

Perinatal Hospice from the Perspective of Alexandra's House Medical Director

E.W.J. Pearce, M.D.

A perinatal hospice is an organization that provides physical and spiritual support to people who discover during pregnancy that their baby has a serious birth defect that likely will result in death either before or shortly after birth. Thus the parents begin to grieve and suffer at that particular time and need both physical and spiritual support. The perinatal hospice is the organization that supplies it for them.

As a well-established practicing obstetrician and gynecologist and professor of medicine, this appeared to me to be an *advance in perinatal care* (the period surrounding pregnancy and delivery) that could profit anyone who was involved in pregnancy, labor and the birth of babies.

I had no idea of how to bring this information to the general public. However I began to talk to various charitable and pro-life groups and ultimately Patti Lewis, a cardiovascular nurse, heard about the idea and contacted me. She had an experience several years ago with the death of a niece who had a birth defect incompatible with life. Patti's niece had Smith-Lemli-Opitz Syndrome. This is a congenital birth defect in which there are a number structural abnormalities but the most serious is the inability to metabolize cholesterol properly. Her niece Alexandra lived six weeks and changed Patti's life forever. Patti demonstrated the classic feeling of parents of a baby with serious birth defects. The parents bond with that baby in-utero. It is a member of the family even before it is born. Consequently when the baby dies either before or shortly after birth they grieve and suffer as they would with the loss of any other family member. They experience the loss of a future of that particular individual. The psychiatrists and psychologists have discovered that *successful mourning is necessary in order for the parents to reorient their lives successfully and especially in relationships to raising the rest of their family and especially the next baby. It has also been determined that memories promote and propel successful mourning.*

This experience moved Patti deeply and she was very interested in providing the services of perinatal hospice. However she did not have the conceptual framework about how to go about it. After she and I met, we began to study the model Dr. Byron Calhoun had developed. Eventually Patti, I and Father Peter, a Catholic priest, developed a little steering committee and began to formulate a program for Alexandra's House.

Previous studies on stillbirths and early infant deaths have indicated that the medical and nursing professions were not very well attuned to these realities of the family. The studies have shown that the physicians especially consider a stillbirth or an early neonatal death a non event, a sort of sign of failure. The parents felt isolated, abandoned and neglected. Nobody seemed to understand their feelings.

This was a problem that had been brought about by modern technology. Forty years ago most birth defects were not discovered until after the baby was born. In the 1960's the first prenatal diagnosis was made. Subsequently, many prenatal diagnoses were made with the advent of universal ultrasound. Almost all birth defects are discovered approximately half way through pregnancy. This is the time, at diagnosis, when parents begin to grieve and suffer and therefore this is the time when they begin to need services.

The services of Alexandra's House as a charitable perinatal hospice include the following:

1. Pregnancy support – Patti attends prenatal visits with the individual involved. She attends labor and birth, gathering mementos for the family, and she visits in the hospital afterward. In addition, she provides various connections that people might need during this particular period of time including other parents that have been through a similar situation.
2. The next service is funeral and burial support. Alexandra's House has provided clergymen for funerals for people who do not have any religious affiliation. Alexandra's House has also provided burial garments and funeral expenses and supported the cost of the funeral.
3. Post event counseling is extremely important. The volunteer staff keeps in contact with the families that have suffered a loss. It has come to pass over time that these people bond and form a group. Alexandra's House has regular quarterly meetings at which time people can come together share their stories, show their baby pictures, relate to each other, and feel good about it because they realize that there are other people who have gone through the same experience.
4. Alexandra's House has sponsored educational efforts. Some of the parents who have been through this before will attend some of our sessions and educate other parents about the grief process. A very important part of the effort is to educate the medical professionals in the community. Patti and I have been involved in the educational efforts at teaching hospitals, other hospitals, doctors' offices, and at nurse's gatherings including grief counselors throughout the metropolitan area. Also in September 2001 we presented a report to the lay public interested in our progress.

At the present time, November 2004, Alexandra's House has provided service to approximately 87 families in the Kansas City metropolitan area. This includes referrals from Topeka, St. Joseph, Springfield, Columbia, and one couple came from Chicago for counseling and other services.

Alexandra's House is incorporated in Missouri as a non-profit organization and has 501©3 status which means that all donations are tax deductible. Alexandra's House will provide services to anybody who needs it without charge, including people who have are post-abortive, because they grieve and suffer just like everyone else. Alexandra's House now has its own domiciliary facility at 638 W. 39th Terrace, which is very close to the intersection of the Southwest Trafficway and 39th Street. As such it is centrally located between St. Luke's, Truman, Children's Mercy and University of Kansas Medical Center. It provides overnight accommodations for people from out of town who need a place to stay. It also provides respite care for the occasional baby whose survives whose parents need a little time off. In addition it is a handy place for some of the meetings for the parents who want to share their experience. Patti Lewis is paid a small stipend out of our funds but she is the only person in the organization who is paid. She has given up her job as a cardiovascular nurse and now devotes full time to the activities of Alexandra's House, and lives at the domicile.

Our group of volunteers has made efforts to educate themselves about some of the problems that occur with these families and their babies. In October 1998 at our own expense four of us flew to the Seattle/Tacoma area where Dr. Calhoun was working in Madigan Army Hospital. Dr. Calhoun marshaled all of his people, nurses, social workers, ultra sound techs, pediatricians, chaplains and so forth and had them educate us abut how they worked and what their problems were and how they solved them. In addition our volunteer group has had educational efforts by pediatric nurses and by people from the Kansas City Hospice. Patti Lewis has taken training and is now a licensed foster parent-respite provider.

Alexandra's House provides no medical or nursing services but we have done our best to acquaint ourselves not only with the problems of these suffering parents but the techniques and the agencies which are available to solve their problems.

Alexandra's House is a Christian organization and provides its services on the basis of Christian love. Generally speaking people who carry through the pregnancy and allow a normal birth tend to have a little more distress during the period of their suffering but usually heal better and faster than people who seek abortion to solve their problem.

The one overriding fact to remember about this situation and I made this clear, especially to all physicians and nurses and other involved in perinatal care who come across a family with a baby with serious birth defects, it is this: *they love that baby and they want you to love it and they want you to pay attention to it. Don't ignore them, don't marginalize them, and don't ignore their baby. On prenatal visits ask about the baby. Is the baby moving, when is the baby most active and so on? Assist these families in planning for labor and delivery. Frequently fetal monitoring is unproductive and unnecessary as many of these babies have markedly abnormal fetal heart rate patterns. Plan for the type of birth, plan for the anesthesia, talk to the pediatrician about how much care and what kind of care will be provided for the baby, allow the parents to stay in the labor and delivery suite as long as they want to and as long as the baby is alive. Allow the children and other family members to participate. Allow the family to see the baby, hold the baby, dress the baby, love it, name it, photograph it, and when it dies to bury it with all the ceremony that one would have for any other member of the family.* In such a way the family will have bittersweet memories that make this baby a special baby and a real person. In this way they will have the memories that which will allow them to mourn successfully and heal from the experience and go on with the business of the raising of the rest of their family.

In 2002, I presented some of this material to the Update 2002 at Truman Medical Center in Kansas City. At that time, one of our mothers who had just lost her baby girl shortly after birth just 2 weeks prior insisted that she be allowed to talk to the physicians and nurses when I presented Alexandra's House. She wanted to educate those doctors and nurses on how to deal with someone who has a baby with a birth defect incompatible with life. She made it quite clear that the best way to deal with this is to pay attention to these people and to allow them to express themselves and to allow them to love their babies just like anybody else.

Another mother told us she selected the doctor to deliver her baby with anencephaly when he said to her, "It will be my privilege to be yours and your baby's doctor."(ed.)

Now the reason that most of us go into Obstetrics and Gynecology is we don't want to take care of sick people. We don't want any failure, and we certainly don't want any deaths. We want to be associated with success and joy and that's why we are willing to put up with the loss of sleep and the disruptive, stressful lifestyle; just so we can be associated with that peak experience of the human race - the birth of a baby.

But it is inevitable that all of us will on occasion make a diagnosis of a birth defect incompatible with life. At that time, we as obstetricians must shift gears from the cure system to the care system.

Learn how to do it. You may not be around a practice setting where you will have the availability of an Alexandra's House to solve your problems. You may have to take the lead. Below is a bibliography of articles in the medical literature that will help you.

Bibliography

Lewis, E. Mourning by the family after a stillbirth or neonatal death. Archives of Disease in Childhood, 1979; V54 pp3030-306.

Chescheir, N.C., Cefalo, R. C. Prenatal Diagnosis and Caring. Women's Health Issues. Fall 1992; V2 N3 pp123-132.

Zeanah, C. H., Dailey, J.V., Rosenblatt, M., Saller Jr., D.N. Do Women Grieve After Terminating Pregnancies Because of Fetal Anomalies? A Controlled Investigation. Obstetrics and Gynecology Aug 1993; V82 N 2 pp270-275.

Hoeldtke, N.J., Calhoun, B.C. Perinatal Hospice. American Journal of Obstetrics and Gynecology September 2001; V185 N3 pp525-529.