

for Val, Jack & Matthew

XXX



Holland

Experience is often what you get when you were expecting something else.

Welcome to Holland...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Colosseum, the Michelangelo David, the gondolas in Venice. You may even learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, Welcome to Holland.

Holland?!? you say.

What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.

But there has been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would have never met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has tulips, Holland even has Rembrandts. But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, Yes, that's where I was supposed to go. That's what I had planned.

The pain of that will never, ever, ever go away, because the loss of a dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things of Holland.

So the next time you feel compelled to stop with your baby to look at the flowers (even though you are late for work), or you laugh when he throws a ball clear across the living room (hey look he can throw!), or you get excited when he actually grows out of his clothes, or you get paranoid about the chicken pox outbreak (even though he HAS HAD the shot), don't let anyone tell you there is something wrong with you.

There isn't, you're the parent of a premie.

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When your baby is premature

Advice for new parents from Preemie-L parents

Having a premature baby can be a very lonely and frightening experience. In our communities there may be very few people who understand the specific problems facing parents of very early babies. Sometimes our babies are transferred to hospitals far from home and this can make us feel even more alienated and lost.

Most premature babies stay in hospital until around the time of their due date, and some for many months after that. The daily routine of travelling, trying to live in the world outside the hospital, maintaining a milk supply and coping with the sometimes all-consuming fear and heartache can be profoundly draining.

This advice sheet has been written by parents of premature babies in the hope that we can bring comfort to new parents.

The early days

The NICU environment is strange and stressful - the bright lights and complex life support machinery, the new language we need to learn to keep pace with our baby's care. For many parents it is like being dropped into a war zone where simply surviving will require every internal resource and every available support just to get through.

Feelings of guilt, grief, terror, anger and impotence are almost universal for preemie parents. So too are feelings of detachment. Very little in our lives prepares us for the helplessness we feel as we watch our medically fragile newborns being cared for by the experts.

Often friends and family don't know how to react, whether to congratulate you on the baby's birth or to look mournful. Even if your baby's health is precarious, it helps to name your baby and announce the birth.

If you want to breastfeed, you'll need to start expressing by the day after the birth. For many of us, this is the last thing we feel like doing but it is a uniquely precious gift to our babies and is something only we can do.

Parents often feel too stressed to be explaining the baby's condition to all the people who are concerned. Some parents find it helpful to leave a daily update on their voicemail rather than speaking to a number of people separately. You could also ask a family member or friend to be a contact person on your behalf.

Some suggestions for helping your baby

Participate in your baby's care as much as possible. Although your baby may look extremely fragile, you can learn to bath and change her, to care for

her skin if it is dry. You can learn how your baby likes to be touched. Through this process, you will come to recognise your baby's facial expressions and signals and become more confident about caring for your preemie.

Learn about developmental care and do what you can to protect your baby from light and noise. There is a pattern for an isolette (humidicrib) cover in one of the resource sites listed below. If your hospital doesn't provide postural support for the babies, ask if you can bring in your own.

Ask that your baby be given pain relief or sedation for medical procedures like intubation/extubation and eye exams. Put a courteous sign on your baby's isolette requesting that staff speak gently to your baby before touching him or beginning any medical procedure.

Begin kangaroo (skin-to-skin) care as soon as your baby is stable. Parents and babies alike find kangaroo care very comforting, and for many of us it is the beginning of feeling that we really are parents, after all.

Questions to ask your neonatologist
written by neonatologist and Preemie-L member Dr Doug Derleth

1. What are my baby's chances for survival, various degrees of handicap, and long-term health problems now?
2. What medical problems are affecting my baby now?
3. How can I get more information about my baby's problems?
4. How are those problems being treated?
5. What side effects could those treatments have?
6. Are there reasonable alternative treatments we could consider?
7. How can I get more involved in my baby's care?
8. What can I do to best nurture my baby?
9. How do I find emotional or spiritual support?
10. Can the newborn ICU's social worker help me with transportation, local housing, financial aid, or other practical problems while my baby is in the newborn ICU?

A few practical suggestions

Clarify how you access the neonatologist and how regularly you will be meeting.

Find out if your NICU provides resources for parents such as books, videos or articles for loan that you can take home.

If you have other children, find out if any inhouse supports exist, such as creche or toys.

Decorate your baby's cot with things that are significant to you.

Take regular photos (without flashlight!) using a constant toy beside your baby so you can measure his progress.

As your baby grows stronger, take hand and footprints to chart growth and to celebrate every step towards her coming home.

Sometimes you'll need to take a break from the hospital routine. Resting when you need to will assist your milk supply and help you "last the distance" when your baby has a long NICU stay.

Some voices from our parents

"I felt somehow like she got "kicked out" of my body and I still feel ripped off about losing the last ten weeks of my pregnancy. Having to go home without her was the worst day of my life. When I first got her home, I used to hold her and cry and cry because I felt like a bad mother for not carrying her to term."

"It was difficult for me to believe that it was O.K. for me to take a day off to get much needed rest. A NICU nurse told me, "If you don't get some rest, you can get sick and then you can't come to see your baby." Wow, so much for the 8-12 hour days when you're riding on postpartum guilt for your early bird."

"What my husband and I ended up doing was creating a tape of us reading stories and singing for the nurses to play to [our son] during those days when I wasn't able to travel to the NICU."

"One thing that I did, because I am very sensitive to smells, was buy some red bandanas and wash them and sleep with them next to my skin for a night or two. I would take them to the NICU and cover [my son's] eyes with it. I also left a note asking that the bandana be removed every time anyone else had anything to do with him. Whenever the bandana was replaced, [he] would calm down no matter what had happened.

"I found my babies did better when I read to them. It helped me feel like I was doing something motherly during those times when I couldn't hold them. After I was able to hold them, I still read to them while I held them. [My son] used to love to place his ear on my chest and listen to my voice rumble. All three liked books with an obvious rhythm, like Shel Silverstein and Graeme Base."

"I know a source that gave me great relief and helped me "keep it together" was seeing photos of the babies who had graduated the NICU ... I would scan the board for all babies close to 29 weeks and gain such relief looking at the "before" and "after" pictures."

"I don't know how common it is but I got postpartum depression only AFTER I got [my baby] home. I thought when I didn't get depressed during the NICU period that it wasn't going to happen."

"When [our son] came home, after 119 days in the NICU, we had local children come to visit via the living room window. They were eager to see their celebrity baby (he had been on TV and twice in the papers) so they all came to the front verandah, stared at him through the glass and had drinks and nibbles afterwards. Sounds daft but it met all our needs!"

Recommended reading

Newborn Intensive Care: what every parent needs to know by Jeanette Zaichkin, NICU Ink, Petaluma (Ca.), 1996. A detailed and friendly book that covers most medical and other issues parents are likely to experience in the first year.

Baby talk: for parents who are getting to know their Special Care babies by Dale Hatcher and Kathleen Lehman, Centering Corporation, Omaha (NE), 1989. This book can help you understand your preemie's facial expressions and signals, so that your interaction can be as strong as possible.

Recommended Web Sites

When you have a premature baby, you may well feel like a stranger in a strange land. If you'd like to talk to other parents who have been there, Premie-L is available as an email list and a web based bulletin board.

So you know someone who's had a premature baby? Advice from Premie-L members for friends and family of anyone who has had a premature baby.

Susan Warren's web page Miracle Sam: Very Important Premie includes guidance on learning to handle your baby without overstimulation, advice on lactation, caring for a central line, and instructions to make a fitted cover for an isolette (humidicrib) which can later be converted to a cot quilt.

Emotional Responses of Parents by Jane E. Brazy, Ph.D. is part of a invaluable web site For parents of preemies: answers to commonly asked questions

Michael T. Hynan, Ph.D, author of The psychological pain of premature parents: a guide to coping, Lanham (Mass.) University Press of America, 1987 has a home page that includes the text of talks given on parent perspectives and a list of academic references. Fathers often find his writing especially

Emotional Responses of Parents

Having a premature baby is one of the most stressful experiences a parent can have. Most parents find it very difficult to go through the experience of having their baby in a NICU (Neonatal Intensive Care Unit) without needing emotional support. It is normal for parents to feel overwhelmed by stress and confused by their feelings.

How can I get help?

The doctors, nurses, and social workers on the unit can be wonderful sources of support. Many hospitals have parent support groups. These groups include parents who have already gone through what you are facing now. Advice from these veteran parents can be very comforting. If your nursery does not have a support group, there are support groups on the worldwide web (see References/WWW links).

What are some common feelings of parents of premature babies?

* I feel guilty that I did something to cause my baby to be premature.

This is a common reaction of many parents. It is important to realize that many parents of premature infants feel some guilt, even if they took excellent care of themselves during pregnancy. Mothers who have had excellent prenatal care, who have watched their diet, and who have neither smoked nor drank alcohol may still have premature babies. It will be important to find out if the doctors know what caused your baby to be premature. In most cases, the cause will be something out of your control. Talking with your doctor or others will help these feelings of guilt go away.

* I worry that I don't feel more love for my baby.

When premature babies are born, almost all parents have some fear that their baby will die. Because of this fear, parents naturally have what is known as anticipatory grief. Anticipatory grief is a way of preparing yourself emotionally, in case your baby would die. Anticipatory grief both helps parents and causes them problems. Anticipatory grief helps reduce the pain already felt by premature parents. For example some parents of premature babies delay giving their baby a name. These parents believe that their baby's death would be easier to adjust to if their baby had no name. This fear of death

parents. And this is the reason why many parents wonder why they don't love their baby more. When their baby starts to get healthy, almost all parents of premature babies re-establish their bonds of love with their baby. If you find that you continue to have problems loving your baby for a few weeks, it would be helpful to talk to someone on the medical staff. They are very familiar with your worries because this worry is very common.

* I am grieving

Having a premature baby involves many losses. It is natural to grieve. During pregnancy and even before, parents create many hopes and dreams for their expected baby. You may have had hopes for a boy or girl, blue eyes or brown, dark hair or blond. You also had hopes for a healthy, full term baby, and these hopes were shattered. You are coping with shattered dreams now, and that involves grieving. Many women also feel inadequate that they did not carry their pregnancy to full term. Often mothers of premature infants feel that they are not complete women or mothers. You want to do so much for your baby, but there is little you actually can do while your baby is sick. It is normal for you to grieve the loss of the pregnancy and health baby, just as you would feel sorry if someone you loved moved away from you or died. Support from others can help you in your grief.

* I am worried that my baby will not know that I am his/her parent.

It is normal to have this worry, but it is very likely that your baby already knows that you are its parent. Babies learn to recognize their mothers voices while they are in the womb. So a premature baby can already tell the differences between its mothers voice and the voices of nurses and doctors. It has been shown that the oxygen saturation of premature babies improves when their parents are close by.

Unfortunately, the treatment of premature babies required painful procedures that are done by doctors and nurses. But this gives babies the opportunity to learn that their parents do not cause pain. So when you gently stroke your baby, talk softly. Your baby will then learn that you have the voice that is special; the voice that gives comfort, the voice your baby will want to go home with.

* I am worried that the treatment in the NICU will have long-lasting emotional effects on my baby, which will be bad.

Research indicates that there are no long-term emotional effects of the painful procedures used in the NICU. Premature babies grow up to be just as emotionally normal as babies that are born healthy at full term.

* I am afraid to ask questions of the doctors and nurses

Having a baby on the NICU is the quickest way for any parent to feel dumb and ignorant. There are so many medical terms and abbreviations used, that no parent (even those with PhDs) can understand them all.

Many parents are afraid to ask questions because they don't want to appear to be dumb. But remember that the doctors and nurses had to go to school for years to learn these terms, so they certainly can't expect that you will learn it all in a few weeks or days. And it is very important you to understand what is going on with your baby. Most of the time getting an answer to your question will help to reduce your worries. Please ask questions. There are no dumb questions. If you feel confused by what is going on, try to have someone else with you (your spouse, your own parent, or a friend) when you ask questions. This may clarify your understanding.

Why are my spouse and I not communicating well about how we feel?

Mothers and fathers tend to cope well together during the early days of having a premature baby. This togetherness comes from the realization that often there is a danger threatening the family. Later on, many mothers and fathers have different ways of coping with a premature baby. This difference is usually easy to understand. For example, many mothers take longer than fathers to grieve over not delivering a healthy baby, and fathers may not understand this. Fathers can also become frightened over the mother's health and become more over-protective than the mother wishes. Both mothers and fathers become frustrated over the roller coaster of emotions they feel when their baby has setbacks. This frustration may lead to anger. Another source of frustration comes when parents feel that they are often powerless to help their baby's recovery. But parents are not powerless. Parents can learn to accept that it is OK for each other to have different ways of coping with a premature baby. Then parents can help each other cope, rather than be irritated because the other person is being insensitive. This understanding is really the best way to cope as a family.

Why am I afraid even though my premature baby is getting healthy?

Unfortunately, many parents find that fearing for their baby's life does not go away as rapidly as they would like. Even when a premature baby comes home, some (perhaps many) parents have flashbacks of fear about their baby's birth or hospitalization. These are normal reactions to the stress of having a premature baby. Sometimes parents feel like they are not normal because they are still afraid, even though they "know in their mind" that their baby is healthy. Realizing that these flashbacks are common helps parents to cope with them. The flashbacks decrease over time and they do go away.

Why do I feel sad and depressed and have so little energy?

Sadness and depression are common reactions to having a premature baby.

Everyone dreams of giving birth to a healthy, full-term baby. Not having this dream come true is a natural cause of sadness. No one in their right mind would want to experience the following sequence of events: mother on bed rest, an emergency C-section, fearing that mother and baby might die, visiting the NICU day after day after day, hearing bad news about the baby's health, worrying about the rest of your family and facing huge amounts of debt.

Even taking a healthy premature baby home is a source of stress. Parents who are sad because some of this has happened are having very normal feelings.

Sadness and depression may become excessive, however. If feelings of depression become very troublesome, it would be wise to ask the medical staff for help.

Are my fears and feelings excessive? Am I going crazy?

The majority of parents of premature infants feel this way, so these feelings are not signs of insanity. Unfortunately, having many feelings of distress is a normal coping pattern for parents of high-risk babies. Here are some common fears and feelings of parents of premature babies.

- * "When the telephone rings at home I panic because it might be a call from the hospital with bad news."
- * "I am afraid to walk into the hospital because something bad may have just happened."
 - * "I am afraid that I won't find my baby in the isolette."
- * "This experience has been so terrible that I sometimes wish that my baby would just die, so that the whole thing would be over. I feel like an awful person for thinking this."

Many times parents are afraid to talk about these feelings because parents are concerned that someone will think that they are coping poorly. Experienced members of the medical staff and other parents of premature infants have come to learn that feelings like these are common. It can be comforting to talk about these feelings with someone who can understand you.

Why am I angry with the medical staff about my baby's treatment?

The causes of anger are pain, suffering, and frustration. Parents of premature babies are in frustrating situations that produce pain and suffering; so, of course, many parents will feel anger. Often parents are

afraid to express anger to the medical staff, but this fear should not stop parents from expressing their concerns. A recent emphasis in perinatal care and neonatal care is called "Family-Centered Care". This means that the medical staff is concerned with the well-being of families, in addition to the well-being of babies. In order for "Family-Centered Care" to work well, parents should be encouraged to express their concern, even if they are angry concerns.

Resources

Helping Parents Cope with High Risk Birth

Mike Hynan's Home Page - links to more detailed information, and resources on coping with NICU

Emotional Survival Guide for Premie Parents - by mother of premie

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Contact jebrazy@facstaff.wisc.edu for corrections or comments.



T-Bone's Survival Tips for New Premie Parents
suggestions to help parents, family and friends cope with
the birth of a premature baby

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Tyler Alexander Bone  
10.23.96  
31 weeks, 2 lbs 15 oz

[IMAGE]

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There are two ways to live your life.  
One is as though nothing is a miracle.  
The other is as if everything is.  
-Albert Einstein (fellow premie)

(page down for contents)

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The Special Mother

Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit. This year thousands of mothers will give birth to a premature baby. Did you ever wonder how mothers of premies are chosen?

Somehow, I visualize God hovering over Earth selecting His instruments for propagation with great care and deliberation. As He observes, He instructs His angels to make notes in a giant ledger.

Armstrong, Beth, son. Patron saint, Matthew.
Forest, Majorie, daughter. Patron saint, Ceceila.
Rutledge, Carrie, twins. Patron saint... give her Gerard. Hes used to profanity.

Finally, He passes a name to an angel and smiles, Give her a premature baby.
The angel is curious. Why this one, God? Shes so happy.

Exactly, smiles God. Could I give a premature baby a mother who does not know laughter? That would be cruel.

But does she have patience? asks the angel.
I dont want her to have too much patience, or she will drown in a sea of self-pity and despair. Once the shock and resentment wear off, shell handle it.

I watched her today. She has that sense of self and independence that are so rare and so necessary in a mother. You see, the child Im going to give

her has his own world. She has to make it live in her world and that's not going to be easy.

But, Lord, I don't think she even believes in you.
God smiles, No matter, I can fix that. This one is perfect. She has just enough selfishness.

The angel gasps, Selfishness? Is that a virtue?
God nods. If she can't separate herself from the child occasionally, she'll never survive. Yes, here is a woman whom I will bless with a child who comes in a less than perfect way. She doesn't realize it yet, but she is to be envied.

She will never take for granted a spoken word. She will never consider a step ordinary. When her child says "Mommy" for the first time, she will be witness to a miracle and know it. When she describes a tree or a sunset to her blind child, she will see it as few people ever see my creations.

I will permit her to see clearly the things I see - ignorance, cruelty, prejudice - and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life because she is doing my work as surely as she is here by my side.

And what about her patron saint? asks the angel, the pen poised in mid-air.

God smiles. A mirror will suffice.

-Adapted from
Erma Bombeck
Motherhood The Second Oldest Profession

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For many parents, the birth of their premature baby leaves them short on support, understanding and compassion from others. It can be an isolating, lonely time. Many parents find themselves depressed, angry, and frustrated, and left wondering if their lives will ever return to normal.

My intention for this website is for it to offer encouragement, compassion, and understanding - the kind that can come only from others who have made the same journey through the world of premature parenting. I hope no other parent ever has to endure the loneliness and misunderstandings that I did when my son was born. It is my hope that the information found here will help make the NICU roller coaster maybe a tad more bearable. I wish that the support you find here can assist you in discovering hope, love and joy that can be found by sharing in your preemie's life. That's what having a child is all about, even for parents of preemies.

Everything here is intended to help others who are faced with a preterm birth. Read the information for yourself. Print it out for friends and family to read. Read the information again. Link up with other preemie parents for support. Read the information once more. Have faith that you will find strength to deal with all that encompasses a premature birth. And once you have found the strength and courage to heal, take my hand and help another new parents. Know wherever you are, you are not alone in what you are feeling. You are the normal parent of a preemie.

If you would thoroughly know anything, teach it to others. - Tyrone Edwards

God Bless You and Your Miracle!  
Kerry Bone,  
mom to Tyler, 31 weeker , 10.23.96

My Story  
Tyler's First Year in Photos  
Photos Page Two  
Photos Three

The Basics Every Parent Should Know From The Start...advice and tips for all preemie parents, those just starting out on their NICU trip and seasoned veterans

Those Special First Visits with your baby

How to Touch a Preemie a guide to overstimulation when touching your baby

Leaving the Hospital without your baby

Riding the NICU Roller Coaster dealing with setbacks

Asking Questions who, what, when, where, how,

Taking Care of Yourself don't forget this!

Pumping and Breastfeeding - part one -the emotional side of expressing breastmilk

Breastfeeding, Part2 - covers beginning breastfeedings and transitioning, along with special situations that affect breastfeeding success

Discontinuing Breastfeeding -discusses the emotional pain that mothers feel when giving up breastfeeding and/or pumping

Emotions and Feelings that every parent feels (75% finished)

Depression post partum and otherwise (75% complete)

How Your Family and Friends Cope insightful explanations on the reactions of grandparents, other children, friends and family

Your Marriage adjustments with your spouse

The Preemie Dad (under construction)

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A Primer for those Touched by a Preemie —What every Friend and Family Member should know...

suggestions for helping, understanding and supporting the parents, which each and every friend or family member should read...

Understanding Preemie Parents Part One -informative guide that explains what parents feel, deal with and go through when they have a preemie.

Understanding PP Cont'd Part Two —

a primer for offering help, support and understanding to the preemie parent.

Must Read Tips!!! suggestions on how to treat the preemie parent.

The Grandparent Factor getting along with the grandparents of your preemie - a guide for the whole family

A Parent's Wish a simple list of wants...

From a Preemie Parent... this letter offers insight and guidance to others as only a parent can put it.

How to Help the Parents a list of suggested ways to help the family.

Special Circumstances

Guidance and support for unique challenges that meet parents of a premature baby.

Insight -a Single Preemie Mom

Facing Surgery in the NICU

Making it With Multiples (under construction)

Discovering a Disability (under construction)

Facing the Loss of Your Baby (under construction)

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Am I The Only One Feeling This Way?

The answer is a resounding "NO!". Here you will find articles from The Early Edition, a web-based preemie newsletter written for parents, by parents.

They offer coping skills for situations specific to a preemie parent.

Dealings-comparing yourself with other parents, preemie and fullterm

Guilt after a preterm birth

Dealings giving yourself permission to fall apart.

Your Thoughts Here-holidays - coping with the holiday blues...

A Home for Your Thoughts dealing with comments from people who Don't Have A Clue (DHAC) about the NICU or preemies

Your Thoughts Here talks of the difficulty of dealing with other's pregnancies after a preterm birth

Support&Understanding - a page listing the links to all the articles in this section, and others!

After the Baby is Home...

Oh the fun never ends! Read on for more help...

Isolation - during RSV season and the early months of homecoming

Homecoming (under construction)

Adjustments, Flashbacks, etc.. (under construction)

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Inspirations, Poems And Stories Related to Preemies Which Offer Encouragement

You can't imagine

Holland

God's Child

Describing A Hero

Why I'm Glad I Had a Preemie

Preemie Purple Heart
In The Palm Of My Hand
Blessings in Disguise
Heaven Scent
Time
Faith
Look On The Sunny Side
Lessons From Geese
Be!

Links to other premature parent support...
Links to the TOP preemie websites which offer understanding and support to
parents.

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Notice: The information provided on this board is not in any way intended to  
be a taken as medical advice or used as substitute for medical expertise and  
advice provided by your doctor, your baby's doctor or a licensed therapist.  
Feel free to Email me at [kbone91@aol.com](mailto:kbone91@aol.com)  
for any questions or comments.  
I welcome any and all suggestions!

Before you leave, please take a moment to email me and share your comments.

Thanks!!!

[Image]

Preemie Channel Featured Site!"

[IMAGE]



## Those Special First Visits

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Fear never robs  
Tomorrow of its Sorrow  
Fear robs  
Today of its Strength.

Welcome to the world of premature babies! You have just had a preemie and will be surely visiting them as often as you can. Treat this information like tips from an insider. Hopefully it can help ease you through the first week of visits to see your new baby.

The first few times you come to visit your new baby will probably be stressful, scary, frustrating, disappointing, and depressing. These feelings are all normal and to be expected when you deliver prematurely.

Some emotions you might encounter... You can feel overwhelmed by the sheer amount of medical equipment - all attached to your baby, the constant activity of nurses and doctors - like some emergency room show, and the aftereffects of the entire birth process, which was most probably quite scary and unexpected. You may be scared of the procedures your baby is undergoing and scared of what may happen to them. You may feel frustrated that you seem so helpless to your new baby, and also frustrated that you don't feel physically well and require help to even make it down to the nursery to visit. You may feel disappointed that your baby does not resemble the picture you had envisioned during pregnancy. You may feel shocked that the pregnancy is really over and you are now a parent. You may feel depressed at the loss of a normal childbirth, an easy baby, and the uncertainty of the near and distant future.

You may also feel joy, elation and happiness intermingled with these other thoughts. You may feel joyous at the birth. You may feel lots of affection and a strong bond of love towards your baby. You may feel like telling the world about your birth - having everyone celebrate the arrival of your baby. You may also feel guilty when you have these joyous thoughts, like you should not be celebrating and rejoicing when your child is so sick. But they, too are normal! It is right to feel this way!

You may get angry...  
at what happened...at your spouse, your family, your friends...your doctor for not preventing this...your God... your world...yourself. You may get angry when people don't know what to say to you - condolences or congratulations. You may get angry when people act as if nothing happened. You may get angry when you realize this won't end anytime soon.

You may feel like you can bargain for the health of your baby. If you promise to do this, then please let my baby (fill in the blank) grow, get better, eat, not require surgery, see, hear, be normal, live. You may find

yourself making "deals" with God and higher powers you believe in. You may tell God that you will handle whatever he gives you, but please just give you your baby, just this once...

You may distance yourself from your baby, choosing not to bond too closely or fall in love with a baby who just might not make it. You may want to put off naming your baby, just in case. You may refrain from visiting or looking at his photos. You may not want to share the news with others.

All these feelings are SO NORMAL and something that nearly every parent of a premature baby feels at some time or another. You may wonder, though, that no one else has ever feel the way you do. No one else could ever be scared about touching their baby, no one else would "save" a great baby name for a child who has a better chance, no one else would not cry for 4 days straight and joke around. But you are wrong, tons of us have thought these thoughts and others just as heartwrenching when we had our preemies. You need to know you are not crazy, strange, abnormal or alone, you are experiencing very real and common reactions to having a preemie.

Now you are probably saying..."How will I ever deal with these feelings?"

The first step is realizing that what you are feeling, saying, doing, is normal and to be expected. There is no one right way to go through the experience of having a preemie, and everyone will do it a little differently. Although they each do it a little differently, most of the reactions and emotions are the same.

It can help just knowing what is common when battling this trauma. Reading this guide is a first step. Try talking with other parents in the NICU. You can approach them as you are entering, when you are scrubbing, when you are sitting in the nursery. You will be surprised at how alone they too feel, and how unsure and scared of the whole NICU trip. You will probably be amazed at how readily friendships are formed in the NICU, because other parents need you as much as you need them.

Another route to meeting with preemie parents - support groups and support families. Support groups are usually run by the Social Worker in the NICU. Check with her to find out. Support families have graduate babies who traveled a similar route to your child. They are available for phone calls, visits, and reassurance. Again your Social Worker will probably connect you with a support family.

If you have internet access, try joining one of the many preemie discussion groups on the web. The best place to start looking for one is Tommy's CyberNursery Preemie Web - Front Door...at <http://www.flash.net/~cyberkid/> . The support and understanding offered by other parents at these websites is invaluable during your child's NICU stay, and after.

Finally, check out premature baby books. For an all-encompassing list try Mary Searcy's Resources for Parents of Premies . Often these books can be

difficult to find in bookstores when you need them and have to be special ordered. But they do offer guides to coping, as well as clear explanations of what your baby is likely to encounter, and are truly worth locating. If your local store does not carry these books, try contacting Birth and Life Bookstore, 141 Commercial Street NE, Salem, OR 97301, customer service and catalog requests (503) 371-4445, orders (800) 443-9942, fax (503) 371-5395. or Centering Corporation, 1531 N Saddle Creek Road, Omaha, NE 68104, phone (402) 553-1200, fax (402) 553-0507.

And don't miss out on reading Holland , which offers a different perspective on becoming a preemie parent.

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## A Parent's Wish

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"Few wishes come true by themselves."

-June Smith

"Far away there in the sunshine  
are my highest aspirations

I may not reach them,

but I can look up and

see their beauty,

believe in them,

and try to follow them."

-unknown

(This letter is written for the friends and family of parents who has given birth to a premature baby. It was based on a wish list from the Atlanta Chapter of Compassionate Friends, an infant loss support group.)

What do parents wish others understood about the birth of their premature baby?

"1. I wish you would not be afraid to speak my child's name and talk of him without the tone of sympathy, sorrow and pity in your voice. My child lives and is important and I need to celebrate his existence.

"2. If I cry or get emotional when we talk about my child, I wish you knew that it isn't because you have hurt me; the fact that my child is struggling and is not quite perfect has caused me tears. You have allowed me to cry and I thank you. Crying and emotional outburst are healing.

"3. I wish you would recognize my child's birth with your words and actions and not center on his chance for survival, disabilities and a "normal" life.

"4. I will have emotional highs and lows, ups and downs. I wish you wouldn't think that if I have a good day my pain is all over, or that if I have a bad day I need psychiatric counseling.

"5. I wish you knew that the birth of a preemie is different from other pregnancies and births and must be treated differently. It is tragedy and celebration, fear and joy, gain and loss, among so many other things. I wish you wouldn't compare it to your pregnancy, or the sickness of a parent, a spouse or a child.

"6. Being a premature parent is not contagious, so I wish you wouldn't shy away from me and my baby.

"7. I wish you knew that all of the 'crazy' grief reactions I am having are in fact very normal. Depression, anger, frustration, hopelessness, and the questioning of values and beliefs are to be expected following the birth of a premature baby.



"8. I wish you wouldn't expect my pain and healing to be over in six months. The first year is going to be very hard for us. I will be raising a child whose early life is very different from fullterm babies. I will be coming to terms with many emotions. I will be mourning many losses, even though I gained a beautiful baby. As with alcoholics, I will never be 'cured' or a 'former preemie parent', but will forevermore be parent to a preemie.

"9. I wish you understood the physical reactions to the pain of emotions, such as the ones I feel now. I may gain or lose weight, sleep all the time or not at all, develop a host of illnesses and be accident prone, all of which may be related to my emotions.

"10. Our child's birthday, his due date and homecomings and those anniversaries are important times for us. We may celebrate, but also mourn and relive the pain. I wish you could tell us that you understand that we are dealing with lots of tough emotions. Don't try to coerce us into being cheerful, even though that is what is expected.

"11. It is normal and good that most of us reexamine our faith, values and beliefs after a preterm birth. We question things we have been taught all our lives and hopefully come to some new understanding with our God. I wish if I am one who must tangle with my religion, you would let me do so without feeling guilty.

"12. I wish you would not offer me drinks or drugs. These are just temporary crutches, and the only way I can get through this process of healing is to experience it. I have to hurt before I can heal. If I need help from counselors and anti-depressants, please help me get it.

"13. I wish you understood that having a premature baby changes people. I am not the same person I was the moment before my child arrived and never will be that person again. If you keep waiting for me to 'get back to my old self', you will stay frustrated. I am a new creature with new thoughts, dreams, aspirations, values and beliefs. Please try to get to know the new me---maybe you will like me still."

with love,  
from a preemie parent

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## What Every Parent Needs To Know: Feelings & Emotions

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"I wanted a perfect ending. Now I've learned the hard way that some poems don't rhyme, and some stories don't have a clear beginning, middle, and end. Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious ambiguity."  
-Gilda Radner

Becoming the parent to a special needs baby is a traumatic experience, especially when it comes unexpectedly! You are filled with shock from the early ending to your pregnancy and the surprise delivery, a situation which in itself can be very scary! Not only will you have to recover from childbirth, adjust to a new baby, but you must also come to terms with having a hospitalized premature baby. No wonder you feel so overwhelmed!

It is normal to go through a whole bag full of emotions immediately following the birth of your preemie, during their hospital stay, and often throughout their first years. Don't be surprised if you find it hard to adjust to the idea that you are not only a parent, but the parent to a baby who needs intensive care.

The following list describes many of the typical emotions that most preemie parents deal with after the birth of their baby. By no means does this imply you will experience only these feelings, or that you will experience each one of them, within a prearranged cycle or time period. Many times parents feel a few of these emotions intensely and alternately, during various times after the birth. Then they may fade away or resolve, and parents will deal with several of the other, "new" feelings. It is not uncommon, though, to experience all these things at once. It is not unusual either for many of these feelings to resurface at a later date, often when something "triggers" a remembrance of that time (like a birthday or NICU reunion).

Some of the feelings may not even surface until months after the birth and some a parent may not ever experience. Basically, there is no "bible" that will tell how, what or when a parent will feel certain things. The only certainty is that their feelings are a normal and expected reaction to preterm birth.

### THE LIST OF NORMAL FEELINGS THAT A PARENT OF A PREEMIE MAY FEEL

**Acceptance** (To accommodate or reconcile oneself to the situation.) Acceptance of the NICU, having given birth prematurely, and having a sick baby all come with time. Normally, it is hard to come to terms with accepting the loss of a very important dream. Learning to accept the losses you have endured will take time, weeks, months and possibly even years. You may learn to accept some parts of the preterm delivery more easily and faster than others.

**Anger.** (A strong feeling aroused by injury, injustice, or wrong.) You may

feel angry at the loss of your pregnancy, the loss of a normal birth experience, the loss of a normal newborn, the lack of "fairness" in the whole situation.

You may feel angry at the loss of control of your life (over your body, your feelings, your baby and your family life), the hospital staff (for telling you what you can do, telling you bad things that are happening with your baby), your spouse (for not understanding you, for blaming you, for being able to adjust and cope as you wish), your parents and in-laws (for their reactions and feelings). You may feel anger at yourself because in some way you believe you caused this to happen. You may feel anger at your doctor or hospital, who didn't prevent the preterm delivery. It is even normal to feel anger at your baby at times (which makes you feel even more angry at yourself).

Anger is a normal response to a traumatic situation where you lose a great deal of control over your life and feel like you have suffered a great injustice. Anger is totally normal and to be expected.

Talking about your anger with close friends will help. Writing about your anger in a journal can also help to pinpoint what your anger centers on. Telling the medical team what angers you will help them to help you. Anger will subside as you regain control and adjust to the reality of your early baby.

Anguish (Excruciating or acute pain, suffering or distress.) Watching your baby undergo treatments and suffering may fill you with anguish. This pain can reach inside of you like no other, leaving you numb and hurting. Anguish tends to worsen when there is nothing you or others can do to ease your baby's pain.

Ashamed (Feeling shame or embarrassment caused by the emotions of guilt, disapproval or disgrace.) It is normal for a preemie parent to feel ashamed of what has happened. With such a large emphasis being wrongly placed on parents causing the preterm delivery through drug or alcohol use or some other oversight, parents might feel ashamed to share the news of their preemie in fear of being charged as "guilty". They also may feel ashamed of their "failure" in the capacity to carry a pregnancy to term and produce a healthy, normal baby. A mother may fear she is a disgrace to her spouse or family because of this.

It helps to ease the guilt and disapproval that parents feel so that they are not ashamed of their situation.

Blame (see Guilt)(To place the responsibility for a fault on a person.)

Controlled (The situation of being under the regulation or command of another.) Because of the number of restrictions and regulations in place in the NICU, a parent may often feel controlled. They feel controlled over when and where they can visit their baby, how they can interact with him, and what they can do. Many times parents do not understand why these restrictions are in place, and they begin to feel angry at the medical staff. It can help to teach the parents not only why the restrictions are in

place, but also how they can become more involved. However, there will probably continue to be feelings of being controlled on the parents' part, even when they do understand the "why's". Often this "control" is so frustrating because it leaves the parents feeling helpless to assist or "save" their baby.

**Criticized** (To make judgements as to merits and faults.) Most preemie parents feel criticized at one time or another. They may feel criticized for how they are handling the situation. They may feel criticized for their behavior or feelings. They may feel criticized for their parenting skills. They may even find their needs and wants criticized as abnormal. It is vital to the parents' well-being that all judgement on their actions, feelings, words, and wishes be sustained. They are dealing with an extremely traumatic time that is filled with pain and stress.

**Crushed** (To overwhelm or squelch.) Dealing with the arrival of a less than healthy, less than perfect baby can leave even the strongest parent crushed. They may feel their dreams have been destroyed, even if only temporarily. Once the parents begin to grieve their losses, they are apt to feel a little less crushed, although they may still feel intense pain.

**Denial** (Refusal to believe in the existence or reality of a thing.) Many times preterm birth occurs quickly, unexpectedly, in an emergency situation. Once the delivery has ended, a parent may deny what happen. They may still want to believe they are pregnant, or that the baby was delivered healthy and strong. They may deny that their baby is very sick and requires extensive help. They may deny the possibility of further complications or even death. It may take several days for reality to sink in, and denial to subside. This is not unusual.

**Depression** (A condition of general emotional dejection and withdrawal, sadness greater and more prolonged than that warranted by any objective reason.) Many times parents of preemies find themselves depressed about the entire preemie situation. They experience sadness and gloominess about their losses, their grief and their future. Depression is a normal reaction to preterm birth. Post-partum depression is also a normal part of delivery. For several weeks, a mothers' hormones are out of kilter and the "baby blues" can be triggered by this. However, prolonged and severe depression can signal other problems that need professional evaluation by a doctor or therapist. Read further about post partum depression and depression in Depression

**Determined** (Unwaveringly resolved.) Parents may become very determined in their efforts with their NICU baby. They may become very determined in such things as visiting the baby as much as possible or expressing breastmilk. Becoming determined to be involved is a means to regain some control over the situation.

**Disappointment** (Feeling as is if the wishes or expectations of a person are not fulfilled.) When a pregnancy ends before its time, and a delivery does not go as planned, and the baby's condition is not as it was wished, parents face disappointment. Their dreams and hopes are not longer possible and their expectations have been derailed. They are suffering from many losses. It is normal to be disappointed after a preterm birth because the parents "missed out" on having their hopes fulfilled. Parents must work through disappointment at their own speed. Also, having something "good" happen is

not likely to "make up" for the disappointment they feel.

Disbelief

Discouraged

Disgust

Doubtful

Embarrassed

Envious

Excluded

Failure

Fear/Terror. Fear of the unknown, fear of losing their baby, fear of a disability, fear about becoming parents before you are ready. You may fear what is going to happen years down the road. You may even fear what others will think and say when you tell about your new baby. Fear is a normal reaction to such the scary and frightening ordeal of emergency, premature birth. Fear will resolve with information and knowledge, although you may tend to be fearful in during other times as your baby progress - follow-up appointments, future pregnancies, etc.

When you experience a great deal of fear regarding your baby's health once they have come home and are doing well, you may be suffering from the "Vulnerable Child Syndrome". This is common among parents of preemies - they continue to constantly fear for the health and even life of their baby long after these fears are valid concerns. Talking to a therapist and your baby's pediatrician can help resolve this kind of fear.

Guilt/ Blame. Many parents find themselves going over and over the pregnancy, looking for something that caused this premature birth. You may blame yourself for your baby's condition. You may blame your body for letting you down. You may feel guilty for not being able to give your child the start in life you had intended. It takes time for the guilt to subside as you come to realize that these things just happen and, usually, it is nobody's fault. Read *Guilt* for help on this emotion.

Hopeful

Hurt

Intimidated

Not only can it be physically difficult to parent in the nursery, with all the machines, wires, and people, but it can be intimidating as well. You may feel less skilled than the nurses at caring for your baby. You may feel as if you have to ask permission every time you wish to do something. When you first visit your baby you may feel as if the nurses, doctors, and other parents are all watching what you do. It is hard to feel such a loss of privacy during such a private time in your life. Do not be afraid to express your emotions to the nurses, or even cry. Most parents go through these feelings at one time or another when their baby is hospitalized, and the medical staff all understand you are dealing with a very difficult situation. You may be scared to ask questions, because you may be negatively labeled by the staff. While these feelings are valid and real, know that the hospital's goal is to help your baby get well, and help you gain confidence

in caring for your baby. Do not be intimidated by your lack of knowledge - everyone was once a first-timer! They all had to learn at some time or another!

Isolation. When you give birth prematurely, you tend to spend lots of time not only recovering, but in the hospital visiting your baby. Not only do you become physically isolated from your friends and family, but because most people do not understand what having a preemie involves, you may find yourself isolated emotionally as well.

You may find yourself easily angered at insensitive comments made about your baby and the pregnancy. This, too, is normal. To help friends and family understand all that is happening, you will be called upon to "teach" them about the world of preemies. This is not an easy task and often your information does not mesh with prior misconceptions they hold about the NICU and preemies. When this happens, you become even more frustrated as they negate your information.

To counter isolation, find people who understand what you are dealing with. Some friends are able to "stretch" and grasp what you are feeling. Support groups at the NICU, other parents and graduate parents can all ease your sense of isolation. Your nurses are also a great source of support during times of isolation. Your partner or spouse also understands and needs to talk to overcome their own sense of isolation.

For help in dealing with people who cannot understand what is happening or how you are feeling, see *A Home for Your Thoughts* .

Jealous

Jittery

Joyous

Judged

Loss. Parents grieve many losses when they have a premature baby. They lost the end to a pregnancy, the chance to celebrate a new birth, the opportunity to go through a healthy delivery and bond immediately with the newborn. They have lost contact and understanding with friends. They have lost control over their life. Most importantly, they have lost a very important dream, one that carries much significance and touches every facet of their life. The pain of that is very real and takes time to heal. Give yourself that time to recover from your experience. Read *Holland* for help.

Misunderstood

Nervous

Powerlessness/Impotence. When you find yourself in a strange and unfamiliar environment, with new people telling you what you can and cannot do, you can feel very powerless. To add to that feeling, you might not be able to take part in very much care of your baby for the time being. If you talk about these feelings with your baby's nurse, she can help find ways for you to be involved. Soon you will find yourself feeling very confident in these surroundings.

Overwhelmed

Pressured

Protective  
Resigned  
Sad  
Scared

It is normal and natural to have fears about your baby. It is absolutely normal to fear they may die. It is also normal to be scared of talking about this fear. This fear can keep you from feeling very attached, or bonded, with your baby. If you feel this way, please talk with a nurse, family care coordinator, social worker, or chaplain. It will take time for the fear of death to ease up and disappear, but the nurses and social workers are there to help you if you are feeling this way. It is important for both you and your baby to form a loving attachment with each other, even though they may be very sick.

Shocked  
Sickened  
Stressed  
Surprised

Unimportant

You may feel that the nurses get to spend more time with your baby than you do. Know that while you feel uncomfortable now, these feelings will go away. Spending time with your baby will help ease these fears, as will talking with the nurses about your feelings.

Unsure

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## Depression, Post-partum depression and finding help.

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If you are melancholy for the first time, you will find, upon a little inquiry, that others have been melancholy many times and yet are cheerful now.

-Leigh Hunt

It is normal to feel some amount of post-partum depression, or baby blues, as it is often called after your baby arrives. When you add the fact that your baby requires extended hospitalization, you may feel unusually sad or depressed.

If you feel:

these feelings of sadness are becoming overwhelming  
you cannot sleep or are having sleeping difficulties you have lost your appetite  
you cannot eat  
you want to sleep all the time  
you feel as if you could cry all the time  
you feel exceptionally irritable  
you feel as if you could physically hurt yourself or another

then you may be suffering from depression or post-partum depression. It is normal to feel overwhelmed and experience some or all of the above feelings at some points during your baby's stay in the NICU.

However, it is important you talk with your doctor and your baby's doctors and nurses if this becomes a pattern of living each day and night. They can help you find ways to get through this difficult time.

A good way to cope with these feelings is to talk with others who have experienced a preemie birth in the past, or who currently have a baby in the nicu. Some times, though, you may need to take more measures to help you cope with your feelings of depression. You may need to meet with a counselor or therapist or discuss taking some anti-depressant medication. Of course, these decisions can only be made with a doctor's advice.

If you are feeling depressed, find help. It is nothing to be ashamed of or embarrassed about. It does not mean you are a failure as a parent. It means that you need some extra help in dealing with a difficult and traumatic time in your life.

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## What Every Parent Needs To Know: Dealing With Family and Friends

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"Love IS everything it's cracked up to be. That's why people are so cynical about it. It really is worth fighting for, risking everything for, and the trouble is, if you don't risk anything, you risk even more."

Part 1:

How the NICU Can Affect

Your Support System of Family and Friends

Part 2: Siblings and Grandparents

Part 3: Three normal responses to expect from friends and family

Part 1:

Family, Friends, Co-Workers and all the other people you know who are affected by the birth of your preemie.

Close friends, family members, co-workers, acquaintances, all fall into this category. What they have in common is, like most other people you encounter, they do not know how to "properly" react to the premature birth of your baby.

They often don't have the luxury of seeing you or your baby often through the traumatic time to help them "figure out" what would help you. Because most of them have not encountered a similar situation they are left without any real understanding of what you are dealing with. What does this mean to you? When they find words and actions that are intended to help you or show their support, they often fall far short of their mark. This can happen very often, leaving you wondering if anyone will ever understand your plight enough so that you will be able to turn to them for support once more. Instead of being able to lean on them for support, you are left feeling isolated, misunderstood, and alone.

Friends and family members will need your help in coming to understand about your baby and the changes you are dealing with in your life. They will need some direction in how to help you. They may also benefit from guidance in what they say and do. All these things are provided in the following sections. Print them out and have them read :

Understanding Premie Parents2

Understanding PP Cont'd

Must Read Tips!!!

A Parent's Wish

From a Premie Parent...

A good article for you to read on dealing with people who don't "have a clue" is found in A Home for Your Thoughts. It is wonderful to share with friends and family so they can better understand how you feel.

Part 2



## Siblings

You may find it very difficult to explain about your new baby to your other children. After all, you may still be questioning what happened yourself! The best route is usually honesty - answer their questions as best you can, share what is happening - in simple terms a child may understand, and explain what people are doing to help the baby.

It can be disconcerting to a child when you give birth prematurely and/or unexpectedly, and you are spending lots of time at the NICU. They may feel forgotten and abandoned while you concentrate on your little one who desperately needs your love and attention. This can cause even more guilt for you. It can help to realize this is a temporary situation and you will be able to return to caring for them once again. Remember that this is often the first time a child will see you so distraught and it is scary to them.

It is common for children to fear they caused the baby's condition or your feelings through some thought or action of their own. They may worry or be fearful about how you are acting, and respond in different ways. Their behavior may worsen, in response to their fears and insecurities, with an increase in tantrums, crying or other behavior. They may also regress to less mature behavior, such as bed-wetting or using a bottle or security blanket. They can fear that what is happening with the baby could happen to them. They can fear what will happen with to their family and whether or not their parents will return to "normal".

### What to do?

First, ask for help in locating children's books on preemies, which are found in Resources for Parents of Preemies. These can help in explaining to the child what is happening. The social worker can also help you find these books and provide other resources, such as counseling or therapy.

### Second

Share how you are feeling with them. Do not act as if things are fine when you are around them. Children are very intelligent and they know differently! Remember to be as honest as you can about the new baby and your feelings. Sometimes saying something as simple as "I am very sad because your new brother is very sick and has to sleep at the hospital until he gets better", may help them to understand and not be so fearful of your actions. Or "I am crying because this baby did not have all the time he needed to grow to be strong and healthy".

Encourage their questions. They may be scared and intimidated to ask about the baby or about you. Let them know it is okay to talk about everything involving the baby, even a fear of death. Be honest and up front when responding to their questions, but be sure to keep the information on their level. Often simple answers are what a child desires. Because parents often think their children want all the detail, they go into a long explanation when the child merely wants a few answers to a couple questions. Give only the information they request, instead of overwhelming them with a lot of detail.

Arrange for them to visit the baby, if possible. This will dispell a lot of mystery and fear for them. Be sure to prepare them for the visit by explaining rules, and also sharing what the baby looks like. Photos or books are great to prepare a child. Often, they accept the situation readily and question about the logistics of the NICU - the wires, machines and noises instead of the baby. It can help them feel closer to the baby if they can send in photos of themselves for the isolette, and draw cards and pictures for the baby.

### Third

Provide extra reassurance and attention. Alternate with your spouse the time you stay at the NICU and the time you stay with your other child. Ask for help from friends, family, or some special babysitters to help take over child care duties and provide "special time" and special outings for the older child and much needed attention.

### Grandparents

Grandparents often feel at a loss as to what to say, how to act, how to express what they feel. Many times they feel they should hold back on talking about their fears, feeling there is nothing they can do to help you or the baby, or that sharing their thoughts will scare you . It is important to be able to share your concerns with them and also allow the grandparents to talk about their concerns with you and your spouse, if at all possible. A must read resource about premie grandparents is available here - special colaborative column . This is an article focuses on the special conditions surrounding a premie baby and grandparents. It can help foster the parent/grandparent relationship and clear up misunderstandings.

It is also important for grandparents to realize that, oftentimes, you need space and privacy to visit with your baby and there may be times when you may choose not to share all information with them. They should respect your right to refuse visitors on difficult days, if you want to spend time alone with your baby. They should also respect that there may be times you do not feel like talking about the baby and this should not be seen as isolating them.

It will help to share with them the Ways to help in found in Taking Care of Yourself so they understand how to help you. Often they need concrete directions on how to assist you.

How Family, Friends, Co-Workers and all the other people you know come to terms with your situation...

People seem to often fall into a few categories after a premie birth: the Rocks, the Wanna-Be-There's, and the Gingerbread Men. It is helpful to know this, because more than likely you will be surprised to learn what type of supporters your friends and family become for you.

But before you read further, understand that you cannot choose what type of

supporter each friend or family member will be during this time. Often we assume people will react in an expected manner. Unfortunately, in times like these, we often find our expectations of others doesn't match with real life actions. This can be upsetting.

It helps to understand that everyone reacts differently to preemies, for a wide variety of reasons, many that we are not privy to comprehending at this point. For now, accept that some people will not meet your current needs, while others will far surpass them. You can just not predict accurately how people react to traumatic times. Which leaves you here, to read more about the three basic ways people react....the Rocks, Wanna-Be-There's and Gingerbread Men...

The Rocks attempt to do anything and everything offer encouragement, support, understanding, and love. These are often your closest friends, although they may very well be a mere acquaintance who has been through a similar struggle and can easily relate to your difficulties and wants to offer support.

The Rocks will do anything they can to make your life easier. They seem to know just what to say and do. However, even Rocks slip occasionally with a clueless remark or action. It can be hurtful when this happens, as it makes you feel even your staunchest supporters don't even understand how you feel. This can cause hurt feelings and alienation.

The best remedy for a comment they have made that missed the mark? Talk about it. Tell them why it upset you. Explain what exactly you wanted to hear instead. This is not easy, but remember your Rocks would do anything at all to ease your pain, and often take suggestions readily. They welcome the chance to better help you. Rocks will be your saving grace during the first year.

The Wanna-Be-There's are often neighbors, casual close friends and co-workers with whom you work closely, but they can also be close family member or friends. Above all, they have good intentions in their hearts. They want to help, but often don't know how. They may call and try to cheer you, or ask about the baby. They may make offers of help, such as meals or driving assistance. They may even want to see photos of the baby. However, Wanna-Be-There's are not Rocks. They either cannot or do not go the extra mile to understand your plight. They do not offer the right type of compassion to you and often see the baby only in terms of how it makes them feel. They are the kings and queens of clueless remarks. They lack the right amount of empathy and understanding of how to help you.

Who really knows why Wanna-Be-There's are not Rocks. It could be your situation scares them, it interests them like a tabloid story, it hits too close to home. Maybe it doesn't seem as traumatic to them as it is, or maybe it seems too critical - with death possible. Or maybe they see their actions and words as helpful to you, and are blind to anything else they could do to help. Perhaps, they are selfish and can only see how the situation affects

their life. Maybe they just don't know what to do, and fail to ask. For whatever their reasons, Wanna-Be-There's say they want to be there for you, but aren't. And we often don't know why (which can cause even more resentment and anger).

This can be very painful for parents. Friends, family and co-workers with whom you felt a close bond are disappearing into the woodwork. They may call a few times, and then they are gone. They make second hand inquiries about your baby, but never make the effort to find out first hand. When they do call, they ask all the wrong questions. They say all the wrong things. They may try to minimize your experience, leaving you angry and sad. They get offended by your actions and words (or lack thereof). Most of all, they leave you feeling isolated. You may wonder when the going got tough, where they had all gone.

The only thing that helps to rationalize and understand Wanna-Be-There's is that they just are not capable of helping you at this point in time. Perhaps, they did not learn the skills of compassion and empathy, or your experience is far too removed from their own experiences for them to relate, or they try to make it less scary for themselves, more like something they have dealt with in an effort to understand what you are experiencing. Or they truly may be at a loss as to what they can do to help improve your situation and give you comfort.

We never really know the reasons Wanna-Be-There's fail to become Rocks for us. What we do know is they can create a lot more pain for us. This is a normal occurrence. It is hard to realize that not everyone is able to help us during this time. It is hard to understand that someone you depended on has failed you. We feel that all of our friends should be there for us in times of need. But this is just not always possible. What can be hardest is to not totally shut them out and disregard them as friends. However, sometimes this becomes the only way you can cope with their lack of understanding and support. Keeping up with them is too draining for you. This too is ok.

Unfortunately the price we parents pay for premature babies can often be the realization that we have lost those we thought we could depend on, even temporarily. While education and information does wonders to build a bridge between those that are falling short of your mark, sometimes the task becomes too much to ask of yourself. You find that for the time being you need to put them aside in lieu of other priorities - namely your baby and your own healing.

Remember that as things improve and you feel up to it, you can try to discuss what happened with them and try to resolve any hurt feelings. But during this time of stress, you are not REQUIRED in any way to put their needs above yours and your baby's.

Maybe at some time in the future you can talk about it with them. There can likely be a rift between the two of you due to their reactions to the birth,

and it may continue for some time, until it is worked out. It may heal with some help, or it may not, and you may just choose to move on without their friendship. Sometimes, though once a distance has passed between you and the NICU, and some wounds have healed over, you can build the friendship again. It takes lots of forgiveness and communication, as well as the ability for friends to "stretch" to understand and empathize with your situation.

It can help to know that just as we all cope differently with the birth of our preemies, so too do others respond in different ways to us during this time. It can also help to recognize that for whatever reason, Wanna-Be-There's are what they are, we can not change them to Rocks. Expecting their behavior to resemble that of Rocks will only lead to disappointment and anger. It might be best to limit contact with them during your most trying times, as they can make you more frustrated, alienated and just plain mad.

Most times Wanna-Be-There's do honestly share a concern for you and your baby's outcome, and you may choose to keep up contact with them casually. If you learn to expect no more than this, you will ease your disappointment and might even at some point enjoy conversation with them about your baby if it steers clear of preemie issues.

This leads us to the Gingerbread Men. Who are they - casual acquaintances, passing co-workers, neighbors. Just like the story, they too run, run as fast as they can from you when they hear of your baby's birth. They will not call or contact you. They might ask, always second hand, about your baby. But go no further.

Why? You are just not close enough to them to really elicit much of a response. In other words, they really don't care too much. But with Gingerbread Men, we expected this, and are, therefore, not very disappointed when they run away with out so much as a backward glance. We might very well have responded the same way if the tables were turned.

What do we learn from the three types of reactions? That everyone reacts differently, based on their experiences, to your premature birth. We need a Rock or two to make it through this tough time, but other than that, the Wanna-Be-There's and Gingerbread Men aren't too essential and often only cause us hurt. It can be wise to focus on all that the Rocks offer you for the time being and put aside the others until you are ready to deal with those type of people again and you no longer need the kind of support and strength that only Rocks can offer. And as always, remember these reactions are a normal part of preemie parenting.

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Let me teach you about my premature baby and tell you how my life has changed...

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A great teacher never strives to explain his vision

- he simply invites you to stand beside him and see for yourself.

- Rev. R Inman

A Letter To My Friend,

I share this letter with you because you care about me.

When someone we care about faces a trauma, it is natural for their friends to want to help. When we do not totally understand what is going on, it makes it that much more difficult to help. You probably are having trouble understanding what is happening, what caused this to happen and why I am having such a rough time coping with the birth of my premature baby. Let me explain what is happening...

Prematurity Facts...

Eleven percent of all babies are born prematurely (before 37 weeks of gestation). 7.4% of babies born in 1996 were Low Birth Weight (LBW) Infants ( less than 2500 grams or about 5 lbs. 8 oz.). This is the highest level reported since 1975! Nearly one and a half percent of babies born in 1996 were Very Low Birth Weight (VLBW) Infants (less than 1,500 grams or about 3 lbs. 5 oz. at birth). This rate has been essentially unchanged for the last two decades at least.

Twins, triplets and other multiples have a greater chance of arriving prematurely. Black women have the highest rate of preterm birth, double that of white, native and mexican americans. In 1965 there were 16 NICUs in the US. In 1993 there were 794 with 13,873 beds. A conservative estimate of the total cost of care for infants and children born at low birth weight is \$6 billion, exceeding the annual cost of AIDS.

There are many reasons that a pregnancy can end with premature delivery: preterm labor, incompetent cervix, premature rupture of membranes, placenta previa, toxemia are among the most common. The greatest majority of preterm births are not related to something the mother did or did not do. It is rarely the mother's fault.

An increasing number of premature babies survive and thrive today. The statistics show that 20% of 24 weekers, 50% of 25 weekers, and between 70-80% of 26 weekers survive their early birth. The rates are much higher for babies born above 30 weeks, hovering around 95%.

The smaller the baby, the more likely it is that they will encounter at least some type of developmental or learning disability, but this is not written in stone. There are many babies who come out of prematurity

unscathed. (By no means should this information imply that a preemie is destined to an abnormal life of disabilities. It merely suggests that they have a higher likelihood of face greater challenges than the full-term baby. These challenges are often a result of the trauma the body suffered from the prematurity and center mainly around : impaired physical skills (such as Cerebral Palsy), learning disabilities, vision problems, feeding difficulties, or hearing problems. Many premature babies qualify for assistance from federal programs, such as Early Childhood Intervention, or take part in the special education programs offered in public schools.

Remember!!! Each child's outcome will be different, depending on how their body coped with the preterm birth. The ability to accurately predict how a baby will develop cannot be determined by their birthweight, time in the NICU nor weeks of gestation. These factors are only indicators of the possible outcome for a preemie.

Why Is Having A Preemie So Upsetting?

The birth of a premature baby, even when it is expected, is the loss of very important dreams. It is the loss of the perfect pregnancy, the right type of birth, a healthy, perfect baby that can come home with you, a bright start to a new family. It is also involves a loss of optimism about the future.

Worry about current and future development cloud my vision. I worry about what he will face later in life. And although my baby may have great odds of survival, I may still be fearful of losing him. Even with great odds like 90% survival mean that one baby in a room full of ten will not go home with their parents. I am worried I could be that one.

I am angry. I am mad that this happened to me, especially if I was exceptionally careful about the pregnancy. I am mad that I lost control over my life and have placed my baby in this predicament. I am mad that I cannot take my baby home or even hold him. I am mad that people are not celebrating his birth, until he comes home and is "safe" from the arms of death. I am mad that others cannot understand how I feel.

Guilt and failure are everywhere. I feel like I did something to cause this. I feel like I should be able to help my baby, not just sit silently by. I feel like a failure as a mother, daughter and wife. I feel like I failed at pregnancy, childbirth, breastfeeding and caring for my baby.

I may still be in shock that this has really happened to me. I may repeat over and over the story of the birth. I may relive the early days with anyone who will listen. I may still even have OB appointments listed on my calendar and maternity clothes I was going to wear hanging in my closet!

Mostly, I feel a total lack of power. I have no control over my body, my emotions, my baby's care, my baby's health. I don't even know how to calm my baby when he is uncomfortable. And I don't have any control over what will happen to my baby.



## Why Does My Advice Upset the Parents?

When there is nothing specific to do to solve another's problem, we try to give helpful advice. Often we tend to draw on past experience or on the experiences of others. The truth: The premie experience is unlike any other and comparisons only minimize the severity of it.

### Reason #1:

Due to the nonstop advances in the field of neonatology, the survival rate of premies has increased at drastic rate. Babies that did not survive 5 or 10 years ago, are now doing so and doing it well. So comparing the experiences of another premie with this baby does not add information and support to the parent.

### Reason #2:

Comparing the NICU hospitalization to another child's sickness or surgery is not appropriate (especially if the child is not a premie). They are as different as apples and oranges. Your well-meaning advice is an attempt to transform an extremely complicated situation into a simplistic little problem and overlooks all the many losses that accompany a preterm birth.

### Reason #3:

Advice on coping with pregnancy, birth, or a newborn baby doesn't apply as well. The feelings surrounding preterm birth are not the same as a fullterm pregnancy and birth. Moms would have liked nothing better than to endure the final months as big and pregnant. Comparing her situation with those of other full-term moms minimizes the trauma and grief she feels and makes her feel even more isolated, angry and misunderstood.

Know that the parents appreciate your advice as an effort of support and consolation, but it is not useful, pertinent and accurate given the nature of the problem, unless you have actually been through the same situation of preterm birth.

### Answer:

The best help you can provide is to be understanding and supportive. It is easier to do this if you can appreciate how devastating it is to have a premie. When you speak with the parent, try to empathize with the burdens on their mind and in their heart. There is nothing you can do or say to make the baby better and take away the parents pain.

### What Can You Do For Her?

When a parent feels so misunderstood and alone, they often begin to fear communication with others. Parents begin to fear that advice, suggestions, or comments will make them feel even more upset and despondent, instead of supported and understood.

The most important thing to remember is that the parents are very distraught and very worried. Listen to what they have to say, but do not judge. Do not belittle their feelings or attribute them to the baby blues and hormones.

Reactions to a premature birth is much more than a hormonal response. Don't try to pretend that everything will be okay. Don't sell her on fatalism with statements like, "What will be will be." If that were truly the case, what's the point of using medical technology to try to accomplish what nature cannot?

Your willingness to listen can be of great help. Premature parents feel cut off from other people. Your ability to listen and support the parents will help them handle the stress they're experiencing. A baby's premature birth is one of the most difficult situations parents will ever have to deal with.

### Problem Situations

Just as an ordinary room can be an obstacle course to a blind person, so can the everyday world be full of hazards for a premature parent - hazards that do not exist for women with full-term babies and children.

Some of the common obstacles that can cause increased pain and suffering in a parent ...

- \* seeing mothers with their new babies
- \* watching parents take home their newborns
- \* catching view of a very pregnant woman
- \* visiting the obstetrician's office for an appointment
- \* hearing other's birth stories or complaints about late pregnancy
- \* seeing babies at the store, passing them in cars, watching them stroll down the block or play at a park
- \* hearing news of a friend's pregnancy
- \* having to be around other pregnant women
- \* passing by a childbirth class
- \* attending showers or a bris
- \* family gatherings, where babies and children are present
- \* a breastfeeding mother
- \* watching TV and being bombarded with baby commercials and programs that show pregnant women, birth, and newborns in danger
- \* receiving and reading parenting magazines
- \* reading parenting books

As you see, there is no escaping painful encounters when you are a parent to a hospitalized premature baby who is not home and healthy.

### The Bottom Line

Because these parents, your friends, have had a premature baby, life is very stressful for them. It will be for some time, even after the initial difficulty of hospitalization ends. They will have to deal with isolation from germs, developmental concerns, and other health complications that often challenge a preemies first year of life.

Your friends are doing their best to cope. Please be understanding. Sometimes they will be depressed. Sometimes they will be angry. Sometimes they will be joyful. Sometimes they will act in totally crazy ways that seem to defy explanation. Most times they will be physically and emotionally

exhausted. They will not be the same old people they used to be.

The parents have no concrete answer to when, or if, their problem will resolve. The fact that babies often ride a roller-coaster of progress and setbacks as they journey toward home only adds to the emotional turmoil. It is certain the NICU trip will come to an end, but when and how is often unknown.

Afterwards it can be a long time before many of the parents' questions about health and developmental concerns can be answered. They will not know the repercussions of the early birth for years to come and this can continue to plague their emotions at certain times, especially anniversary dates.

During this time, though, they will form a close, loving bond with their child. They will accept any and all challenges and limitations their child meets. They will grow to see their child as perfect, regardless of any disabilities, for the love of a child is perfect.

Never will the parent be the same as they were before the birth. They will be forever changed by the event. You will have to accept this as a result of the premature birth if you wish to continue supporting them as a friend.

Your friend wants you to stretch and accept the new person she has become. She needs your support. Please care about her. Please be sensitive. Please be a friend...

with much affection,  
a preemie parent

adapted from a guide  
entitled "About \_\_\_\_'s Infertility", found in  
Getting Pregnant When You Thought You Couldn't  
written by Helane S. Rosenburg, Ph.D and  
Yakov M. Epstein, Ph.D

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## How to Help the Parents

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"What do we live for if it is not to make life less difficult for each other?"

-George Eliot

While a premature baby is in the hospital parents will need help from friends and family. Share the following list with the parents' family and close friends. If anyone else offers their help, show them the list, too. Many times, people are not sure of how they can help. If they are given the chance to read over suggestions, it will help them find a way to help, one that the parents need.

~Drive to and from the hospital, especially for several days after vaginal childbirth, and often for 3-4 weeks after a cesarean section.

~Prepare meals, or help coordinate others to do so each day, at least for several nights each week during the first month of hospitalization and homecoming.

~Grocery shop, run errands, drop off film to be developed.

~Help locate nursing bras, pumping supplies, and clothes that fit mom's new figure.

~Do laundry, clean up house, mow grass, walk and feed pets.

~Take over bill paying and keeping track of hospital bills for awhile.

~Offer your company to the parent while they visit with their baby. The NICU can be a lonely place. Or offer to meet them for lunch, if they are unable to take you into the NICU.

~Offer to take notes while they meet with doctors and nurses.

~Babysit other children, or take over their care temporarily. Offer to take them on a special outing to the movies, a park, a toy store, or a zoo.

~Address and mail birth announcements. Help with thank you notes.

~Shop for necessities when the last minute homecoming is announced. Help them prepare for discharge.

~If the parents request it, call other family members to pass along communication about the baby

~Help to coordinate or arrange assistance from other who offer their help.

~Offer to help care for the baby, and provide meals when the baby comes. Or offer to help care for the household duties while parents relish having their baby home and get adjusted to caring for him. Offer to take other children for a day or two during this time if so desired by parents.

~The new parents will need a lot of support, time to adjust, and time to recover from all that has happened in the NICU during this time of homecoming. Do not be offended if they exclude you temporarily. Be there when they need a hand.

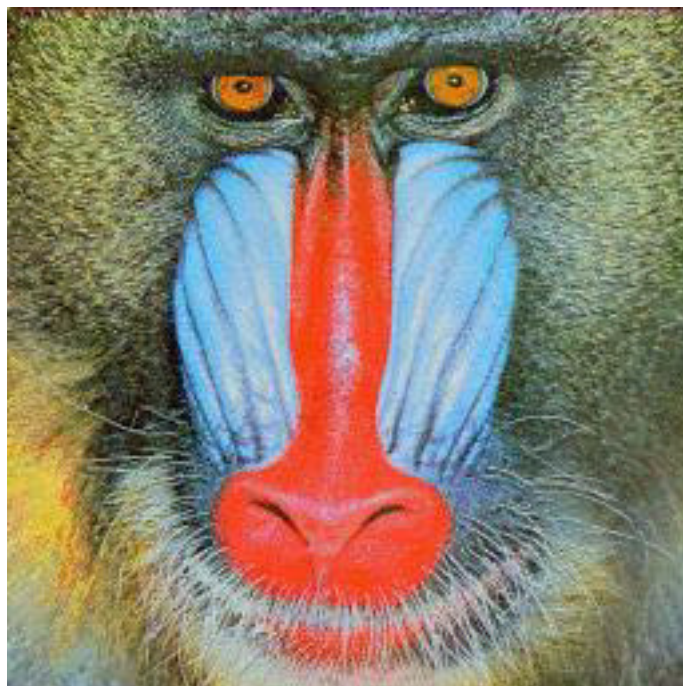
~Don't forget to offer babysitting and additional help continuously during the early months. It takes a long time for a preemie to get past the "newborn" phase, and this is draining for parents. They need help and an occasional break.

~Offer to run outside errands or shop after the baby comes home. Parents will probably not be allowed to take their baby out for some time, especially during fall and winter seasons.

~Don't visit when you are sick or have been around others who are sick. Premies are fragile beings with compromised immune systems. Respect the parent's right to keep them as healthy as possible.

~Help parents celebrate the joys that their baby brings to the world.

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## Must Read Tips for Anyone Involved with a Premie Parent

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People learn something everyday, and a lot of times it's that what they learned the day before was wrong.

- Bill Vaughan

The following tips are offered as guidance in how to treat the parent of a premature baby. It covers thoughts, actions, words and responses.

Many tips come from suggestions I provided to neonatologist Jane Brazy, M.D. for her website called For Parents of Premies (EXCELLENT!!!) Check out this all inclusive premie site at [jane brazy](http://janebrazy.com) .

Suggested comments and actions...

Offer your unconditional love and acceptance to the parents and baby. Express this love of the baby opening to the parent.

If the parents express sadness and grief, offer a hug or a tear.

Help reassure the parents, especially the mother, that they are not at fault for the birth and the ordeal the baby is enduring. Suggest ways to resolve the guilt...talking with her doctor, other premie parents, or the baby's nurses.

Mark the birth and signs of progress with celebration, if the parents so choose. (Some parents do not feel like the premature birth is a time to mark with celebration.) Send flowers, cards, balloons, or baby gifts. Find a sign to place on their front door at home or the hospital room announcing the birth. (Don't forget to celebrate the homecoming with a big sign!) Help order and send birth announcements. Show off photos of the baby. Call relatives. Post the announcement in the newspaper.

Acknowledge the toll the NICU takes on the parents life. They do not have the luxury of sleepfilled nights, days of relaxation or time for dates out alone. This is not a vacation with free babysitting provided.

Offer your assistance in the NICU. Offer to "baby-sit" so the parents can be relieved of an occasional NICU visit occasionally. Act as a transcriber when a medical meeting is called. Keep them company as they spend their days visiting the baby. (It can be lonely.) Offer to become the official photographer.

Be empathetic and compassionate. Try to understand their pain and worry. Do not compare it to another situation involving hospitalization or sickness - it is different.

Let parents be the guide in discussing outcomes - ranging from length of

NICU stay, to disabilities, to prognosis of adult weight, to death (and anything in between!) This is very private information for the parents to consider alone. Do not feel as if you need to play the "infomer" or "the devil's advocate" or the one who will share "the truth". The truth is: no one can predict what will happen with any premature baby. And 99.9% of the time, parents are made full aware of what could happen. (This is a trap that medical friends are especially prone to falling in. In actuality, they often know very little about the current outcomes and treatments of premature babies, since it changes so rapidly.)

Dismiss them from family obligations - gifts at holidays and birthdays, family gatherings, etc.

Put aside any differences, disagreements and hurt feelings that stem from the NICU experience, as well as previous problems. Family issues can be resolved at a later time. By doing this, it allows the parents to keep their focus on their new family, instead of being forced to worry about other's reactions and other's feelings in response to the parents actions.

Accept the family's need for privacy. The parents need time alone with their baby, time to feel like a "family unit" and not under the constant intrusion of visitors - even family visitors. (Remember, you would not take up residence at the baby's house if they were fullterm.) Do not do this in the NICU, without being asked.

Schedule a time for visiting and respect if it is cancelled unexpectedly. (Remember, the baby does not know to adhere to that schedule!)

Respect that the NICU is the parents' private "home turf", even though it is an open hospital room with many workers. They may limit your time with the baby, or reserve special moments for themselves. They may have special rituals that they practice alone with the baby. Do not be surprised if they ask you to leave when they try to nurse or bottle feed or say goodbye at night.

Accept, without question, their need for privacy. (This can be especially hard if a regularly scheduled visit is revoked.)

Practice restraint when you are visiting the NICU. It is not your right to ask questions about all that is happening or ask for privileges the parents have not granted or discussed with you previously. Do not expect to hold, bathe, or change the baby. Do not ask to do so, unless the parents bring up the subject and give permission. (Doing so takes away control from the parents.)

Ask about participating with the baby outside of the NICU. When this is done during a visit, it can leave the parent in an uncomfortable position and they may feel forced to agree to something they don't want to do.

Respect the parents' trust and intuition. Refrain from questioning the ability, skill, or intent of any medical person attending to the baby. Do not call into question the judgement of the medical team or the parents. The parents' trust and faith in the NICU team must remain firm. The bond needs to be strengthened, not undermined.

given time for a number of reasons. Often they are exhausted and merely want time to recover for the next day. Or they may need time to digest difficult information themselves before they share it with others. Sharing difficult information may rehash their pain. They may feel that some information is private. Respect their boundaries. They will share what they feel ready to share.

Understand the reaction to the baby and the situation is not a function of hormones. A mother's pain is not a reaction to out of balance hormones. Her emotions will not disappear when the hormones balance. Her emotional response is the reaction to one of the most upsetting and painful things a parent will ever endure.

Use visiting time to visit the baby and admire her. Do not use this time to check out other babies, question nurses, or discuss what else is going on.

Place the parents needs for respect, privacy, and time to heal (emotionally and physically) above your own needs to not feel excluded, overlooked or avoided. The focus should always be 100% on what is needed for the baby and the parents.

Celebrate the miracle of the baby. Find something to compliment at each visit and during each phone call, even if it is only "she's a real fighter!".

Allow the parents to be the decision makers. It is their baby. Opinions and advice should be offered only when asked.

Do not compare babies. This baby has different needs than a fullterm baby. They are as different as apples and oranges. Do not compare the baby with other preemie, either. Each preemie follows a very unique and personal development pattern. In addition, because of the ever-changing science of neonatology, treatments and outcomes for preemies is constantly being modified.)

Do not compare the circumstances surrounding the pregnancy. This pregnancy took on a very traumatic turn and does not compare with full-term pregnancies. Do not minimize the pain and loss by commenting on a low weight gain, a fast labor, or a small baby, or the luck of escaping the final months of pregnancy.

Offer to pass on information to people the parents want to keep informed. Find out how, when and what and follow through. Make sure you are giving information only to those "approved" by the parents.

Be there when they need you. Often parents call out for support when they are in dire need - the baby is facing a surgery, a setback, or worse. Rise to the occasion without allowing any past or present resentments to cloud your vision. Now is not the time to rehash your hurt feelings or the fact that you feel "left out".



Provide the little things...

dinner, laundry, transportation, housework, grocery shopping, pet care, yardwork. Help to coordinate others who wish to help.

Offer help with other children. Provide babysitting, transportation, schoolwork assistance, meals, special outings.

Commend the parents on their adjustment. Compliment them on a newly acquired parenting skill. Praise their efforts to breastfeed and pump. They need to hear this praise to overcome their feelings of failure as parents.

Keep watch over the parents' health. Now it a prime time for moms to neglect the needs of recovery. Both parents can neglect needs for sleep and nourishment. Suggest help from a counselor or therapist if the pressures become too much. Help them in all these areas.

Help parents get through setbacks. They are disheartening, scary and upsetting. Do not minimize the difficulty of the setback for parents, even if it seems minor. Offer encouragement and help the parents reflect on all the prior challenges the baby has overcome.

Schedule visits with the baby at times convenient for the parents. Do not ask them to stay later than they planned or keep them waiting on you. Their schedule is already compromised.

Take the parents lead when discussing homecoming. It is common to not know a discharge date until 1-2 days before it occurs. Continually asking about homecoming is upsetting to parents. This goal is always first in their mind, and as the saying goes "a day late, and a dollar short". Bringing up homecoming can reinforce how much longer the stay might be as well as how long it has been already - both disappointing topics.

Common traps that people fall into...

For lack of better things to say, or in an effort to ease parents pain and offer consolation, or just plain because they are an "outsider", people easily put their foot in their mouth around premie parents. Here are some things NOT to say...

"He'll be home soon." Soon is never near enough.

"He's in so much pain." "How can you stand his pain?" "I can't bear to see him this way". Don't pity this baby. This makes the parents feel guilty and helpless.

"He's sooo.... tiny!!!" "I've never seen anything sooo... tiny!" This is interpreted as blame and criticism by the parents. It can also make them feel as if they are equating his size with his chance at survival, as in "he's too tiny to make it".

"What should be will happen." "Don't worry, it'll all turn out as it should." This implies that losing a child or enduring a very rough start for your baby is something you deserve. Besides, if this were true, then why do we need the medical field at all?

"If you hadn't of \_\_\_\_\_, then this wouldn't have happened." "Didn't you feel contractions?" "Didn't you think something was wrong?" "Why didn't you doubt your doctor's advice or follow your intuition?" All these are hunting to find blame. They only add to a mother's guilt that this was somehow her fault.

"How can you hold something so small?" "What do you do all day since you can't hold him?" These statements attempt to ignore that a parent loves and bonds with their baby, irregardless of complications and size. It makes the parent doubt their actions and view their love as a risk that perhaps shouldn't be taken.

"You can always have another baby." This is a lack of understanding of the bond of love. It is a rejection of the worth of this baby. It attempts to forecast possibilities of the future.

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## Pumping and Breastfeeding

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"You have to do the best you can  
under the circumstances  
and realize there's no point in getting upset.  
You'll run into difficulties,  
and if you can change or improve the situation, change it.  
If you can't,  
don't fret about it."  
-Bob Bole

Many emotions and feelings surround the breastfeeding struggle that premature moms face. Part One of this guide will discuss how the mother's emotions are affected by accepting pumping, the logistics surrounding pumping, suggestions from others, the spouse's role, and problems with milk production.

### First Impressions and Expressions

At first, until the mother finds out she is indeed able to participate in breastfeeding, she may feel very upset and grieve her loss of a very important part of mothering her baby. She may feel angry and sad that nursing was "taken" away from her. Even if she was previously uncertain as to whether or not she would breastfeed her baby, she can be mad that the decision was made without her - she had no input.

However, when the news is shared about pumping breastmilk for her preemie, a mother's outlook is likely to change. If she chooses to try pumping, she may start to feel excited and joyous. She can actually **DO SOMETHING** for her baby! She can be an active participant in mothering, even if she can't yet hold or care for her baby. This is very reassuring to the mother - she is still very important to her baby. Mixed in with her joy, though may be other emotions - fear, worry, embarrassment, disappointment, disgust.

### Fear and Worry

The mother is likely to fear that she will be unable to produce any or enough milk for her baby. The feelings can be similar to performance anxiety. With many nurses and lactation consultants watching and "waiting for the milk to appear", she may start to doubt her abilities when the milk takes the normal few days to "come in". She may even want to give up now. This waiting can make the mother upset and feel like a failure. It is important for the mother to receive lots of reassurance and support during this time - from everyone. It is also important to educate her on the normal process of beginning breastfeeding - the wait for milk, colostrum, typical amounts that are produced at the start, and why. It also

is important to make sure her pumping techniques are correct. (Too often a mother is issued a breastpump and not instructed in how to operate it. Or her techniques are not reviewed and perfected by a nurse or lactation consultant.)

Once the milk begins to flow, she may still have fear that she will not produce a suitable amount or that it will unexpectedly stop at any given time. Here again, education and support are vital for the mother. It is not likely that the milk will disappear when a good pumping routine is established, so that fear can be eliminated with education. Also, it should be stressed over and over that producing any amount of breastmilk is a great accomplishment, whether or not that amount is able to be the sole source of feeding or only a portion. A mother should understand that any amount of breastmilk she can produce for any amount of time is worthwhile and great for the baby.

#### Embarrassment, Disappointment and Disgust

Because expressing breastmilk is not the usual route to breastfeeding a newborn, a mother can be embarrassed at what she is trying to do. She may be embarrassed that she cannot feed her baby like other mothers do. She may feel embarrassed to have to learn to pump while in the hospital. (A closed door and a door monitor can help with this!) She may feel that others see her as a failure as a mom because she cannot do it the way as other moms do.

She is likely to feel disappointed that the cozy bond of nursing has been replaced with attaching her breasts to a mechanical pump. She may even feel disgusted at the technique and feel that she is milking herself like a cow.

It can be hard to view pumping as worthwhile and important when these feelings enter her mind. It can help to praise the mother's fortitude for "sticking it out" and trying to "do what's best for the baby". It can be especially reassuring when she sees her baby receiving her milk, via tube or bottle feedings. It can help to reinforce that feeding in this style does not mean it is permanent, usually it is temporary until the baby learns to nurse.

#### Supporting the Mother's Choice to Express Milk

Many times, friends and family members, even spouses will encourage the mother to give up the struggle of pumping milk. While their intentions are good, the mother needs encouragement and support to persevere and hang in there until she chooses to stop expressing. Often instead of hearing compassion, the mother hears doubt about her abilities and discouragement hidden in these well-intended suggestions. She may wonder if others

understand how intensely she feels about breastfeeding. She may not be able to explain why she feels this way. She may be ashamed to admit that breastfeeding and pumping is the only way she feels successful as a mom and it is "making up" for her failure in pregnancy, childbirth, or delivering a healthy baby. She may not be able to express how pumping makes her feel connected to her baby, how often it is the only bond she feels with motherhood at this time.

If she were to admit these things, many friends would try to persuade her that she is not a "failure" and that she can be bonded with her baby in other ways. This increases the lack of connectedness she feels with friends. It may also leave her feeling as if her feelings have no value and they are not normal. She may refrain from discussing the matter any further because she doesn't feel safe to share her true feelings. It helps if friends can understand all that expressing milk offers to the premature mother. It is suggested that friends and family unconditionally support the decision to pump and breastfeed as long as the mother sees fit.

#### The Logistics

Pumping breastmilk is not anywhere near as convenient as nursing. The logistics that are involved can bring up more feelings in the mom.

#### Finding a Pump

It can be frustrating, scary and worrisome to locate a pump. The mom is under pressure to pump routinely, but between traveling, sleeping, and visiting baby, finding a routine is all but easy. It can be frustrating to have to time travel and visits around a pumping schedule. It can be worrisome, especially when leaving the hospital the first time, that she won't be able to easily find a pump to rent at home. Worry also crops up when a pump is not readily and easily available near the NICU. This happens often when there are not enough pumps available, or too many hospital employees are allowed to use it. The mother attempts to regularly schedule pumping sessions, but cannot do so because of the inaccessibility of pumps. She may need to resort to bringing her own pump if the NICU cannot work this problem out.

There are other worries, too. Not only does the mother have to worry about finding the pumping room, physically getting to it (especially when recovering from C-section), but she concerns herself with getting to it in time as well. Make sure the mother knows the location of all pumps, has help in getting to the rooms (wheelchair if necessary) and someone to help her schedule pumping accordingly. Since parents often get wrapped up in what is happening in the NICU, perhaps a nurse can be asked to remind her of when she should leave to pump.

Finally, many times there are misunderstandings about the what to do with breastmilk. Freeze it?

Refrigerate it? How much should be brought to the NICU and when? It is important to fully explain milk storage procedures to a mother. Even if she fully understands them at the time, the procedures should also be written down for her to review if a question arises. Too often a mother spends hours pumping milk, to find out she stored the milk improperly and it must be dumped. How disheartening this is to the mother! Make sure she comprehends what amount of milk is to be kept "fresh" for immediate use. Too often a mother is not told just how small an amount of milk is taken by the baby at first and she is disappointed to find out her baby may only take a few cc's. Prevention through education can nip disappointment, discouragement and upset in the bud.

Got Milk, but what about everything else?

A mother often worries that she may forget her supplies for pumping. This can cause her to feel pressured which in turn makes pumping more difficult. She may get to the pumping room, get undressed and ready to pump, and realize she forgot one part of her pump. It is not uncommon for a mom to go to the trouble of pumping, only to find out she forgot empty bottles or a cooler for the milk. Help her make a check-list to carry on trips to the NICU. Double check that she has all supplies in the NICU and at home. Know who she can contact in a pumping emergency.

The Role of the Spouse

While physical limitations will keep the husband from pumping (although there has been a mention or two in history of men lactating!), they can play a vital role in it. The spouse should help encourage and support the mother as long as she chooses to express breastmilk and attempt to nurse.

Many times the spouse may encourage his wife to give up expressing and nursing before she wants to stop. He often does this out of concern and caring - he wants his wife's life to be a little less stressful and upsetting for her.

He may view pumping as an inconvenience not only to his wife, but to himself, as well. It takes lots of time (as much as nursing a baby!) to successfully attempt expressing milk for many days, weeks or months. It can put a damper on schedules, and tie down the mother in terms of what she can do and where and when she can go places. It is normal for both the mother and father to resent this "inconvenience". However, it is best to acknowledge it as such, and move on to finding ways to positively support and encourage the mother as long as she chooses to pump for her baby.

In addition, the dad may feel discontinuing pumping could ease some stress he feels. He may feel more secure in the knowledge that his baby is getting a determinable amount of milk at each feed and may doubt less about weight gain.

On the other hand, he may encourage her to continue expressing when she is

otherwise ready to stop. Again, while she should consider his opinion when making her choice, she should ultimately be the decision maker, for it is her body and mind that is bearing the stress. The husband needs to support her choice totally, either way it goes. If she chooses to continue, he needs to not undermine her courage, perseverance and determination with his own doubt and worries.

They husband can do much to relieve the stress of pumping and help make expressing milk easier for the mother. He can turn pumping times into a relaxing event in several ways. He can help prepare the supplies for pumping - empty bottles, a timer, pump parts, as well as set up a comfortable pumping station, stocked with pillows, a blanket, the remote control and a cordless phone. He can turn on some relaxing music, a movie or television show. Or he can provide some magazines or a book to read. The husband can prepare a warm drink or a glass of water to sip before and during pumping. If possible, it helps for him or another helper to stay close in case she needs assistance. The support of a spouse can be very reassuring to a mom during this time.

Whoa - is THAT your milk???

Because pumping breastmilk (versus nursing at the breast) gives the mother a visual result of her efforts, it can stimulate many, mixed reactions. Obviously, the visual result offers a few advantages. It can be reassuring and encouraging for the mom to see that she can take an active part in mothering her baby. It can add to her feeling like a "real mom". It can make her feel special and important - for she is the only one who can provide this special milk. The problems with this visual "report card" seem to arise when the mother's production is either on the high or low end.

**A large amount of Breastmilk**

For the mom who produces a large amount of milk, it can feel wonderful. She may feel a sense of control return to her and sense of accomplishment. However, this mom can also be embarrassed and upset at her body's large production. This is especially true if nurses and lactation consultants call attention as an abnormal function ("You need how many bottles?!", "Oh she makes so much milk, she could feed the whole NICU!"). It can make her view her body's response as inappropriate or abnormal, especially if the baby cannot take any or very little milkfeeds. She may feel like the milk she is producing is a waste. This mom may often be embarrassed to ask for bottles to store the extra milk and instead throw it away.

**A Small amount of Breastmilk**

At the other extreme is the mom who produces too little milk. She is also likely to be upset. At a time when she already feels like a failure in the pregnancy department, a lack of success in

pumping can be a final blow to this mom's esteem. She may be ashamed to take the half-filled bottles to the NICU. She may decrease the time she pumps, since it appears to be so unproductive anyway. This only adds to the problem - the less she pumps, the more the supply dwindles. Or she begins spending more and more time pumping during the day and waking herself up multiple times in the night. As she becomes more fatigued and stressed, her supply drops even lower. When she shares her struggle with friends and family, they may encourage her to give up pumping in an effort to reduce stress, fatigue and depression. This leaves her feeling even more alienated and misunderstood.

If she accidentally spills or wastes any milk, she can become extremely upset. Don't be surprised to find her obsessively sopping up spilled milk in an effort to save it and hysterically crying. She may even become so stressed that she becomes forgetful with her pumping procedures. She may accidentally forget to store her milk when she finishes pumping or she may forget to take her pump parts to the NICU. It is normal for this mother to start asking for help and searching for remedies to her problem. If the proffered remedies do not offer a solution to her low supply, she gets even more upset and can become compulsive. She can get into a vicious cycle of seeking out many new remedies, anxiously trying them, then becoming even more upset and disappointed when they don't work. Or she may stop asking for any help at all, even if she has not tried all suggestions, for fear that nothing will ever work. It is a shame that at a time when a success with breastfeeding could help resolve feelings of failure as a mother that surround preterm birth, it is only adding to her feelings of failure.

In both instances, the mothers feel abnormal and ashamed. They both can feel anger at the loss of control over their bodies and their babies. They both can feel depressed at not being able to nurse her baby. They may start to see nursing as the ultimate or only goal and lose perspective of all else. Their esteem may suffer under the pressure of pumping.

What to do?

For the overproducer...

Help them see the long-term benefits of pumping for the baby. Reassure her that the efforts of her pumping do have a goal - actually nursing her baby - and are not in vain. If she is in need of an immediate reward, and it will be awhile before the baby is to begin feeds with the milk, suggest possibly donating some of her milk to a milk bank. Have a nurse and lactation consultant work out the bottle supply and storage logistics with her. She should always have an ample supply of storage bottles for the milk. Talk with the doctors about the schedule for introducing and upping feeds - it helps to have a plan of action for using all the milk that is building up. Reinforce how proud she should be of her success. Help develop a sort of "advent" calendar to help her look forward to the goal of breastmilk feedings and nursing with mom.

For the underproducer...

Help the mom feel pride in her efforts to produce milk, regardless of the



amount. It is difficult work, tiring, and added stress for the mother. Let her know that her efforts are acknowledged, for a worthy cause and not in vain.

Make the nurses aware of her struggle. They can be more careful with their words. Let them know NOT to comment at all on her production amounts (comments such as "don't waste that milk - we don't have much!" or "don't you have any more?" can really hurt). Help the mother focus on other aspects of mothering she can participate in and not just breastfeeding. Ask nurses to teach her ways to touch or massage the baby, if allowed. Help her pick out some special children's books to read when she visits. Help her decorate the nursery or shop for some premie clothes if she chooses. If she is kangaroo-ing, include many times for just cuddling without the pressure of trying to nurse. Assist her with pumping (wash parts, store and label milk, keep her company or provide and entertainment while she pumps). Encourage her to set up a meeting with the lactation consultant to review her pumping techniques and discuss possible suggestions.

For both moms...

Reinforce the normalcy of their emotions. Help them connect with other premie mothers experiencing a similar problem, through a support group at the hospital or perhaps the internet. Help them keep their focus on the baby's progress as a whole, not just the feeding aspect. Do not encourage or insist that the mother should stop pumping in either instance. Often, she feels this is her only link to the baby, her only way to compensate for her "failure" in the mother department. If the mother brings this up, help her weigh her choices objectively, without adding your personal opinion. Help her find a lactation consultant to help her with any and all difficulties.

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## Breastfeeding, Part 2

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Part Two of Breastfeeding offers insight into the emotional struggles moms face when learning to nurse their baby at the breast, special situations in the NICU, and transitioning to the breast at home.

### Taking on Breastfeeding

It normally takes lots of practice for a fullterm mother to become adept at breastfeeding. For a preemie mom, it can take even more practice because the baby is still learning how to coordinate sucking and swallowing, if not overcoming other barriers to nursing. While most NICU's breastfeeding policies seem have slight differences, it is common for the mother to work 1-2x per day on feeds at the breast, once the baby is ok for nipple feeds. (This is usually due more to the logistics of time mom is present, more than anything else.)

### Feelings

This time can be exciting and stressful. The mom is anxious for the baby to latch on readily and nurse effectively. Some latch on immediately and learn to nurse quickly and proficiently. A great many, though, face challenges at this time. Because all babies are different and each learns to breastfeed in their own manner and at their own speed, a mother can become easily discouraged and frustrated if breastfeeding does not come instantaneously. Nipple confusion, refusal to latch on, difficulty coordinating suck and swallow reflexes, or a weak suck are some of the normal preemie complications that can contribute to difficulty in learning to breastfeeding.

This can be discouraging and disappointing to the mother who is so anxiously awaiting nursing her baby. Feelings of failure may resurface. She may blame herself for not getting it right. She may be embarrassed about asking for help with something that is assumed to come "naturally". It is also intimidating for many mothers to try to learn breastfeeding with little or no privacy. While nurses can be quite supportive, they can also contribute to "performance anxiety" and feelings of failure with their constant "interference" with questioning before, during and after the breastfeeding about the "success" of that session. (This "interference" is necessary, though, for the nurses to record how the baby is doing with feeding.) Moms can feel judged by their ability to get their baby nursing properly. The nurses may also add extra pressure and stress to the learning mother by requiring her to stick to breastfeeding regulations of the NICU. Some of the normal restrictions/regulations are supplemental feedings by bottle, limiting amount of breastfeeds, limiting time at the breast during each feed. While each NICU normally places these restrictions for valid reasons, the mother

still feels a loss of control over her baby and her body. Sometimes, though, shift changes and such interrupt a breastfeeding session and this can be especially frustrating. She may feel angry at the NICU's restrictions and feel that if she could do it her way, she could be more successful.

### The Link to Homecoming

Since breastfeeding success is also linked to homecoming, becoming successful at

breastfeeding can place extra pressure on the mother. She feels a need to help her baby learn it quickly, so he can come home that much faster. If she is unable to successfully breastfeed or encounters many obstacles to it, she may be angry at herself. She may blame her breastfeeding abilities for prolonging the separation between her and her baby.

### Choosing the bottle temporarily

When the choice comes down to learning to breastfeed successfully or speeding up homecoming by teaching the baby to nipple feeds from a bottle, it is not unusual at this point to choose learning to use a bottle as the quickest route to home. If this is chosen, there may be a sense of loss, but also a sense of relief for the mother. The burden of delaying homecoming is lifted from the mother's shoulders and she can focus on the joy of baby's imminent discharge. She may also be quite hopeful that once she has her baby home, she will be successful with breastfeeding - when she can learn at her own pace, without the watchful eyes of the nurses and the clock ticking away, without any rules and reg's. The loss is normally viewed as only temporary and may not be as upsetting to the mom.

### How to Help

It is important to offer support and understanding during this time of learning. Be sure the mother is receiving all the assistance she needs from nurses and lactation consultants. Help her understand that it is normal to need help in learning to breastfeed. Most fullterm moms receive instruction, too! Reassure her that many, many preemies face challenges when they begin nursing. Be sure the nurses and doctors specifically explain about the difficulties that are hindering breastfeeding and how most other babies overcome them. This can help relieve the blame and burden from the mother. Never blame the lack of success with breastfeeding for keeping the baby from home. Offer support to the mother if she chooses the bottle feedings temporarily. Remind her of the opportunities to nurse that await her at home. Empathize with her about how difficult and stressful it must be to try to learn such a private skill in such a non-private arena as the NICU, with a baby who has special needs.

### Special Situations

#### Pump and Dump

Sometimes a mother will not be able to give her breastmilk to her baby because she is taking a medication that does not mix with breastfeeding. The milk must be dumped in the drain instead of fed to her baby. She may feel extra frustration at this time. She might feel rather unconnected to the baby and

burdened by pumping milk to throw away. It is important to help her understand why she is continuing to express milk at this time - it is because she will be able to give the baby her milk again shortly. Reassure her that continuing to follow her schedule will help keep up her supply. Help her find a way to feel close to the baby during this time - perhaps finding a special book to read aloud to baby may help or some extra time kangarooing.

### Introducing Supplemental Feeds

Sometimes, when a baby's weight is not increasing at an expected rate, supplemental feedings may be introduced. This can be accomplished by adding MCT oil or polyose to the breastmilk to up the fat calories, by adding breastmilk fortifier to the expressed milk, or by introducing some high calorie formula to the baby's feeds. A nutritionist explained supplementing in this way, "It is NOT that your breastmilk is deficient or lacking in any way. It is that your baby needs an extra boost to grow at this time, because his body is requiring some extra help beyond what breastmilk is giving him. This is no fault of the mother. It is not what she is eating or failing to eat. It is not because her body is not making the right type of milk.. All breastmilk varies in content, and this is through no fault of the mother."

Even if a mother understands the supplementing is not in response to her milk quality, she can be quite upset. It is not unusual at all for her to feel as though she is to blame, that she is failing at her responsibility of providing proper nutrition, guilty of letting her baby down. She may wonder if she will ever get anything right with this baby. These feelings can be quite intense and may not easily resolve unless someone takes the time to explain the medical reasons behind supplementing, reassuring her that she is doing her best.

### Being Asked to Back Off

Occasionally, a mother may be asked to back down from her nursing attempts. This is often in response to the baby's medical condition. It can be hard for the mother to give up nursing sessions when she was just beginning. Again, it is extremely important that the reasons be explained in detail to the mother. If not, she is left feeling confused and powerless. It is also important that she does not receive conflicting viewpoints on this issue. The doctors, nurses and lactation consultants should all be in agreement with backing off. Otherwise, feelings of doubt, confusion, loss of control and anger are likely to surface in the mother. Be sure the mother is offered lots of comforting, encouragement and reassurance during this break time. It helps to offer a proposed schedule of when breastfeeding may begin again as well as other alternatives to breastfeeding, such as

kangarooing.

### Transitioning at Home

If a baby is ready to be discharged but is not on full feeds by breast, there will be a transitional period after the homecoming. Many moms try immediately to go to total breastfeeds, starting during the rooming in period, only to meet disappointment, exhaustion and frustration. Learning to breastfeed exclusively is hard on a preemie and his mom. Often, it takes slowly increasing the number of feeds by breast over a period of days or weeks, or even months to achieve total nursing at the breast. This can cause lots of stress for the mother.

She wonders if she will ever be successful with exclusively breastfeeding. She may doubt herself over and over. She may worry that she is not doing something correctly, but not know how to get help, since she is now away from the NICU. She may feel overwhelmed with breastfeeding which is supposedly so easy and natural to learn. She may feel like less than a perfect mother. She may begin to obsess about breastfeeding. This can cause fatigue and undue pressure, as well as depression over a loss of power and control. Feelings of unfairness may resurface, as the mother questions why she has to deal with a high/special needs baby.

It is important for her to work within her own timeline, and maintain large reserves of patience. She will need extra encouragement for her efforts, extra praise for her perseverance, and lots of reassurance of the possibility of a positive outcome. She will also need help with supplemental bottle feedings, and watching the baby while pumping. It is a tiresome venture, both physically and emotionally, which many moms pursue relentlessly for weeks and months. Sometimes the mother is successful at transitioning the baby totally to the breast and sometimes she must accept partial feedings by breast/others by bottle. For some mothers, although they try extensively, their baby may not adjust to the breast at all. This is quite common with preemie moms. It is by no means the fault of the mother.

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## What Every Parent Needs To Know: Taking Care of Yourself

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The difficult we do immediately.  
The impossible takes a little longer.  
-Army Corp of Engineers

### Caring for Yourself

It is important for you to take care of yourself while your baby is hospitalized. You are recovering from childbirth, possibly major surgery or extended bedrest, and at a time when most moms recover at home for a few weeks, you must travel to the hospital to visit your baby in addition to recovery. It is easy to take care of your baby during this time, and forget about your own needs. Don't forget, your baby needs a mom who can take care of them once they come home!!!

To maintain your strength and heal properly, it is important for you to eat as best as you can and get some additional rest during the day. Of course, both of these things will take on a modified version while your baby is in the NICU. Rest may mean taking a nap in the NICU chair or waiting room a couple time each day or sleeping in the car on the drive to the hospital. Since you often want to spend as much time as you can with your baby, you may choose to eliminate resting. This is not good choice. Getting extra rest will help to keep you from feeling any more stressed than you already do and is just as important to your mental and physical health as is seeing your child. This is especially important if your are pumping breastmilk.

Meals on the other hand, are a whole other story. You must adjust your thoughts on what regular and nutritious meal mean during the NICU stay. If you have volunteers to cook for you, by all means take up their offers. If those offers are short, which they often are, (people fail to realize you need the help as much as a mother whose baby is home) then venture to the hospital cafeteria. They may even reduce your costs if you ask. Other options: take-out, delivery, and good old McDonald's. Remember eating like this is temporary and a survival skill, and you can return to "regular, nutritious meals" once your baby is home. When you visit the hospital, take along a snack each day. This way, you won't have to leave the area if you get hungry or spend extra money you may need to save.

If your baby is going to stay for more than a few days, you need to start scheduling some breaks for yourself. Remember that everyone needs an occasional break from visiting the hospital, even moms and dads. It can be upsetting to do this - you may feel like a negligent parent, or worry about your baby receiving love and attention while you are gone. You may be fearful that something will happen while you are away. You may even worry that the nurses will judge you as a "bad parent". All these feelings are valid and normal. However, you are not a "bad" or selfish person for needing an occasional break from the NICU.

Consider taking one day off a week to rest and take care of other duties, or leave early two nights a week. Spend one evening with your spouse and talk about all that is going on with the two of you. You will feel renewed and better able to cope with your baby's stay.

It is not uncommon for mothers to have to return to work before their baby comes home. Be sure to explain to your boss about your needs. It can be difficult to work, rest, eat, and visit your baby, but it can be done. You will probably need to cut down on your work schedule or your visiting schedule during this time. Don't forget to give the nurses your work number so that they can reach you.

### Stress and Your Body

It is not unusual for the stress of the NICU and a preemie baby to take a toll on your physical health. Depending on the amount of stress you are feeling, the support systems you have to help you, and your body's recovery from childbirth, you may experience different physical symptoms resulting from stress.

It is not uncommon to suffer from headaches, stomach pains, nausea, gastric distress (such as diarrhea), or difficulty sleeping (nightmares, sleeplessness, flashbacks, sleepwalking, etc), all as a result of stress. Depression is another symptom that your body is dealing with an overload of stress. (see more under Depression )

You may notice that on particularly rough days, your symptoms increase. Or you may see a trend where your symptoms appear during routine times - when phoning the NICU for an update, on the drive to the hospital, riding on the elevator to the NICU floor, during rounds. It is normal to feel apprehensive, worried, and scared during these moments of "uncertainty".

It is important to talk to your own doctor about the stress you are under. Not only can they help you, but it is wise to ensure you are not actually sick with something you could pass onto your baby.

### Letting Others Know How They Can Help You

While your baby is in the hospital you will need help from friends and family. To help others understand what they can do, see [How to Help the Parents](#) and share it with friends and family.

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## Getting Along with the Grandparents of Your Preemie

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a special collaborative column!  
Getting Along with the  
Grandparents of your Preemie

(Note: this column appears in The Early Edition, Feb/Mar 98 edition. See Links for the connection.)

By: Kerry Bone, Mara Tesler Stein, Psy.D. and Deborah L. Davis, Ph.D.

Besides the changes that a new baby will bring to daily life, it is normal to experience changes in how you perceive your family relationships and even your upbringing. Having a baby of your own is particularly certain to influence the nature of your relationship with your parents in subtle and/or obvious ways. How they react to you and your baby can be very important to you.

### HIGH HOPESÉderailed

Part of the preparation for childbirth includes envisioning how your new baby will join your family. You imagine welcoming your newborn, along with your other children, your siblings and your own parents. You imagine how they will respond to this new little one.

Perhaps you imagined including them in the birth or at least the early days after homecoming. You probably imagined the pride and admiration they would show over your precious little bundle. Particularly if your relationship was distant or rocky, and this was your first child, you may have hoped that your baby could provide a bridge between you and your parents, or at least smooth the way. Perhaps you imagined leaning on them for advice and support, or commiserating with them about "normal" newborn antics.

But when your baby arrived early, your best "grandparent plans" are derailed. It may have been impossible to include your parents in the delivery and those first days after birth. Instead of being able to show off, and pass your baby to eager arms, you at best can only lead them to your baby's bedside. Instead of greeting your little one, they may hang back in shock and grief. Instead of hearing congratulations and delight, you may hear only sympathy and sorrow.

When your pregnancy does not go as expected, how your parents react can be even more important to you. If what you need does not match up with what they actually do, you may find yourself faced not only with grief about the preterm delivery and all those special "grandparent moments" you've lost, but also about your parents' failure to help you in the ways that you want.

You may be very hurt if your parents fail to form a bond with your baby. You may even have to bear your parents' feelings of helplessness, anger and



blame. At a time when you need their support most, they may be utterly unable to give it to you. Rather than commiserating, they may be speechless and stunned, or worse yet, provide you with "advice" that does not fit your circumstances.

If you paired the arrival of your baby with the hopes of a reunion with your parents, their response to your situation may instead further alienate you. You may harbor feelings of failure, that you have failed to provide a perfect grandchild to them, or that you are a blighted branch on the family tree. If you had shared a close bond with your parents, this experience might make you (at least temporarily) feel alienated from them.

### GRANDPARENTS GRIEVE TOO

As much as you and your spouse are finding it difficult to adjust to your preterm delivery, so too are the grandparents. Not only are they concerned about a dear grandchild, they may also find it difficult to see their adult child in such pain. Often we fail to remember this "double sorrow" that they feel. We may also revert back to the childhood thoughts that our parents automatically know what we need in terms of help and support. They should know what to do -- they should know what we need, right? Haven't they "been there, done that?" For most grandparents, the answer is no. There is no secret "grandparenting manual" that tells them what they should do, just as there wasn't one to help you. They are likely feeling overwhelmed and paralyzed, unsure of what will help.

Just as parents are faced with losses and adjustments with the birth of a preemie, so too are grandparents. There are a few different types of issues that parents face with grandparents when their babies are born prematurely. The following quotes were chosen to show parents' reaction to grandparents' understanding and support—or lack thereof. Reading about a wide variety of experiences and responses, you may gain a sense of how normal your reactions are, and how normal your baby's grandparents are too.

### FEAR, or coping with the unknown

Until you delivered early, you may never have had the opportunity to see your parents cope with a major crisis or family trauma. Some grandparents are more skilled than others at coping with their anxiety and fear and can tune in to the needs of their adult children. Others are more easily overwhelmed by what is happening around them. In any event, your need for them to respond to you, to help you to cope with your own feelings doesn't go away no matter how skilled they are in providing support. If their coping clashes with yours, you may feel even more alone. If it meshes well, you may feel more supported than you could ever have imagined.

It is common for grandparents to hang back, not offer congratulations or get very involved. Bonding with a baby who may die can seem unbearable to some grandparents. You too may feel inadequate, like you've let them down, and you may fear your parents' criticism for not having a smooth pregnancy. Your vulnerability and theirs can sometimes keep you far apart.

Hanging back:

"My mom had a hard time bonding with such a sick baby. I felt the same way initially, but it still hurt me."

"They never acknowledged the birth with anything - no card, no flowers, balloons, nothing for the baby. It felt like they were just waiting to see if he made it."

"They were totally intimidated by him...it created a lack of bonding for Marcus and a feeling of desertion for me."

"I felt like I'd let my daddy down by not having a 'perfect' child."

"They both quickly left town to return to their home. I felt abandoned. They gave new meaning to the saying 'When the going gets tough, the tough get going.'"

Just right:

"The first night when my husband was told that his wife and baby might not make it through the night...his mother just held him and let him cry on her shoulder."

"(They) were supportive in so many ways possible...my mom watched my older son, she took total care of the house, and helped to keep us from falling apart. I totally resent my mother in law...she was disgusted by how jaundiced he was and she didn't want to hold him because he was so small."

"They were happy and celebrated the birth. It made his early birth seem a little more normal."

**BOUNDARIES**, or respecting your role as parents

Under even the most ideal circumstances, new parents struggle with how much input they want from their own parents. When you have a baby who requires special care, your sensitivity to the advice you receive, and your desire for your parents' respect is heightened. Some grandparents pull back too far, leaving parents feeling abandoned or rejected. Others move in too close, trying to take control in order to soothe their own feelings of anxiety and panic. They may even seem to feel some emotions more intensely than you, the parent.

Too close:

"No matter what the nurses said, my father-in-law always made a point of telling us how much it 'pained' him to look at our baby. He said he 'knew' he was suffering - even when he was just a feeder and grower!"

"My mom watches (visitors) like a hawk, and will allow no one that even thinks they have been sick to visit them."

"I hated to let them visit unsupervised. I knew they would quiz the nurses, and the nurses would let them do whatever they asked for, with no regard to my wishes. It had no control over anything, I didn't even feel like the mom."

"I was expected to let anyone in the family visit him, when I couldn't even get out of bed to see him myself. It killed me that I was expected to allow my brother's girlfriend, who I had met once, to see my son. It was such a loss of control over my baby."

"They wouldn't even give me time alone in my room. I just wanted to sleep and learn how to pump in solitude."

"They would expect to visit him when it was convenient for them, not the baby or us. If we said no, it created major problems."

"They left messages for us to call them with the news for the day. Some days it was more than I could do to relay what had happened. When we did, they kept hounding for more details, some we just didn't wish to share."

Too far:

"(Their) first comment was 'Are these kids sure they want to take extraordinary measures?'"

"I limited the info I passed on...she always made it sound like it really didn't matter to her anyway."

Just right:

"When my parents called, they waited for me to offer anything. If I didn't, they respected my wish to not talk about it."

"Many times I had information overload and they really helped sort it out with me."

"My parents had no problem just watching her and leaving holding time for mom and dad."

PERSPECTIVE, or understanding what it means to have a preemie  
When your baby was born early and needed extra special intervention, your parents probably didn't know what to think or expect. Many grandparents have no clue as to what a preemie looks like or needs, nor do they always understand all the implications. They don't want to see you struggle, and they don't want to imagine their grandchild having difficulty, either. Some grandparents can move past this conflict, learn about their preemie grandchild and fully support their children. Others continue to struggle, and can't fully assimilate or accept their preemie grandchild's special beginning.

The struggle:

"They acted afraid to touch her, like she had a communicable disease or something."

"When I sent pictures my father didn't like them and asked me not to send them. It really hurt that that my parents didn't want to be involved."

"I felt sorry for my mother in law...it's been kind of hard for her to brag about her grandkids without having to explain the WHOLE preemie story."

"They always asked how much she weighed, it wasn't the right question to ask (on difficult days), but it was the easiest thing for them to follow."

"My father kept saying there was no need to use her adjusted age."

"My mom whines about not seeing the baby enough and has not been very supportive."

"I think they didn't know how fragile that baby was. Medical concerns were either overlooked or not paid attention to."

BEING THERE, or giving you the kind of support that YOU need  
With an early delivery, feelings of fear influence how well people can come together and support one another during this emergency. Feelings that you and your parents had about each other, old patterns, and hopes you had for the future can be magnified during the crisis. Some people are able to use this as an opportunity to repair rifts and bridge distance. Others are too flooded with hurt and fear, and feel more comfortable avoiding you, the baby and the whole situation.

Rifts:

"I was afraid they would just assume that there was nothing they could do and stay away."

"She left on a scheduled vacation because she needed some time to get away. It left me wondering if she had any clue as to how much help, and not just support we needed."

"After my father in law said maybe it would have been better if he died at birth, I started to limit my phone communication with them."

Bridges:

"We constantly asked for help, support and advice and they were constantly there for us giving, giving, giving."

"My mom helped tremendously...with the other daughter, going on doctors

visits to help with the monitors, getting information, running errands so Mandy wouldn't have to go out."

"She came back after he was released to help with the night shift for a couple of weeks."

"They cooked for us the entire time, as well as after they got home."

"My parents have acknowledged what a difficult time we experienced, which is all that I wanted to hear."

"She was dying to hold him, but would just look at him while I held him. She knew how much I needed to hold him."

### COPING...

As each parent learns to cope with the birth of a preemie, so too do grandparents. And there is no one "right" or "wrong" way to adjust. It is important to allow them to cope on their own terms, but it doesn't change the fact that you still require incredible amounts of support and understanding from them during this time. If you feel you are not getting the support you want, you can try several things:

Try to remember that you may share many similar kinds of disappointments and worries. Share your sorrows and fears, and you may find an empathic partner.

Remember that it is normal for grandparents to hold back their emotional investment in a baby who may die or be "abnormal". Give them time to adjust their expectations and to get to know your baby as an individual.

Make it clear that you do not expect or want your parents to "fix" your feelings. Let them know that you just need them to listen without criticizing, minimizing or lecturing.

Avoid the trap of trying to protect their feelings. Be honest about the situation, your emotions, their role and your baby's condition. If they are angry or sad, let them have those feelings.

Remember that your parents may be clueless, but earnest in their desire to help. Educate them on what you need. Let them know when they make a remark or gesture that is hurtful. If they want to be supportive, they will appreciate your efforts to let them know how they can help.

Share your knowledge about what your baby needs. Teach them how to interact with your baby in ways that will help your baby stay calm. Share information sources with them. Include them in NICU rounds, follow-up visits or therapy appointments so that they can learn more about your baby's special needs.

If you are receiving unwelcome advice, or if your parents ignore your attempts to inform them about your baby's needs, emphasize to them that preterm babies are not just "little full term babies". If your parents are

insulted that you don't consider them to be the "experts" in the parenting arena, let them know that you welcome their efforts to join you in learning how to parent a preemie or a chronically ill baby. Invite their partnership in navigating new territory.

If you are having trouble dealing with comments or overinvolvement of grandparents, you can pull back. Let them know that you need some space to figure things out for yourself. Set limits and stick to them. Grandparents are NOT entitled to free reign to take over; you have a right to protect yourself and a right to privacy. Temporary distance is a reasonable alternative to constant coaching about preemies or fighting for your needs and wishes.

You deserve to get what you need. If your parents cannot be supportive, find other sources of support in friends, other parents, and professional counseling. Don't rely on your parents if they are not reliable.

Kerry Bone stays home full time to raise her son Tyler (31 weeks) who is now a crawling ball of energy. She sometimes misses her teaching career, but enjoys using what free time she has to work in organizing her son's hospital NICU parents group and writing for this preemie newsletter.

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## Understanding Premie Parents

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"Prematurity is a world you never know exists, unless life takes you there."

Unless you have actually been the parent of a premature baby, it is hard to understand what is happening with the baby and grasp what is going on with the parents.

As a friend or family member, you may be uncertain as to how you should react - celebration? condolences? avoidance? grief? What kind of help should you offer? What should you say and do?

This guide is intended to help you understand what parents going through when they face a preterm birth. It is provided in the hopes that you will be better prepared to support them during this difficult time.

What is the Parent Feeling?

The parents are experiencing a wide range of emotions - guilt, failure, shock, fear, disappointment, impotence, denial, grief, loss, joy, sadness, elation, anger, terror and powerlessness are among the top emotions. Parents may feel all or only some of these feelings. They may feel others ones not listed here as well.

It may be hard for an "outsider" to understand why parents feel some of these things. (Here, an "outsider" is anyone who is not the actual parent.) Some reactions may seem illogical or extreme or even absurd. However, they are the normal kinds of reactions that parents face when they have a premie, and quite common.

What is the normal cycle of reactions?

The parents will feel some of these emotions often when they find out the birth is imminent and otherwise after the baby comes. Since there is no pre-set cycle of when parents will experience these emotions, it can be difficult to understand how they are feeling on a given day. While some reactions tend to be a natural response to the whole birth, others can be triggered by specific instances in the NICU - a set-back, a bad test result, some disheartening news. It is important to understand all these feelings are normal reactions to a preterm birth and can come in any order. It is common to go back and forth between experiencing these emotions for a long while, often months after the birth. It is also normal to have these emotions heighten during the toughest part of the NICU stay, and gradually ease up as the course gets closer to homecoming. Of course, this does not mean the feelings are totally "gone", only that they the parents have begun to resolve them.

What else are the parents feeling?

Here are some additional feelings the parents might be experiencing...

They feel alone and abnormal.

Because the NICU experience is out of the norm and a relatively "secret" place, there are not many people the parents may know who have experienced it first hand and can lend support and guidance.

They feel uneducated.

In addition, since there is usually little, if any, preparation for a premie birth, there is not time to prepare and educate yourself on what will happen. Consider that parents normally spend nine months reading, attending classes, talking to doctors in preparation just for the birth process that is only 1-2 days in total. In comparison, premie parents are thrust into a birth that was unexpected, with terms that are unknown, with an outcome that was totally unprepared for, and without any teaching or education to arm themselves for an experience that often lasts several months. Can you believe that many parents do not even know if their premie will survive the birth, let alone what happens behind the NICU doors! You can understand how little they know at the start and how this can lead to feelings of powerlessness and fear.

They feel isolated.

As parents start to learn information about their baby at an incredible rate to overcome these emotions and cope with a special needs infant, they become educated about premies. However, just as they begin to understand it all themselves, they find they are now the "outsiders" because they are the only ones who understand this NICU world and their premie. Now, unless they explain every detail to friends and family, they are left feeling alone and isolated when they try to communicate.

They feel alienated.

This fine line they walk can leave parents in a tough spot. When they do not explain, people do not understand and do not know how to react. But when they do explain, people still sometimes do not know how to react. Parents can feel even more alone and alienated from those to whom they are close. They feel burdened with their role as teachers.

Because parents are the only ones who can explain to others what is happening with the baby and the implications of it, they are under pressure to constantly educate and dispell misperceptions and fallicies regarding premies to "outsiders". It can be disheartening, tiring and maddening to be constantly fighting the stereotypes of premature babies that peope hold in their minds.

They feel pressured.

At a time when parents want to focus totally on their baby and their own adjustment, they can feel immense pressures from family and friends.

Grandparents and family members can unknowingly place a huge amount of undue pressure on the couple. They want to be included, be informed, be a part of what is happening, be present. They may also want their feelings acknowledged and their questions answered. They may feel it is a priority for others to address their own needs and feelings.

Family members may also have expectations of how you as parents should be acting. They may have a preconceived notion of how their role with the baby should play. When their expectation are not met, they feel hurt, excluded, unimportant and angry. This may lead to feeling of competition with other



family members who seem to play a greater role than themselves. Or they may draw back from the entire scene. Family member may even resort to persuasion, causing conflict or using guilt to get their expectations met.

Friends, too have expectations. They believe they know how you and your spouse should be acting. When, and most likely, if, you do not meet their expectations, they may feel alienated from you. They may draw further away from you, creating a distance in the relationship. If it is your spouse who has not met their expectations, they may voice their concerns to the parent. This can stimulate both anger or fear in the parent's mind that the spouse is not reacting properly.

In both situations, the friend or family member may try to force their point of view upon the parent. All this accomplishes is hurt feelings, disappointment, anger. It can fuel increased separation and resentments between the couple, adding even more stress and pain to the situation.

When will they feel and act "normal" again?

It takes some time for all of the feelings and emotions surrounding a preterm birth to resolve and heal. It is normal for them to subside as the baby's health and outlook improves and they get close to discharge. However, there are also normal "residual" emotions which will take much longer to resolve, usually about one year or longer. It is not uncommon to face some recurring emotions surrounding the preterm birth even years later.

Preterm birth forever changes a person, just as any other trauma or tragedy changes a life. It affects your outlook on life, your beliefs, your faith, your own strength and courage, and your relationships with others. The changes are not necessarily for the worse, and often for the better, but they are present no less. Having a preemie leaves a parent a very different person than before the birth.

What can help to make progress towards healing?

There is no one "cure" to heal a parent's pain. More likely there will be a slow dance towards healing, as feelings resolve and acceptance and understanding take their place. There are several things, though, that seem to help move that resolution along:

- \*the baby's health improves and development is progressing as expected and according to corrected age

- \*the parents learn to relieve themselves of the guilt and blame they feel for "causing" the birth

- \*they allow themselves to bond more closely with the baby as the baby's condition improves and can give up their the fear that the baby won't make it

- \*they learn to interact and treat the baby more "normally", usually once they come home, as they become increasingly involved and responsible for the baby's care

- \* the parents adjust their expectations for their baby - they accept that their baby's growth and development will be different than other fullterm children, as was the start of their baby's life

- \*friends and family come to acceptance of the baby, as he or she is, and not as a full-term baby, with normal needs
- \*the parents are able to talk with other preemie parents and understand they have experienced the normal set of reactions
- \*the parents emotions are acknowledged and accepted by friends and family

How should you react to the parents?

Adjust your expectations.

When a premature baby is born, expectations of everyone involved must be adjusted. If they are not, misunderstandings and hurt feelings can occur in everyone. Adjust your expectations of the parents. Accept that they will each react and cope differently, and you cannot judge what way is right and what way is wrong.

Adjust your expectations of the parents' needs. Expect them to have a need for privacy. Respect their boundaries and acknowledge these boundaries are temporary. Forming boundaries is often a reaction to danger, done for self-protection. The parents are "protecting" their family and their feelings during this most fragile time.

Once the situation improves, parents will most likely wish to include you more. (Improvement can mean when the baby is close to discharge, or finally home, or after they are settled in at home.) Be patient and take their cues. Respect that their timetable may not move as quickly as you wish.

Adjust your expectation of your "rights".

You are not the parent. The parents do not owe you a piece in any decisions they make. They do not owe you explanations for their behavior or decisions, not matter how this isolation makes you feel.

You were not given a right to any of the baby's information. As a family member, you are not automatically entitled to visitation privileges. These are privileges that the parents grant you, according to their reactions, needs and emotions. Do not view their "exclusions" as personal. They are merely boundaries they have set for now (not always). The parents expect everyone to respect their boundaries around their baby and their lives, no matter how they make people feel. Remember, in your own life you choose when and how to share your personal parts with your friends and family - you, too have boundaries. Respect them.

Refrain from advising on how a spouse's reactions.

Refrain from judging any reaction from either parent. Just as there is no one "right" way to grieve a death, there is no one "right" way to cope with a premature birth. Each person must find the way that suits their needs.

Revise your role in relation to the baby.

You will have plenty of time to play the grandparent, aunt or uncle. Right now, let the family place the formation of their role as parents as the primary importance. Give the parents time to adjust to this without adding

the task of incorporating your role with the baby into their lives, as well.

Separate your own feelings and deal with them privately if necessary. If you are a close friend or family member, you are probably experiencing some of the same emotions that the parents are feeling. It can be hard to separate how you feel from the parents or "hide" it from them. But when you are with the parent, you may need to adjust your reactions and watch closely what and how you say certain things. Offering this type of respect is similar to watching what you would say to any other friend during a time of trauma, such as death. A preterm birth is a time of trauma and great stress.

Keep up communication, but take the parents' lead on how, what and when to share.

It is important to keep the lines of communication open and share your concerns and worries, but not to add undue stress to the parents or contribute to, instead of ease, their emotional burden.

Expect a parents' mind to stay primarily on the NICU and their baby. Parents are often lost in thought and feelings. They might endure periods of silence, where they seem totally unaware of what is happening around them. They may seem distant quite often. They may try to participate in a conversation, and totally lose track of what is being said. When they catch themselves doing this, they may feel embarrassed or upset. They may start a thought and not be able to finish. They may run from one topic to the next without any pattern. They may repeat certainThey may feel as if they are losing their mind.

This is a common reaction to stress. Help them through this. Respond to their worries and their concerns. Do not be offended when they wish to sit in silence. Do not feel the need to make small talk unrelated to the baby. Let them talk as much as they want about a subject. If often takes rehearsing it over and over to come to a resolution.

Do not add extra concern to the parents' stress. Do not bring up implications of the birth if the parent has yet to mention it. Refrain from discussing the possibility of poor outcomes and of setbacks, until the parents so choose. (Examples: development, complications, death.) It is not that they are denying these things, it may just be that they do not want to discuss it openly with you or are not ready to do so.

Place primary importance on the effects the parents are feeling. If you are dealing with your own feelings about the birth and baby (especially common if you are a grandparent, aunt or uncle), be sure not to place greater importance on how you are feeling. Do not superimpose how the baby has affected you over how it has affected the parents. The baby has affected its parents' lives more than anyone.

Abstain from unknowingly adding to the parents' grief. Watch that your comments do not add to feelings of guilt or failure. (Avoid:

Didn't you know this was happening? Whose fault is this? I can't stand to see him in so much pain!)

Acknowledge the baby's birth and treat it as normally as possible.

Watch that you do not treat the baby as abnormal. Find something to admire about the baby when you see it or a picture. (Avoid: Why is she so tiny?

Does she have all her body parts? I don't know if I could hold a baby like him.)

Lavish the attention and gifts that you would if the baby had been fullterm. Lend congratulations to both parents. Hug them. Tell them you can't wait to meet the baby.

Acknowledge the great difficulty of a preterm birth. Realize that parents are facing many challenges and do not have time to relax or recover from childbirth, as much as the misconception adds to that belief. Do not minimize the stress and struggle. (Avoid: Gee, I bet it's nice to have the nights to yourself. You are lucky you didn't have to go through the end of pregnancy. I wish I had nights full of sleep when I had a baby.)

Accept the parents fears and worries.

Offer compassion and empathy. Try not to compare it to the worry you feel for your own children when they are sick. It is very different, since they have never had the luxury of worry-free time with this baby, and often the concerns are much greater than parents usually endure with children.

Accept the parents feelings of love and pride for their baby.

Understand that parents still have the normal feelings towards their baby.

The love him. They admire her qualities. They bond with him. They want to brag about her achievements. The baby is their child, not a doll to visit nor a distant relative to occasionally worry about. Do not compare the baby in size to dolls or animals. Add positive comments when proud parents show you photos and videos. Let them talk about how much love they feel, the deep affection and how they are bonding.

(Avoid: How can you bond with him while he is away from you? Do you spend each day with the baby? What do you do with him since he is in the NICU? She is kinda like a small mouse!)

Try to understand the time pressures.

Call and check up regularly on the parents and baby, but understand they may not have the time, energy or desire to talk long or call back at all. Do not expect them to hold up previous commitments, even family get-togethers, such as holiday get-togethers. Their primary focus is nurturing their baby, whether it is home or not.

Respect the parents' need for privacy.

Take the lead of the parents when deciding how much to become involved with the baby. They may not be able to have visitors to the NICU (regulations), or they may not want them at certain times. Respect that parents need time to bond with the baby alone, and time to adjust to everything. Understand that some days are better than others for visits, even from close friends

and family members. This is most true when it has been an especially trying and upsetting day for the parent. Accept that they may need time to themselves to resolve what is happening.

Help out...

with housework, other children, cooking, driving to the hospital, yardwork, pets, shopping, errands, etc., so that parents can spend as much time with the baby. Help organize others to help.

Put other problems and obligations aside.

Help the parents to put their needs and their baby's needs first. Now is not the time to bring up past grievances or present disagreements. It is not the time to share that you are feeling left out or isolated from visiting or information on the baby. The parents main and only concern should be for their baby's healing. Focusing on your own needs and wants only distracts them from their duty. This means they may not be able to attend family or work functions at this time, too. Do not press them to do so. It forces them to take an already limited amount of time away from the baby.

Don't abandon the parents!

While the time crunches and pressures of the NICU take its toll on relationships and friendships, accept that this is a temporary condition. Do not be offended when the parent doesn't respond to phone calls and visits. They will when they can, which sometimes is weeks away. Often when the baby gets better and comes home, the parents will have more time for communication. Until then, don't forget to keep up with them. Things that especially appreciated...prepared dinners, thoughtful cards, small baby gifts, encouraging messages on their answering machine, decorating the house when discharge time arrives.

Rise to the occasion when they need you.

Often parents will call when the tough really hits and they need your support. Offer company, prayer, compassion at these times. This is when they need you the most. Don't allow their prior lack of communication to affect the support you offer them now.

What if I still make a mistake?

Relax. The parents understand that not everyone can do the "right thing" 100% of the time. Talk with them. Explain your intentions - you merely wanted to help. Then listen to what they tell you. You may be surprised to know how they reacted to you, and also surprised to know that they forgive you. Preterm birth provides family and friends with opportunities for growth, understanding and experience, not just parents! We all learn from it if we allow it!

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## Understanding Premie Parents, Part 2

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"You cannot live a perfect day  
without doing something for someone  
who will never be able to repay you."

- John Wooden

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Part Two of Understanding Premie Parents builds on the information learned in Part One about the normal emotional reactions of a premie parent. It helps people avoid the many pitfalls that most people fall in when trying to help a parent of a premie. This information can help improve the way words and reactions are offered to premie parents, which eases the trauma of the whole experience for everyone.

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What can I specifically do for the parent?

Adjust your expectations.

When a premature baby is born, expectations of everyone involved must be adjusted. If they are not, misunderstandings and hurt feelings can occur in everyone. Adjust your expectations of the parents. Accept that they will each react and cope differently, and you cannot judge what way is right and what way is wrong.

Adjust your expectations of the parents' needs.

Expect them to have a need for privacy. Respect their boundaries and acknowledge these boundaries are temporary. Forming boundaries is often a reaction to danger, done for self-protection. The parents are "protecting" their family and their feelings during this most fragile time.

Once the situation improves, parents will most likely wish to include you more. (Improvement can mean when the baby is close to discharge, or finally home, or after they are settled in at home.) Be patient and take their cues. Respect that their timetable will probably not move as quickly as you wish or expect.

Adjust your expectation of your "rights".

Since you are not the parent, you are not responsible for making any decisions regarding the baby, nor are you responsible for adding input. Parents do not owe explanations for their behavior or decisions, no matter how this isolation might make others feel.

When the baby was born, no one but the parents was given unconditional rights to the baby and his medical information. As a friend and/ or family member, your interaction with the baby is valued, BUT you are not automatically entitled to visitation privileges. These things are

privileges that the parents grant you, according to their own adjustment, condition, needs and emotions at that specific time as well as the baby's current needs and condition. Do not view their "exclusions" or "limitations" as personal. They are merely temporary boundaries they have set for now (not always). The parents expect everyone to respect their boundaries around their baby and their lives, no matter how they make others feel.

Remember, in your own life you choose when and how to share your personal parts with your friends and family - you too have boundaries. Give parents respect for theirs.

Refrain from advising or judging on a spouse's reactions.

Refrain from judging any reaction from either parent. Just as there is no one "right" way to grieve a death, there is no one "right" way to cope with a premature birth. Each person must find the way that suits their needs, no matter how strange or odd it may seem to another person.

In addition, a parent may act in ways very abnormal for them. They may have bursts of anger or say hurtful things to loved ones that they don't really mean. These things are triggered by stress and are not necessarily a true reflection of their feelings or character.

Revise your role in relation to the baby.

You will have plenty of time to play the grandparent, aunt or uncle. Right now, let the family place the formation of their role as parents as the primary importance. Give the parents time to adjust to this without adding the task of incorporating your role with the baby into their lives, as well. Step aside with the formation of your role until the parents are better established with their own adjustments.

Separate your own feelings and deal with them privately if necessary.

If you are a close friend or family member, you are probably experiencing some of the same emotions that the parents are feeling. It can be hard to separate how you feel from the parents or "hide" it from them. But when you are with the parent, you may need to adjust your reactions and watch closely what and how you say certain things. Offering this type of respect is similar to watching what you would say to any other friend during a time of trauma, such as death. A preterm birth is a time of trauma and great stress.

Encourage the parents to communicate by offering them a safe outlet for their emotions.

Let them speak and share what they feel without fear of judgment or criticism. Allow them to talk without encouraging them to change or alter their feelings in any way or means. Do not tell them a feeling or thought is silly. And even though their thoughts may seem strange or excessive, they are normal reactions that almost all parents feel after a premie birth. Their feelings are normal, expected and important. Reinforce this and offer yourself as a safe, comforting, empathetic ear. Reassure them that you will accept whatever they share with you without judging in any way.

Understand there is not an instant cure for healing the pain of a parents' emotions.

Much as it would seem to help, neither the you, nor the parent can make these emotional feelings disappear with some "cure". Telling a parent to "get over" the feelings or get on with life only makes them feel as if their emotions have no value. It increases their sense of misunderstanding and alienation.

It will be some time before they can "get over" these feelings, usually many long months before they resolve most of the issues. Give them the time to work through everything they feel and allow the parent to work at their own speed in efforts to find peace.

Offer empathy instead of a solution.

The solution to the entire problem would be for their child to return to the womb, wait out the pregnancy and be born full term and healthy. Obviously, this is not feasible.

Refrain from attempting to offer "solutions" such as these: your baby will grow and you will forget all about this, or she will be home soon and things will be normal then, or just wait until your hormones work themselves out. These "solutions" and others can not and do not solve the problem of having given birth prematurely to a less than healthy baby. It only attempts to lessen the emotional impact of having a preemie.

Instead of solutions, try offering empathy and support. It may help to offer something along the lines of "I can understand why you would feel that way, with all that you and your baby have gone through". Or a simple "I can't imagine how difficult this is for you and I wish there was some way I could help you" is may be all they want to hear.

Communicate that you value all of their feelings, wishes, and emotions.

As odd or absurd as they may sound at the time, never discount a thought the parent shares with you. This is the best way to encourage parents to feel safe talking with you and to offer them support. Show them you value their emotions by reinforcing how you understand the normalcy of their reactions and empathize with their situation. While you may not be able to fully grasp what they are telling you, nor totally understand why they are feeling a certain way, you can offer empathy. This also help them feel connected to others.

Keep up communication, but take the parents' lead on how, what and when to share.

It is important to keep the lines of communication open and share your concerns and worries, but

not to add undue stress to the parents or contribute to, instead of ease, their emotional burden. This means waiting for the parents to address a concern you have instead of bringing it up yourself. This also means accepting graciously what information the parents do choose to offer without



asking for more details, or questioning reasons behind their choices, or enacting what if scenarios. These things do increase doubt, fears and double guessing. They do not lend support.

Expect a parent's mind to stay primarily on the NICU and their baby. Parents are often lost in thought and feelings. They might endure periods of silence, where they seem totally unaware of what is happening around them. They may seem distant quite often. They may try to participate in a conversation, and totally lose track of what is being said. When they catch themselves doing this, they may feel embarrassed or upset. They may start a thought and not be able to finish. They may run from one topic to the next without any pattern. They may repeat certain stories about the birth or baby over and over. They may feel as if they are losing their mind when they do any of these things.

All these things are common reactions to stress. Help them through this. Respond to their worries and their concerns. Do not be offended when they wish to sit in silence. Do not feel the need to make small talk unrelated to the baby. Let them talk as much as they want about a subject. It often takes rehashing it over and over to come to a resolution.

Do not add extra fears to the parent's stress. Do not bring up implications of the birth if the parent has yet to mention it. Refrain from discussing the possibility of poor outcomes and of setbacks, until the parent so chooses. (Examples: development, complications, death.) It is not that they are denying these things, more likely it may just be that they do not want to discuss it openly with you because they are not ready to do so.

Place primary importance on the effects the parent is feeling. If you are dealing with your own feelings about the birth and baby (especially common if you are a grandparent, aunt or uncle), be sure not to place greater importance on how you are feeling. Do not superimpose how the baby has affected you over how it has affected the parent. The baby has affected its parent's lives more than anyone.

Abstain from unknowingly adding to the parent's grief. Watch that your comments do not add to feelings of guilt or failure. (Avoid: Didn't you know this was happening? Whose fault is this? I can't stand to see him in so much pain!)

Help restore some feelings of normalcy. Acknowledge the baby's birth and treat it as normally as possible. Watch that you do not treat the baby as abnormal. Find something to admire about the baby when you see it or a picture. (Avoid: Why is she so tiny? Does she have all her body parts? I don't know if I could hold a baby like him.) Lavish the attention and gifts that you would if the baby had been fullterm. Lend congratulations to both parents. Hug them. Tell them you can't wait to meet the baby.

Acknowledge the great difficulty of a preterm birth. Realize that parents are facing many challenges and worries and have not even had time to relax or recover from childbirth. Do not minimize the stress and struggle of the pregnancy, the delivery or the NICU. (Avoid: Gee, I bet it's nice to have the nights to yourself. You are lucky you didn't have to go through the end of pregnancy. I wish I had nights full of sleep when I had a baby. With such a small baby, I bet your delivery was a cinch!)

Accept the parents fears and worries without feeling the need to compare them.

Offer compassion and empathy. Try not to compare it to the worry you feel for your own children when they are sick. It is very different, for many reasons. They have never had the luxury of worry-free time with this baby. Often the concerns surrounding a preemie are much greater than those parents usually endure with sick children. There are life long implications from prematurity - it is not like an illness you recover from.

Accept and acknowledge the parents feelings of love and pride for their baby.

Understand that parents still have the normal feelings towards their baby. They love him. They admire his qualities. They bond with him. They want to brag about his achievements. The baby is their child, not a doll to cuddle nor a distant relative to occasionally visit.

Treat the baby with the respect you would give a newborn.

Do not compare the baby in size or actions to dolls or animals. While photos are and can be shocking to others, do not add to the shock the parents see on your face with statements of pity or grief for the baby. Find some positive comment to share when proud parents show you photos and videos. Hold back tears or gasps for when you have left the parents' company. Encourage them talk about how much love they feel, the deep affection and how they are bonding. It helps you to see this baby as a valued and very important individual. (Avoid: How can you bond with him while he is away from you? Do you spend each day with the baby? What do you do with him since he is in the NICU? She cries kinda like a small mouse!)

Try to understand the time pressures.

Call and check up regularly on the parents and baby, but understand they may not have the time, energy or desire to talk long or call back at all. Do not expect them to hold up previous commitments, even family get-togethers, such as holiday get-togethers. Their primary focus is nurturing their baby, whether it is home or not. Their secondary focus is keeping themselves together. Help them do both by letting them know you accept being lower on the priority list.

Respect the parents' need for privacy.

Take the lead of the parents when deciding how much to become involved with the baby. They may not be able to have visitors to the NICU (regulations), or they may not want them at certain times. Respect that parents need time to bond with the baby alone, and time to adjust to everything. Understand that some days are better than others for visits, even from close friends and family members. This is most true when it has been an especially trying and upsetting day for the parent. Accept that they may need time to themselves to resolve what is happening or they may just wish for some privacy to sit and cry.

Help out...

with housework, other children, cooking, driving to the hospital, yardwork, pets, shopping, errands, etc., so that parents can spend as much time with the baby. Help organize others to help.

Put other problems and obligations aside.

Help the parents to put their needs and their baby's needs first. Now is not the time to bring up past grievances or present disagreements. It is not the time to share that you are feeling left out or isolated from visiting or information on the baby. It is not the time to begin competing for the role of top grandparent. The parents only concern should be for their baby's healing. Focusing on your own needs and wants only distracts them from their duty. This means they may not be able to attend family or work functions at this time, too. Do not press them to do so. It forces them to take an already limited amount of time away from the baby and may leave them feeling incredibly guilty.

Don't abandon the parents!

While the time crunches and pressures of the NICU take its toll on relationships and friendships, accept that this is a temporary condition. Do not be offended when the parent doesn't respond to phone calls and visits. They will when they can, which sometimes is weeks away. Often when the baby gets better and comes home, the parents will have more time for communication. Until then, don't forget to keep up with them. They need to feel your continued support and love even when they do not have time to acknowledge it. Things that especially appreciated...prepared dinners, thoughtful cards, small baby gifts, encouraging messages on their answering machine, decorating the house when discharge time arrives.

Rise to the occasion when they need you.

Often those same parents who you thought were in "hiding" will call when the tough really hits and they need your support. Offer company, prayer, compassion at these times. This is when they need you the most. Don't allow their prior lack of communication to affect the support you offer them now.

Remember, it's not that they are shutting people out, it's that prematurity and the NICU have shut them in.

What if I still make a mistake?

Relax. The parents understand that not everyone can do the "right thing" 100% of the time. Talk

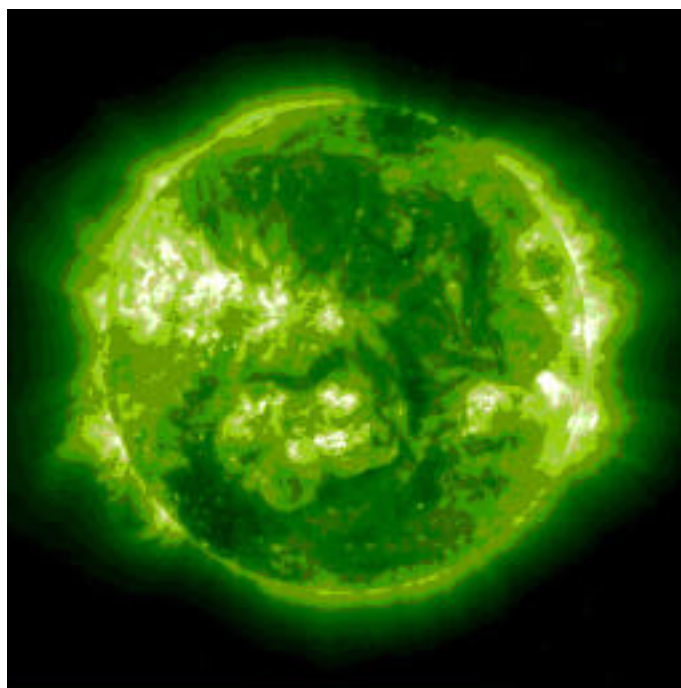
with them. Explain your intentions - you merely wanted to help and be supportive, even if it was the ideal way to do so. Then listen to what they tell

you. You may be surprised to know how they reacted to you, and also surprised to know that

they forgive you. They may even have some suggestions that make all this easier on everyone. Preterm birth provides family and friends with opportunities for growth, understanding and experience, not just parents! We all learn from it if we allow it!

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## How to Help Premies Develop Well

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### How can I parent my preemie?

There are many things that you can do to help your baby progress in each of the five areas of development described under UNDERSTANDING PREMIE DEVELOPMENT:

- \* Learn to read your baby's behaviors. You will come to know when your baby is stressed and needs some rest time, and when he or she is relaxed, can be handled, and is ready to respond to you.
  
- \* Learn how to interact with your baby - what are the things he or she likes, doesn't like; what are the best times during the day; how long at a time does he/she have the strength to respond to you?
  
- \* Make the environment as comfortable for the baby as you can:
  - o keep light and noise levels moderate.
  - o keep the baby's position flexed.
  - o allow undisturbed periods of sleep.
  - o provide opportunities to interact when he/she is awake.
  
- \* Accept that each baby is different and may be a challenge to understand, and that progress will take time.
  
- \* Give yourself permission to feel disappointed, helpless, or incompetent when you can't figure out what the baby wants or needs; your baby may not know, either. Feel happy and proud when you can read your baby. The important thing is that you are trying to understand what your baby is telling you.
  
- \* Trust your instincts. You have known your baby longer than anyone.





## The Physical Environment

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In the physical environment of the NICU, there is a lot of equipment being used in and around the baby; a lot of people and machines that make noise; lighting that is often kept very bright so that the doctors and nurses can see well as they care for the baby; a place to stay (an isolette or radiant warmer) that does not make it easy for the baby to stay in a relaxed, curled up position; and many treatments that may be stressful or painful for the baby (e.g., suctioning, heel sticks for blood tests, having IVs placed, having X-rays or ultrasound, etc.). These treatments may mean that the baby is disturbed many times over the course of the day, disrupting sleep. For the very small preemies, just being handled for daily care (diapering, feeding) can be stressful.

The physical environment can be changed to:

- \* reduce the amount of sound
- \* reduce the amount of light
- \* provide rhythms in light levels
- \* provide some support for the baby's position
- \* make treatments less stressful
- \* reduce the number of times that the baby is disturbed.

## Sound

Why are loud sounds a concern?

Loud sound is a concern because:

1. it may damage the baby's ears and lead to loss of hearing,
2. the baby feels it as stressful.

(1) The sound of the isolette motor is at a level (55-60 decibels) that is comfortable for adults. If the baby has respiratory equipment (mechanical ventilation, CPAP), this makes it noisier. Other sounds then raise levels to what an adult would find uncomfortable (75-85 db). Loud, sharp sounds can raise levels to 100-200 db, which may damage cells in the ear. This is more likely to happen when the baby is on certain medicines that make the ear sensitive.

(2) Loud or sharp sounds can cause physiological changes (high heart rate, fast breathing, apnea, a drop in blood oxygen levels). They also may startle the baby and disturb sleep.



How can the level of sound be reduced?

Sound levels can be reduced by talking quietly, closing doors and portholes gently, not dropping things on top of the incubator, turning down machine alarms and phone ring levels, and turning off radios.

Are some sounds helpful?

The sound that seems to impress preemies the most is the sound of your own voice. Providing a tape recording of you talking and reading to your infant may be one way to provide sound that will calm your baby.

Keep in mind, however, that for the very small preemie, extra sound when other things are going on may be disturbing. It is important, therefore, to watch your baby when you turn on the tape to be sure that he or she likes it.

Light

Why is light a concern?

\* Light is a concern because:

- o bright light may cause injury to the eye;
- o constant light may disturb body rhythms;
- o bright light may keep your baby from opening his/her eyes and looking around.

\* Studies done with animals show that bright light can damage the cells in the eye. Preemies are at risk for getting Retinopathy of Prematurity (ROP), changes in the eye that can lead to loss of vision, if severe. Although not yet proven, constant bright lighting may increase this risk.

\* Constant levels of light may slow the normal development of sleep-wake cycles. Preemies that have been in nurseries where the lighting is dimmed at night advance more quickly in their sleep-wake patterns. This means that they begin to spend more time during each sleep period in deep sleep and less time in light sleep sooner than babies kept in constant light.

\* Light can affect the level of arousal of your baby. In bright light the baby is less apt to open his or her eyes when awake, thus misses

chances to explore the world and to interact with you and others.

How can the amount of light be reduced for my baby?

- \* Isolettes can be covered to block the amount of light reaching your baby. Laying a blanket over the top of the isolette is the easiest thing to do. Letting the blanket drape over the sides, or using a specially fitted cover (now available commercially), can block light from the sides as well as the top of the isolette. With current monitors displaying heart rate, breathing, and oxygen levels, the staff know how your baby is doing even with the isolette covered.
  
- \* When lights are dimmed, procedures requiring the use of extra light can be done with an additional light at your baby's bedside (e.g., a lamp or ceiling spot light). The staff also will try to be as quick as possible when the use of bright light is necessary.
  
- \* If overhead phototherapy lights are being used, a special mask will be used to cover your baby's eyes. Staff also will try to reduce the amount of light other babies are exposed to during the treatment.
  
- \* In many nurseries, a "quiet time" is held during the day, when lights are dimmed for several hours and your baby is not disturbed unless a procedure is really needed.
  
- \* In some nurseries, lights are dimmed at night. This helps in starting a day/night sleep schedule and supports daily changes in hormone and temperature levels. The dimmed light also gives some extra protection from the higher light levels needed for daytime activities.

Positioning

Why is positioning a concern?

Positioning is important because:

- \* The preemie cannot get into a comfortable position on his/her own.

- \* Over time, positioning affects your baby's motor development.

What is important to know about positioning?

- \* The preemie does not have the muscle strength to control movements of arms, legs or head that full term infants have. It is hard for them to move against the force of gravity. Therefore they tend to lie with their arms and legs straight, or "extended", rather than tucked in, or "flexed".
- \* Being in an extended position for long periods of time can lead to stiffness - "abnormal tone" - in the shoulders and hips, and this can delay the baby's motor development.
- \* It probably is not very comfortable for the preemie to be on its back out straight, or extended. If left this way, some preemies may try hard to get into a more relaxed, curled up position, using up energy that could be used for growing.
- \* Small preemies maintain better oxygen levels and temperature, and sleep better, when on their tummies or sides than when on their backs. (However, when the baby goes home, he/she should be put on the tummy only when awake, not for sleep.)

How can the baby be kept in positions that are comfortable and help motor development?

Sometimes it is hard to place the preemie in a curled up, flexed position because of necessary equipment, such as IVs, CPAP, or mechanical ventilation. But usually it can be done.

Guidelines for positioning include:

- \* Place the baby on tummy (when in the NICU and on monitors) or side, with arms and legs flexed.

\* Cover, clothe, wrap or swaddle the baby, to help keep the flexed position. This also gives him/her the feeling of being cuddled.

\* Make a 'nest' around the baby to hold him/her in a flexed position. Nurseries use different ways to do this. Some use blanket rolls. The inserts made for car seats make good nests - the baby lies on the insert, therefore it stays in place better than blanket rolls.

There also are products for sale to keep the baby in a flexed position, such as the "Snuggle Up", Children's Medical Ventures, Boston MA.

\* Leave the baby's hands free so that he/she can get them to the face. Sucking on fingers or hand, and even just touching the face, is one way babies calm themselves.

\* As a part of the nest, give the baby something to push against with his/her feet. This allows the baby to feel more stable.

\* Encourage the baby to hold on to - grasp - something, like your finger, the edge of the blanket, or a small rolled-up cloth. This helps the baby feel more stable.

## Handling

Why is handling preemies a concern?

How preemies are handled is a concern because:

- \* It may lead to physiologic stress
- \* It may lead to behavioral stress.

When handled for medical care, preemies often show that this is physiologically stressful by a rising heart rate or dips in heart rate (bradycardia); rising respiration rates or periods of holding the breath (apnea); falling levels of blood oxygen (desaturations); color changes to dusky or flushed; and other responses such as hiccups or yawning. Even pulling adhesive tape off can cause these responses.

During daily care, such as diapering and feeding, preemies may react in the

same ways.

When handled, preemies also may show in their behavior that this is stressful, for example, by more moving, more jerks, startles and tremors, and fussing/crying.

What is important to know about the effects of handling?

When a baby's blood oxygen level drops (desaturations), this can directly affect the brain. Therefore, it is important to prevent this during activities that happen over and over again, such as taking temperature and blood pressure, diapering or feeding, as well as during treatments that are especially stressful or painful.

Preemies learn. They learn that certain things are not comfortable or not pleasant. When this happens over and over, they may learn to dislike being touched.

How can the baby be handled to make it less stressful?

Handling can be made less stressful to the preemie by using a "developmental approach". This means:

- \* Position the baby comfortably and securely, and provide special supports to hold the baby in a flexed position during the handling. This includes "containing" or holding in the baby's arms and legs to keep him/her flexed and to prevent jerky movements.
  
- \* Pace the care according to how the baby reacts. For example, stop (give the baby a break) and gently contain the baby when he/she starts to get upset, and don't start again until the baby has settled down.
  
- \* Give the baby ways to keep him/herself calm. This would include a pacifier, something to hold onto, something against which to brace his/her feet, and helping him/her to keep hands up near the face to allow sucking on fingers.
  
- \* Keep other stimulation at a minimum. This would include not talking or trying to make eye contact if the baby shows signs of stress, and

keeping general noise levels low.

\* Most of all, adjust to the preemie's behavior as much as possible, letting him/her tell you what feels OK and what doesn't, and when to keep going, when to stop, and when to start up again. See the section below on How Do I Interact with My Baby?

## Touch

Handling is touching. The sense of touch develops very early in fetal life. For very small preemies, the skin is so fragile that touching has to be done with great care. For preemies younger than about 30 weeks gestational age (GA), studies show that touch may be more stressful than soothing. For older preemies, however, gentle touching can be helpful.

Preemies react in different ways to different kinds of touch. A light, feathery touch may be upsetting. A firm, steady touch is more likely to calm the baby. Giving the stable preemie gentle human touch or massage for a short period every day has been shown to be helpful, for example, it may help babies gain weight faster. As with everything, how and how often the preemie is touched needs to be based on his/her responses.

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[Image]

## Periventricular Leukomalacia (PVL)

What is periventricular leukomalacia (PVL)?

Periventricular leukomalacia (PVL) is damage and softening of the white matter, the inner part of the brain that transmits information between the nerve cells and the spinal cord as well as from one part of the brain to another.

- \* "periventricular" means around or near the ventricles, the spaces in the brain containing the cerebrospinal fluid
- \* "leuko" means white
- \* "malacia" means softening

Why is periventricular leukomalacia a concern?

With PVL, the area of damaged brain tissue can affect the nerve cells that control motor movements. As the baby grows, the damaged nerve cells cause the muscles to become spastic, or tight, and resistant to movement. Babies with PVL have a higher risk of developing cerebral palsy (a group of disorders that prevent the child from controlling their muscles normally), and may have intellectual or learning difficulties.

PVL may occur alone or in addition to intraventricular hemorrhage (bleeding inside the brain).

What causes periventricular leukomalacia?

It is not clear why PVL occurs. This area of the brain is very susceptible to injury, especially in premature babies, whose brain tissues are fragile. PVL may happen when the brain receives too little oxygen. However, it is not clear when the trigger for PVL occurs < before, during, or after birth. Most babies who develop PVL are premature, especially those born before 30 weeks gestation. Other factors that may be associated with PVL include early rupture of membranes (amniotic sac) and infection inside the uterus.

What are the symptoms of periventricular leukomalacia?

PVL may not be apparent until later months. Each baby may experience symptoms differently. The most common symptom of PVL is spastic diplegia, tight, contracted muscles, especially in the legs. Symptoms of PVL may resemble other conditions or medical problems. Always consult your baby's physician for a diagnosis.

How is periventricular leukomalacia diagnosed?

In addition to a complete medical history and physical examination, diagnostic procedures for PVL may include:

- \* cranial ultrasound, a painless test that uses sound waves to view the baby's brain through the fontanelles, the soft openings between the skull bones. With PVL, the ultrasound shows cysts or hollow places in the brain tissue.
- \* magnetic resonance imaging (MRI). This test uses a combination of a large magnet, radio frequencies, and a computer to produce detailed images of internal structures. MRI may show some of the early changes in the brain tissue that occur with PVL.

Treatment for periventricular leukomalacia:

There are no treatments for PVL. Management of the problems that can result from PVL will be determined by your baby's physician based on:

- \* your baby's gestational age, overall health, and medical history
- \* extent of the condition
- \* your baby's tolerance for specific medications, procedures, or therapies
- \* expectations for the course of the condition
- \* your opinion or preference

Babies at risk for PVL may need special care after discharge from the hospital. Follow-up may include physical therapy, occupational therapy, and speech therapy.

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Having twins: When they are premature  
by Colleen Plimpton, ACSW and Elinor Davis

“Bonding with preemies just takes a lot longer than you wish it would...By the time they were a year old I knew we were all in love with each other the way we should be, but it happened very slowly.”  
-Mother of twins born two months early

Over sixty percent of multiples are born prematurely or weigh less than five and one-half pounds. These low birth-weight babies may need special care and frequently must be hospitalized for a period of weeks or even months. But despite the extra problems at the beginning, most “preemies” nowadays survive and grow up to be healthy.

As a parent of preemie multiples, you will naturally have many fears, concerns and questions about the babies and about their care in the hospital. Mothers have the combined challenges of postpartum physical recovery while also making the emotional adjustment to the birth of twins, or more, who may be in fragile health. Fathers may feel helpless and left out of a traumatic delivery and a high-tech intensive care nursery environment.

The situation is further complicated by the fact that if both twins are sick, there are two sets of hospital personnel for you to deal with. The confusion and stress can be overwhelming. In the face of all this, you will need a lot of emotional support from family and friends. Allow your self to accept any help and comfort that is offered, both before and after the babies come home.

### Visiting Your Babies

There may be a number of practical problems, as well. Even if insurance pays the medical costs, the extra needs can pose a financial burden. Along with the double expense for equipment, clothing and childcare, there is the expense of frequent trips to the hospital. If one baby is severely ill or disabled, he or she may be sent to a

high-risk center for specialized care while the other twin remains in the birth hospital. In that event, you must get from one to the other for daily visits. Or if one baby is home, you must leave that tiny newborn to go visit the sick one.

These are problems with which a hospital social worker can help you cope. Social workers may refer you to agencies that might provide transportation, for example, or help you arrange child care for siblings at home. If friends offer to help, let them know specifically what they can do—pick up and babysit your older child, give you a ride, or prepare a meal.

The combination of all these stresses is likely to strain your relationship with your partner. Try to make time for each other — go out for breakfast, see a movie, or just walk around the block together. You need to take good care of yourselves so you can take good care of the babies. If the pressure of the situation becomes too great, ask the hospital social worker about support groups and/or counseling.

Keeping open the lines of communication with doctors and nurses will help you feel connected to the babies. Visit as often as you can. Ask questions and participate in the care as much as is medically feasible. One very important thing mothers can do is pump breast milk and bring it in regularly. Even if babies are unable to nurse, they can get the nutritional benefits of human milk and their mother will be maintaining her milk supply until they can breastfeed.

If you plan to breastfeed at home, nurses can do a lot of teaching, especially if you are a first-time mother who needs to learn various positions for nursing two babies at once, and how to get the babies sucking when their reflexes are weak. However, not all nurses know how to teach mothers of twins. If your twin-related questions are not being answered by hospital staff, you can get specific advice from TWINLINE phone counselors or publications.

### Developmental Lag

If one twin has a chronic condition and must stay in the hospital much longer than the other one, a developmental delay may occur. Even with stimulation from the nursery staff, the hospitalized baby is at a disadvantage because he or she can't get to know you

very well in a hospital setting. To counteract this and facilitate bonding, some hospitals occasionally allow a pass for a baby who is medically stable to visit home for a day. Ask your babies' doctor if this is possible. A home visit is especially important if older siblings have not been allowed to come to the Intensive Care Nursery. They need to be reassured that their newborn sister or brother is alive and growing. Remember that preemies, in general, will be developmentally behind for a time. If they come home at three months, they'll be more like newborns than three month olds.

One mother whose twins were born two months early says, "To me, the hardest thing about having premature babies is the developmental lag. Even though you know that they'll be behind, when you work so long and hard and at four months old they still don't look at you or smile, you get very discouraged. My twins were born at the end of August, and at Christmas they still didn't notice me in particular. Bonding just takes a lot longer than you wish it would, and you begin to think it'll never happen. It developed so gradually with us that I can't really say when we bonded. By the time they were a year old I knew we were all in love with each other the way we should be, but it happened very slowly."

### Preparing to Bring Them Home

Before your twins leave the hospital, be sure you have had some practice caring for your babies and been taught to use any special equipment they may need. Ideally, you and the staff should develop discharge plans together, based on the reality of your home situation. The discharge plan helps you understand the care the babies need-how and when to administer medication, what signs to look for, and when it's necessary to call the pediatrician, as well as routine wellbaby care.

Follow-up appointments for the babies to come back to the hospital to be checked should be made before discharge. You may also want to arrange for visits by a public health nurse-a free county service in many communities. It works best when the nurse meets you in the hospital or makes a home visit before the arrival of the babies. PHN's do a home assessment and can suggest the best placement of furniture, for example. Their role is not to give hands-on care but rather to offer support, educate parents, provide community referrals and act as a communication link between pediatricians and parents.

## Getting Help

The most important thing you can do for yourself is to get some help when the babies come home. You may have spent three months shuttling between hospitals and then take home two sick babies on apnea monitors or oxygen, or with other special needs. Here is what one mother told us. “Against better advice, we didn’t get enough help. In retrospect, I would have done whatever I could to get high school kids, or somebody else that wouldn’t have cost a lot, to give me a break. And I wouldn’t have been so reluctant to ask friends to help. The exhaustion of caring for preemie twins is cumulative. If you can stop it from happening, you’ll feel better and everything will be better.”

However you can manage it, try to get some “respite”-regular in-home help with the care of the children, which allows mom a break to leave for awhile or take a nap, knowing that someone will care for the babies and the house. Relief from baby care and housework is imperative if your family is to get through the babies’ next two years-the high-risk period. During that time, the babies are very prone to respiratory infections and doctors continue to evaluate what their long-term medical future will be.

If you can afford it, hire regular household help or pay for the services of a visiting nurse. Find out if your insurance policy covers visiting nurses. Some families have even taken out loans to pay for child care and declare that having this aid during the difficult early months was well worth the expense.

If hired help is out of the question, try to arrange paternity leave for the twins’ father or enlist extra support from relatives and friends. This can work fine if it’s regular and dependable. The discharge planning and teaching should include anyone who will be caring for the babies. When no such support is available, ask the hospital to arrange for a public health nurse to keep in touch with you.

The premature arrival of twins or more is a very stressful situation for any family. Parents who make it through the first year of caring for tiny, needy infants with their sanity and close relationships intact are to be congratulated!

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This article was prepared with the assistance of Colleen Plimpton, A.C.S.W., a social worker at Children's Hospital and Regional Medical Center, Oakland, California.

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Boy Makinson Twin II  
D.O.B. 7/2/02.  
Bw = 650g = 1lb 7oz



Twin I Boy Makinson  
840g 1lb 13½oz.



