

## **MONITORING SURVIVORS**

*by Dr. Elizabeth A. Pector*

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Raising children is a tough job, even when good advice is easy to find. Parents guiding survivors of a multiple birth loss find themselves navigating uncharted waters without a paddle. To help us steer a bit better, I have brought together medical and psychological facts, parent anecdotes, and recommendations from experienced counselors who work with bereaved parents and survivors.

### **Introductory Cautions**

We may never know whether medical problems or unusual behaviors in a surviving multiple are related to the child's inborn genetic traits, pregnancy or birth complications, physical or psychological trauma from the loss, parenting style, or family grief responses. Psychological relationships between intact sets of multiple children have not been studied as thoroughly as one might expect. Psychologists' opinions vary on the impact of womb experiences on children and adults. Many are skeptical about the significance of losing a wombmate shortly after birth. On the other hand, anecdotes and studies verify the importance of these losses for survivors and their families. Each family needs to draw their own careful conclusions after considering the information that applies to their particular circumstances.

### **How often do twins vanish or die in the womb?**

Between 1 in 2 and 1 in 5 pregnancies that start with two or more fetuses result in a twin or triplet vanishing in the first 12 weeks. If no loss occurs during the first trimester, death of one multiple later in pregnancy occurs in 4-8% of twin pregnancies, and 11-17% of triplets. Identical (monozygotic) multiples are at greater risk of prenatal complications and loss than fraternal (dizygotic), mainly due to placental problems and a higher rate of anomalies (malformations). Male multiples have a slightly higher risk than females of dying during or shortly after pregnancy. Looking at birth order of multiples, the first multiple baby out of the womb has a slightly better chance of survival than the second- or third-born in the same pregnancy, although these differences have become minor since medical care for multiple pregnancies has generally improved since 20-30 years ago.

What is the infant mortality rate? (How many twins or triplets die in their first year?) 1997 U.S. statistics revealed that 3.2% of live-born twins and 7.18% of live-born triplets died in the first year. Most of these losses occurred soon after birth. Prematurity contributes to many multiple losses. Multiples arrive early much more often than singletons, with half of twins and 9 out of 10 higher order multiples born before 37 weeks of pregnancy. The risk of SIDS is about twice as great for a twin baby as for a singleton. Loss of both twins from SIDS is thankfully a rare event, with

fewer than one in 100 families who lose one twin to SIDS at risk of a second heartbreak. Monitoring survivors of a co-twin's SIDS death is still usually recommended as a precaution.

### **Medical Consequences of Twin Loss**

Medical studies show that death of a co-multiple before 16 weeks of gestation generally does not result in any increased risk for the mother, or for the survivor, during pregnancy. A recent study, published in *Lancet*, revealed that about 20% of surviving multiples are at risk for neurological problems or delayed development if their co-multiple died in the womb. It is unclear how this compares to intact sets of multiples, who are also at greater risk of neurologic problems and developmental delay than singletons. Monochorionic (one-placenta identical) surviving multiples are probably at greatest risk of problems. Small studies have documented some fortunately rare, but serious, side effects in the survivor after a co-twin's death in the womb. These include brain, skin, kidney, gut or lung problems. Luckily, the outlook is very good for most survivors, but it is worthwhile to inform surviving child(ren)'s doctors of these findings so they can be on the lookout for problems in your little ones as they grow. Early intervention with therapy or special education can help children with challenges make great strides.

### **What do we know about multiple interactions in the womb?**

It is important to keep in mind that even genetically identical twins don't have an identical environment, even before birth. Differences in placenta circulation, fluid in the amniotic sac, and position in the uterus make each child's stay in the womb unique. Ultrasound studies can reveal differences in multiples' temperaments by the fourth month of pregnancy, with clear differences even in monozygous ("identical") pairs. Traits shown by each baby in the womb tend to persist after delivery, including tendencies to be active or quiet, to have regular or irregular cycles of movement, and to seek or avoid physical contact. Intriguing ultrasound studies done by Alessandra Piontelli showed that at 10-12 weeks, most monochorionic (one-placenta) twins, who are usually separated by a thin membrane, respond to their neighbor's movements. By 13 weeks, the dizygous (fraternal) multiples start responding to co-twin kicks, and by 15 weeks, all multiples react to stimulation by their wombmates. Patterns of interaction that develop in the womb between multiples tend to remain similar after birth, until about age 2-3, when other factors start to influence the twins' relationship with each other.

Although these observations are meaningful for parents who try to imagine how their children might have interacted, ultrasound findings don't prove the existence of complex prenatal social relationships. We know fetal multiples sense and respond to each other's movements, but we can't know if they interpret these movements as a sign that they have company next door. Detecting emotions such as love, jealousy, or longing for one's co-twin isn't possible with ultrasound. Even newborn twins often are surprisingly indifferent to each other. Some cry when they are placed close together, preferring to have their own separate corners of a crib. We do know that most survivors whose twin or triplet "vanished" in the first trimester would not have been physically aware of their co-twin in the womb before the early miscarriage.

Some mothers who have experienced intrauterine loss of a multiple report a period of peculiar, or increased, activity in the womb around the time one baby died.

Whether this movement was from the baby who died or from the survivor is unknown, and doctors have not discussed such reports in medical literature.

### **Are memories from the womb real and reliable?**

I am aware of children (usually starting about age 4) and many adults who report feeling unusually lonely after early loss of one or more co-multiples in the womb. Some children were never told that a co-twin or other co-multiples existed, yet state they felt sad inside their mother or ask where their twin or sibling is. Some sets of two or more surviving multiples have been overheard by their parents, again around age 4, talking about their memories of the "good ol' days" inside mom, including mention of co-multiples who died. Elizabeth Noble, author of *Having Twins*, believes she herself is a survivor of the early death of her co-twin in the womb. One mother of surviving multiples is a counselor who uses hypnosis in her practice. She has verified the accuracy of many prenatal or early childhood experiences recounted by her patients. There may be something real in such reports--something that scientific, analytical studies cannot easily identify. However, it is still important to take a careful, skeptical approach, as my counselor acquaintance does, and confirm as much factual detail as possible before drawing any conclusions.

Controversial techniques discussed in Noble's book, including primal therapy and hypnotic regression, produce troubling accounts from patients who "relived," under therapy, prenatal emotional trauma purportedly caused by the death of their co-twin. Prenatal awareness and prenatal memory are just as controversial as the techniques used to explore them. It is important for expectant parents who just learned about the death of a multiple in the womb to try to put these accounts in perspective. Even if there is some truth in tales evoked by hypnotic regression, studies reveal that most adult surviving multiples are psychologically well-adjusted, although some have a very real sense of loneliness or something missing. (More on this later).

### **Selective Reduction, Conjoined Twins, Selective Termination**

Several studies have been done on couples who selectively reduced a high-order multiple pregnancy from three or more fetuses to one or two in hope of a better outcome for the remaining children. These studies show positive psychological outcome in the parents, and no obvious difficulties in early childhood for the live-born children. Several sole surviving conjoined twins whose co-twin died during or after separation surgery have also been reported to have satisfactory psychological adjustment, although questions sometimes arise about their unique birth, surgeries and co-twin's death. Psychological studies of surviving co-multiples born after selective termination of one abnormal fetus have not been done, but it is reasonable to expect the outcome would be every bit as positive as the preceding two situations. Careful counseling of parents in all of these situations before any procedures are undertaken is imperative so they can be as knowledgeable as possible about the possible physical and psychological outcomes of any proposed treatments.

### **How can parental grief reactions affect children?**

Most studies of multiple birth loss have focused on the parents' grief reactions to loss. These studies reveal that parents grieve just as intensely for loss of a twin as for loss of a singleton. The grief process is, if anything, more complicated than

singleton loss. One obvious reason for this is that parents are trying to attach to an infant while simultaneously mourning deeply. Parents also are working through the loss of a special type of parenting (raising a full set of multiples together). They may additionally be adapting to other complications such as prematurity and special medical needs in survivors. Parents have been known to reject a surviving child, or alternatively might become smothering, overprotective and unreasonably fear that the survivor will suffer illness or death. As with any child, parents raising surviving multiples must strive to protect their children from infection or injury while still allowing him or her to explore the world, take risks, and learn from their own mistakes.

Parents who have lost a child, those who have been treated for infertility, those raising intact sets of multiples, and those who are raising premature or special needs children are all at greater risk of depression than the average singleton parent. Marital problems are also more likely in these situations. It is important for parents to take steps to enhance their own psychological health. This will prevent overburdening children with issues beyond their understanding, or saddling them with feelings of inadequacy, failure or guilt. Our children cannot, and should not, be our therapists. Some adult survivors report feeling rejected by their parents because they were not the same gender as the child who died, or feeling inadequate because however hard they tried, as a single individual they could never be "twins" to make up for their parents' disappointment. Psychologists, survivors and bereavement organizations reinforce the point that parents need to seek help for their own grief, for the sake of their children's mental and physical health.

It is important to avoid idealizing the child who died. In this regard, referring to a "guardian angel" or "angel twin" might have some negative impact on a surviving twin whose behavior is less than angelic. Many parents believe their deceased child's spirit is guiding their survivor, and I myself have referred to my deceased son being "with the angels and God." However, as children get older and understand our words, we should make sure we're not unintentionally conveying the message that the deceased child is perfect or better than the child who lived.

Finally, it is wise not to burden children with decisions about final disposition of their co-multiple's remains. Parents who have cremated deceased multiples, or have buried them in a "Babyland" section of a cemetery, wonder whether the surviving child should determine when, or where, to scatter ashes or determine a final resting place for the child who died. Some survivors may want to take part in such decisions as adults, but it is probably best to spare younger children from these choices. This issue hasn't been explored in professional literature, but parents have wisely pointed out that it could be unhealthy to keep cremated remains in a survivor's bedroom, or to place them too prominently on a shelf in the home.

### **How do surviving children react to early twin loss as they grow older?**

This question has received surprisingly little attention from researchers. An ongoing study in Australia should give us more answers about the medical and psychological effects of multiple birth loss. Studies of surviving multiples have involved adults who had lost twins at varying ages, and most of them actively responded to researchers' public calls for surviving multiples who wanted to take part in research projects. Virtually all writings about childhood survivors report on small numbers of children. There are important limitations in such data. For example, it is impossible to know without a systematic survey whether surviving twins have imaginary playmates more

often than singleton children. Anecdotal reports might not represent the majority of surviving multiples. Keeping these cautions in mind, the following is a summary of what is known.

Nancy Segal found that female survivors seemed to consider their twins' loss more significant than surviving twin men. Identicals in her study seemed more affected by loss than fraternal. Betty Jean Case and Joan Woodward noted the same trends in their interviews with survivors.

Anecdotes shared by a few dozen parents with me over several years, and reported in print by Dr. Elizabeth Bryan, Elizabeth Noble, Eileen Pearlman and others, indicate that some, but not all, surviving children exhibit behaviors that are typical of children affected by other types of loss and grief. A child's responses will obviously depend on his or her age and ability to understand death and twinship.

Talking with survivors about the loss from the time of birth is recommended by all authorities. Teens who are not told about their twin until adolescence may feel betrayed by their parents' withholding of vital information. However, other children told later about their twin are only vaguely curious about their co-multiples, or even proud of their newfound special history. Adults often find revelation of their twin's death to be a relief, giving them a reason for their lifelong sense of loneliness and incompleteness. When talking to younger children, you can mention the dead child's name, and that you are sad he or she died but also quite joyful that your survivor lived. Dr. Elizabeth Bryan has recommended that parents avoid creating a "shrine" for the child who died, although displaying photos or mementos around the house is a helpful way to maintain awareness of the deceased sibling.

In infancy, according to Dr. Eileen Pearlman, babies tend to absorb the emotions of people around them. It is therefore important for parents to get support for their own grief and to seek help from others to be sure their surviving children's emotional and physical needs are met during the time of the parents' most acute grief.

Some survivors have cried in a uniquely distressed way at the moment of their sibling's death, even if it occurred miles away. Others actually seemed to stabilize when a co-multiple died in NICU. Infant and toddler twins have reportedly been very clingy, sometimes wanting to be held or cuddled more often. A tendency for survivors to seek sleep or cuddling positions that mimic crowding or positioning in the womb have also been noted. Several parents have mentioned that their older infants and toddlers will stand in the crib, staring into space or babbling to the empty room. Mirror fascination starting at an early time in infancy has been noted by many parents, especially those with surviving identical twins. Sleep problems, including night terrors or nightmares, frequent awakening, or wanting to sleep with parents or older siblings has been mentioned by some parents. My son dances with his shadow, as does at least one other survivor I've known.

Consistent, tender loving care is critical for your living multiples in infancy. They depend on you and other adults to meet all their needs, including nourishment, stimulation and affection. This can be hard to provide if you, like some parents, feel distant from your survivor(s), possibly even struggling with feelings of rejection or blame toward them. Try to make sure that someone reliable will help care for your infant's physical and emotional needs if you are unable to do so. This may help minimize the long-term impact of parental grief.

Early childhood (three to five years old) is a time when survivors still react strongly to their parents' emotions. They are developing their own identity, show "magical thinking," and cannot understand abstract concepts such as heaven and the permanence of death. Children may think that they caused a death by wishing it, or might think their parents can bring their dead sibling(s) back. They often don't clearly understand what twins are until age 4, 5 or older.

Many parents of 2 - to 7-year-old survivors have observed their survivors playing with a fantasy playmate of the same age and sex as the child who died, even if they hadn't been told of the loss. Some children complain of loneliness or sadness. Dreams about the co-sibling by name (even if parents didn't tell the survivor about the twin who died), and/or sightings of an invisible person or child in the bathtub or on the stairs have been noted. Some solo twins may draw two people in a self-portrait, or one person with parts missing. A few children seem particularly drawn to intact sets of twins in preschool or daycare as best friends and playmates. Others become angry at intact sets or at drawings and photos of twins together, or tend to point out toys with broken or missing parts. Children may ask why their twin can't come visit from heaven to play with them.

### **Children need explanations about death to be as clear as possible.**

Avoid confusing euphemisms, such as explaining that their brother is on a long trip or is sleeping. Try to react neutrally to your child's pretend play and questions about death. Avoid overemphasizing your regrets about not being able to raise all your multiples together. A survivor shouldn't be made to feel she is inadequate because there is only one of her. Play with puppets or toys, and art activities, may help children express feelings about their loss. Picture books and early childhood books about life cycles may be useful. Introduce the topic of twins or multiples and reassure your child he/she is still a multiple, although this should not be a major focus in interactions with your young child. Cemetery visits or memorial rituals to honor the deceased twin, can be included in a survivor's life early on, although he/she may not feel sad or understand your own sorrowful feelings.

Middle Childhood (five to nine years old) brings greater understanding of death, although magical thinking is still apparent. School-age children can better understand abstract concepts, and can begin to understand the complicated feelings of parents raising surviving multiples (sadness at loss combined with gladness at having a living child).

Children at this age sometimes want to discuss the facts behind a sibling's death in great detail, often repeatedly, sometimes searching for causes. Survivors may feel guilt, wondering why they survived or if they caused their twin to die. Curiosity about what it would have been like to grow up with a twin might be expressed. They might tell perfect strangers either matter-of-factly or excitedly about their siblings who died at birth, or they might hide the fact from all but a few close friends.

Patience, availability, and willingness to answer your survivor's questions honestly while not blaming him or her for the death are healthy actions. Encourage creative expression of thoughts and feelings in writing or art. Accept your child's decisions about how and when to reveal their history. At this age, two surviving triplets can make their own choice on whether to refer to themselves as twins or as surviving triplets. Visits to a cemetery or memorial offer opportunities for survivors to express their feelings by releasing balloons, or leaving toys, drawings, or poetry. Don't be

surprised if they decide to run off youthful energy around the cemetery, as my 2-year-old surviving son and a 7-year-old surviving twin girl did a couple of years ago, when they chased each other during a visit to the twins' graves.

Pre-teens and adolescents may have difficulty verbalizing their feelings. They understand that death is not reversible and are both fearful and fascinated about it. They are preoccupied with establishing their identity and very concerned about how they appear to their peers. A tendency toward perfectionism, or feeling one has to "live for two" to prove their worth to their parents, has been described by some survivors in adolescence and early adulthood. There are many books about death or special needs in a multiple-birth sibling available (check with Dr. Pector for a book list), and reading fictional accounts of similar situations may help children of this age explore their complex feelings.

Adult survivors, as earlier noted, sometimes report a deep sense of loneliness or something missing. Since they don't have conscious memories of their twin, they may find it difficult to verbalize exactly what they feel they're missing. Many have found it incredibly healing, even in their thirties, to visit their twin's gravesite, to hear about their parents' memories of the twin pregnancy and birth, and to be given tangible mementos of their twin. Some survivors who lost a twin later in life have felt liberated by not enduring constant comparisons to their sibling, expressing a sense of freedom to develop as an individual.

### **Closing Thoughts**

Many survivors have entered helping professions such as medicine, ministry or teaching. They often show surprising empathy toward others in need. Studies in the 1970s showed surviving twin children, as a group, to be intellectually equal to singletons, while intact sets of twins showed delays relative to their singleton peers. Although surviving multiples may need to be watched for medical or psychological difficulties, the vast majority will prove to be normal, talented and sensitive individuals of whom we can be proud.

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