

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.

1. 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.

2. WHAT ARE SOME COMMON FEELINGS OF PARENTS OF PREMATURE BABIES?

2.1 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.

2.2 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 creates a temporary separation of the bond between premature babies and 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.

2.3 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.

2.4 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 mother's voices while they are in the womb.

So a premature baby can already tell the differences between its mother's 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.

2.5 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.

2.6 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.

2.7 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 why to cope as a family.

2.8 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.

2.9 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.

2.10 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.

2.11 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-Centred 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.

3. STAGES OF ADAPTATION

Some parents feel that learning about the emotional stages or phases of adaptation helps them understand what they are going through and what to expect. Although these can be listed as stages, the stages are not clear cut and often a parent is in more than one stage at a time.

Therefore, we have grouped them as early and later emotions.

Many of these feelings are discussed in greater detail in Emotional Responses of Parents.

What are the early stages of emotional adaptation that a parent goes through in adjusting to the experience of having a sick infant?

3.1 EARLY REACTIONS (STAGES) ARE:

- ◆ Shock - A feeling of being stunned or dazed. Your mind is completely occupied by the problems surrounding early delivery. How will this affect my life? How will it affect my baby's life? Will my baby live? During this stage it is often difficult to think clearly or remember what has been said. You may need to hear the same information several times. Others may be able to understand and remember information better than you.
- ◆ Denial - Not wanting to believe that the whole event is occurring. Hoping that you will wake up from this bad dream. Hoping that it will just go away and everything will be all right. Wanting proof that what doctors and nurses say is wrong with your baby is really true. Sometimes seeing your baby, seeing the isolette with your baby's name on it, looking at x-rays or other indicators of "proof" makes the situation more believable.
- ◆ Grief, fear and sadness - Grieving away the perfect baby that every parent hopes and expects to have. Grieving away the ideal birth experience, happy celebrations, bring your baby home with you. Feeling sad for yourself and everything you are going through. Feeling sad for your baby, especially about the pain and suffering that s/he might endure. Fear that you baby might die or not be normal.
- ◆ Anger and guilt - You are angry that your baby is sick. You wonder why did this happen to me? What did I do wrong to make my baby sick? (Most mothers did nothing wrong and could have done nothing to prevent it). Because you can't be angry with your baby, it is common to direct your anger toward your spouse, your friends, relatives or those caring for your baby.

3.2 CAN I HAVE MORE THAN ONE OF THESE EMOTIONS AT ONCE?

Most parents experience all of these emotions, both immediately before and after the baby is born.

3.3 HOW LONG DO THESE FEELINGS LAST?

Different emotions may last for different lengths of time. Shock and denial usually resolve more quickly than the grief, sadness, anger, and guilt. Even after you think you have resolved your feelings, you may find yourself going back and experiencing these feelings again. Parents vary in the time course of resolving these emotions. Some of this relates to the degree of illness and the time course of the infant. Sicker infants take longer to stabilize and keep their parents on an emotional roller coaster for longer periods of time.

3.4 WHAT HAPPENS LATER?

Later is a period of attaining equilibrium and beginning to reorganize. It includes:

- ◆ Adjusting to the guilt of having a sick baby - Having faced the fact that you did not have a normal labor and delivery, you can now move on to focusing on your baby.
- ◆ Giving up anticipatory grief and fear of death - This comes gradually as your child becomes healthier, when s/he begins to grow and develop.
- ◆ Understanding your own baby - Understanding your baby involves adjusting your expectations to what your baby can do. You focus more on the normal aspects of your baby, not what is wrong with your baby or the baby's medical problems.
- ◆ Increasing interaction with your baby - You become involved in the normal aspects of baby care such as changing diapers, holding, and feeding your baby.

3.5 HOW LONG DOES IT TAKE TO FINALLY ADJUST?

Resolution of these emotions usually takes months to years. During this period some parents become involved in support groups or parent organizations.

3.6 WHAT CAN I DO TO HELP MYSELF?

Some things that parents tell us are helpful are:

- ◆ Learn about common emotional reactions so you understand that what you are experiencing is normal.
- ◆ Talk to someone. This may be a spouse, family, clergy, or the baby's caregivers. Many parents become involved in parent support groups or offer to talk to new parents of babies with similar problems. Through sharing their experience, they hope that they can make the emotional transition of other parents a little easier. Most new parents find contact with other parents who "have been there" to be helpful.
- ◆ Seek information about your baby and his/her problems. Ask lots of questions. Understand as much as possible about your baby.
- ◆ Get involved in the care of your infant as early and as much as possible.
- ◆ Appreciate that having a sick baby is likely to be the biggest life stress that you have encountered. Don't hesitate to get help or counseling if you think that you might need it.
- ◆ Take care of yourself - adequate sleep and good nutrition
- ◆ Keep a Journal
- ◆ Learn relaxation techniques; listen to soft music, take a warm bath
- ◆ Give yourself permission to take a day off from the NICU. The stresses of the NICU can take such an enormous emotional toll on you. These pressures can cause you to become physically run-down and ineffective in the care of your baby. It might be worthwhile for you to consider taking a break.