

**First, a quick disclaimer is in order. This note, in a form only slightly different from the wording here, is designed to be given to parents of a baby who might be born between 22 and 24 weeks at one specific medical center, and only along with a personal chat with a neonatologist. The survival statistics and some of the medical practices noted here might not be true in other medical centers. The information about overall long-term handicaps among survivors is more likely to be accurate for other NICUs. If you are in this situation yourself, it is very important that you talk with a neonatologist yourself.**

## **AN INTRODUCTION TO EXTREMELY PREMATURE BABIES**

### **Dr Doug Derleth**

This note is intended to help parents who may have an extremely premature baby, a baby born 22, 23, or 24 weeks into a pregnancy. Although we understand that having an extremely premature baby is one of the most difficult experiences imaginable, the tone of this note is straightforward and dispassionate, with the goal to be as clear as possible.

This note contains a lot of information. It can be hard to take it all in with just one reading. This is especially true with the inevitable stress that comes with being in this situation. Also, some of the drugs often given to a mother in premature labor may affect her ability to think clearly. For these reasons, you may want to read this note more than once. You may have to make one of the hardest decisions of your life based partly on what you read here.

This note emphasizes the chances of an extremely premature baby's survival and the chances of various degrees of permanent handicaps for the babies who survive. Parents of extremely premature babies must understand these things, because the law and our society in general have decided that parents have the right to choose whether or not intensive care is the best thing for their extremely premature baby. Deciding whether or not to choose intensive care for your baby is the "hardest decision" mentioned in the previous paragraph.

The alternative to intensive care is hospice care, where the emphasis is on comfort and being with loved ones, rather than on curing disease. For an extremely premature baby, this usually means being held by parents, being kept warm and, when appropriate, being given medications for sedation and pain relief. Beginning hospice care is often referred to as "withdrawing intensive care" in this note (and elsewhere).

Most of this note is about the negative things that can result from an extremely premature birth. The negatives are emphasized because most people do not know about them. We assume you already know the many positive things about the very existence of a child, the things that make up every parent's hopes for their baby.

### **Before 22 and after 24 weeks**

Babies born before 22 weeks into a pregnancy virtually never survive. Therefore, we provide hospice care for such babies, unless there is a significant chance the baby is really more mature than we thought.

At 25 weeks and beyond, although much risk still remains, the chances that a baby will survive and be healthy in the long run are better. Therefore, once the 25 week point has been reached, intensive care is given at least initially unless there are special circumstances.

### **22 week babies**

Nationwide, most 22 week babies are given hospice care. Very few 22 week babies have survived. Our estimate of the chance of a 22 week baby surviving with intensive care, 10%, really is just an estimate, because we have not yet succeeded in sending a 22 week baby home alive here despite several attempts.

Most of those 22 week babies died after the brain was badly injured by severe bleeding into the brain and intensive care was withdrawn.

Before we begin the intensive care of a 22 week baby, we want to be as sure as possible that the baby's parents are fully aware of the high odds against the survival of such a baby. Also, little is known about the outcomes of such babies, except to guess that the risk of handicaps is higher than it is at 23 and 24 weeks.

### **Survival at 23 weeks**

Nationwide, many 23 week babies are given hospice care. However, we have given intensive care to most, but certainly not all, 23 week babies born here since 1990. About 50% of 23 week babies given intensive care here survive. About half of the deaths have followed withdrawal of intensive care after severe bleeding into the brain.

An individual baby's chance of surviving may be much different from that 50% overall figure, however. These individual differences are mostly due to four issues:

1. the time into that week (a baby barely 23 weeks is less likely to do well than a baby almost 24 weeks),
2. the baby's gender (girls tend to do better than boys),
3. multiple pregnancy (singletons tend to do better than individual babies from multiple pregnancies), and
4. whether there was time before birth to give the steroid (betamethasone, also called Celestone) shots to the mother (which helps the baby's chance of surviving and avoiding severe brain bleeding).

Depending on these factors, we might estimate an individual baby's chances for survival to be anywhere from 25% to 75%.

### **Survival at 24 weeks**

At 24 weeks, most babies are given intensive care nationwide, but some are given hospice care. We have given intensive care nearly all 24 week babies born here since 1990. Overall, about 75% of 24 week babies given intensive care here survive. As noted in the last section, there are reasons that an individual baby's chances may differ from the overall figure. Depending on those same factors, we might guess an individual baby's chances for survival to be anywhere from 50% to 90%.

### **Long term health and handicaps at 23 or 24 weeks: "Quality of life"**

It is important to keep in mind that there is much more to this difficult situation than survival.

Most extremely premature babies who survive have at least some degree of handicap. The problems related to the brain are by far the most important, because brain injuries often affect what is most human about us, and brain injuries cannot heal themselves.

The outcomes of babies who have gone home from the newborn intensive care unit (ICU) are usually divided into four categories, which will be described in the next four paragraphs. At 23 and 24 weeks, each of these four types of outcomes is nearly equally likely, so there is about a 25% chance your baby will be in any one of the four outcome groups, presuming your baby does survive. Please understand that some babies within each group will not exactly match the description of that group. Our intent here is to give you a realistic picture of the spectrum of handicaps faced by extremely premature babies, without going into all of the many possible outcomes.

1. Children in the no handicap group have intelligence and physical abilities within the normal range, and they perform normally in school when they are older. Even in this group, however, children may be physically small or need to wear glasses to see well.
2. Children in the mild handicap group have intelligence within the normal range, although it is usually somewhat below average. They also usually have some sort of problem that makes things difficult for them in school. Attention deficit disorder is a common example. Children with attention deficit disorder are easily distracted, and may be hyperactive. Other problems found in this group include learning disabilities, language problems, difficulty with math, and social/emotional issues. Many children in this group are also somewhat clumsy, but are able to do what they need to do. Some of these children will need special education in school.

3. Children in the moderate handicap group have borderline intelligence that falls between "low normal" and mildly mentally retarded, and also often have mild cerebral palsy. The mild cerebral palsy means these children have permanent difficulties with muscle control (such as awkward walking or difficulty with handwriting), need physical therapy, and usually begin to walk much later than most children. Vision may be somewhat impaired, even when using glasses. Most children in this group will need special education in school. Many children in this group will not be able to live independently as adults.

4. Children in the severe handicap group are mentally retarded and/or have severe cerebral palsy, usually to a degree that keeps them from ever walking without assistance. Children in this group also tend to have the most serious problems with their vision. While blindness is quite rare, vision is often impaired enough to be a significant problem, even with the best possible glasses. Virtually all children in this group will need special education in school, and most will not be able to live independently as adults.

We all fear the extremely handicapped outcome, the child who grows up unable to communicate, and perhaps not aware of what is happening around him or her. Fortunately, even when there is serious bleeding into the brain, such extreme outcomes are rare. Most of the children in the severely handicapped group are capable of carrying on at least a simple conversation.

The important point of this section is that long-term outcomes are not simply a matter of being either perfectly normal or extremely handicapped. On the contrary, the outcomes of extremely premature babies cover a wide spectrum. Few will be truly normal, but very few of the handicaps we see are as serious as our worst fears.

### **Predicting outcomes for extremely premature babies as a group**

An equal chance for each of the four outcome groups, as given above, is the best guess we can make at this time. It is a guess because, to really know how a child will do, we must wait until that child is at least eight years old. It is only around that age, when the child is working with letters and numbers and is in a more complicated social setting, that we can finally begin to estimate a child's adult potential with reasonably good accuracy.

Because we must wait eight years to know how a child will do, we are by necessity basing our guesses for the future outcomes of babies born today on the current outcomes of babies born eight or more years ago.

However, newborn intensive care has changed a great deal in the last eight years. Extremely premature babies are surviving more often now than they did eight years ago and before. It is tempting to assume that today's survivors will also have better outcomes than the survivors of years ago.

However, the trend over time has been that the percentage of those extremely premature survivors who are handicapped to varying degrees has remained fairly constant as their survival has improved over the years.

In other words, there are more normal survivors now than years ago, but there are also more handicapped survivors. It is likely that this trend will continue, so our outcome estimates for today's babies will probably be fairly accurate.

### **Predicting outcomes for individual babies**

Of course, you do not want to know how other babies similar to yours will do as a group. You want to know how your own baby (or babies) will do. Unfortunately, our ability to predict how an individual baby will do in the long run is rather poor. This uncertainty is one of the most difficult things about this whole situation.

Babies can be vigorous and very healthy as fetuses and yet have great problems after birth. This can happen because life outside the womb has very different demands than life within the womb.

It is generally better when a baby is vigorous at birth, but vigor at birth is still a poor predictor of the later health of individual babies. Even extremely premature babies who need CPR at birth have outcomes not much different from those who did not need CPR.

The same is true for the overall health of a baby during the time spent in the newborn ICU, with one exception that will be discussed in a moment. It is generally better when a baby has minimal difficulty with immature lungs, blood pressure, infections, and the many other problems that can happen after an extremely

premature birth. However, there are too many exceptions (in both directions) to rely on overall health to predict the outcomes of individual babies.

One problem that does predict handicaps at least relatively well is the problem of severe bleeding into the brain, which happens to some extremely premature babies. There can be small amounts of bleeding in the brain (called grade 1 or 2 bleeds) that have little or no effect on a baby. On the other hand, severe bleeding in the brain (called grade 3 or 4 bleeds) often cause significant permanent handicaps.

When severe bleeding does happen, it almost always happens in the first three days after birth. That is why we look at the brain with ultrasound after the first three days. If no severe bleeding is seen, that is a major hurdle successfully cleared. If severe bleeding is seen, the chances for severe handicaps are much greater. The likelihood of needing surgeries (and the additional pain and inconvenience that goes with them) later for hydrocephalus (excessive fluid accumulation within the brain) or for complications of cerebral palsy also greatly increases if severe bleeding occurs.

Even though the brain ultrasound is probably our best predictor of permanent handicaps while a baby is in the newborn ICU, it is still far from perfect. Some extremely premature babies who do not have severe bleeding in the brain have severe handicaps later in life. A few babies with severe bleeding manage to be fairly close to normal later in life.

In general, we are better at predicting severe handicaps, largely because most of those babies have severe bleeding in the brain, or perhaps a rarer problem (called periventricular leukomalacia) that shows up later during the hospitalization on other brain ultrasound tests. However, we have no good way of predicting which babies will be normal and which will have mild or moderate handicaps.

### **Other medical issues**

So far we have concentrated on survival and brain-related problems, because those issues have the most permanent impact. There are other health issues that must be mentioned. Infections are not uncommon, and can cause a baby to become much sicker. Some babies die from infections. The ventilators that help babies breathe and keep them alive also damage the lungs. This can lead to problems with wheezing or pneumonias through the early childhood years or perhaps longer, and may require more time in the hospital. Many extremely premature babies grow poorly, have feeding problems, and/or have difficult dispositions.

Parenting an extremely premature baby can be a difficult, frustrating experience.

### **Multiples: Twins, triplets, or more**

Multiple pregnancies make this already difficult situation even more complicated. For example, if one of a set of triplets is in serious trouble before birth at this extremely premature stage, do we do a c-section to try to save one baby? Doing so could endanger the lives of the other two. On the other hand, the death of one fetus can, in some circumstances, endanger the health of the remaining fetus(es).

Extremely premature multiples, as individuals, appear to have a somewhat lower chance of surviving than single babies. However, the chance of one of your babies surviving may be better than that of a single baby, but that is at the price of the lower chance that all of your babies will survive.

### **Suffering**

Clearly, no one would choose to be a patient in an intensive care unit. It is a difficult experience at any age, although we do everything we can to keep babies comfortable.

Extremely premature babies are generally kept heavily sedated with morphine, which is also a potent painkiller, during the first three days of life, so we feel they are comfortable during this time. (We must admit that our ability to estimate how much pain a baby is having is imperfect, but we do give enough morphine to keep the babies very sleepy the great majority of the time.) Most babies are then allowed to awaken so they can breathe on their own without the ventilator.

Needle pokes are kept to a minimum by using long-term IVs and arterial lines. Long term IVs can be left in for weeks, sparing babies many pokes for standard IVs. Arterial lines also usually last for weeks, if we need them for that long, and are used for drawing blood samples, sparing babies many pokes in the elbow for

drawing blood. Most extremely premature babies begin their stay in the ICU with an IV and an arterial line placed in the umbilical cord's blood vessels. This is good from the comfort point of view because the umbilical cord has no sensation at all, so placing these devices is virtually painless.

When a hospital stay goes smoothly, the amount of suffering experienced by a baby is relatively low. (We understand that the words "relatively low" are not very comforting when we are talking about your child's suffering.) Some complications that can occur later on in the hospitalization, on the other hand, may cause pain that is less manageable.

### **The effect on the family**

There is always grief when a baby is born extremely prematurely because, no matter how well things go thereafter, the dream of a full term pregnancy and a big, healthy baby has been lost. As with grief that follows the death of a loved one, overwhelming emotions of all kinds are common. Please be aware that such extreme emotions are a normal part of grieving.

It is almost impossible not to feel guilt about the birth of an extremely premature baby. This is especially true for a mother, who often feels the premature birth is her fault, no matter how carefully she took care of herself and her pregnancy. In most cases of premature birth there is no fault, just bad luck.

When children grow up to have serious handicaps, it is hard to predict how the family will be affected. A seriously handicapped child can be a cherished member of one family, while another family may be torn apart by the experience. Other children in the family may feel neglected because of the greater attention a seriously handicapped child requires, but they may also learn important lessons in compassion.

Having a child with many medical problems can also be a heavy strain on the family budget. If expenses are high enough, financial aid can be obtained, but this is a time-consuming process for parents who are already pressed for time.

Even when things work out well in the long run, families can be affected greatly by the experience of having an extremely premature baby. Some parents experience something similar to the post-traumatic stress disorder seen in veterans who experienced extremely stressful combat situations. Some marriages fall apart under the stress. Varying degrees of depression are not uncommon, and may require treatment.

### **Breast milk**

If you had not originally intended to breastfeed your baby, you may wish to reconsider that decision due to your risk of giving birth so prematurely.

There is some evidence that premature babies fed breast milk have fewer brain-related problems later in life than do those fed commercial formulas.

The intestines of extremely premature babies work rather poorly, and can cause serious illness. Some premature babies die of this intestinal illness (called necrotizing enterocolitis), while others may need surgery. Babies fed breast milk are less likely to develop this intestinal illness than are babies fed formula.

We strongly encourage you to use a breast pump so we can use your milk for at least the first two months or so of your baby's life. Both your obstetric nurses and the newborn ICU nurses can help you with this.

During this time, your milk can be given to your baby through a tube that goes into the mouth and down to the stomach. Tube feedings are necessary at first because of poor swallowing ability. At about two months of age the risk of intestinal disease is much less, so, if you wish, we can switch to formula feedings around that time. This is also about the time we begin to give some feedings by mouth instead of by feeding tube.

Using a breast pump is a difficult process that is not always successful. We will help you any way we can.

It is usually the ability to take all feedings by mouth that determines when a baby is ready to go home. This usually occurs shortly before the original due date.

## **Blood transfusions**

Extremely premature babies need many blood transfusions during their stay in the hospital. It is natural to worry about blood transfusions, but the risk of complications from blood transfusions is very small compared to the many other risks faced by extremely premature babies.

## **Options**

The first difficult choice is whether or not to have a c-section if your baby is showing signs of being in serious trouble before birth. A c-section could save your baby's life or minimize brain injury. However, as with any baby born this early, the brain could be injured or your baby could die later on. A c-section this early in a pregnancy may mean that you will have to have any future babies by c-section. A c-section done this early may also add a small risk that your uterus could rupture in a future pregnancy, which is dangerous for both your future baby and for you. Your obstetrician can tell you if these latter two risks could apply to you.

Once an extremely premature baby is born, we may provide either intensive care or hospice care. This decision is best made before birth, because the intensive care of an extremely premature baby should begin immediately after birth, to minimize the chance of brain injury. There are no reliable ways to predict a baby's long term health at the time of birth, unless the baby's maturity is clearly much different from what we had thought before birth.

Beginning intensive care does not mean it must be continued no matter what happens. For example, we can reconsider continuing intensive care after the first three days, when the breathing and blood pressure problems are usually resolving and the first brain ultrasound has been done. If things are going well, it is reasonable to continue intensive care. If there is severe bleeding into the brain, on the other hand, hospice care might be considered.

If something serious happens later in the hospital stay, we may approach you again about continuing intensive care. That does not mean that we think hospice care is the right thing to do. It simply means that the outlook has significantly changed since our prior discussions.

Please do not hesitate to discuss your baby's care with us at any time, whether there has been a major change or not. Just ask your baby's nurse if you wish such a meeting. Issues we might discuss include the following:

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?

## **What will be done if there is no parental decision about intensive care?**

For a variety of reasons, we sometimes do not have a clear parental decision about intensive care when a baby is born. In that case, we will usually provide intensive care to 23 and 24 week babies and hospice care to 22 week babies. This is done because, in our experience, those are the wishes of most people.

### **Conclusion**

We have reviewed the chances for survival and varying degrees of handicaps for extremely premature babies. The emphasis has been on long term outcomes, because that is what is most important when choosing between intensive care and hospice care.

Perhaps it all comes down to this: If you were in your baby's (or babies') place, would you want a chance at life despite the medical problems, the suffering, and the likelihood of at least some degree of handicap, or would you feel that is a fate worse than death? We cannot know what a baby would want to do, but we do know that people eventually tend to share their parents' views about such things. Therefore, it is a baby's parents who are most likely to make the same decision that a baby would make if he or she were able to do so.

The choice is clear to some parents, to keep their baby alive if possible and deal with whatever problems may come. Other parents just as clearly feel they cannot put their child through those same problems. Both views are held by well-informed, reasonable, loving parents. Many parents see both views clearly, and find this an excruciatingly difficult decision to make. A mother and a father may have different views, an especially difficult situation with no easy solution.

At the risk of oversimplifying this difficult situation, there are basically three options here, at least for the first few days.

1. If the risk of mild and moderate handicaps seems too great, then perhaps hospice care should be provided at birth.
2. If the risk of handicaps seems acceptable, but you also want to try to minimize the risk of severe handicap and minimize discomfort, then perhaps your baby should be given intensive care and heavily sedated for the first three days and then the decision can be made.
3. If the risk of severe handicap is acceptable, then perhaps intensive care should be continued unless the situation becomes hopeless.

We are perfectly willing to talk with you at length to clarify and expand on the points made in this note. Your pregnancy may have special circumstances not covered here. We can talk about emotional issues that are not covered in this intentionally dispassionate note. If you wish, we can try to put you in touch with parents who have been in the situation you are in now. Ask your nurse to contact us if we can offer any help. We are here to help you and support you in any way we can.

We hope that your pregnancy can be safely prolonged to a point that is safer for your baby, to 25 weeks or even to 30 weeks. Even that best outcome is difficult, however. If only there was an easier way out of this frightening situation!