

Preemies Today

Families Helping Families

PREEMIE OF THE MONTH:

Our first preemie of 2006 is Conrad Stryker Lee. Once a tiny preemie, he is now an active toddler. Here is his story, as told by his mom, Erin.

I can't believe this little guy, Conrad Stryker Lee, 20 months and bounding all over the living room, started out at 2lbs, 12ozs with a team of amazing doctors and nurses caring for him at the Washington Hospital Center. I remember those early days when the words, CPAP, A's and B's, and ROP were so foreign to me, but I learned the lingo quickly when I realized I had to be strong for my son, I had to know exactly what was going on with his care, I had to be his greatest advocate.

One minute I was seven months pregnant, roughly 29 weeks, and the next minute, emergency C-section. What happened? I, like many other preemie mothers, had some sort of unexplained "pre-term labor." I remember the morning after he was born feeling sad and guilty. Why didn't I get to the hospital sooner? Maybe they could've stopped the contractions. I'll never really know what happened medically speaking, but Conrad was ready for his debut and I had to be ready, too.

The first time I saw Conrad was the evening after delivery. The nurse wheeled me down to the NICU. I had to laugh at the irony as we passed the room marked childbirth class. We were supposed to have our first class the day Conrad was born. The hospital surroundings were so unfamiliar to me because I had never visited the labor, delivery, or maternity rooms – that was supposed to be part of the class.

I got my first taste of the NICU – saying the magic password, washing my hands,

meeting the nurses and doctors. My husband, Allan, had shown me some digital pictures of Conrad so I was a little prepared for the tubes. Conrad was so small, but already I could see what he might look like. The respiratory therapist told me Conrad should go off the ventilator the next day – that's good, I think.

Already I loved this little guy so much and I prayed very hard for his health and



safety. I had no idea what would lie ahead. And like every preemie mom who decides to breastfeed I got my first experience with the breast pump; we would become very close friends for the next eight months.

My first Mother's Day and Conrad was doing well in NICU. What more could a mother ask for, except that she really wanted him to be in her stomach still, but here I am holding him and watching those machines like a hawk.

During the eight weeks Conrad spent in the hospital, I couldn't really see friends or enjoy the birth of my son until I knew he was home and he was o.k. I was jealous of other pregnant moms who were making it full-term. I felt awkward when I told people I just had a baby and they

would say how quickly I lost the pregnancy weight (well I never really had a chance to gain much, but thank you.).

Everyone was very supportive and I felt like I had an opportunity to educate. To tell people what kinds of health issues a preemie might have, to be able to explain terms, signs to look for if they were pregnant. I remember being home after giving birth looking at my book, "What to Expect When You're Expecting" and buried in the back was something about having pre-term labor. I guess I missed that chapter.

Conrad's entry into this world was tougher than I imagined, but so is having a toddler. Motherhood is certainly a challenge, but I know that I am so blessed, my family is so blessed. Conrad is doing terrific. And when I used to think, when will he crawl, when will he walk, when will he say "mommy," I have to tell myself to slow down, don't rush him, enjoy every moment.

I could go on about specific health issues, but what I really want to tell you about is the incredible joy I get from watching Conrad play, run, and laugh. When he wakes up in the morning and he sees me, oh, that smile, that look of sheer joy! I look at the IV scar on my son's hand and I think how brave he is, how strong he is. He will never remember those first weeks of his life in the hospital and I will never forget them.

I owe so much to the nurses and doctors at WHC! They gave my husband and me such reassurance and hands-on training, a blessing in disguise. We are so thankful that Conrad is doing well. God bless all of our sons and daughters.

Focus of the Month:

Loss of an Infant

A baby's death is one of the most painful and traumatic experiences a parent will confront in a lifetime. Although nothing can take away the pain you feel right now, it may be helpful to know what others have experienced or found comforting as they struggled to deal with the intense grief that followed the death of their child.

It is important to give yourself permission to grieve. Grieving the death of a baby may last far longer than you and others expect. Frequently, those around you may be uncomfortable with the intense emotions you experience. Be patient with yourself, and do not expect too much too soon.

No matter what age, your child was and is a part of you, and when your baby dies, so did many of your hopes and dreams for the future. Choosing a name as well as having a funeral or memorial service can help affirm that you are a parent and have the right to grieve as long and as intensely as necessary.

Symptoms of Grief

When a baby dies, normal symptoms of grief are varied. Parental reactions and intensity of feelings may differ. Typical reactions include the following:

- Crying, loneliness, a feeling of isolation.
- A need to talk about the death and the details of what happened.
- Feelings of hopelessness, helplessness, depression.
 - Anger, guilt, blame.
 - Loss of appetite, overeating, sleeplessness, irritability.
 - Inability to concentrate, comprehend, or remember.
 - Loss of goals and aims in life, a sense of despair about the future.
 - Aching arms & frequent sighing.

Grief can last far longer than you or others may expect and has many ups and downs. The first year can be especially difficult when parents torment themselves with painful questions and statements such as the following:

- Why did this happen to my baby, my child?
- Why did this happen to our family?
- Why didn't I know something was wrong?
- Why didn't I go to the doctor sooner?
- It's all my fault!
- If only . . .

There may be no adequate or satisfying answers to these questions or statements. Anger and guilt are common reactions and usually accompany grief. Try to share and express these feelings as a way to release them.

The Impact of Grief on Marriage

The reaction to the death of a baby is as individual as the person experiencing it. Spouses or partners often grieve in different ways, frequently misunderstanding each other's reactions or needs. You may be reluctant to express feelings of sadness when your partner has had a "good day" or vice versa. Some partners may not want to talk about the death, yet still feel comfortable when the other needs to do so.

Many parents feel they must be "strong" for others in the family by not crying. Yet this stops a natural reaction. Tears are a tribute to the child who dies and a healthy release.

Grieving is emotionally, physically, and mentally exhausting and leaves little energy for anything else, including communication between spouses. While a shared grief brings many couples closer together, care must be taken to preserve relationships. Understand that the bonding between each parent and the baby may be at different levels, causing grief of different intensities. Share your feelings while keeping in mind that outward expressions of grief may indicate only a portion of what a person is feeling inside.

Husbands and wives may react differently to intimacy as well. While one partner may need and seek this closeness and the assurance that not everything has changed, the other partner may take the suggestion of intimacy as an affront, not understanding how anyone could think of intimacy when a baby has died. Recognize that these reactions are normal. With time and patience, most couples reestablish intimacy when both feel ready.

It is important for couples to understand that there are no simple solutions to these problems, no timetable or recipe for recovery. Every effort should be made to share what you are feeling. Your relationship may be uncomfortable for a while as you cope with these intense feelings and emotions.

Coping With Family and Friends

Friends, relatives, and co-workers may be uncomfortable around you. They may not understand the intensity of your grief or may feel helpless to console and comfort you. Consequently, many offer clichés or platitudes as a source of comfort. You may hear some of the following statements:

- You will have more children.
- You were lucky; it was early in your pregnancy.
- You're still young enough to have more children.
- You're lucky you did not bring the baby home from the hospital.

Statements like these hurt, but there is little you can say to well-intentioned people. Since they have not had your experience, it will be difficult for them to understand the length and depth of your grief and sadness. Another way family and friends may offer comfort is to suggest you have another baby. Let your family and friends know how important this baby was to you and ask them to be supportive by listening.

Subsequent Pregnancy

The decision of whether to have another baby belongs to you and your partner. There is no "appropriate" waiting period.

No matter what decision you make regarding a subsequent pregnancy or adoption, it will probably not change the length of your grief for your baby who dies. When planning another pregnancy, be aware that aside from the physical stress, subsequent pregnancies can often be difficult emotionally.

Surviving Siblings

Young siblings grieve, too, and can be passed over for support as being "too young to understand." Encourage your surviving children to talk about their baby brother or sister. Your children may find it helpful to share their feelings with others of their age who have experienced the death of a sibling. Reading material can be helpful.

Questions About Religious Faith

Your baby's death may cause you to challenge or question your faith or philosophy of life. For a time you may feel that life is unfair and meaningless, and that you have nothing to live for. Some of

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Local News:

Announcements:

New Resource Brochure
Preemies Today is proud to announce we have revised and printed our resource brochure, "Helpful Resources for Families of Newborn Premies." We will begin distributing this brochure this month in local NICUs as well as doctor offices.

January Outing

This month's outing will take place on January 21st from 3:00-5:00 in the conference room at Reston Regional Library. Please bring a snack to share. Preemies Today will provide drinks. We will have a winter storytime! You can RSVP to Mary Beth Hazelgrove at marybethhazelgrove@yahoo.com. Please be advised and follow the Preemies Today Illness Guidelines when bringing your preemie (especially during cold and flu season.)

Support Groups:

Take a Break

Preemies Today offers meal preparation assistance, babysitting, and other additional support options for preemie families in crisis. If you are in need of assistance or would like to help others please contact Sara at sara@teamchae.com

"A Friend to Talk to"

Our "Friend to Talk to" support line is up and running. Please feel free to give us a call and one of our preemie parent volunteers can offer you some much needed support. We now have a new toll free number to better serve families everywhere. The number is 888-712-3208.

NICU Support Group

INOVA Healthsource is continuing to offer a NICU Support group for current INOVA Fairfax NICU families. The meetings are held on the unit and vary month to month. The group is led by

Lynn Kuba, RN and is a great opportunity to talk about your experience in the NICU. For more information contact INOVA Healthsource at 703-204-3366.

Preemies Today Online Chat

Join us every 1st and 3rd Thursday of every month at 8:30 pm for an online chat. For more information contact Julie at jkippers@lmi.org.

Local Support Groups

Local support groups are going strong! On the 2nd and 4th Wednesdays at 7:30 pm we hold our local support group meetings. For more information contact us at preemiestoday@yahoo.com.

Yahoogroup!

Come and join our yahoogroup and meet some of our wonderful parents where you can exchange information on preemie parenting. You can look to subscribe at <http://groups.yahoo.com/group/PreemiesToday/>

Helpful Resources:

The following are some helpful resources available by phone and online:

Prince William County Social

Services:
www.co.prince-william.va.us/csb/programsandservices/

Fairfax County

Department of Family

Services:
(703) 324-7500
www.co.fairfax.va.us/services/dfs/

Social Security

Administration:

1-800-772-1213
www.ssa.org

SIDS Mid-Atlantic

(703) 933-9100
www.sidsma.org

March of Dimes

1-800-326-BABY
(703) 425-BABY (Metro DC)
www.marchofdimes.com

Sidelines National Support

1-888-447-4754
www.sidelines.org

Early Intervention/Infant Toddler Connection

Fairfax County- (703) 246-7121
Alexandria- (703) 838-5060
Prince William- (703) 792-7879
Calvert County- (410) 535-1955
Arlington County- (703) 228-1630

WIC

Manassas- (703) 792-4703
Woodbridge- (703) 792-7319
Springfield (703) 569-1031
Mount Vernon (703) 660-7100
Fairfax- (703) 246-7100

For a list of online resources please go to:
www.PreemiesToday.com

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your anger may be directed at God and, you may need time to re-examine your religious beliefs.

These feelings may be frightening, but it is important to allow yourself the freedom to raise these questions without feelings of guilt. A sense of purpose and control will return to your life, but this is a gradual process and there is no time limit. For many, however, faith provides support and often helps parents to accept the unacceptable.

Substance Abuse

It may be tempting to dull the pain of grief by using alcohol and/or (prescription) drugs, but this may only delay and therefore prolong the normal grief process. You cannot escape the pain of grief and disappointment until you have faced the intensity of these feelings head-on.

Suggestions That May Help

Pictures and other mementos seem to help parents grieve. Parents, however, who experienced miscarriage or infant death may have few of these. Many parents create memories by keeping a baby book or a special box containing hospital records, certificates, sympathy cards, pictures, and blankets.

Spend time with and talk with other parents who have experienced a similar loss. Sharing with these parents, in an atmosphere of acceptance and understanding, can ease the loneliness and isolation of grief. Those who have "been there" can truly understand and accept your grief. These parents can help you to understand that the most painful aspects of bereavement will soften over time and that you are not alone in your grief.

This article was reprinted with permission from The Compassionate Friends. Please contact them for support if you have lost a child.

Contact Information:

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The mission of The Compassionate Friends is to assist families toward the positive resolution of grief following the death of a child of any age and to provide information to help others be supportive.

Membership/Subscription Information:

We offer the Premies Today newsletter, family outings, parent support groups, preemie playgroups, and “A Friend to Talk To”, our call-in line for parents and families of preemies.

To subscribe to the newsletter please email us at premienewsletter@yahoo.com. If you would like to become a member of Premies Today please email us at premiemembership@yahoo.com. Our website is **www.PremiesToday.com**

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Mission of Premies Today:

The birth of a premature infant is an extremely frightening and life altering time. Premies Today strives to form a network of families to offer help, comfort, and understanding to one another through their knowledge and personal experience.

Premies Today
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