

REBUILDING LIFE AFTER LOSS IN MULTIPLE BIRTH

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Dreams and fears

For most parents, the ideal birth experience is a full-term health pregnancy with one or two babies, and bringing healthy children home in a few days. When many parents learn they are expecting twins or more, worries about premature birth, and loss of one or more babies, loom large. The outlook for most multiples is good, with the majority of multiple-birth parents eventually bringing all of their babies home, even if they arrive early; but there is a very significant number of families who experience the death of one or more, both or all of their babies at some time during pregnancy, or at or after birth.

When nightmares become real

What can parents expect when they do suffer losses during or soon after a multiple pregnancy? They may need to make tough, practical decisions first, then begin the hard work of grief--adapting to life without the outcome we expected. Grief for loss of a fetus or infant is a highly individual process, different for each bereaved person who must slowly weave the experience of loss into his or her life tapestry.

Mourning is complex when a multiple dies. There are many possible loss scenarios. Parents may grieve not only for children who died, but also for their past fertility problems, the premature end of pregnancy, and disability or health problems in survivors. Whether some of the babies survive, or whether parents' arms are devastatingly empty, mothers and fathers have lost the dream of raising all of their children as a set--the prestige and privilege of parenting twins, triplets, quads or more. Many parents find it painful for years to see healthy, intact sets of multiples in public. Parents may need more than the usual amount of time and empathy to cope.

Several studies show that mothers and fathers feel a similar intensity of grief and use similar coping strategies after multiple-birth loss. Yet differences, such as longer-lasting sadness in mothers or distraction through work and recreation in fathers, also exist. A good discussion of these issues is in Deborah Davis's book, *Empty Cradle, Broken Heart*. Learning about typical gender differences in mourning can help a couple avoid misinterpreting each other's behaviors, especially when they are also dealing with infertility, long hospitalization of a preemie survivor, and other issues.

The Center for Loss in Multiple Birth, <http://www.climb-support.org>, has been working for 13 years to support parents and professionals affected by multiple birth loss. Anyone suffering a loss in multiple birth is strongly encouraged to contact them for empathetic advice tailored to their needs. Lynda Haddon of Multiple Births Canada, www.multiplebirthsfamilies.com, has likewise aided bereaved parents of multiples for over a decade. Her leaflet, Loss in Multiple Birth, http://www.multiplebirthsfamilies.com/articles/ber_q1.html, outlines some of the important things parents can get and ask from their caregivers.

1. Mementos of an all-too-brief existence

Families have a short time to create priceless memories. A keepsake box with mementos of each child, including ultrasound or photo images of all multiples together, prenatal monitor strips, clinical items used for a preemie's care, caps, clothes, blankets, crib cards, ID bands, hand- or footprints, hair or fingernail clippings, should be offered after birth by the hospital.

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The most valued mementos are often images or sketches of all babies together. It is important for parents to have a chance to see and hold all babies together, at least once, or to be with them all in the same room if survivors can't come out of their isolettes. Parents who lose their entire set of multiples also need individual photos and mementos of each child to show each one's uniqueness; they have not lost a "combined baby," but two, three or more cherished lives. Even if parents or caregivers feel squeamish about placing a deceased baby next to a living one, most parents are glad later to have these memories. Without these experiences, parents may feel denial or confusion. In my case, it didn't seem that I had truly given birth to twins since I never saw my living and deceased babies side by side. Another woman who did not see her stillborn twin felt she was dressing her survivor for his own funeral instead of his brother's memorial service. Some cultures discourage contact between the dead and the living twin. Parents who do not want them together need to inform their caregivers so their wishes are respected.

2. Finding answers-Why did my babies die?

It is vital for parents to learn as much as possible from their medical professionals about the cause of loss. Autopsy and analysis of the placenta often reveal a great deal, even when death happened long before delivery. Autopsy is done with respect, and there is usually not much change in the appearance of the baby's body. Certain tissue samples must be obtained promptly to maximize the information learned, but a full autopsy can be delayed for a day or two if the mother is very ill and wants to see the baby before the procedure. Some parents refuse autopsy unless it will help their surviving child or other babies with a similar condition.

A conference with doctors a few weeks after delivery, when test results are back and parents are less stunned, gives families the best chance to hear and remember crucial information about their child's death. A list of questions and a notepad are essential tools. Parents often ask if such a tragedy could happen again, if there will be any long-term effects of the loss on any surviving multiples, and when they can consider another pregnancy.

Sometimes, even with written notes, a parent's memory gets confused. New questions may pop up months or years later, perhaps when planning another pregnancy. Parents may just need reassurance that they or the doctors made the best possible decisions. Parents need not be afraid to contact doctors for additional answers and discussions. While information can be found elsewhere about the conditions that led to death, the professionals who treated the child are best able to answer specific questions, taking into account the child's and family's unique factors.

3. Laying beloved children to rest

Important choices must be made for final arrangements when one or more multiples has died. Some parents are simply too overwhelmed to make these decisions themselves. A trusted relative or friend can then discuss the available choices with a hospital bereavement counselor or clergyperson.

It is hard for some parents to make final decisions for deceased child(ren) when their sick survivor(s) are clinging to life. Some choose to wait until surviving babies' outcomes seem clearer. If other multiples die, these grieving parents find a small sense of comfort in knowing their children are together in death. However, most parents with survivors prefer to finalize arrangements for the deceased baby within a few days. They can then focus positive, hopeful attention on their living children. It is normal for parents to feel guilty about leaving a survivor's side, even for a brief memorial service for the equally loved sibling.

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It can also be difficult to decide what to do for a "fetus papyraceous," a fetus who died in the womb between about 12 and 20 weeks gestation. This fetus is often identifiable in the placenta or in its own sac when its multiple siblings are born after a prolonged pregnancy. Parents must clearly let the hospital know their wishes for final disposition. Private burial and cremation are often preferred, and are not extremely expensive. Another option is hospital disposal, which is like cremation, but the dead fetus's body is not separated from other hospital tissue samples, and parents will not be able to get their child's ashes. Some hospitals offer periodic group burial of miscarried fetuses when death occurs before 20 weeks of pregnancy, or when a stillborn baby weighs less than one pound. The group burial site may be marked (although not with an individual headstone), and a ceremony may be held at the time of burial or annually.

4. Symbolic ceremonies

A family clergy person or hospital chaplain can be called for a special blessing, urgent baptism of a dying child, or a religious service after death. A service that recognizes all multiples as an intact set can be very healing. Some parents combine a memorial service for deceased child(ren) with baptism or dedication of survivors, either in the hospital or long after birth. There are services that can be developed to recognize the desire to baptize deceased children; some are available in Not Out of Mind by Althea Hayton <http://www.wrenpublications.co.uk/>.

5. Moving on through grief: Resources

My website, www.synspectrum.com/multiplicity.html, lists abundant resources for complications in multiple birth, including loss. Organizations, publications, websites and Internet support groups offer help for any scenario imaginable. For online support, ELIMBO, LAMBS, and Multiple Angels Network are among the larger. <http://www.tamba-bsg.org.uk/contacts.htm> lists some UK resources. My articles at www.synspectrum.com/articles.html, and Lynda Haddon's at www.multiplebirthsfamilies.com, help parents understand grief & special needs challenges and offer more resources.

In addition to specific resources in this article, many books on perinatal loss are available through organizations listed below and through online booksellers. Deborah Davis' Empty Cradle, Broken Heart has been cited by many parents and has excellent advice for parents who have suffered multiple birth losses.

Organizations:

SHARE www.nationalshareoffice.com

RTS www.gundluth.org/bereav

Compassionate Friends www.compassionatefriends.com

The Centering Corporation www.centering.org,

A Place to Remember www.aplacetoremember.com,

Perinatal Loss in Oregon www.tearsoup.com,

Pregnancy and Infant Loss Center in Wayzata, MN.

SANDS (Stillborn and Neonatal Death), Great Britain.

Professional resources (and for interested parents):

CLIMB articles: Multiple Birth Loss and the Hospital Caregiver, and articles for counselors in loss of one or loss of all multiples.

Multiple Births Foundation: booklets on bereavement, multiple pregnancy and special needs in multiples

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Dr. Pector & Dr. Smith-Levitin's articles in *Female Patient* and in *Seminars in Neonatology* on loss in multiple birth.

Limbo and Wheeler's [When a baby dies: a handbook for healing and helping.](#)

Wisconsin Stillbirth Services Program-- www.wisc.edu/wissp/

James R. Woods, Jr. and Jenifer Esposito Woods, *Loss During Pregnancy or in the Newborn Period*

Michael Berman's book [Parenthood Lost](#) and his website, www.hygeia.org

When grieving parents are patient and gentle with themselves, communicate honestly with each other and with caregivers, and seek professional help and peer support when needed, they maximize the chance of a gradual, healthy adaptation to their child(ren)'s sad death.

6. Supporting surviving multiples and siblings

A very thoughtful photo booklet by Judy Kidder, [The Special Brother](#), explains to young children from an older brother's point of view the death of a newborn twin, the parents' sadness, the funeral, and the continued importance and special status of each child in the family. Kidder is the grandmother of twins, one of whom died after surgery. Another book by Valerie Samuels, [Always my Twin](#), written for surviving twins, also is excellent for explaining this unique loss and letting the survivor express his or her own unique feelings about the situation. Lynne Schulz, the mother of a surviving twin now in late childhood, authored [The Survivor](#), with many anecdotes about surviving multiples.

Suggestions to parents on how to explain death to their children are found in:

- Dr. Sheri Siegel's compilation of developmental stages of grief, <http://www.synspectrum.com/childgrief.doc>.
- Elizabeth M. Bryan, [Twins, Triplets and More](#).
- Eileen M. Pearlman and Jill Alison Ganon, [Raising Twins : What Parent Want to Know \(And What Twins Want to Tell Them\)](#).
- Elizabeth Noble, [Having Twins](#).

Support for adolescent or adult surviving multiples is available through the Lone Twin Network in England, Twinless Twins International located in the U.S., and Lonesome Dove in Australia.

Special needs survivors

Support for parenting surviving multiples who have special needs is available through CLIMB, MOST (Mothers of Supertwins), other multiples groups, and groups dedicated to the special needs situation.

Special aspects of grief

1. Loss of all multiples

The silence is deafening when all babies die, as a mother of 37-week stillborn twins remarked to CLIMB. The sense of grief, failure and depression can be especially overwhelming if the multiples were conceived after long, expensive treatment for infertility, or if parents endured a complicated pregnancy or a long stay in the neonatal intensive care unit (NICU). Grief may be more intense than for loss of a single child. The parents, after all, lost two or more unique babies. Mourning might also go on longer than after a singleton's death. Two books that poignantly describe the depth of grief and challenges of life after both

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twins die is Christine Howser's [A Different Kind of Mother](#) from www.1stbooks.com and Donnali Fifield's [William and Wendell](#) available through www.timestwopublishing.com.

2. Loss with survivors: Sorrow and joy entwined

When some, but not all, babies die, parents face an emotional paradox: grief, hope and joy together. Mothers may feel confused--that they delivered one baby, half alive and half dead; or had two separate pregnancies with different outcomes, instead of twins. Parents, and those around them, may expect survivors to make up for the loss and eliminate sorrow. They bring consolation, but are not compensation. Jean Kollantai of Center for Loss in Multiple Birth has remarked that no person can replace another, even a genetically identical individual born at the same time. Most parents feel their surviving multiples are a source of joy...yet sadness may persist indefinitely. Occasional parents even feel resentment or blame toward survivors.

The sorrow for losing one twin or triplet is just as intense as when a singleton baby dies. For some families, sadness dominates, and parents are afraid to bond to a survivor because he or she could also die. Other parents are so busy with preemie survivors, or even a term baby, that grief is temporarily put on the back burner. Some of them feel guilty that they don't feel sad enough about the loss during these months. Delayed or interrupted grief is a normal reaction to a very abnormal multiple-birth outcome.

If a survivor will be in NICU for a long time, parents must tell caregivers how much they want to discuss their loss, if at all. Some deeply want to talk about children who died, while others, in the words of one parent, "keep grief in a shoe box under the bed" while concentrating on the complicated course of their survivors. Parents also should clarify with staff what they want surviving children to be called, and what labels they want on isolettes, e.g. triplets B and C, or Bryce and Caitlin Jones. Death of two triplets doesn't create a pair of twins. Most parents consider a living multiple to be one of the original number conceived, especially after a late pregnancy or newborn death. One mother of quadruplets feels she has B and C without A and D...two of her children will always be missing. Some parents, however, do call two survivors twins, especially after an early pregnancy loss.

Each parent finds his or her own way to cope with the emotional tug of war deep in the heart. Most authorities who work with bereaved parents of multiples say the sadness must eventually be faced...but it can take a few years for parents with premature or special needs survivors to have enough emotional energy to mourn for their child(ren) who didn't survive. Amy Tracy's article, *A Silent Sorrow*, from *Twins Magazine* is a good review of typical parents' feelings (including my own).

<http://www.preemieparents.com/articles/silentsorrow.htm>.

One practical concern is how to announce the birth. CLIMB has sample birth announcements which have proven helpful to newly bereaved families trying to find the right words to express their mingled joy and sorrow.

3. Trying again

Parents may face hard choices in their quest to build a family if they had difficulty conceiving before their multiples. While heartbroken, they must decide if they can physically, financially and emotionally go through assisted reproduction or pregnancy again. Some may need to try again quickly due to their age. Others will be unable to try again, and need to consider other options such as a surrogate mother, adoption, foster care, or a child-free lifestyle. Resolve, <http://www.resolve.org/>, and Inciid,

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www.inciid.org, two national organizations for infertile parents, offer peer support and information on these options.

Some parents crave a chance for a repeat multiple pregnancy, while others are terrified of the thought. It is important for parents to realize that no other baby, including even other multiples, will make up for the previous loss, although they may bring some joy and healing to bereaved parents. CLIMB now includes many families with "multiple sets of multiples," with various outcomes including loss. Online groups also help parents deal with anxiety following a multiple pregnancy loss.

Special loss scenarios

In the sections below, each circumstance discussed is accompanied by resources and suggestions.

1. High risk of loss or abnormality

With more than one fetus in a pregnancy, situations quickly become complicated. The threat of loss hangs over parents for days weeks or months in some high-risk situations. The anxiety can be draining. Parents should seek whatever support they can from family, friends, medical caregivers, community and clergy. Other help includes:

- local premie parent groups
- books about multiples, bedrest or preemies
- www.rarediseases.org,
- Sidelines (www.sidelines.org)
- Premie-1 (www.premie-1.org),
- Triplet Connection (www.tripletconnection.org)
- National Organization of Mothers of Twins Clubs (www.nomotc.org),
- Mothers of Supertwins (www.mostonline.org).

2. Early pregnancy loss

a. Vanishing twin/triplet before 12 weeks

Most parents, especially those who were very worried about carrying two, three or more babies to term, adjust well to the reabsorption of one fetus in the early weeks of pregnancy. However, parents who greatly wanted twins, or who knew about all of the fetuses soon after conception and saw them several times on ultrasound, may feel some grief. During the rest of the pregnancy, these sorrowful feelings usually ease. Parents have time to choose if, and how, they want to memorialize the fetuses who died early. They may or may not want to consider the ongoing pregnancy to still be twins, triplets or more. Lynda Haddon offers some thoughts on Vanishing Twin Syndrome at http://www.multiplebirthsfamilies.com/articles/ber_q10.html.

Medically, a fetal loss before 16 weeks does not appear to put the mother or surviving fetuses at any greater risk. There may not be much fetal tissue identifiable at the time of delivery when the death occurred before 10-12 weeks. Most parents choose to have the hospital arrange for disposition of fetal tissue with the placenta after delivery of surviving babies. Doctors and pathologists need to be notified

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after birth if parents want them to search for a fetus papyraceous so private disposition arrangements can be made.

For parents who feel strong sorrow after early pregnancy loss, it is hard to express feelings when there is little tangible evidence of loss. Some parents name the fetus, and remember with the help of an early ultrasound photo showing all fetuses together, scrapbooks, poetry, journaling, memorial websites or gardens, angel figurine collections, or a sketch of the surviving baby(s) with an angel or other symbol for the deceased.

There is controversy about the psychological impact of a vanished twin on survivors. From ultrasound studies by Piontelli, we know that one multiple fetus does not respond physically to a co-multiple's movements until about 12 weeks in a monochorionic pregnancy (one placenta, with thin membranes between fetuses) and about 15 weeks in a dichorionic (two-placenta) pregnancy, where the membranes separating twins are thicker. Although some adults whose co-twin died early in pregnancy consider themselves emotionally traumatized, most research does not suggest this is common or inevitable. The remaining babies have an excellent chance of healthy life and near-term delivery. For the mainstream viewpoint, see Joan Woodward's The Lone Twin and Nancy Segal's Entwined Lives. For the controversial viewpoint, see www.vanishingtwins.com, Elizabeth Noble's Having Twins, OPERA <http://www.opera.org.uk/> and William Emerson's writings on prenatal and perinatal psychology, <http://www.birthpsychology.com/healing/point2.html>. Regardless of one's opinions, a positive parental attitude and consistent, loving care in infancy go a long way toward nurturing the mental health of survivors.

b. Multifetal pregnancy reduction

Some parents face the unthinkable dilemma of being pregnant with "too many" after years of being unable to conceive. The option of reducing the number of fetuses, through multifetal pregnancy reduction at 10-12 weeks gestation, permits a better outcome for a pregnancy that otherwise might have been doomed to complete miscarriage, extreme prematurity, neonatal death or severe disability. Knowing that results are better for a smaller number of fetuses does not make this an easy choice, and decisions often must be made quickly.

For information about the procedure, see ASRM's pamphlet, http://www.asrm.org/Patients/FactSheets/Multiple_Gestation-Fact.pdf, and Dr. Tal Rapaport's booklet, The Dilemma within a Miracle, available through her at empathy4me@yahoo.com. An essay by Vicki MacLeod on factors considered by parents is available through loss@multiplebirthscanada, and a similar thoughtful essay by Dr. Deborah Davis is available through CLIMB.

The procedure itself distresses many parents, and grief reactions are fairly common for about a month in most cases. A minority of couples in some studies--about one-fourth to one-third--had anniversary sadness one to two years after the procedure. The vast majority of parents feel they made the right decision, even if a complete miscarriage occurred after the procedure, a possibility in 5% or more. Many parents are quite private about the reduction and tell no one, including immediate family. For thoughts on whether to tell surviving multiples or others, see Dr. Rapaport's The Dilemma within a Miracle, and Lynda Haddon's article at http://www.multiplebirthsfamilies.com/articles/ber_q111.html. One woman told me she planned only to tell her surviving children that other babies had died before they were born...without mentioning that it was during the same pregnancy.

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Parents sometimes ponder the sex or appearance of the reduced babies when they give birth to the remaining singleton or twins. They may wonder if they should have reduced at all, or to a different final number. Like many other decisions in multiple birth, parents would like to know where the other fork in the road would have led...and there is, unfortunately, no way to be sure.

3. Mid-pregnancy loss

a. Continued pregnancy with survivors after one fetal death

Lynda Haddon's article, [I Am Pregnant With Twins. One Is Alive, One Is Not](http://multiplebirthsfamilies.com/articles/ber_q14.html), http://multiplebirthsfamilies.com/articles/ber_q14.html summarizes the emotions and options parents face. Lynne Schulz's book, [The Diary](#), journals a mother's long hospitalization after one twin died in the womb.

It is common for parents continuing a pregnancy after one fetus's death to feel isolated, fearful, or freaky. Some parents grieve deeply and continuously until delivery and have trouble attaching or feeling hopeful toward remaining babies. Others push grief aside until after delivery, concerned that their grief could trigger labor or hurt the living babies still inside. Most parents feel distress initially, then compose themselves enough to consider options more calmly. In addition to Lynda's excellent article, CLIMB provides a newsletter with articles by parents who have faced this scenario. Some parents find it helpful, while still pregnant, to contact CLIMB and communicate in online networks such as ELIMBO to get support for prenatal loss of a multiple.

Possible choices include:

- Obtaining ultrasound images from earlier pregnancy as a memento
- Scheduling doctor's visits when other mothers expecting multiples aren't there
- Deciding whether to view the deceased fetus on ultrasound during the rest of pregnancy
- More frequent exams, ultrasounds or testing for the mother's and remaining baby(s)' health
- Naming the baby who died to help parents, survivors and siblings discuss feelings
- Photographing the deceased baby and all babies together after delivery
- Choosing burial, cremation or hospital disposition
- Deciding whether to view the baby at delivery, or later at the hospital or funeral home
- Developing a memorial service

b. Delayed interval delivery

In another situation unique to multiple births, sometimes one baby is delivered before it can survive, or when viability is questionable. Doctors may then hospitalize the mother and use medication to try to prolong the pregnancy. This can be successful for up to 3 months...but at other times does not work, and the rest of the babies are delivered within a few days or weeks. Of reported cases, roughly 40% of all the babies survive. Parents and doctors are guardedly optimistic.

Sometimes the firstborn lives in NICU for weeks or a couple of months while the mother is hospitalized on another floor. She is already a mother, yet unable to act out her role due to her continued high-risk

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pregnancy. This obviously causes frustration. It is important for a mother whose firstborn multiple is living to get pictures, see and touch her child as much as possible.

At other times, the firstborn dies, or is taken off life support, before birth of the other children. Doctors may hesitate to allow a still-pregnant, high-risk mother to hold a dying child. Either the grief of saying goodbye, or the mother's anguish at not holding her child alive, could trigger more contractions. Neither situation is easy. The mother may be afraid to hope or to grieve, feeling she's in limbo, "waiting to exhale."

Some mothers describe feeling "not pregnant" after giving birth to the first multiple, or missing "my twins." Mothers sometimes worry that the firstborn baby struggling for life misses those in the womb, or that the remaining babies in the womb are lonely. Due to sadness at a first baby's death, they may not feel much interest in the ongoing struggle to save the remaining children. On the other end of the spectrum are mothers who want no part of funeral arrangements when there are babies still waiting to be born.

As with a fetal loss in ongoing pregnancy, this situation raises many concerns and urgent choices at a time of high stress and emotion. Parents can consider:

- Holding the firstborn baby to the mom's belly to "say goodbye" to co-multiples
- Delaying final arrangements for the firstborn until the mother delivers the remaining child(ren)
- Scheduling a memorial or funeral service while the mother is still hospitalized. The hospital chaplain, funeral home director, and/or doctors can cooperate to let the mother help plan this.
- Photographing a firstborn baby who died, including some poses that will allow later computer manipulation to create a group photo.

4. Extreme prematurity (limit of viability)

Parents whose children are born very prematurely often do not know if the babies will live, or their future quality of life. Parents alternate between hope and despair, joy and sorrow, confidence and terror. With multiples, these feelings are additive and often conflicting. One may be doing well on the same day his or her sibling is at death's door. Parents are dealing with the shock of preterm delivery, learning the ropes of NICU, and trying to comprehend the reality that they indeed birthed two or more unique babies at once. William Woodwell's book Coming to Term: A Father's Story of Birth, Loss, and Survival, Jackson, U of Mississippi Press, 2001 gives a father's view of this experience.

Not surprisingly, the stress of NICU seems to be a bit worse for parents of multiples than for parents of singletons. Attaching to multiples in NICU may take longer than for singletons. It is important for parents to work with the entire NICU team: doctors, nurses, social workers, clergy, ethicists, and later, discharge planners, to make this stressful experience as understandable and positive as possible. Many parents have suggested that team discussions with many staff members (for instance, medical, social work and clergy) are worthwhile for complicated scenarios, such as deciding to continue or discontinue life support, contemplating surgery or an experimental treatment, and before discharge of any survivors.

If a baby is expected to die in NICU, most parents want to be present during resuscitation efforts and want to hold the baby alive before he or she dies. Photos before and after discontinuing life support, and if possible, photos with the other multiples, are treasured. Parents may want to bathe and dress the baby and

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have private time either in the NICU itself or a family room near the unit. Parents can choose to have clergy present during this time.

The first return visit to NICU after one baby's death is often the hardest. One woman described taking a shower, putting on make-up and getting ready for her "Academy Award-winning performance." The last place a grieving parent wants to be is right back in NICU. Some grief-stricken parents of preemie surviving multiples expect the remaining child(ren) to die, too, and do not dare to hope they will bring home a living baby. They may find it emotionally hard to visit their survivors, and may delay planning for discharge until the last minute. Other parents refuse to deal with grief until much later, living at the bedside of their surviving babies and pouring all their love into them. Counseling may help parents who find it hard to attach to the remaining child.

A resurgence of grief is common on the survivor's homecoming day, when parents confront the fact that the babies who died will never come home. Rooming in for one to two days before discharge, a formal discharge conference, and verifying that all home health care equipment and home nursing and therapy are arranged well in advance, enables a smoother transition home with survivors.

Grief support and preemie parenting support are recommended after discharge so parents don't feel abandoned. It is normal for preemie parents to feel unqualified to care for a child who was nurtured for months by a professional team. It is even more common to feel this way when one or more of the baby's wombmates died soon after birth.

Ongoing grief issues for some parents include second-guessing decisions to start, continue or discontinue life support. Later feelings of guilt may arise, regardless of the decision. Parents have contacted medical professionals years later, asking for a frank answer to whether they made the right choice. Reassurance from professionals involved in these decisions might help. It is important to understand that people usually make the best decisions they can with the best information available at the time. Counseling may help parents become comfortable with their choices and learn not to review them repeatedly.

5. Some abnormal, others healthy: agonizing options

Parents pregnant with some normal and some abnormal fetuses in a multiple pregnancy have heartbreaking options from which to choose. Sometimes the abnormal fetus is certain to die within a short time after delivery. In other cases, the abnormality might not be fatal, but the child's quality of life would be terrible. Parents make decisions out of love, choosing the better of bad options while considering the quality of life their child would have, and the impact of their decision on the healthy multiples. It is important for parents to find support for their choice, since they may encounter criticism, regardless of what they decide.

- The entire pregnancy can be terminated. Support is available from www.aheartbreakingchoice.com. Review the sections on choices and recommended reading. Publications from Wintergreen Press, Pineapple Press and the Centering Corporation may be particularly helpful. Also contact CLIMB, at www.climb-support.org, which can put you in touch with other parents who have made this decision and send you a newsletter, including stories from other couples.

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- The abnormal fetus can be selectively terminated, and the pregnancy continued with normal fetuses until delivery. Parents who choose to terminate an abnormal fetus grieve just as intensely as parents who suffer a spontaneous stillbirth. Again, support from A Heartbreaking Choice and CLIMB is likely to be quite helpful. A helpful booklet for parents who are grieving the selective termination is Embracing Laura, Martha Wegner-Hay, 1998. Available through Centering Corporation.
- The whole pregnancy can be continued to delivery, with an occasional risk of premature delivery or complications threatening the health of the normal babies. Parents who elect this choice may find help in planning from *Waiting With Love* at <http://www.erichad.com/wwl/multiples.htm>. Please review the suggestions from CLIMB for birth planning. Mothers in this situation sometimes don't want pregnancy to end, knowing the multiples alive together in the womb will be separated by death soon after birth. Writing letters to the baby who will die, and keeping a pregnancy journal helps some mothers cope with jumbled feelings. Some parents attach more strongly to one baby or the other. Dr. Elizabeth Bryan encourages parents to spend as much time as possible with a dying baby, since there will be a long life ahead to get to know his or her siblings. Hospice care enables families to spend meaningful time at home with a seriously ill baby whose life may last weeks or months. One mother whose singleton daughter died in hospice made a list of what she'd want to do in a lifetime with her girl. Before she died, her daughter enjoyed chocolate and a pedicure from mom.

6. Challenges of monochorionic (shared-placenta) twins

a. Conjoined twins

Decisions concerning medical care of conjoined twins are complicated by medical and ethical issues. Many conjoined twins are stillborn. Of liveborn sets, often one is stronger and has the major share of common organs, while the weaker baby may suffer from additional abnormalities that could be incompatible with life. Undesired media attention hounds many affected families, and most prefer to remain anonymous.

Some parents choose to terminate a pregnancy after diagnosis of conjoined twins; others continue the pregnancy and hope for the best. When parents opt for delivery, consultation with a center experienced at managing conjoined twins offers the best chance for survival and good health of at least one of the twins. Conjoined Twins International, available by phone at 520-445-2770 in Prescott, AZ, was founded by a grandfather of conjoined twins. The organization offers support and advice to a little more than half of affected U.S. families, according to <http://www.twinstuff.com/conjoined.htm>. When I interviewed the founder in 1999, he was very informative and supportive.

When surgery results in one conjoined twin's death, the adjustment of the survivor appears to be fairly good, according to articles referenced by Raffensperger. Parents who lose one or both may have private grief, not comfortable sharing their entire story in detail with others. Affected parents may find loss support from CLIMB from other parents of conjoined twins who died.

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b. Monoamniotic monochorionic twins

In about 1% of monozygotic (identical) twin pregnancies, there is no dividing membrane (amnion) between fetuses, and two fetuses share the same sac. The risks of cord entanglement and/or twin-to-twin transfusion syndrome are quite high, with up to 50% death rates of affected twins according to some studies. Others have quoted more optimistic figures with very careful management. Consultation with a high-risk perinatal specialist is mandatory. The Monoamniotic group, www.monoamniotic.org, is an online support network of parents who have been diagnosed with this type of pregnancy. Parents who have lost twins to this condition, as well as those with survivors, are members.

c. Twin-to-Twin Transfusion Syndrome (TTTS)

TTTS affects about 15% of monochorionic pregnancies (pregnancies in which twins share the same placenta). Dizygotic (two-placenta) twins do not experience this condition.

TTTS exists in a number of forms: acute or chronic, mild to severe. The prognosis is worse the earlier in pregnancy it is diagnosed, and the greater the difference in size between fetuses. There are several ways of managing this condition, including serial amniocentesis and laser coagulation of affected vessels. The latter is an emerging form of treatment sometimes still considered experimental. Either way, significant risk of loss can cause parents worry. Parents sometimes second-guess their choices later, wondering if they should have opted for the other form of treatment.

The TTTS Foundation, www.ttsfoundation.org, offers TTTS information, discussion forums for loss of one or both twins to TTTS, and excellent pamphlets on loss of one or both twins from any cause. Other specific resources include:

- Fetal Hope, <http://www.fetalhope.org> Founded by a family whose twins had TTTS.
- Twin2Twin in the United Kingdom at www.twin2twin.org. They list several sources of laser treatment, including:
- The Florida Institute for Fetal Diagnosis and Therapy, www.fetalmd.com. Support, including bereavement support, is available for patients of this institute.
- <http://www.twinttts.8k.com/main.htm> a nonprofit site with information and support.
- <http://www.twin-twin.org/>, an Australian support network for loss from TTTS.

7. High order multiples (triplets and more)(also called supertwins)

All statements in this article about the complexity of grief when multiples die are even more true when three, four or more fetuses were present at the beginning of pregnancy. It is important to understand that even when all babies are born healthy, parents of high-order multiples experience greater financial, physical, marital and emotional stress than parents of singletons or triplets, with higher rates of depression and divorce. Disability rates are significantly higher in sets of triplets, quadruplets and more. Loss rates are also correspondingly higher, and quadruplet and higher pregnancies are particularly at high risk of fetal loss, premature delivery, and/or health problems for the mother.

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Parents are first faced with the need to promptly decide if multifetal reduction is an acceptable option. There are many potential complicated scenarios, such as a set of identical twins, one anomalous fetus, and a healthy fetus all together in a set of quadruplets. If no losses occur during pregnancy, parents of very low birthweight babies may face the nightmare of two or more deaths in their set of multiples...possibly taking none home in the end. One boy may need emergency surgery during his triplet sister's funeral. Survivors may have serious, lifelong medical problems.

With so many considerations, parents will react to each new crisis differently. It is hard to stay afloat in a constantly changing sea of bad news, grief, and hope. Parents may never feel they can completely grieve. Those with two survivors may not be recognized as parents of triplets or more. They commonly hear from both family and strangers about how cute their "twins" are, and need to decide how aggressively to correct this natural misunderstanding. Parents may not fully process what they've endured until years later...and should seek whatever support they need, even if it's five years down the road. They will likely not find total understanding from any one source, but high-order-multiple organizations, preemie organizations, CLIMB, bereavement and special needs parenting resources can supplement their own sources of support.

No decision in a high-order-multiple pregnancy is easy, and parents may understandably review their choices for years afterward, wondering if they should have chosen differently. Parents who opt for multifetal pregnancy reduction may wonder what the reduced babies would have looked like. Parents who did not reduce might look at survivors, especially those who are very disabled, and wonder if they made the right choices for their children.

8. Loss from suspected medical error

Parents in this circumstance are in a touchy situation. They need information from the same caregivers they suspect caused their loss. Survivors may even be under care of the same team. Communication is vital, about both medical and emotional issues. Not all parents will choose to bring legal action. Poor communication and suspicion of cover-up are often at the heart of lawsuits. I know of parents who requested transfer of a seriously ill preemie to another institution because of lack of trust, and this may be an option, although not to be considered lightly. One study documented that civil litigation caused increased stress in people who were in psychotherapy for another reason. Independent counseling may help parents decide for or against litigation, and help them cope through the process. An emotional but insightful book, Barry Werth's Damages, follows a family, obstetrician and lawyers for both sides as a suit is brought on behalf of a severely disabled surviving twin following his birth with his stillborn twin. It might be difficult for some parents to read soon after birth.