



# How Can I Help?

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**Suggestions for health professionals, from moms who have traveled the road of pregnancy loss or infant death**



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Pregnancy is a unique time when a woman's life is so intertwined with people in the medical profession. From prenatal visits to lab tests to ultrasounds to labor and delivery, she is pricked and poked and prodded and makes small talk and serious talk with a plethora of people who used to be strangers, but now know her on the most intimate level – all with the expectation that this year-long relationship will end with a healthy baby to take home.

When that doesn't happen, it catches everyone off guard. Babies aren't supposed to die, not in the 21<sup>st</sup> century, not when modern medicine has advanced so far.

They aren't supposed to die. But they do. The accepted statistic today is that at least one in four pregnancies ends in loss. The reality of that is hard to accept – impossible for the parents, but also hard for the health professional whose job is to help heal, but who now must deliver the blow to the parents without being able to do a thing to change it.

But as awful and as difficult a task as this is, health professionals also have the amazing responsibility – and the awesome privilege – of being one of the first to guide

bereaved parents on the path of loss. Many others will take over from you in the days to come, but your actions and words can set the tone for the future and can make a painful, impossible loss more survivable and less traumatic than it otherwise could be.

This booklet has been compiled by a cross-section of bereaved mothers in the hopes that their suggestions and experiences can help you, the health professional, usher other parents onto this path with gentleness and compassion.

May God bless your efforts to bring healing and wholeness into this world.

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"I had such compassionate nurses during the D&C. They all started out by saying how sorry they were for our loss. They made sure I wasn't in any physical pain which interferes with how I feel emotionally. They made a huge impact on my emotional recovery."  
Margaret

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## Words

Doctors and nurses use a lot of words, many of them so specialized they seem like a new language. When a woman is experiencing a pregnancy loss, the choice of words can make a world of difference in whether or not she remains open to hear the rest of the conversation, or she shuts down emotionally to protect herself from further pain. Below is a brief list of what helps and what doesn't.

### Words that hurt

- *Abortion*, whether “spontaneous” or “failed” or “missed” or any other descriptor. Yes, this is the medical term for a miscarriage, but many bereaved mothers have been hurt by the careless use of it.
- Other medical terms that, for some parents, may fail to recognize the humanity of the baby who has died: *products of conception*, *fetal demise*, *fetus*, *embryo*, *tissue*, *dispose of*.
- Anything that says this was for the best, or that this is nature's way of dealing with anomalies, or that the baby or they are better off because it would not have lived long, or that “at least” they have other living children that they should be thankful for, or **anything** that minimizes their loss.
- Saying that a woman can have another baby, she's young, etc. First, you simply don't know if she can, and second, that is not what she is worried about right now, usually. She wants *this* baby, *this* child.
- Anything suggesting that she should not cry or feel a certain way.

### Words that heal

- Referring to the baby as a baby, a child, or a son or daughter. Better yet, refer to the baby by name, if the parents have chosen one.
- Asking about the baby's name if you don't know it.
- Sharing your own story of babyloss, if you have one.
- “I am so sorry for your loss.” This works almost every time.

## Specific moments

There are several specific events in the process of pregnancy loss or infant death. Allow us to share what is helpful and what isn't during each of these instances.

### When telling parents about a loss.

Usually, parents hear the bad news from you first – a doctor, a nurse, an ultrasound technician. Sometimes they know from the way you get quiet, or the way your face tightens, or how you suddenly tense up with concentration. When you talk with them about it, keep these things in mind.

- *"I am so sorry."* Again, this one phrase goes a long way.
- *Don't be afraid to show sympathy and emotion, even tears.* At the same time, be sensitive to the parents' need to receive comfort.
- *Don't talk about other light-hearted topics while doing an ultrasound or exam.* It may be "routine" to you, but it's life-changing for them.
- *Don't rush parents to make a decision.* Too often, they are presented with the news that their baby has died, and on the heels of that they have to make decisions about whether to wait to miscarry, or about going to the hospital and when, or a myriad of other choices that they aren't ready to make yet. Unless there is a medical reason to hurry (such as an ectopic pregnancy), give them a little time to grieve and to get past the initial shock.
- *Give parents privacy.* Provide a room where you can talk with the parents in private about what is happening.
- *Help a mother leave your office quickly and privately* after getting bad news, letting her deal with paperwork and payment later.
- *Don't assume a very early loss is less painful emotionally.* If your patient has an early loss, sometimes called a "chemical pregnancy", these can help:

- *Acknowledge the loss.* Don't suggest that it wasn't really a baby yet, or that she wasn't really pregnant.
- *Don't insist that she grieve a certain way.* Some women are not as affected by an early loss, and that is okay, too.
- *Take your cues from your patient* in talking about future pregnancies. Some women want to try again right away, and others don't want to think about it yet.

## Companionship with parents during a loss

This is an extremely stressful, painful time for parents, and the kindness and compassion of health care professionals can make all the difference in the world. Nothing will make this experience “good”, but you can make it “better”.

- *Offer privacy.* If a mother must wait for services, try not to leave her in a public waiting room in the emergency room or in a room with a lot of pregnant women or crying babies
- *Touch is important.* We know you have to be professional, but a simple touch on a shoulder, a hand, a hug, or at least genuine eye contact – all of these communicate compassion and caring to a hurting parent. Don't be afraid to close the gap and give the gift of touch.
- *Pray with them.* If you are a person of faith, and you know that your patient is, too, don't be afraid to offer to pray before a medical procedure. Such a gesture has touched many parents deeply.
- *Make the final good-bye as peaceful as possible.* Don't ask a parent to just leave their baby alone in a room. Make the final transfer as personal and gentle as you can (see the story immediately above.)

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“So Joe and I said our good-byes and laid him wrapped up in his blanket by his stuffed bear and sat across the room. The nurse came in and oh so gently picked his remains up, cradled him like one would a full-size alive sleeping baby and looked down at him. She didn't avert her eyes or handle his remains harshly....the last image I have of my son is this nurse seeming to care so deeply for him. And I can't tell you how thankful I am that that's my last memory.”  
 Courtney

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- *Be aware of, and let them know about, their rights as parents.* Share Pregnancy and Infant Loss Support has an excellent list on their website (<http://www.nationalshare.org/rights.html>) – things like the right to hold, touch and be with their baby as much as possible, to name their child, to observe cultural and religious practices. Many of these are things parents may not think of on their own.

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“Even when (I’m sure) the evident shock that froze me (and my decision making abilities) was crystal clear to her, she educated me and offered recommendations or let me know something would need to be decided but give me time. When I said I didn’t want pictures....she simply said, “Ok.” a little later, she asked again and mentioned that it may be hard to see it now, but that it was a way of creating memories....she coaxed and encouraged me at the right intervals.”

Dawn

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- *Offer to contact people who can help,* such as clergy or a hospital chaplain, a bereavement photography service such as Now I Lay Me Down to Sleep, and a loss doula or perinatal hospice on behalf of the parents. There are several organizations whose mission is to walk through a loss with parents. *Getting a parent’s permission to have pictures taken is one thing worth pushing a little bit.* Parents may refuse at first, but this is the only opportunity to take them, and they will look the best taken immediately after birth. If parents are concerned about a baby’s appearance, remind them that pictures can be edited later.
- *If nurses are taking pictures instead of a professional agency,* train them to take the best pictures possible – not sterile looking (e.g., not in a bowl or on a tray, but cleaned up and lying on a blanket), and both clothed and unclothed. Request a selection of cloth diapers from Teeny Tears ([www.teenytears.blogspot.com](http://www.teenytears.blogspot.com)) if you need something on hand to give babies dignity. Use the macro setting on the camera to avoid blurry pictures.
- *Provide sensitive memorial items.* Many hospitals have these kinds of procedures in place; if yours doesn’t, you can suggest them. Memorial items for a late loss may include footprints, hand prints, measurements, a blanket that the baby was wrapped in, pictures,

and a memorial certificate of birth (even if a birth certificate is not possible due to state law). Find out if your state has a certificate of stillbirth available and how parents can get one. Some hospitals even provide small burial boxes for babies who are born before the time when they are required to be handled by a funeral home.

- *Don't ask more questions than is absolutely necessary*, and don't have grieving parents tell their story over and over again. Make sure hospital personnel are communicating with each other to prevent embarrassing questions.
- *Be mindful of the environment a grieving mother is in*. Avoid talking lightheartedly or about children or babies within earshot, and try not to put a grieving mother on the maternity floor of a hospital or, especially, in a shared room with someone who is pregnant. Consider putting some kind of symbol on the door of a hospital room to let people know about her loss, or post a note sending visitors and hospital workers to the nurse's station for information before entering her room.
- *Don't leave a mother alone* when getting ready to leave the hospital, if her husband has gone to get the car. Stay with her.

### When you see a parent after a loss

Follow-up visits generally catch the bereaved parents at a point that is past the initial shock, but nowhere near a point of "healing". Here are some things that may help.

- *Give parents information* about local support groups or at least helpful websites with that information. You can start with Naomi's Circle ([www.naomiscircle.org](http://www.naomiscircle.org)).
- *Notes of sympathy* sent to a patient's home are a wonderful way to show that you care.
- *Be sensitive when scheduling follow-up appointments* – preferably not at the same time that a lot of women will be coming in for pregnancy check-ups.

- *See parents in a different room*, if possible, than the one where they got the bad news that their baby died.
- *Express concern for a woman's emotional health*, not just her physical health. Discuss the possibility of grief counseling with her and the baby's father (loss can be very difficult on a relationship).
- **Flag a woman's medical file** to alert anyone handling it that she has had a loss so they don't say something insensitive by accident.
- *Show patience and sympathy*. Your patient's son or daughter has **died**. No one "gets over" that, and you are seeing them during their most raw and painful days, in a place with painful memories.

## Negative prenatal diagnosis

A negative prenatal diagnosis can vary greatly, to include: fetal anomalies that are incompatible with life; birth defects that may require surgery or other life-saving procedures at birth; *in utero* situations (such as Twin To Twin Transfusion Syndrome) that will require careful monitoring throughout the pregnancy; and genetic abnormalities such as Down Syndrome that will present challenges in life, but are not life-threatening in themselves. Whatever the case, it is unique in that a parent begins grieving (if not the eventual death of their child, then at least the "normal" pregnancy they had hoped for), while their baby is still alive. Here are some other things to keep in mind:

- *Give parents time to take in the news*. This is a shock to them, and their whole world just changed. Use layman's terms as much as possible.
- *Give parents all the information you can*, including:
  - information about the diagnosis that they can read later
  - information about support groups for parents who receive this diagnosis
  - a perinatal hospice organization such as *A Gift of Time* ([perinatalhospice.org](http://perinatalhospice.org))

- information about counselors who can work with them

Sometimes, when parents are told about a negative prenatal diagnosis, this news is quickly followed with the quiet suggestion that they can choose to terminate the pregnancy – a devastating decision for parents to consider when, five minutes before, they were thinking about nurseries and strollers. ***Whatever your personal stance on abortion is, please consider the following before opening up this line of conversation:***

- One of the primary deciding factors for parents who choose to continue a pregnancy after a negative prenatal diagnosis is the presence of a perinatal hospice program, or similar support. If your hospital does not have one, please contact A Gift of Time ([perinatalhospice.org](http://perinatalhospice.org)) for information.
- Do not assume that termination is the best, or even a good, option. Do not overestimate the benefits of terminating or underestimate the negative effects of medical termination on parents, compared with continuing a pregnancy to term or until the natural death of a baby in pregnancy. In fact, women who terminate a wanted pregnancy for medical reasons are almost always at high risk for developing psychological trauma after the termination. Two research-based articles about this topic can be found at: <http://afterabortion.org/1999/women-at-risk-of-post-abortion-trauma/> and <http://pjsaunders.blogspot.com/2013/10/psychological-trauma-after-abortion-for.html>.
- Please note that one of the factors contributing to psychological trauma ***after*** such a decision is the parents' stance on abortion ***before*** being told of their baby's diagnosis. If they identify themselves as being “pro-life”, you may help them more by showing them how to walk through their situation and avoid termination than you will by persuading them to consider it, contrary to their value system, at a time when they are emotionally vulnerable. ***Please do not push for termination*** if the parents make it clear that it is not an option for them.

- Do not assume that a child with a negative diagnosis cannot experience love, cannot be a blessing to others, or cannot have purpose even in his or her brief life. There are some amazing stories to the contrary.
- Encourage parents not to rush into a decision. This is a life-changing choice that cannot be undone, and it is difficult to make a good decision under pressure, especially when going through emotional trauma. They need time to talk with others who are in their support network, to speak with others such as perinatal hospice, and to think and pray and begin processing what is going on.

## Loss of a multiple

The live birth of one baby, along with the loss of another, presents a complicated emotional situation for parents and health care workers. It is easy to focus on the living baby, and ignore the fact that the parents have lost one (or more) of their children. If you find yourself in this situation, here are some specific things you can do for the parents:

- *Give them time* with the child who did not survive, both to say “Hello,” and to say, “Goodbye.”
- *Don’t minimize their loss* by reminding them that “at least” they have one (or more) living children.
- *Recognize what they have lost* – a child, a twin sibling for their surviving child, and even the specialness of raising multiples.
- *Provide them with resources* such as the Center for Loss in Multiple Birth, Inc. (<http://www.climb-support.org/>) and Twinless Twins Support Group (<http://www.twinlessstwins.org/>). An excellent book to give to parents to keep for when their surviving child is older is *Always my Twin*, by Valerie Samuels.

## Don't forget the dad

Most care during and after a loss is focused on the mother’s emotional and physical well-being, but it is important not to forget the father in the midst of your concern for your patient. Some simple suggestions:

- *Ask how he's doing.* Don't just treat him as the caregiver for the mother. It was his child, too, and he is hurting as well.
- *Speak to them as a couple.* Talk with them about how men and women grieve differently and that loss can be difficult for couples.
- *Give him information* that is specifically for men. Two excellent resources are the website is [www.copingtogether.info](http://www.copingtogether.info) and the book *A Guide For Fathers* by Tim Nelson.

## Providing information

It's easy to overwhelm a bereaved parent with too much information, but they will need at a minimum this kind of information in the days to come.

- What to expect emotionally and physically (including information about postpartum depression)
- Local support groups for pregnancy loss and infant death
- Local funeral homes and cemeteries

## Helpful resources for medical care providers

### Books/DVDs:

*Companioning at a Time of Perinatal Loss: A guide for nurses, physicians, social workers, chaplains and other bedside caregivers*, by Jane Heustis and Marcia Meyer Jenkins

*Hannah's Hope*, by Jenni Saake

*The One Year Book of Hope*, by Nancy Guthrie

"I hardly knew you...What happens next?" DVD with segments for both medical caregivers and for parents, offered through Babies Remembered (Wintergreen Press) – [www.wintergreenpress.org/shop](http://www.wintergreenpress.org/shop)

## Recommended websites:

Babies Remembered ([www.babiesremembered.org](http://www.babiesremembered.org)) –support/tesources for parents and caregivers; begun by Sherokee Ilse, a pioneer in the area of infant loss.

A Gift of Time ([www.perinatalhospice.org](http://www.perinatalhospice.org)) – provides support for parents whose unborn child has received a negative prenatal diagnosis. An excellent article in the Canadian Medical Association Journal about their services can be found here: <http://www.cmaj.ca/content/183/5/E267>

Naomi’s Circle ([www.naomiscircle.org](http://www.naomiscircle.org)) – our website provides an up-to-date list of all support groups in the greater Columbia, SC, area. We also have a very comprehensive list of websites, books, and other resources.

Now I Lay Me Down to Sleep – [www.nowilaymedowntosleep.org](http://www.nowilaymedowntosleep.org) – free professional bereavement photography services.

Share Pregnancy and Infant Loss Support – [www.nationalshare.org](http://www.nationalshare.org)

## About the Author

Kristi Bothur is the mother of five – two on Earth and three in Heaven – and the wife of one, her husband Eric. Their daughter was just over a year old when they lost their second child, Naomi Faith, at 18 weeks gestation, from a maternal abdominal infection. Their second loss, at eight weeks, came eight months later, followed by an early loss six months after that. Their son was conceived a year later, and was born living and healthy after a complication-free, but still anxious, nine months. Today, Kristi is a pastor’s wife, a homeschooling mother to their two living children, and the founder of Naomi’s Circle, a ministry to parents who have experienced the loss of a baby during pregnancy or early infancy. While they focus on providing information about resources and support groups for the Columbia, South Carolina, area, most of the information on their website is applicable regardless of location. See their website ([www.naomiscircle.org](http://www.naomiscircle.org)) for more information, or contact her at [naomiscircle@gmail.com](mailto:naomiscircle@gmail.com).