (In this article, Kollantai refers to Diane and Deron; their story appears on page 37.)

Diane and Deron’s loss of their son Brady, one of their triplets, places them in a very special group—bereaved multiple-birth parents who have experienced the death of one or more beloved babies. Our situations and causes of loss may be different, but the grief is universal and lasting.

For many, the loss comes after months or years of efforts to conceive with the help of fertility technology. With the increase in multiple conceptions, many parents who appear to the rest of the world to be parents of twins or triplets are in reality the parents of triplets, quads or more. Many other parents have a single living child who is actually a twin—as I do—and many more parents who do not have a survivor are, nonetheless, parents of multiples. All parents who face the tragedy of loss need support. There are things that those suffering loss and those helping them—or even meeting them casually—can do to ease the pain. Furthermore, parents can sometimes reduce the risk of loss.

Reducing the risk of loss

With two or more babies, anything that

might come up in a singleton pregnancy is just that many more times as likely to come up in a multiples pregnancy. Some of the risks are congenital, as in Brady’s case.

Although not always possible, losses sometimes may be prevented if parents choose to be well informed and assertive. Premature labor is the most well known risk. Learn the symptoms of premature labor, which may not be recognizable as labor, and be aware of how early in the second trimester labor can occur. It also is important to be aware of the risks in the third trimester and at birth. Talk with your doctor about the timing and management of the delivery and make informed choices—many of us have lost big, near-term babies in ways that may have been preventable.

Certain risks are specific to monozygotic pregnancies. From what we have seen here at CLIMB over the years, we cannot stress enough the importance of knowing as soon as possible in the pregnancy whether the babies share a placenta or an amniotic sac. Armed with this knowledge early in pregnancies, doctors can closely monitor at-risk women for twin-to-twin transfusion syndrome and monoamniotic complications.

We also recommend consulting a perinatologist or maternal-fetal medicine specialist at least once, and more often if the babies even possibly share a placenta.

Insist on medical attention for anything that may not seem right at any time in your pregnancy. Knowledge is power for your babies’ lives and health.

Unique grieving

Grieving for your baby or child who has died is an intense and demanding experience—emotionally, physically, mentally, spiritually and physically. It doesn’t come in neat stages that someone graduates from in a certain amount of time. There are not any “TV miracles.” We would all like to get around it, but it’s a “pay me now or pay me later” situation.

As bereaved multiple-birth parents, we face an especially complicated situation for many reasons. We are either grieving for two or more babies without survivors, or grieving for one or more babies while caring for a tiny survivor. In such a case, we experience the realities of parenthood and of loss at the same time. We grieve for the

“Finding a new normal” continued on page 36

loss of the set and the status of being the mother of visible multiples. Furthermore, many of us have a survivor who is physically identical to the baby who died. Of course, all of us with survivors are concerned with the effect of the loss on them.

Many parents have been through months of a traumatic pregnancy and horrifying scenarios in the NICU, which bring their own grief. Often active grieving of the

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loss doesn't really begin until we bring home our survivor(s) and we have time to mentally and emotionally process a very complex experience. About this same time, others may assume that everything is OK, or expect us to "focus on the survivor," or even tell us how lucky we are. As one of CLIMB's original members whose triplet son was stillborn at 32 weeks put it, "Two out of three is not good when it's your baby who died."

What parents can do

Parents can help themselves by knowing that grief for a loss in multiple birth is truly complicated, and the process of trying to cope and heal is likely to be long. We grieve not because there is something wrong with us, but because we love our babies and something terrible has happened. It's easy to get confused, exhausted, isolated and angry. It's important to know that there can be some pitfalls and sticking points. Seek help if they occur, or if you become clinically depressed.

Every person and every situation is different, but if parents know they are not alone and that their feelings are valid, most can find within themselves the wisdom to know what to do. They also can be patient with themselves and others as they move toward a "new normal" in a future that is completely, unexpectedly altered.

When parents' support needs are met, it is much easier to relate to survivors in a

healthy way about their sibling who died. Support also helps parents find joy with a single child in a subsequent pregnancy, all without having to "try" so hard, or enshrining the multiples who died and making it hard for the other kids to match.

Friends and family can help

Even though it is often painful to see living multiples, their parents usually best understand our loss. They could never imagine

which of their babies they could live without. Rarely would a parent of multiples tell us "at least you have one." Parents of living multiples, and twins and multiples organizations, can help by letting parents know that they always will be parents of multiples, even though it is so sad that one or more of their babies could not be here with them. Avoid making anyone, including a prospective club member, feel that they have "flunked out" or been rejected by an elite group.

In families like Diane's with multiple survivors it's very important to know how they wish to have their living children identified—as twins or as surviving triplets. This is a major, constant source of discomfort and other parents of multiples are in a position to be sensitive about it.

What is most helpful is knowing that others appreciate what a really complicated and long-term loss experience this is, and that even though parents may be relating to any one part of it at a given time, it is really the whole thing they are reacting to.

Kindness and patience are never wrong. The willingness to try to see their experience from their point of view and what it means to *them* is important. Although people are tempted to make comparisons when it comes to loss, this tends to minimize loss rather than offer comfort. The words "easier" or "at least" are usually signs that an unhelpful comparison is being made.

People who say, "I don't know what to say" are much more empathetic than those

who try to tell us what to think or do in order to make it more comfortable for themselves. Asking, "How are you?" and then being willing to really listen is one of the biggest gifts anyone can give. For a caring person to simply say, "I can't imagine how difficult it must be" can be the biggest comfort at times.

It is not helpful for parents to "stay busy." Family, friends and multiples groups can help with meals, childcare, transportation and other practical things. Having time to rest and do what is needed in relation to the baby who died is very helpful. So is remembering birthdays and anniversaries of the babies, and mentioning the baby's name.

Nine helps for healthy healing

Many factors contribute to healthy healing. Here are the ones we at CLIMB find most influential.

1. Treatment by caregivers at the time of loss and how effectively they meet emotional needs
2. Supportive family
3. A willingness and ability on the part of the parent to reach out, even a little
4. Personality
5. Circumstances
6. Resolution of any medical questions; was the loss preventable?
7. Forewarning that a loss may occur
8. Religious belief; worldview
9. Availability of honest support over a period of time

Down the road

For many of us, it was a real surprise to find that we didn't wake up one day with everything suddenly OK ... that it was like it never happened... that we were the same person we were before.... that if we do everything right, some kind of "closure" and wisdom will suddenly arrive. This loss is not like broken bones or a very bad case of flu. It is more like adapting to something that is painful but has to be adapted to, and of getting comfortable with something that is very uncomfortable.

For most of us in the 5- to 10-year period and beyond, life is good—and at the same time, while our loss is much less painful, we will always have a love for our child or children who died and a loyalty to who we are as people and as parents as a result of our experience. ♡

After trying every means possible for three years, my husband Deron and I finally, through IVE, got pregnant—with triplets. We were overjoyed and felt like the pain and heartache of trying to conceive and build a family was behind us and we could move on to life's joys. Then, at about 20 weeks an ultrasound revealed that one of our sons had hypoplastic left heart syndrome. He would survive in my uterus because his blood flow was through my heart but would not, without major medical heroics, survive for much time after he was born.

We began the journey of seeing specialists, at first to confirm our son's diagnosis and then to seek answers to our questions. A pediatric cardiologist at Children's Hospital in Denver, Colo., was the first to confirm the diagnosis. After a three-hour ultrasound during which I was violently sick, we went to a room where he sat across from us and, in a very matter of fact way and without any emotion, gave us four choices: Do nothing, let nature take its course and provide only comfort care after the birth; put the baby on the list for a heart transplant, with little hope for success; perform a series of risky and controversial heart surgeries; or terminate the pregnancy altogether.

I can't put into words my state of mind at the time. Thinking back, I wonder if I weren't in some form of shock, like time was standing still. For a few brief minutes I focused on the doctor. I got the feeling that for this doctor, the news he was delivering was so ordinary, so matter of fact, completely clinical. I wanted him to tell me that he felt my grief and that he understood that the news he had just given us was devastating.

At that appointment I realized what I wanted from the medical professionals. I wanted someone to step out from the security and comfort of the clinical role and take a minute to acknowledge our personal tragedy. While most of the specialists during our pregnancy kept us at arm's length, we were incredibly fortunate to have a wonderful OB/GYN and a team of amazing nurses after our babies were born.

Upon hearing our four choices, without speaking the words to each other, we both knew the right answer for our son—to treasure him while I was pregnant and then provide him with comfort and love for how-

ever long we would get to keep him. But as the days went by we found ourselves doubting our decision and spent several uncertain and difficult weeks researching hypoplastic left heart syndrome, talking with experts and asking their opinions.

In our final medical interview, we asked



Jackson and Maxine, 22 months

Loss and blessing

by Diane Grothe

a very senior pediatric cardiac surgeon what he would do if it were his son. He gently told us he couldn't tell us what to do, but that death for an infant waiting for a transplant was excruciatingly painful, drawn-out and ugly. And that the heroics required to keep our son alive until a heart was available would be beyond extensive.

We circled back to our original decision. I think we knew all along that comfort care would be our final choice, but we needed to be good parents to our son by making the most informed and loving decision we were capable of before he was born. We also had to do our utmost to protect the pregnancy for our other two babies.

At 32½ weeks, Maxine Taylor, then Brady Alan, then Jackson Thayer were born by Caesarean. Each baby was swaddled and presented to their daddy and me, then whisked away to the special care nursery. While teams of experts poked, prodded, inserted tubes and put Jackson and Maxine on ventilators, Brady was simply given oxygen and love.

One of our babies' amazing nurses, Pam, was determined to get Brady's footprints while he was still with us. Now we have a treasured page with three sets of tiny footprints lined up. Prior to delivery, we also asked our family, friends and nurses to take as many pictures as they could and to not feel like they

were intruding. I knew that some time down the road we would be grateful for the pictures.

We had spent nearly four months planning for this, yet we were completely unprepared for the depth of love and sorrow we would feel. Deron brought Brady to me in the recovery room and we spent the rest of his short life holding and kissing him, touching him and trying to visually and emotionally capture for permanent memory every second of his short life.

As soon as I was stabilized, the nurses wheeled Brady and me from recovery into the special care nursery so our family could be together. It was important to us that Brady spend some time with each of his siblings, so the nurses moved aside the tubes and monitors to let them briefly be together in this world. Then, Brady rested on my chest, eyes closed, skin to skin. Finally, just four short hours after his birth, he slipped away. As Brady left us, our family gathered closely around my bed and we prayed. My mom recalls the nursery being filled with a powerful divine presence.

After Brady died, our family and friends went home, leaving Deron and me with our three children. As I lay in my hospital bed, I watched Pam gently guide my husband through the process of bathing and dressing our son. It was done with such dignity and respect. Then she led my husband, cradling Brady, to a room to take his picture.

My first experience as a mother was saying goodbye to my first-born son. We got to keep Brady for only four short hours, but his birth, life and death have left a hole in our hearts that will remain always.

It has been 22 months since our children were born and Brady died. We are able to see now that along with so much grieving over the loss of our son, his life also gave us countless gifts and blessings. So, when someone asks me, "How many children do you have?" or "Are they twins?" or says "At least you did not have three," I can't help but think, "I am the mom to three: two I am rearing and one who watches over us from heaven."

Diane Grothe lives with her husband and her twins in Ft. Collins, Colo.

Note from Diane: Deron and I realize that there are many options with HLHS and no right or wrong decisions. Every family must decide what is right for them and their children. Their decision may not be the same as ours.