Life Link Support System for Women with At Risk Pregnancies

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This paper was presented at the annual meeting of the Association for Interdisciplinary Research in Values and Social Change in June, 2001 at Charlotte, North Carolina. The author is a registered nurse, staff member of Wisconsin Right to Life, and Executive Director of the National Association of Pro-Life Nurses.

The Life Link support group concept was established by Wisconsin Right to Life in response to the reinterpretation of the Waukesha Memorial Hospital policy which expanded permissible abortions to include pregnancies deemed life threatening to the fetus. The Life Link support group includes women whose babies have been diagnosed with conditions incompatible with life as well as women with pregnancies which were assumed to likely result in the birth of a child with a handicap or disability. At the present time, there are seven women in the support group who are willing to counsel other women. To date, members of the support group have counseled three other women. There are also others who have expressed a willingness to counsel with women whose pregnancies have been diagnosed as incompatible with life. These are the testimonies of the women in the support group who have given written permission to print their story.

Breast Cancer During Pregnancy

Pam Goris

My name is Pam Goris. I am thirty-three years old. Five years ago, when I was pregnant with my third son, Thomas, I was diagnosed with breast cancer. It was a stage two, grade four cancer, which is an aggressive growth cancer. I was only a couple of weeks pregnant and my doctors worried about the possible effects of mastectomy surgery and the chemotherapy and/or radiation on the baby. They told me that they could not use radiation on a pregnant woman. The oncologist advised me to have an abortion. I was stunned. I thought that the doctors should try to save both of our lives, not just mine. I was told my chances for survival might not be as good if I decided to continue with my pregnancy because the increased levels of hormones in my body could speed up the growth of the cancer. We were also told that there would be a high probability of malformations in the developing baby and possibly retardation from the general anesthesia during the surgery and the chemotherapy to follow.
When we asked the oncologist for names of women who had been through this situation before me, she said she did not know of anyone. I was desperate to find someone with more hopeful advice and refused to believe that I was the only one to ever be diagnosed with breast cancer while being pregnant. With the help of the breast care coordinator at the hospital, we started doing some research. We asked her to find any articles on the medical databases related to pregnancy and chemotherapy. After many discouraging articles, she finally found what we had been hoping for. Good news! She gave us an article written by Dr. Theriault of the M.D. Anderson Cancer Center in Houston, Texas. This is a world renowned cancer treatment and research facility. Dr. Theriault specialized in treating pregnant women who also had breast cancer. We wondered why our doctors in Milwaukee had no knowledge of this. Dr. Theriault had come up with a chemotherapy regimen that used the least harmful combination of drugs for the developing fetus, but would also be as effective as other drugs in eliminating cancer from the mother. He had successfully treated 26 women as of November, 1995, and all of them had delivered healthy, normal babies. Incredible news! My husband and I immediately flew to Houston to meet with him. He assured us that there was absolutely no proof that the pregnancy would speed up the growth of the cancer. He also said the chances for a malformed or retarded baby were much less than we had been led to believe, especially if we waited until the start of the second trimester to start the chemotherapy. This would allow our baby's organs to form properly, and he said it would not decrease my chances for survival by waiting a few more weeks to start chemotherapy. This was the hope and encouragement we needed to feel good about not aborting our baby. I became woman number 27 in Dr. Theriault's study. He gave the chemotherapy protocol to my oncologist in Milwaukee so I could receive all of my treatments here.

My baby was born between the 5th and 6th cycles of chemotherapy. Although he was 10 ½ weeks early, he was otherwise a "normal" and healthy baby. He needed to spend two months in the neonatal intensive care unit at St. Joseph's Hospital due to his pre-maturity. My doctors were not sure why I went into premature labor. Thomas is four years old now and is a beautiful, intelligent, healthy and happy child. We are so grateful we did not abort him. If Thomas had been born with a malformation or retardation, I am sure we would love him just the same.

My advice to a pregnant woman with breast cancer is this: You do not have to have an abortion. Talk to someone who has been there, like me. I would love to help you through the process. Also remember that doctors are only human, and that they have a liability issue to consider when advising their patients. They will always tell you the worst case scenario but that does not mean that it will happen. Don't be afraid to question your oncologist and to educate yourself as I did. This is your baby! You will be the one to live with the decision, not your doctors or family members and friends who may pressure you to have an abortion. They have their own fears and uncertainty. You have to be the one to make the decision.

Another thing to consider is that chemotherapy may cause your body to go into premature menopause. If that happens, you may never be able to have a baby again. I have a friend who had cancer in her early thirties. She was engaged to be married to a wonderful man and they wanted children. Her chemotherapy caused early menopause and now they cannot have children. This is very painful for them. I believe that it was a "hidden blessing" to be pregnant while I was going through chemotherapy because the pregnancy prevented me from going into menopause. I have since had a fourth healthy baby boy and I am so thankful!

Have faith! Be positive. Your mental health has such a profound effect on your physical body. Be proactive in your treatment and use "alternative" methods for healing in addition to surgery and chemotherapy. For me, these included meditation, visual imagery during the chemotherapy to guide the
chemo to the cancer cells and away from the baby, dietary changes, exercise, stress reducing breathing techniques, and juicing carrots and other fresh vegetables and fruits. Five years later I am doing great and have no signs of cancer in body. My "cancer" baby, Thomas, is also doing great. We are both cancer survivors!

Editor’s Note: Pam Goris and her breast care coordinator realized that a comprehensive search of medical databases was very important to her situation. A large data base is maintained by the National Library of Medicine called PubMed which is free and readily available. It includes Medline and other life science information for searching medical information on a wide range of subjects. It has special databases and can be searched by name of author or journal. Abstracts or Full Text Articles may be obtained. CancerLit is another large search engine which has been established by the National Cancer Institute and is a good source of information on cancer-related issues.

Researchers at the M.D. Anderson Cancer Center where Pam Goris received the proper medical advice recently published a review article on Breast Cancer During Pregnancy in the journal Oncology (Huntingt) 15(1):39-46, January 2001. They concluded from the available studies that, "termination of pregnancy does not appear to improve survival." Other recent review articles have reached similar conclusions.

Ovarian Cyst

Connie Camp

Twenty-five years ago, I had another painful episode with an ovarian cyst, similar to an appendicitis attack. When I was finally diagnosed as having a cyst and calcium deposits in my left ovary, surgery was scheduled. Uneasy about the suggestion of a hysterectomy, my husband transferred me to a Madison hospital where it was discovered that I was 2 ½ months pregnant - something we had discounted because of the ongoing experience with the ovarian cyst. We were told that the surgery could be done, safely, at 4 ½ months gestation; but that the "fetus" surely was not normal because of the pain killers and x-rays I had received. When we said that we did not believe in abortion (in fact, we were chairmen of the local pro-life group), the harassment started.

In the evening, after hours, the doctor came to my room to suggest that I abort the baby and have the needed surgery. When I repeated our intention to keep our baby, he became irritated and said, "You know that baby is retarded!" Two months later, I did have the surgery, and was reminded, again, that the baby was retarded. We were treated with cool disdain by the surgeon and our local doctor for the rest of the pregnancy. Our oldest daughter was studying special education in Eau Claire at the time, and we prepared her for guidance in raising our retarded child as best we could.

Our little daughter was born a month early, had jaundice and a viral rash, but was our "angel baby". She will be 25 years old in the Fall, graduated as valedictorian of her high school class, graduated with honors from the UW-Milwaukee Architectural College, and is now finishing her spring semester of graduate work with the University of Minnesota - in Venice, Italy.

I sometimes cry when I think of our loss if we had aborted our "retarded" baby. If someone needs reassurance about a difficult pregnancy, a call will be most welcome. We always felt that there needed to be a support group for parents going through a similar ordeal. There was none for us. We found that the doctors are “pro-choice” - until you choose not to abort your child.
Editor's Note: A director of maternal-fetal medicine at a large Los Angeles hospital has observed that since Roe v. Wade permitted abortion for virtually any reason, the doctor may see fit to suggest or recommend abortion for almost any reason, especially if there are doubts about the effect of the pregnancy on maternal or fetal outcome. Thomas Murph Goodwin, Medicalizing Abortion Decisions, First Things, March, 1996

Anencephaly and Spina Bifida

Nora Orgovan

Our seventh child, Mary Margaret, was born and died on September 10, 1996. In my third month of pregnancy, she was diagnosed with anencephaly and spina bifida. Abortion was mentioned by some, but was never an option for us. We chose to love our little girl by giving her every chance at life, just as we would have for any of our other children. God would decide the outcome.

We always try to accept the good with the bad in life. We understand that there is an order in nature and that God is a God of order. It may have been against nature for Mary to live a long, normal life, but it was in our nature (and God's) for us to love her with all our hearts. Our hope for Mary was not for her future on earth, but for her future as a beloved child of God in heaven. In that we could, and do, rejoice.

Mary died a dignified death as a baptized child of God. She was cuddled and caressed by a mommy and daddy who cried and mourned as she peacefully slipped away. Mary received a Christian Mass and burial which helped bring closure for our whole family.

Although we often felt a sense of helplessness throughout the pregnancy, a great peace came in staying with Mary and loving her until the end. We knew we had done all we could for her. We had no remorse that we had not given her every chance. We felt no guilt that we had done something we knew was wrong. In the end, our experience increased our understanding to the meaning and purpose of human life. It helped our faith to grow deeper and our love for each other to grow stronger.

Make no mistake about this, our experience was not "fun" or something we considered easy to go through. Doing the loving thing is not always the easy thing to do. But, doing the loving thing is always the right thing to do.

Dottie Zanoni

About four weeks before our last baby was born, we learned that he would not live because his brain had not developed properly. He was diagnosed as having anencephaly. It was devastating news for us.

My doctor had simply sent me to the hospital for an ultrasound because the baby did not seem to be settling down - he didn't seem to be getting ready to be born. I had always delivered my babies before the due date and he wondered why it wasn't happening this time. While at the hospital, I was put on one ultrasound, then another. Finally, the sonographer called in the radiologist. No one said anything to me. Of course, I suspected something was wrong, but I continued to think that I probably just needed to have a caesarean section.
Two days later, my doctor visited my home to inform me of the bad news. I was told that the baby would be born breech, and that he would probably live for only a few hours. My husband and I were both shocked. For eight months my pregnancy had seemed to be proceeding normally, and now this. We cried and we prayed. I did not know how I could go through a birth and a death all in the same 24 hours. It was a difficult time. Even after being told that it was not possible for our little one to live, I continued to hope and pray that the doctors were wrong. I prayed that the baby that seemed to be so full of life within me would not die.

Our children were so excited about the baby and so looking forward to his/her birth that we decided to tell the older children that the baby probably would not live. We would have found it difficult to live with the growing excitement and constant questions. Fortunately for me, the day I went into labor I was kept busy keeping track of our two-year old. What a blessing he was. He kept my mind off the birth and death I was about to face.

The delivery I feared because it would be breech went well and was considerably easier than some I had experienced. Our little Joseph was born on March 22, 1983. My husband baptized him and I held him. I unwrapped the little blanket that held him and found that he was perfectly formed from the neck down. I did not hold him for very long because he lived only an hour and a half. We buried him in a little coffin in the children's section of the cemetery and, later, with all of our family present, we had a memorial Mass said for him. It is such a sad event to lose a child. He would be 17 now.

It was weeks before I realized how emotionally draining the experience was, and what a vulnerable state I had been in. How grateful I am that I had a doctor who never mentioned the word abortion. I am so glad that my child was able to live as long as he did, that we were able to baptize him and hold him. Thank God I was not encouraged to end his life in a painful way. I believe in the sanctity of each human life, but if I had been pressured to have an abortion at that time, given the emotional state I was in, I am not sure what I would have done. What an awful memory that would be.

One year after the birth of Joseph, I received a call from a pregnant woman whose child had been diagnosed as having microcephaly or anencephaly. Her doctors were pressuring her to abort her child. She was being told that she would retain an incredible amount of fluid during her pregnancy and would have a horrendous delivery. She too, believed in a Supreme Being. She believed abortion was wrong and did not want to do what they were pressuring her to do. I told her what my experience had been. I would be happy to share that with any woman who is facing a similar situation and is seeking support to do the right thing. Because I have had the opportunity to talk to many women who have had abortions, I know how devastating that decision has been for their lives. I believe women can face difficult situations and give birth to their babies - they just need support and encouragement. It is my hope that all our doctors will recognize the dignity of all of their patients, including the unborn. It is the best way to help women.

Editor's Note: Pregnant women and their families are likely to be in a vulnerable state when a diagnosis of an at-risk pregnancy is made. Prenatal diagnosis is frequently very stressful. Moral, religious, or philosophical concerns may predominate. Reflections on Prenatal Diagnosis: The Consumers Views, Rice & Doherty, Social Work in Health Care 8:47, 1982. If there is a crisis, a minimal amount of effort by a counselor or doctor may be able to exert a maximum amount of leverage on the stressed individuals. W Morley, Theory of Crisis Intervention, W Morley, Pastoral Psychology 21:203,1970
Genetic Anomaly

Melissa Horne

Six years ago, my daughter Cameron was born. She was born with a genetic disorder known as trisomy 13. From the day she was born we knew that she wouldn't live long. She spent her first 10 days in the hospital and then came home to live with us - myself, my husband, a sister, and a brother. During her hospital stay, we had a different neonatologist nearly every day. And the interesting thing was that none of the doctors could really answer our most pressing question- "How long will she live?" Trisomy babies can live for minutes, hours, days, months and rarely, years. Cameron lived for seven weeks.

At the time I gave birth to Cameron, I was considered advanced maternal age. I was 36. The only testing we opted for was a general ultrasound that wasn't designed to pick up abnormalities like trisomy 13. We chose not to do invasive testing because we knew that abortion was not something we would choose. And now I know that if we would have found out about Cameron's condition, we would have faced the question, "How long will she live?" with as much medical uncertainty as we faced when she was born. Each person is different. No one can predict their life span, the quality of their life, what a disability means to that person. We were fortunate. Cameron lived well until her last week of life before things like oxygen and medications became necessary.

Those seven short weeks have changed my and my family's lives forever. And how glad we all are for that. You see, her little life made a deep impression. We had seven weeks to hold her, love her and get to know her - as did our extended family and friends. How glad we are that we didn't cut her little life any shorter than it was. I had a friend who asked me after Cameron died if it wouldn't have been better not to have her at all. My response was - and is - absolutely not. The pain we faced was offset by the love we gave and got from Cameron's little life. There was an incredible purpose to our lives that we missed after she died. To cut her life short would have been to cut the cycle of life short. And what would I have told my other children? If a life isn't perfect, it doesn't matter? If a person isn't complete, they shouldn't have the right to live? They were seven and four at the time. They knew Cameron was sick but they didn't care. They held her and loved her and are now telling their two little brothers - age four and almost two - about their sister that someday they'll meet. What has helped us so much is that people knew our daughter. The fact is that she was, and still is, acknowledged as a member of our family.

We were fortunate to have the help of Children's Hospital Hospice during her life. When she died we were supported by family and friends and the society that no parent wants to belong to - parents that have lost children. We were active in a grieving parents group and have since gone on to support other parents who have lost children. I have worked with parents from the Resolve group at St. Joseph's Hospital, and with a group called TLC, that ministers to grieving parents.

The support that we got after Cameron died was invaluable, because it's such a difficult situation to deal with and most people don't have a clue how to help. Even to this day I have carefully consider how to answer when someone asks me the simple question of "How many children do you have?" There was nothing like being with other parents who have faced what we faced. I have in turn tried to give that back. And I will continue to do so, especially for the women who are patients at Waukesha Memorial Hospital who think they have no recourse other than abortion.
Editor’s Note: Melissa Horne said that a hospice helped during the short period of her child’s life. A perinatal hospice is an alternative for induced abortion where there are severe congenital abnormalities. In this setting, the infant is handed to the parents immediately after delivery to share the baby’s remaining life. Many infants are stillborn, but some live from minutes to days. Parents are allowed to stay in the delivery suite with their child as long as they wish. They freely experience and mourn the bittersweet birth and all-too-soon departure of their child. Grief lessens as time passes, and they can rest secure in the knowledge that they did not dismember or destroy their baby.

In a setting where women with pre-born children with severe congenital anomalies can seriously consider a life-affirming alternative of a perinatal hospice such as the perinatal hospice at Madigan Army Medical Center in Tacoma, Washington, the vast majority will not opt for early abortion when fatal anomalies are detected. JS Reitman, BC Calhoun and NJ Hoeldtke, Perinatal Hospice. A Response to Early Termination for Severe Congenital Anomalies in Genetic Engineering. A Christian Response, ed. TJ Demy and GP Stewart, Grand Rapids: Kregel Pub. (1999) 197

Theresa and Maria Danner

I was a very busy volunteer and mom of two girls when I became pregnant at age 35. After losing a baby in the second trimester, I was still determined to add to my happy family. I was once again pregnant in January 1999, certain that everything would go well this time. In my fourth month of pregnancy, my baby was diagnosed with Down syndrome through amniocentesis after a suspicious-looking ultrasound. This news devastated me and sent me into a depression. I felt trapped, even worse than after losing my other baby. Instead of being able to "try again." I felt that this diagnosis of a permanently disabled baby was a life sentence for me and that I had ruined my perfect little family by selfishly wanting another child. Several people encouraged me to abort my child. and one even offered to take me horseback riding to "get rid of the problem." I read many library books on Down syndrome and was discouraged to see how many medical problems could potentially affect her. I was encouraged, however, to see that most are only mildly retarded because of the therapy services they now can receive, and that many can go on to hold jobs, have apartments, drive and even go to college and marry.

While still pregnant, I toured our local Birth to 3 Center and met the wonderful women who would soon help us with physical, occupational and speech therapy. They helped me to feel that I was not alone in facing our new life and that many other people handled similar situations every day. I felt much more confident in myself as I approached childbirth, but was still a little bit sad and afraid for her future. The most difficult part to accept is that no amount of therapy, medical attention, or love will ever make her completely normal. She may always have some limitations in her choices as she grows, although I have read several examples of young adults with Down syndrome who now lead remarkable, fulfilling lives.

Maria’s birth was reasonably smooth. I felt that I was as prepared as possible emotionally but still had a serious bout of crying the next morning after visiting her in the Intermediate Care Nursery. Family and friends were lifelines of support during this time of acceptance. She had great difficulty in nursing and taking a bottle because of severe low muscle tone and almost died at six days old from dehydration. Seeing her near death in the Children’s Hospital emergency room changed me, as I begged God to let her live. I knew that I could not go through another pregnancy three years in a row, with no guaranteed outcome next time either. I resolved to make the best of the situation we were given and to love and cherish her with all my heart and help her to reach her potential, just as I would for my other girls.
She was evaluated for therapy a few days after leaving Children's Hospital and began physical and speech therapy soon after. I worked with the speech therapist and three lactation consultants on her feeding problems, but she still had trouble gaining weight for the first two months. She had severe low muscle tone and was weaker on one side of her body. The Birth to 3 people encouraged me, educated me and motivated me to advocate for her needs. Now 18 months old, Maria has tested at the low side of normal in her skills! She is active, curious, mobile, happy, and radiates joy to everyone around her. Her smile draws the affection of strangers everywhere we go. She can take four or five steps, well ahead of average for children with Down syndrome at this age. She likes to point to pictures in books, play with her favorite doll, try to put her "Baby Mozart" videotape into the VCR, knock over trash cans, and chew anything within reach.

I have become active in advocating politically and with the media for the Birth to 3 therapy program. I have had the privilege of counseling diagnosed pregnant women and new moms of babies with Down syndrome. I bring them information, listen to their stories and fears, and show them how precious and near normal Maria is. I can also tell them that there actually is a waiting list of families who want to adopt babies with Down syndrome. Babies with Down syndrome are BABIES, not problems, and are much more normal than not. I can offer them (even while they are still pregnant) instant friendships through a support group of local women who have babies and toddlers with Down syndrome. In the beginning of my journey, I did not want to see or hear about older children with Down syndrome, but was open to those with babies who were going through similar experiences. The support of other moms is a very powerful tool against fear.

Loving Maria has enriched my life in countless ways. But first I had to give birth to her and accept this new direction for my life with which God had blessed me.

Editor's Note: Melissa Horne and Theresa Danner appear to be in the minority as a considerable number of studies have reported that a substantial majority of women have an abortion upon learning their unborn child has Down syndrome. A review article of studies published between 1980-1998 reported that the overall incidence of induced abortion following prenatal diagnosis of Down syndrome was 92%. C Mansfield et al, Termination rates after prenatal diagnosis of Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes, Prenatal Diagnosis 19(9):808, 1999

Conclusion

I believe that this is an aspect of pro-life work which we all need to promote. It is extremely practical, totally relevant, and not as difficult or expensive as some of the other projects we have undertaken.

Having been a chapter leader at the grass roots level for a number of years, I know how often we hear this "must do" message attached to a recommended project. But it occurred to me as we were involved in this how great the need is, how relatively easy it is to do, and how well it is received. Especially if your local hospital does not have an abortion policy permitting such abortions, it would help keep them from thinking that they need to offer abortion as an alternative in such cases as considered here.

As with all other projects we undertake, we cannot just create and offer it, and then not utilize it, because we are involved in so many other aspects of our mission. We must put a program in place to encourage and promote it in order for it to thrive and have real meaning. Ask someone in the medical profession in your community to undertake and oversee the project as their own personal contribution to the pro-life movement.

Marianne Linane, R.N.