

The loss of a twin or multiple in childhood



Every year, more multiples are being born. Sadly, every year there are many twin, triplet or higher babies who lived past pregnancy and birth, and even past the higher risk of SIDS and later complications, but then died after their first birthday from congenital problems, illness, accidents and other causes. Tragically, everything that can happen to take the life of a young child is twice as likely to come up in a set of 2 children, and three times as likely in 3... 4 times in 4... These precious children leave behind heartbroken parents and a survivor(s) who had been their companion 24/7 since birth. If you are having to cope with this tragedy, we are very sorry—and this is dedicated to these children and to their surviving siblings.

Other bereaved families are the ones who can most truly understand what you may be feeling now. The following is from a mother 5 years after her twin daughter died in a home accident when the twins were almost 2. She gave birth to twin boys 4 years afterward. We hope her thoughts and those of other parents in this pamphlet will give you some comfort and hope as you live through your grief and live with the unique challenges of the loss of a child from a multiple birth.

It is almost 5 years now that Kylee died. It has been hell, a lot of counseling and hard work to climb out of hell and a lot of love from people that care about us to help us find our new life that is full of blessings. People who meet me for this first time think I am so lucky, and I say, "No, not lucky but blessed." It is still very hard to explain to people about what happened but we do, Kylee is always our child. I miss being the mom to a little girl, no barrettes (hers sit by my computer), no Barbies, fill our house. I still hope for another little girl someday maybe via adoption.

Some days are still hard and I cry terribly for her. Some days I remember that awful day she died and it is unbearable. But then, I am called by one of the boys and I keep going for them. I know she would want me to be a good mommy for them. I am writing a children's grief book about our experience and hope maybe someday that will be helpful for other families that have experienced this awful pain.

My heart still physically aches that Kylee is not here and not playing with Kevin. He asked me recently if it was his fault Kylee died, Pam's fault, or Kylee's fault that she died. His questions come out of nowhere and I had to explain to him that it was no one's fault, don't ever think it was yours, unfortunately Kylee died in an accident. Those things still take your breath away, but we get through them one day at a time. I still get frustrated when people say stupid things like, "I could never live if my child died," and I have learned to say, "Well, you don't have a choice!" I can't stop living, I have to be here for Kevin, Cooper, Cole, my husband John, my family. Life goes on

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and the best thing I can do is honor her life, her memory, and be a good mommy, a good person and fill this world with joy and hopefully laughter, just as it would have been for Kylee if she were here with me.

Grieving-wise, I still have a heavy heart. But, I have mostly all good days now. Certain days are hard, all holidays, Mother's Day, first day of school, last day of school, birthdays and anniversaries are all hard. But we always do something to include Kylee. We go to the cemetery, we call it Kylee's place. We were able to move Kylee out here and she is buried at a beautiful cemetery in rural farm country (20 minutes from our house). Moving her there from where we were in the Midwest was extremely hard, like burying her all over again. But we have a family plot where we have planted trees, roses, and flowers near her grave. We can sit at her grave and see three mountain ranges. Foxes, bunnies, birds and squirrels surround her there and Kevin gets a tractor ride from Mr. Miguel the groundskeeper whenever we are there.

Probably the single most prevalent cause of the death of a multiple in childhood that we have seen is accidental drowning, most often but not always with children who are toddlers, as well as freak accidents in the home and elsewhere. Many twin or higher multiple birth children have also been lost to sudden illness, to cancer, to congenital problems or the longterm effects of prematurity (now that technology is allowing some children to live longer but yet is not always able to "save" them). We have known a number of families who have lost a twin or multiple child to SUDC, Sudden Unexplained Death in Childhood, the death of an otherwise healthy child who is over a year old. Though statistics do not exist (as far as we know) it is possible that childhood loss is somewhat more prevalent for twin and multiple children because of the greater rate of prematurity and of congenital problems and the possibility that young multiples may be more at risk for some kinds of accidents (some have speculated though we have no statistics). Either way, as with the other kinds of multiple birth loss, there is the sad reality that anything that can come up with a singleton child is more likely to affect a set. These children are usually the center of their parents' world, and so many of them have been born after years of trying to have a family. And even when there is a known illness, there is truly no such thing as an "expected" death emotionally—it is devastating for all parents no matter what else, and no matter how many others survive, along with carrying some very special challenges.

The loss of a young twin

There are many immediate challenges:

- **planning for a service and burial** Most families recommend including the survivor, no matter how young he or she is, because later they appreciate knowing they were there to say goodbye to their co-twin. Many recommend that the survivor, no matter how young, have the chance to see and spend time with his sibling at the funeral home or elsewhere as many times as they or the parents wish before the burial or cremation, and to place some special things with them of his and the parents' choosing. This is less frightening than having it seem like their twin disappeared from their life, perhaps without a chance to say goodbye or tell them something important. Parents who are grieving and distraught can ask for help from close relatives or friends with planning for the funeral and with helping their child with this, and with helping their child at the

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funeral. Parents also may face, and need support in, a painful decision of whether to purchase at the same time another burial plot so that the twins can eventually be buried next to each other.

- **the survivor** Parents may have a young survivor who is very upset by his twin's death, and may (for example) have witnessed the accident that caused it. Some parents have had young survivor who—like the parents—was especially distraught at night and had difficulty sleeping without the parents' complete care. In other families, the child may not seem to “notice” or react just yet, but needs the care of parents who are deeply grieving. It is important to communicate with the child's physician, and seek the help of a counselor who is attuned to bereavement in children. (The counselor, in turn, can consult by phone with others who have experience with twin bereavement.) It can be especially difficult to understand the reactions of preverbal and special-needs children, and experienced counselors can have ways of seeing what the child is expressing and suggesting what may be helpful. Again, it is important for parents to have the help of relatives and friends in caring for young children while grieving themselves.
- **fear for the survivor** Parents may find themselves feeling very protective of their surviving child, and anxious about what may happen to him, especially depending on the circumstances of the loss, and especially if the children were monozygotic (“identical”) twins. A family-oriented physician, a counselor sensitive to bereavement issues, and supportive, trusted family and friends are very important here too. (If someone is not sensitive or supportive, it's worth it to trust your feelings and seek and find others who are.)
- **dealing with others** Depending on the circumstances, parents may have to interact with many others: media, authorities, people who must be contacted about the death and the funeral—along with coping with the reactions of relatives, friends and new people. All of these take a huge emotional toll and require support for the parents. Parents are sometimes confronted by people who try to minimize their loss by saying that they still have a child, or know what they would have looked like because they were identical, and it is difficult to respond.
- **immediate decisions and realities in caring for the surviving child** One mother writes, “We were confronted with ‘the car seat’...oh my God, I can't tell how it impacted me when my Mom took out our daughter's car seat to make ‘room’ in the car for another person—purely logistical but so poignant for me that even now I cry thinking about it... it was just such a harsh reality. Also immediate was feeding our son alone, whoever feeds their young twins separately? I remember throwing a cup of yogurt across the kitchen and breaking down when I tried to feed my son for the first time without her. It was unbearable—and the same for bath time, bedtime routines, you need help with those but at the same time you need to keep some things the same for your survivor but also change some because they are so painful. We still sang and read books to him as much as we could, but we could NOT give him a bath, his dad started giving him a shower instead, since we could not bear to bathe him in the bathtub alone. Having help or someone staying with you helps this. Then there were all those firsts: going to the grocery store with one child, buying clothes, going anywhere where you brought them both is incredibly sad, overwhelming, and there's no getting away from it...parties, vacations, trips to the hospital can all cause huge panics, overwhelming sadness, and in a way isolation, because you just can't absorb all that pain every day.”
- **physical reactions** One mother said: “One of the immediate challenges was the physical ache for my child, I felt that a part of me was actually missing, as I imagine so does the surviving twin. Truly my body and heart ached for her for a LONG time –

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years actually, but you really don't know how to process this at the beginning." Sleep difficulties and difficulties functioning normally physically are also likely for parents over a period of time.

...and then:

- **the missing twin** One of the biggest challenges, during and after those first days, is what some have called having to adapt to a one-baby or one-child life, or (if there are other siblings) a family without "the twins". You will always be the parents of twins: but deciding what to do about sleeping arrangements for the surviving child... what to do about all the things of the twin who died... going out as what seems to be an ordinary, singleton family... seeing your child play alone... changing the way you did so many things because there were two... all of this and more are major, heartwrenching, ongoing challenges for parents and families. Parents stress that it's very important that these decisions about the child's things be family decisions, and not to permanently remove things immediately. The feeling of seeing half of what once was a whole, the feeling of half of a broken set are of course very common, along with being concerned for the survivor and what he is or may be feeling. There are also the constant reminders, especially for parents of identical twins who constantly see the image of who they also lost. With twins, most photos tend to be of both of the babies or children together, and there is really no way, even if parents wanted to, to go back and make "history" different... How to display photos, and if, when and how to let others know that their child is the survivor of twins and of a tragic loss, is a major challenge.
- **loss of "our twins"** Loss of being the parents of twins in the eyes of society, and of people who don't know the family, is also huge. At the same time, many mothers are involved in twins and multiples clubs, and find it a major challenge that now all their friends have living twins. Other mothers of multiples can empathize almost better than anyone else, and clubs can provide vital support, but it is difficult too. Many mothers find themselves realigning their social world and their support networks at a time when they are already feeling isolated and challenged emotionally and spiritually, and when what used to be the simplest thing can be a struggle.
- **the survivor** An ongoing process is talking with the surviving twin, and relating to all of his emotions and his questions, which will depend on his age and developmental stage at the time of the death of his twin, and then come up again and again in different forms as he grows and goes through more developmental stages. The mother whose twin daughter died at age 2 in a home accident, shared the questions that her daughter's twin brother asked then and in the coming years:

Questions Kevin asked after Kylee died

Why do some sisters have to die?

Why can't Kylee come down from heaven to play with me like Mary Poppins does?

How did Kylee get to the church (for the funeral)?

Why did Kylee go away at church? (after the funeral)?

When/how did Kylee go to heaven?

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Why did Kylee's body stop working? How did she get stuck? Why couldn't the doctors save her?

Was it my fault Kylee died? Was it Pam's fault Kylee died? Or was it Kylee's fault?

What does Kylee do in heaven?

Is your heart cracked because Kylee died?

When will I get to see Kylee again?

Why did you have to put her body in the ground, can't we dig it up and get her?

Why do you have Kylee's picture on those papers for the Giving Tree?

The same mother also writes: “You just feel like life is a fog. Everything is changed, and it never is the same. It is really a sad, lonely, isolating few years even with TREMENDOUS support and doing all the right things (counseling, Compassionate Friends, etc.). You spend a lot of time trying to make sense of what happened, you just feel no grounding for a long time. I think it is best to listen to your instincts about when you are overwhelmed or too tired or too sad. A lot of rest and healthy diversions are needed.”

A little further on ...

We have the impression that the initial adjustment period—the painful, complicated time involved for the family and surviving child to begin to adapt and regroup to the loss and to the changed family and be able to cope with the ongoing challenges—is something like one to three years.

And even then there are the ongoing challenges, “what about’s—“:

- **birthdays** — especially the first one, and especially if the birthday falls not long after the anniversary of the death. It can be really helpful to talk with others and see how they dealt with them. We have the feeling that for the first birthday after the loss, especially if it is not too long after, an appropriate goal for the parents and for the surviving child(ren) is just making it through. After that, traditions start to evolve in the family about how to include the child in some way who died while honoring and celebrating the living child, depending on what the living child needs and wants at that time. It can be really helpful for parents to take the day before the birthday to focus on the child who died, and to do anything that they want to in relation to that child (including feeling as badly as they want without having to put on a good face, and to do nothing else all day if that’s what they prefer).
 - Of course, much of this goes for **holidays** too, and it is especially difficult if Christmas or another special day is around the time of the loss. It is really important that parents make decisions about how things are done, and be honest about what their emotions and needs are, rather than going with pressure from others to ignore the child who died. Many families have special traditions they follow to include and honor the memory of their

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missing multiple.

- **counseling for parents** Sensitive counseling by a counselor attuned to bereavement issues has been really essential for almost everyone we've known, and especially if there are some special sticking points like guilt and self-blame (as there often is in accidental deaths)... Many parents recommend it as an "insurance policy" on coming through it all emotionally healthy, no matter how much other support there is. Some have been helped anti-depressants, though we don't know anyone who felt helped by them if they were not also accompanied by "talk therapy".
 - Most parents have found that they needed and benefited from **marriage counseling**. Men and women tend to grieve differently, and even when they don't, it is all a heavy burden for a marriage or relationship. With multiples, one parent may tend to focus on the child who died, and the other on the child(ren) who lived, and that can make things complicated too.
- **counseling for the surviving child** Many children have been helped by a counselor attuned to children's bereavement. Some have used a technique involving sand tray play with miniature people and objects to bring out what the child is experiencing and learn what would help most. Sometimes a local counselor can consult by phone with another therapist who is experienced in the "multiples" aspects if one is not available locally. More local programs for grieving children are being established and many children (including the little boy who is quoted above) have been really, really helped by participating in one for several years, and in summer camps and other activities for grieving children. A girl who witnessed her twin brother's drowning when they were 8 was helped by regular counseling and participation in summer camps and other events for bereaved children. The child may need to revisit therapy as needed if he or she is having trouble in school or reexamining aspects of their twin's death because of entering a new developmental stage. This counseling can also help parents know what is helpful. One mother writes, "We were told by several professionals to keep her things out, make a picture book for her twin, let him see, feel, touch her things when/how he wanted. We did this and he went to it when he needed/wanted to." Another mother says that one of the things that helped her son, whose twin sister died when they were 10, most of all was when he met another surviving twin teenage boy.
- **support groups** Many parents and grandparents who have lost a young multiple have immensely benefited by participating in a chapter of The Compassionate Friends or a similar group for the loss of a child (as opposed to pregnancy, birth, infant loss). All bereaved parents have so much in common, no matter what else our circumstances. We recommend checking out a group in advance by talking to the leader. These groups can also be a valuable source of other referrals in the community, including experienced grief counselors, and a source of resources such as books for bereaved parents.

and:

- **the family** — whether or not it is possible to have another child or children and if so, whether or not to do so. Some families gave birth to their twins at an age when they were grateful to have them as their entire family, or as the final additions to their family, and are now at an age when childbearing (and also often adoption) is usually not possible. Others face decisions about trying again, including with fertility technology, and then about whether they may have twins or higher multiples again. (If they do, there is the challenge of their survivor seeing what he is missing, and of others' needing to know that these are the family's second set of twins.)

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- **how to incorporate and remember the child in the life of the family** for all the years to come...while relating to the survivor's feelings, and to the many landmarks that come along, whether it's the first day of school, or so many other things. As the living child gets older, his relationship to his twin and the death of his twin, how important it all is or not to him, becomes more of a determinant in what the family does, and in most families this all evolves over time as well, and can change constantly as children go through developmental stages and life events.

With twin and multiples, there are some special challenges: when families talk about the birth of their surviving child, it is "when *they* were born", and what it was like when "they" were babies; photographs of the living child almost always include their twin, and so the twinship can always be an issue including with people who didn't know the surviving child or family before their loss. It's not really possible to not have the child who died not in the family history even if anyone wanted to do that, and yet it is a challenge of how to relate to others about the co-twin and the loss in so many different situations, and for the surviving child to do so.

From what we have seen over the years, we think that that the overall process of being in a "new normal" life that is truly satisfying—even though the child will always be dearly missed, and even though the parents will never be the same, "innocent" people that they were or as if the death of their multiple birth child had never happened—is 5 to 10 years, depending on a lot of these variables. At the beginning, that seems like an impossibly long time... later on it doesn't really...

Loss of a young triplet (or quadruplet or more)

Almost all of these things are also true for families with the death of one of their young triplets... but with some challenges from having multiple surviving multiples. It can be even more important to have the support of a caring physician, a sensitive counselor, and helpful relatives and friends in coping with the physical, emotional and other challenges while caring for the living children and for their needs in relation to the loss of their co-sibling. We have the impression that the period of acute grief and depression may be even longer for these parents, especially the mothers, because of their being stretched out, pulled in many directions by the care of the other children.

If the child who died was an "identical" (monozygotic) twin to one of the living children, there may be more concerns about how that child is relating to the death, and about his or her health and safety, than for the other, fraternal child. No studies have been done, but it is possible that the identical child is even more deeply affected than a fraternal survivor—but it could be the reverse, depending also on gender and relationship issues. The child who died may have been a special needs child after prematurity or other complications, and everyone may have had a "special" relationship to him or her. Or he or she may have been the healthiest of triplets who had been premature, and the loss was a special shock.

It is very difficult for most parents to go from the special status of being the family of triplets/high order multiples to appearing to be a family of "just twins"; and if the parents are members of a group for high order multiples, there are issues similar to those of twins parents with twins and multiples clubs. As the living children grow and develop, they may each have different feelings at different times about their lost sibling, and about whether they

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wish to be known as twins or as surviving triplets (or both depending on the situation). They may have different feelings about whether and how to include their sibling who died in their birthday, just as they may have feelings about whether to have a separate or joint birthday celebration with their living co-multiple.

Because the surviving children are multiples, and usually visible as multiples to others, there can be many daily challenges. One of the most difficult for all who have lost a high-order multiple is whether to allow their living children to be called, or known as, twins instead of triplets, or triplets instead of quads or more; and if not, whether to always refer to them as surviving triplets, quads or more. This is an intensely-felt issue that has so many dimensions, and families' ways of relating to it tend to evolve over time and experience. Another is events such as photographs: some families who have lost a young triplet always include a special teddy bear with the kids in their annual photo portraits.

Remembering

All families—twin, triplet and higher, and no matter at what age or circumstances their child died—have found that with time, they have mementos and remembrances, and ways that their child is always part of life. Some of these are: website posts, annual memorials, sending balloons to heaven, money to charities in their name, a bench in their name, a plaque, a rose garden, making stepping stones together... butterflies and candles at special milestones like graduations. Some families have founded annual walks and charitable foundations in the name of their child, with the participation of their surviving children. Some have become active in bereavement support. One mother, who lost her twin daughter when the children were 10, had the opportunity to sit and talk with a number of others who had also lost a child who was a twin or triplet and writes, “We also spoke about the answers we give to ‘how many children do you have?’ For some it was natural to mention their child who died, for others it depended on the situation and who was asking the question. But we all agreed that we always remember our precious children.”

There are no published studies, and few resources in this area...we very much hope that there will be some, as well as more mental health professionals' becoming knowledgeable in it. Some of what does exist, and some personal stories by parents, are included in CLIMB's website... A national and international parents' support group especially for the loss of a multiple in childhood is very, very much needed and hoped for. This article relates to the loss of a multiple who is about 10 years old or younger—information, research, resources and support are also intensely needed for the loss of a multiple in adolescence, teens and young adulthood.



Jean Kollantai, Center for Loss in Multiple Birth (CLIMB) Inc., September, 2007 ©
With thanks to Traci Lillich, Pam Bennett-Santoro (parents) and Elizabeth Pector MD
(editor)

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