

Angel babies

PRACTICAL INFORMATION FOR PARENTS COPING WITH LOSS IN LATE-STAGE PREGNANCY OR EARLY INFANCY



WHEN I WAS PREGNANT WITH MY THIRD CHILD, I had a feeling that something was very different. The twenty week ultrasound confirmed my fears when our sweet baby was diagnosed with renal agenesis (Potter's Syndrome), and we were told that she would either be stillborn or live for only a very short time after birth. Elizabeth Jane slipped quietly into the world at 31 ½ weeks gestation and graced us with three wonderful hours of life. Those weeks between the diagnosis and her birth were an emotional roller coaster, and full of difficult decisions. We wished that there were some sort of a handbook to tell us how to prepare for her birth and death. I wrote this pamphlet to honor the life of my daughter, in hopes that this information will make the path easier for other couples facing the loss of their baby.

Whether you are carrying a baby who has just been diagnosed with a fatal or potentially fatal defect, or have been told that your baby has already passed away, there are things you can do to prepare for the birth to help you and your partner come out of it more emotionally and physically intact. You are not alone in this. This brochure is a compilation of medical facts as well as the wisdom gained from the experiences of others who have gone before you.

Second Opinions

One of the most important things you should do if you are facing a poor prognosis is to get a second opinion. Hopefully your health care provider will steer you toward this automatically. You need to feel completely comfortable with the expertise of the doctors giving the diagnosis, and it is wise to have more than one pair of trained eyes take a look at your baby. Write down a list of questions to ask during your appointment, making sure that you understand all of the answers and feel that all of your concerns have been addressed. Ask about specific tests that may be done to further confirm the diagnosis (see descriptions below).

Testing

- **Maternal Serum Alpha Feto Protein (MSAFP).** This is a blood test performed between 16-18 weeks gestation as a screening tool that provides a probability ratio that the baby has a potential for genetic disorders. It is not useful by itself, but as a guide for which other tests are appropriate. Mothers over age 35 already have high ratios simply because of their age. Results come in the form of a ratio, such as 1:480, which would mean that 1 out of 480 women with that level would carry a baby with a particular disorder. A high ratio will most likely lead your doctor to recommend amniocentesis or other testing to verify the results.
- **Amniocentesis.** An ultrasound is used to guide placement of a needle through the wall of the abdomen into the uterus to obtain a sample of amniotic fluid. The fluid may be tested for fetal maturity, gender, genetic and chromosomal abnormalities, hereditary metabolic disorders (e.g.: cystic fibrosis), some anatomic abnormalities and fetal distress (denoted by discoloration of the fluid). This test carries a risk of causing a miscarriage.
- **Amnioinfusion.** This is a procedure in which fluid is infused through a needle placed into the uterus under ultrasound guidance. This may be done for therapeutic reasons (generally to promote lung maturation in extremely low fluid states, or to detect a leak), or for diagnostic purposes in extremely low fluid states.
- **Chorionic Villus Sampling.** Performed between 8-12 weeks of gestation to detect genetic and metabolic disorders. A catheter is placed through the cervix and into the uterus, and a needle advanced through the catheter under

ultrasound guidance into the developing placenta to take a sample of cells. This test carries a risk of causing a miscarriage.

- **3D and 4D ultrasound imaging.** Multidimensional ultrasound that can provide a more detailed image of the fetus.
- **Fetal MRI.** MRI of the uterus, which for some specific birth defects may provide more diagnostic information. These must be read by a radiologist who specializes in fetal MRI, and may not be available in all areas.
- **Biophysical Profile.** Ultrasound to evaluate fetal activity, which correlates with fetal well being. Measures five parameters, with up to 2 points being awarded in each area: fetal heart rate reactivity, fetal breathing movements, fetal body movements, fetal tone (flexes and extends arms and legs), and amniotic fluid volume. A score of 0-2 may indicate the need for immediate delivery.
- **Non-stress Test.** Fetal heart rate monitor and uterine contraction monitor are placed on the mother's abdomen for a period of up to 40 minutes to evaluate the reactivity of the fetal heart rate, and the response to any fetal movement. This is a noninvasive way of determining general fetal well being.
- **Contraction Stress Test.** Performed if the non-stress test is unsatisfactory or not reassuring. Pitocin is given to the mother through an IV to stimulate contractions, during which the fetal heart rate is monitored for reactivity.
- **Amniotic Fluid Index.** During an ultrasound, the uterus is divided into four sections on the screen. The largest pocket of fluid in each section is measured in centimeters and they are added together to come up with the total amniotic fluid index (AFI).

Decision Making

If your baby is still alive, but has a poor prognosis, you may be given the option to either induce labor at the time of your choosing, or to carry to term. This is a complex, emotionally charged decision. Many factors go into this decision, including your religious beliefs, the emotional well-being of you and your partner, your physical health, and the support level of your doctor.

Each person and each pregnancy is a very different situation, and you need to feel good about your choice. It may help to write out a list of the pros and cons of each option, and discuss it with your partner and your doctors. Don't rush into a decision. Allow your emotions to settle for a few days before you proceed. Most moms who choose to carry to term for the possibility to spend

even a few minutes with their babies alive are glad they did so. If you choose to induce labor very early (before 24 weeks), be aware that the younger the baby, the more likely the baby will not survive the labor process.

Whether you decide to induce early, or deliver at term, it is a good idea to meet with a neonatologist to help you understand how your baby will likely react to being born. You may also wish to meet with the manager or social worker from the labor and delivery unit you will be using to familiarize yourself with the special services that will be available during your delivery, and to discuss your birth plan. Your doctor's office will be able to help you schedule these appointments if you so desire.

Birth Plans

Birth plans are a good idea for any delivery, but they become even more important in a delivery situation such as what you are facing. A birth plan is your opportunity to list things that are the most important to you and your partner during your labor and delivery process. The doctors and nurses may not be able to fulfill all of your wishes depending on circumstances, but they will try. It is difficult to articulate what you want in the midst of your delivery. Having your requests down on paper is the best way to communicate your desires. Give one copy to your doctor, and bring a couple of copies with your doctor's signature on them to the hospital with you. Here are some suggestions of what you may want to address in your birth plan:

- **Pain control: Epidural vs. IV medication vs. natural birth.** An epidural will give you pain relief during contractions, but won't affect your level of alertness. It will allow you to rest during labor so that you will hopefully have more energy after delivery. Epidurals carry a risk of spinal fluid leak, headaches and infection as possible complications, in addition to lingering numbness and lack of mobility for up to several hours after delivery.

IV medications can offer quick relief, but can also make you and the baby sleepy. Several different medications are available, including Fentanyl, Stadol, Nubain, Morphine, and Demerol. These medications can give relief for anywhere from 30 minutes to two to three hours, depending on which one is given.

Natural birth without any kind of medication typically allows a more rapid recovery, and with no side effects such as drowsiness or excessive numbness that you may have from a medicated birth. However, if the labor is prolonged, you may use up your energy reserves during labor and be exhausted by the time

you deliver. Consider what kind of delivery you've had in the past (if any), and talk to your doctor about what method of pain control will be best during this delivery.

- **Fetal monitoring.** Most labor monitoring is done via external monitors placed on the mother's abdomen. Sometimes if the monitor has a difficult time following the heart rate, an internal monitor is attached to the baby's head (if the water is broken). You may choose to only do external monitoring. You also have the option of refusing it all together, or to only be monitored for a few minutes each hour.

- **Room placement.** Generally, hospital staff will try to place you strategically so that you don't have to be near the nursery, but it doesn't hurt to remind them of this request. Sometimes you may be offered the option of being transferred to another medical unit away from the maternity ward. While this may seem like a good idea, the maternity nurses are likely to be better in tune with your emotional and physical needs than nurses that aren't used to working with new moms.

- **Resuscitation.** If you are going to deliver a baby who will still be alive after birth, you have the right to specify how aggressive you want to be with resuscitation. This is discussed in the "Resuscitation Options" section on page 7.

- **Care of the infant.** Specify whether you would like the staff to bathe and dress your baby, or if that is something you and your partner want to do. Cutting the umbilical cord can also be addressed here. If you have special towels or washcloths you want to use, or special clothes, make the staff aware. Address how long you want to keep your baby with you.

- **Mementos.** Most hospitals offer hand and foot molds, clippings of the hair, hand and foot prints, photographs and other little keepsakes as a matter of routine. If there is something special that you want, let them know. If the hospital does not offer these services, many areas have volunteer organizations which will come in at your request to perform them, or can provide kits for you to do molds yourself. Photographs will be discussed in more detail in the "Photography" section on page 11.

- **Religious rites.** If you have a particular ceremony or rite that you wish to carry out, list it, as well as any people who will need to be involved in it, such as clergy or particular family members.

- **Siblings and family involvement.** During deliveries where the baby is not expected to live, generally the staff will bend visiting policies to accommodate your needs. If you have other children, list their names and ages, as well as other family members that you would like to be in the delivery room. If

your other children will not be in the waiting room, list the phone number of the person who will be caring for them so that the hospital can contact them if needed. You may request that the staff explain how the baby will look before bringing the siblings in to the room.

- **Autopsy and genetic testing.** Depending on your situation, your doctor may recommend one or both of these. Specify your wishes to perform or refuse them. Some people also choose to enroll in studies for the particular diagnosis their baby has. If this is the case, address any paperwork, blood or tissue samples that need to be performed at the time of birth, as well as contact information for the study leader.

- **Organ and tissue donation.** You may have the opportunity to give the gift of life. Newborns are too small to donate organs, but may be able to donate heart valves and other tissue. Your baby may be eligible if born past 35 weeks gestation, takes a first breath, and is over five pounds. If you choose to donate, this will be at no cost to you. You can be assured that the donation process will be handled with dignity, respect and compassion.

- **Funeral home arrangements.** If you have already chosen a mortuary, list the name and number. Many people find it difficult to face this preparation in advance. If you haven't chosen one prior to delivery, the nurses or a social worker will be able to help you choose one that is appropriate for your needs.

Delivery Decisions

Each situation is different, so your delivery decision will be a judgment call between you and your doctor. Vaginal birth, if you have no factors that would prohibit it, is the most desirable for a number of reasons. It is typically less traumatic to your body and carries fewer complications with it than a C-section, in addition to having a much shorter recovery time in the hospital and at home. If you will be giving birth to a baby that is not likely to live for very long, you will be able to interact fully with your baby more quickly after a vaginal birth since you will not need to be surgically closed. Discuss with your doctor whether a vaginal birth will be too traumatic to your baby. Some fetal defects can render the baby very fragile to the point where the vaginal birth process would be fatal. Some mothers choose to have a C-section in order to spare their baby the trauma of a vaginal birth, and possibly give the baby a few more minutes of life. Communicate your needs and desires with your doctor to make a delivery choice that will lead to the best experience for you.

Resuscitation Options

If you will be delivering a baby with a poor prognosis, you will need to decide how aggressive to be with resuscitation after birth. Ask your obstetrician or perinatologist to refer you to a neonatologist (a doctor who specializes in the care of newborns) who can help you decide what is the most appropriate for your situation. There are two major directions you can choose: comfort care only, or full resuscitation. Your decision may affect which hospital you choose for your delivery, depending on what resources, such as a neonatal intensive care, are available.

Comfort care means that your baby will be stimulated and cleaned off after delivery. It may also include non-invasive respiratory care, such as a trial with a bag/valve/mask resuscitation device to help inflate the lungs, and/or blow-by oxygen therapy (a tube or mask placed near the baby's face that blows oxygen). The baby may attempt to breast feed or eat from a dropper or bottle at your request, and will be kept as comfortable as possible at your side. Specify on your birth plan which measures you want to be taken.

Full resuscitation may include chest compressions for CPR, placing a breathing tube into your baby's mouth and throat, and connecting your baby to a ventilator, intravenous lines, medications for sedation and to stabilize vital signs, heart monitors, invasive blood pressure monitoring through a tube in the artery, feeding tubes and other equipment. Your baby will need to be in a neonatal intensive care unit.

If your baby has been diagnosed with a disorder that may allow him or her to live for a few days or weeks, ask your doctor to help you make arrangements with a hospice agency that specializes in infants. Hospice nurses are highly skilled at making their patients comfortable, and in helping families make a comfortable transition to home care. Getting introduced to your hospice nurses in advance will ensure a smooth discharge from the hospital, and will also familiarize you with the resources available, including emotional support, medical supplies, aides and nurses to help with care, and education for you and your family.

Appearance of Your Baby

This is a common worry, and something that is good to be prepared for in advance. Generally, infants who are born very prematurely have fragile skin, may be red, but are fully formed little babies. Infants who are stillborn are fre-

quently a little discolored. The skin may be purplish or pale, and the face and limbs may have a slightly squashed appearance. They also have very fragile skin, so extra care is needed during washing and dressing. Certain diagnoses may manifest as outward deformities, such as cleft lip, club feet and others. Ask your doctor about specifics in your situation. It may be helpful to look at pictures of other similar babies before you deliver to help you emotionally prepare.

Things to Consider Doing With Your Baby

Depending on your situation, your baby may pass away before birth, or may only live for a short time. Think carefully about what memories you want to create with your baby. In your ultrasound visits before delivery, you may request extra pictures printed as well as tape the ultrasound and heartbeat sounds. Some families find it therapeutic to journal through the pregnancy, recording the movements and personality traits of the baby in utero, as well as the thoughts and feelings of the parents. At delivery, ideas include cutting the umbilical cord, a bath with soap and lotion of your choosing, dressing in a special outfit, pictures with your whole family, pictures of specific poses (addressed in the “Photography” section), singing a song or reading a special poem or letter you have written, letting grandparents or other family members come see your baby, wrapping your baby in a special blanket, feeding your baby some of your own breast milk (breastfeeding if the baby is able, or with a dropper or syringe), recording video or audio clips of any sounds, religious rites, etc. This is a very individual experience. Address your desires in your birth plan so that the hospital staff can help facilitate the experiences that are most important to you.

Allowing Other People to be Involved

It is very difficult to share the news of an infant death or poor prenatal diagnosis. If you have some time before the birth, mailing out an announcement that explains the situation and asks for the support of your friends and family may ease this burden for you. Online journals and blogs are an excellent way to keep loved ones updated in a non-intrusive way.

You may find that your family and friends have difficulty knowing how to react to your situation. Generally, people will follow your lead. If you are open about your feelings and about details of your situation, then they will likely

feel more comfortable discussing their feelings and asking you questions. If you feel uncomfortable sharing, then people will likely not talk about your baby and pregnancy as much. However, most people want to help in some way and would be honored to take part in the birth of your special baby.

Don't be afraid to ask for help with tasks that are too emotionally difficult for you, such as inquiries about burial plots and mortuary services, or shopping for or making tiny clothes. If you want to choose some of these things yourself, you may find it comforting to have someone accompany you. Allow people to bring you meals, watch your children or assist with other household tasks. Make a blanket and allow people to "stitch their love" into individual squares. Ask people to write letters or give small trinkets to be buried with your baby if you wish. Decide whom to have come to the hospital. There is no right or wrong number, just what you are comfortable with. Sharing the life of your baby is healing and validating.

How to Involve Siblings at the Hospital

Even though it may be difficult for you, if you have other children it is important for them to see your baby. Small children deal with concrete things. In order to understand that there is a baby, the other children need to see it. If your baby is discolored or deformed in some way, ask a nurse or a family member to explain what they will see before they come in to the room. Don't be surprised to see a wide spectrum of emotions. Some children may be totally fearless, very curious, and have no qualms about exploring and touching your baby. Other children may be hesitant to get too close to the baby. Don't force anything. Give them the opportunity to look at your baby as much as they want, and offer the chance to help with a bath or dressing your baby. Consider taking pictures of your children with the baby, especially if they are very young, so that they will be able to look at the pictures later and remember that they were involved in the life of your baby.

If you have time to prepare before the birth, your children may enjoy picking out a stuffed animal or blanket to bring as gifts. Consider having them draw a picture for your baby, or choose a story to read to him or her. Depending on the age and emotional capacity of your children, you may prepare them as much as months in advance by bringing them to see ultrasounds and listening to the fetal heart beat, reading them stories, drawing pictures and talking about your baby's situation as frequently as they want to. There are many excellent books for siblings. See the website resource list at the end of this pamphlet.

Hospital Bereavement Services

Each hospital is a little different, but most of them will have a bereavement specialist. Some are social workers; others are moms who have been through a similar experience. Chaplain services are available for a variety of religious denominations upon request as well. They will offer services to you ranging from providing little keepsakes to grief counseling and support groups. Know that you won't go home empty handed. If you are facing a fatal prognosis for your baby, but have time before your delivery, you may ask to meet with the bereavement specialist in advance to prepare yourself better for the experience. The hospital may offer some or all of the following: hand and foot molds of your infant, hand and foot prints, clippings of hair, hospital arm bands and crib tags, a little ring, or other special jewelry, an outfit and blanket if you don't have your own, and photographs.

Items to Bring With You

If you have time, it is nice to bring some things of your own to the hospital.

- Choose a special outfit with the ease of dressing your baby in mind. An outfit that opens completely in the back or the front is preferable instead of an over-the-head style. See the websites in the additional resources section for preemie and micro-preemie outfits, or visit our website for patterns and instructions to make your own. Bring two outfits if possible: one to dress your baby in the hospital, and take home with you as a keepsake; and another for burial.
- The same idea applies for blankets. Consider having two, one to snuggle your baby in at the hospital and bring home, and another to bury your baby in. Ask your mortician about size limits inside the casket before you choose an oversize, thick blanket for burial.
- You may wish to bring extra soft washcloths to bathe your baby with, and again, take home with you. Hospital linen is typically fairly rough.
- If you have started a baby book already, bring it along in case the nurses can do the footprints directly in the book for you.
- Camera and extra batteries. At the very least, pack a disposable camera. A video camera is also highly recommended.
- Any items you may need for religious rites.

- Keepsakes, such as a place to put hair clippings, special teddy bears, bracelets, hair bows, etc.
- A copy of your birth plan signed by your doctor.
- A list of phone numbers either for you and your partner to call people, or for hospital staff to notify important people for you. This may include whoever is watching your other children, close family, clergy, bereavement photographer, etc.
- A snug sports bra and nursing pads.

Photography

Pictures are so important. Even if you think you may not want to look at them for a long time, they will be important to you and your family at some point. They validate the existence of your baby. Especially for other children who were very young at the time of the birth, photos will reinforce your baby's role in your family. Some professional photographers offer compassionate infant photography at no cost (see the web resources at the end of the pamphlet). If you cannot find one in your area, consider asking a family member or friend to take pictures in order to allow you and your family to interact with your baby.

Take pictures at several angles to capture the profile and features of your baby's face and body. Pictures taken against a dark background will highlight physical features better. You may want to have a sweater that you can put on over your hospital gown to take more formal family pictures. Recommended poses include whole family, parents and baby, each individual family member and baby, bathing and dressing, and close-ups of hands, feet, face and any other distinctive features.

If professional photography services are unavailable in your area, there are organizations that will retouch a limited number of your own photographs at no charge.

Paperwork

If your baby is stillborn, the certificate at birth varies from state to state. Some offer a certificate of stillbirth, others simply a death certificate. If your baby takes even one breath, a birth certificate and death certificate will be issued, and you may choose to apply for a social security number. You do not

have to have a social security number for tax purposes, though you will have to mail your taxes in rather than electronically filing them in order to attach copies of the birth and death certificate. Some states will allow you to claim a stillborn baby as a tax exemption for that year, and all states as well as the federal government allow you to claim any baby that is alive at birth, even if just for a few moments.

You may receive a hospital bill for your baby, even if he or she only lives for a few minutes. Most insurance plans require that you add babies to your insurance plan within 30 days of birth. Verify your coverage within the required time frame to avoid any payment issues.

Funeral and Burial Options

You may be given a few options to care for your baby's body. One option offered for very early losses is for the hospital to dispose of the body. Procedures vary by hospital. If this is an unanticipated loss for you, and you have not had time to plan, this may appeal to you. However, most people are grateful to have a place to go visit their baby later, whether they choose to bury or cremate. Weigh your decision carefully. Many funeral homes offer their services very inexpensively to care for infants and children. Depending on the gestational age of your baby, size and condition, the funeral director may or may not be able to embalm. If embalming is not possible, your baby can still be preserved in a solution, but will be more fragile and less able to be handled prior to burial. If it is important to you, you may request to dress your baby for burial. Otherwise, the funeral director will handle this task for you.

Some cemeteries allow infants to be buried in the same plot as an adult, just at a shallower depth. Other cemeteries have whole sections dedicated to infants. The cost for plots and burial varies widely among cemeteries, so it is worth calling around. This is typically an emotionally painful task for most parents. You may wish to have another family member or close friend do this for you.

There is no right or wrong way to handle your baby's funeral. Do what feels comfortable to you. You may wish to do a little graveside service, or opt for a more traditional funeral. Recognize that funerals are a time for people to share with you. There are many great, thoughtful ways to involve siblings. See the websites listed in the additional resources section for ideas.

Feelings and Emotions

You will experience a wide range of emotions, sometimes more than one at the same time. Guilt, grief, denial, anger, sadness, depression, fear, frustration, acceptance, peace, happiness and joy are all possible. All of your feelings are valid. Your family and friends will also experience some or all of these feelings, but maybe not at the same time as you. Be patient with your partner and your other children as it can take everyone a different amount of time to process through his or her feelings, anywhere from weeks to years. You may find that you cycle through several emotions over and over. This is also normal. For some people, talking is the best therapy. Others prefer quiet time alone. Writing, whether a little or a lot, can help. Some can move on with life and continue to function in everyday roles, and for others this seems impossible. If you feel very sad, angry or depressed, or find that you are having trouble sleeping or eating, or feel you want to hurt yourself or others, talk to your doctor about whether medication may be needed temporarily.

Grief counseling services are also helpful for some, and may be obtained through your clergy or a licensed counselor. Ask your doctor for a referral to someone who specializes in grief issues. You may find it helpful to join a local support group to talk things through and connect with other people who have been through a similar situation. There are also many internet forums for families who have lost a baby (see the resources listed at the end of this pamphlet).

There are many nice ways you can commemorate the life of your baby. Examples are birthstone jewelry, trees or plants, charity races and fund raisers, scrapbooks, pictures, ornaments and other keepsake items (see website recommendations), and yearly memorials. Some people choose to give a gift or service to someone in need on the day of their baby's birth each year. Certain times of the year will be more difficult for you and your family, such as Mother's Day and Father's Day, birthdays, and Christmas in particular. Be especially sensitive during these times to your partner and other family members. Time will ease the pain; be patient.

Dealing With Your Postpartum Body

After birth, you will have the same bleeding and pain issues as with any other delivery. Also, depending on how far along in gestation you are at delivery, your milk will most likely come in on day three or four after delivery.

For many moms this is acutely painful, both physically and emotionally. There are no medications usually given to stop the milk from coming. The following will ease the discomfort: wear a snug sports bra soon after delivery, along with nursing pads in case you leak milk. Cold cabbage leaves or ice packs tucked inside of your bra will help with engorgement, and ibuprofen is appropriate to take for discomfort. Avoid heat or nipple stimulation of any kind as it stimulates more milk production. Sage tea may also help dry your supply up more quickly.

Remember to get adequate rest. Many people have difficulty sleeping for the first few weeks after losing a baby. Ask your doctor if a prescription sleep aid is appropriate for you and your partner for short term use.

Be kind to yourself. Gentle exercise, yoga and meditation are excellent ways to help you heal physically and emotionally. If you are returning to work, make sure you are fully healed before resuming your routine. Six weeks is a good guideline for any pregnancy. Ask your doctor about returning sooner if you feel that you are physically and emotionally ready. If you are staying home, you may find it helpful to take up a new hobby or enroll in a class to stay busy. Be careful not to become too isolated as it may foster depressive tendencies.

As with any pregnancy, it may take a few months for your menstrual cycles to resume in a normal pattern. If you are planning on getting pregnant again, ask your doctor about how long you should wait before trying. Opinions vary, but two to three months are usually the minimum to allow your body time to heal. Be sure that both you and your partner are emotionally ready before trying.

Family and Friends: Ways you can help

It can feel awkward and difficult to know how to react or what to say to a loved one that is in the midst of the loss of an infant. There really is no right thing you can say that can fix the pain, and each couple has different needs. Here are a few suggestions that you may find helpful.

- Acknowledge the loss. Don't let fear or awkwardness keep you from expressing your love and support. How you go about this will depend on how close you are. Something as simple as a card or an email is very welcome. A donation to charity in the baby's name is thoughtful. A hug and a simple "I'm sorry" or "I'm thinking about you" given with love and not pity are definitely appropriate.

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- Let the family be emotional and give them some allowances. Do not hide good news out of respect for their grief, like the fact a sister or friend may be expecting a baby, or someone may be getting married. The family needs to feel part of the social group. Also don't be surprised or overreact if one of the family members leaves the room during such a conversation or becomes very emotional over particular news. Emotions swing wildly when dealing with infant loss.
 - If you have a close relationship with the family, don't be afraid to ask specifically what they need. Grief is a funny thing. Sometimes a good laugh is just as therapeutic as a good cry. It's often difficult for a family in the midst of grief to even articulate what they need, so don't be afraid to just show up and help with cleaning, cooking and childcare.
 - Some statements that are said out of love and concern may turn out to be upsetting for the family. Avoid statements such as, "This is probably for the best" or "it's good that you already have other children" or "you can always adopt" or "you can always have another baby." Especially avoid saying anything that could make the couple feel like something they did caused the birth defect or demise.
 - Trite expressions of faith such as, "your baby's in a better place now," or "you'll be together again some day," or "at least you already have one child that made it to heaven," are generally more painful than comforting. If the parents have some type of religious belief, they are quite aware of it and don't need reminding. No matter where you believe their baby is, he or she is not with the parents, and that is heart wrenching. Simply express your love and sympathy to them rather than making statements such as those above.
 - If there are other children in the family, take them to go do something fun and distracting while the couple spends some quality time with each other. If you live far away, a special package in the mail will be an equally welcome distraction
 - Simply be there. Your presence at the hospital, if appropriate, and at the funeral speaks volumes about how much you care, even if you can't find the right words to express your feelings. A well chosen gift can be very meaningful. Consider artwork, jewelry, ornaments, books, plants, donations to charity and other items that last. Flowers are beautiful, but some families express sadness when the flowers shrivel and fade, that it's another reminder of death. A blooming potted plant that will continue to blossom year after year is a life-affirming alternative.

- Don't forget the dad. Men grieve differently from women, and are often left out of the limelight during these times. They need the opportunity to express their feelings in their own way as well.
- Check in with the family often over the first few months. The first year is full of painful milestones. Let them know that you haven't forgotten. Acknowledge each birthday as an angel day. This does not have to be elaborate, but a simple card, phone call or message that you remember how important this baby is to the family may be very meaningful. Be considerate of how the family deals with their loss. Make your acknowledgement appropriate and comfortable for the family.

Additional resources

These web pages were accurate as of June 2010. They are subject to change at the discretion of each page's owner.

www.angelbabiesinfo.com Our website with a digital version of this pamphlet as well as stories, bereavement gown patterns, and additional resources

www.nowilaymedowntosleep.org Professional photographers who donate their services to record the birth of babies who are stillborn or have a poor prenatal diagnosis. Many links to additional resource sites, including the family forum at *www.nowisleep.org*.

www.babycenter.com Free registration gives access to generalized pregnancy information, as well as bulletin boards for moms with dozens of different pregnancy issues, including support for carrying to term with a poor prenatal diagnosis or terminating for medical reasons.

www.benotafraid.net A site dedicated to sharing positive stories of families who have chosen to carry to term. Also has a long list of links to websites for specific birth conditions and defects.

www.acpepg.org American Child Photographers Charity Guild is also a group of professional photographers who donate their services for infant bereavement.

www.babyloss.com An online resource providing advice and support for pregnancy loss, stillbirth and neonatal death.

www.misschildren.org Extensive bereavement information, including ideas for funeral services and how to include other children in that process (under "Professionals" tab). Products available for sale, including memorial wrist bands, books appropriate for children and adults and several other remembrance items.

www.climb-support.org By and for parents who have experienced the death of one or more of their multiple babies (twins, triplets, etc.) from the point of conception through childhood.

www.angelsinheaven.org Angels in Heaven Ministries is a nonprofit, nondenominational, Christ-centered ministry dedicated to families who have lost a loved one, particularly a child.

www.october15th.com Official site of Pregnancy and Infant Loss Remembrance Day, October 15th of each year. Many links to other resources, as well as commemorative memorabilia for sale.

www.nationalshare.org/parents.html Online forums as well as links to local support groups that provide services at the time of delivery such as hand and foot molds and other keepsakes.

www.perinatalhospice.org Links to local hospice agencies that provide care for families prior to and after the birth of a baby with a poor prenatal diagnosis.

www.aquietrefuge.com Addresses the needs of families who have experienced the loss of an infant or unborn child, including offering a small photojournal album.

www.hygeia.org Support for pregnancy loss, miscarriage, stillbirth or neonatal death. Includes professional information and online parent support groups.

www.centering.org Provides literature on death, dying and coping with bereavement issues, including infant loss and death of children.

www.griefwatch.com Perinatal Loss Project. Support items and literature. Items for purchase including customizable announcements, certificates of life, ceramic keepsakes, urns and literature.

www.babylinq.com Premie and micropreemie clothing.

www.aplacetoremember.com Many products available to purchase for coping with grief – long list of books for a variety of situations and audiences, gown and cap sets for preemies according to gestational age, birth/death announcements, hand and foot impression sets, and other remembrance items such as jewelry and ornaments.

www.stringofpearlsonline.com Support services before and after birth. Keepsake kits and other information links.

www.castingkeepsakes.com - Supplies for purchase to create hand and foot mold keepsakes.

Sites for specific birth defects:

- www.anencephalie-info.org Anencephaly
www.cherubs-cdh.org Congenital diaphragmatic hernia
www.congenitalheartdefects.com Heart defects
www.acds.org Down Syndrome
www.sbaa.org Spina bifida
www.waisman.wisc.edu/~rowley/sb-kids Spina bifida
www.trisomy18support.org Trisomy 18
www.graceannenugent.netfirms.com Trisomy 18
www.trisomyonline.org All trisomies
www.livingwithtrisomy13.org Trisomy 13
www.potterssyndrome.org Potter's Syndrome/renal agenesis
www.healthline.com/galecontent/triploidy - Triploidy
www.ghr.nlm.nih.gov/condition=thanatophoricdysplasia –
Thanatophoric Dysplasia

To stop the majority of mailings of baby supplies to
your home, contact the following:

Direct Marketing Association
Mail Reference Service
P.O. Box 9008
Farmingdale, NY 11735

To stop phone solicitations:

Direct Marketing Association
Phone Reference Service
P.O. Box 9014
Farmingdale, NY 11735

Written by Heidi Vawdrey RN, BSN, CCRN in memory of Elizabeth Jane Vawdrey. Edited by many other caring Mommies and Daddies of Angels. For more information or additional copies, please email hvawdrey@gmail.com.