Are you called upon to work with challenging topics on a short-term basis? Do you ever feel lost or confused about what you can actually accomplish in your interactions with families in crisis?

This guide is for you — a realistic overview of how you can help and how to define your role.

Includes a special section with ideas for doulas and other birth professionals.

Other helpful guides by this author:

Talking to a Battered Woman:
A Guide for the Short-Term Helper

A Quick Guide to Successful Volunteering:
Notes from the Field
Other Guides by this Author:

A Quick Guide to Successful Volunteering: Notes from the Field

Talking to a Battered Woman: A Guide for the Short-Term Helper
Dedicated to all the families to whose stories I have had the privilege to listen.

And to my husband--a constant source of love and support.

Special thanks to Barbara Johnson for her editing assistance.
Author's Note & Disclaimer

This book is intended for use as a general guideline for interacting with families of critically or terminally ill children. It is not a substitute for formal training, experience, or education. Working with people whose children are dying is a complex and challenging task and should not be undertaken lightly or without seeking appropriate training and resources. The author has made every attempt to ensure the accuracy and appropriate nature of the material contained herein. The author and the publisher assume no responsibility for how the material is interpreted or applied by the reader.

I would like to order additional copies of Talking to Someone Whose Child is Dying:

____ copies requested at $4.00 each (orders over 100 pieces, $3.00 each).

Shipping & Handling at $1 each booklet (bulk shipping available for orders over 20, contact Stonehaven Place LLC for rates).

My check or money order for $____ is enclosed.

Payment must accompany orders. Allow 3 weeks for delivery.

Name

Organization

Address

City/State/Zip

Phone E-mail

Make check payable and return to:

Stonehaven Place LLC
RR1 Box 301R
Rolla, MO 65401

www.stonehavenllc.com
Author Biography

Molly Remer graduated with a master’s degree in social work from the University of Missouri-Columbia in 2000. She also earned a bachelor’s degree in psychology from the University of Missouri-Rolla. The bulk of her professional experience has been in short-term crisis oriented settings. Presently, she works as an author, childbirth educator, community volunteer, and mother. In the past, she has served as a professional volunteer in an agency serving families of critically ill children, a full-time unpaid coordinator of volunteers at a shelter for battered women, and as a crisis-line volunteer in a shelter for battered women. She lives with her husband and sons in central Missouri.

Table of Contents

Using the Guide ........................................6

Developing Rapport .................................8

Active Listening Skills & Empathy ..........9

Boundaries .............................................11

Interaction Tips—Do, Don’t .................12

Sharing Pain .........................................16

Self-Care .............................................18

When a Baby Dies ..............................19

Resources ..........................................23
Using the Guide

This guide is intended to serve as an aid for people working with families of terminally or critically ill children on a short-term basis. These may include: volunteers in residential or hospital settings, hospital or crisis workers, childbirth professionals, and informal helpers such as friends. This guide will be particularly useful to helpers interacting with families on a one-time, crisis oriented, relatively informal encounter and to those with an ongoing, though still short-term, episodic helping relationship. Individuals who will have a long term or counseling relationship with the grieving family will still find these tips helpful, but should seek complete and in-depth strategies for helping over the long term.

This guide is intended for use in training sessions and for ongoing use as a quick reference. It can be viewed as a small primer or crash course in interaction skills. Suggestions for further resources are offered at the close of the booklet.

Brief definition of some key concepts:

- Short term helping relationship—occurs over a period of hours, days or weeks. This is usually a one-time, crisis oriented encounter that occurs on an informal, as-needed basis (with no appointment). Volunteers, crisis workers, hospital workers, and friends often fall into this category.

Resources

Books:

- Crisis Intervention, by Donna Aguilera, 1998 Mosby-Year Book
- Field Manual for Mental Health and Human Service Workers in Major Disasters, by Deborah DeWolfe. Available without charge from the Center for Mental Health Services, P.O. Box 42490, Washington, D.C. 20015 or: www.mentalhealth.org
- Help, Comfort, & Hope after Losing Your Baby in Pregnancy or the First Year, by Hannah Lothrop, 1997 Fisher Books

Websites:

- M.I.S.S. Foundation: http://www.missfoundation.org
- The Compassionate Friends (loss of a child at any age): http://www.compassionatefriends.org
A Note Regarding Gender Differences in Grieving

Women and men will express grief over the death of a child in different ways. Frequently, the baby’s father will show less outward grief and may seem less affected by the baby’s death. It may be helpful to explain to the mother that just because the father doesn’t seem as upset as she feels, he is still grieving and does still care about the baby.

However, depending on the stage of pregnancy in which the loss occurred, the father may indeed feel less grief over the death than that felt by the mother. Fathers often note that the baby does not feel as real to them as it does to the mother. If the couple is struggling over these differences, it may be helpful to bring them into the open and share that each individual’s method of grieving is different and that there is no “right” way to grieve.

Encourage the couple to talk about the baby and about their experiences of grief, but also be mindful that “talking it out” is not necessarily the right method of coping for everyone.

- Long term helping relationship—occurs over a period of months, frequently on a formal or weekly appointment basis. Counselors, therapists and close family members or friends fall into this category.

- Empowering—reminding people that they are in control of their own lives and helping them develop skills and resources for making decisions for themselves and the direction of their life paths (helping people help themselves).

- Enabling—taking control of someone else’s life and making decisions for them (helping too much).
Developing Rapport

Begin by offering caring eye contact and a calm presence. Then, add listening with your heart. Rapport refers to the pattern of communication that develops after demonstrating feelings of interest, understanding, and genuine concern for another. Conveying respect, caring, and being non-judgmental are necessary ingredients for building rapport.

- Encourage the parents to make birth art and to journal.
- Some people like to plant a tree in memory of their child, but it can be very traumatic if the tree doesn’t survive (as many planted items don’t). You may wish to mention this possibility in a supportive manner, if such a memorial is planned.
- Suggest using a special box for the ashes (if the baby is cremated).
- Make sure to acknowledge that the parents are still a mother and father. They are parents whose child has died. Do not forget the doula’s role of “mothering the mother” and make sure the parents do not feel abandoned just because they do not have a live baby to show for the pregnancy and birth experience.
- Depending on your personal boundaries, you may wish to send a card or note on the anniversary of the baby’s birth (or death).
- Make sure the parents know of professional resources around them and that you are involved only as their doula (or other role), not as a professionally educated therapist or counselor.
- If your personal boundaries tell you that the parents are becoming overly dependent on your emotional support or suggestions, strongly encourage them to seek the services of a professional.
- Again, remembering to affirm the fact that the baby lived and that it had a life is of utmost importance. The baby was real, its death was real, their feelings and grief are real and very valid.
- Remember to use the other suggestions and resources contained in the rest this booklet.

one yourself as well). Also encourage the father to record his memories of the birth.
Encourage spending time alone with the baby after it is born.

Encourage the taking of photos—of the baby alone and with the parents.

Encourage naming of the baby and refer to the baby by name when talking to the parents.

If the baby died several days prior to birth, be prepared and inform the parents that it may not look unblemished (skin may be peeling, etc.).

Use honest language: “I’m sorry that your baby died.” “I cannot take away your pain or imagine the depth of how you feel, but I am here to listen if you need me.” Don’t sugar coat or mince around sad words.

Provide emotional support while funeral arrangements are being made. “Doula” the parents through this phase of their child’s life as well.

Still make a postpartum visit.

If the baby was premature, make sure to make contact with the parents on the due date.

Parents struggle a great deal with feeling like people will forget their baby or like it will be as if he or she never lived. Encourage memory recording and anything else that reinforces the baby’s life.

Encourage the recording of all memories of the baby—what s/he was like prenatally, what the pregnancy was like, etc.

Suggest the creation of a memory box or book and make a written or symbolic contribution to it yourself.

Do not be afraid to talk about the baby, call it by its name, acknowledge its life, and that it was a being with a presence in the world.

Encourage the mother to write her birth story (and perhaps write

Active Listening Skills & Empathy

Active listening skills involve integrating your genuine caring concern with your ability to listen to the story being shared, both verbally and non-verbally (through body language).

Empathy involves compassion for others—listening to people, understanding their concerns, and communicating that understanding to them. Empathy involves understanding that people feel, noticing what those feelings are, expressing what you perceive, and communicating that these feelings are okay and are caringly understood by you. (This is not the same as “knowing exactly” how someone is feeling and telling them so.)

The following techniques can be employed while speaking with a family whose child is dying, in order to communicate your interest and concern about their experience:

- Allow silence. Simply being with the family members in their difficult time can be extremely helpful.

- Attend non-verbally—making eye contact, nodding your head, expressing caring facial expressions, and saying “mm hmm” appropriately.

- Paraphrase what you’ve been hearing. This communicates understanding, interest, and empathy and lets the family know that they’ve been heard. Suggestions include saying: “So, you are saying that…” or “What I’ve heard you say is…”

- Empathy involves compassion for others—listening to people, understanding their concerns, and communicating that understanding to them. Empathy involves understanding that people feel, noticing what those feelings are, expressing what you perceive, and communicating that these feelings are okay and are caringly understood by you. (This is not the same as “knowing exactly” how someone is feeling and telling them so.)
Reflect feelings back to the family members by paying attention to their tone of voice and non-verbal gestures that communicate their feelings. Respond by saying something like “you sound scared, sad, etc.” or “sounds like that was a really sad experience for you.” Always ask about their feelings instead of assuming that you know how they feel.

Allow and be comfortable with expression of strong emotions. Create a safe space for the family where it is okay to cry or be mad. Let them know that it is okay to feel.

When a Baby Dies
Before, or Shortly After, Birth
Ideas for birth professionals, doulas, & friends
Self-Care

Helping people who are dealing with an intensely stressful situation can be a very emotionally challenging task. Take time out for yourself if you need it. Make sure to ask for help from your own friends, family members, colleagues, or a professional if you feel stressed out or overwhelmed. It may be helpful to remember the following things (these can also be suggested to the family members in crisis):

- Eat, drink, & sleep as normally as you can.
- Do not turn to using alcohol or substances for self-soothing.
- Breathe deeply.
- Try to relax your body through yoga or gentle stretching.
- Use journaling to explore your feelings.

Boundaries

Though it is important to connect on an empathetic level with people you are trying to help, it is also important to maintain your boundaries. Boundaries can be thought of as the lines that separate you from the family members. Remember that their problems are not your problems and do not take them on as your own. Instead, try to help the family members find their own solutions or resolution. When faced with a grieving family’s intense emotions and experiences, it can be tempting to rush in and “save them” by helping in every possible way. This is not in the best interest of the family or you. It is best to provide an empathetic listening ear and to empower the family to take care of their own situation. This will help them feel more capable, competent, and better able to cope with the challenge. Remember to pay attention to the difference between helping someone and doing for them.

It is also important to pay attention to your personal competence boundary. This is the boundary between your level of experience, confidence, skills, and general comfort level and the situation you are encountering. If you feel that a family’s needs are beyond your level, then refer them to someone who is better suited to meeting their needs.
Some Interaction Tips

The following are some suggestions for interacting with families who have critically or terminally ill children:

**Do**

- Be willing to listen.
- Listen openly, actively, and responsively.
- Listen without judging.
- Be satisfied to simply “be there” for the family.
- Follow the family members’ cues. Use a lead-in question or comment and then proceed based on the person’s response (talkative vs. not). Pay special attention to non-verbal communications.
- Remember to avoid meaningless small talk.
- Be comfortable with silence. Remember, you are not there to make conversation, you are there to provide what the family members need. They may need something to drink, a listening ear, a counseling referral, or a shoulder to cry on.
- Look at pictures of the child if they are offered.
- Always offer a resource if you cannot provide what the family members need or answer their questions.

A Note for Professionally Trained Helpers

Social workers and counselors are warned repeatedly during their education not to “take clients home” with them. Despite this, it is both possible and valuable to carry people’s stories with you without needing to carry a corresponding wound on your own psyche. This is accomplished by accepting the pain of others and then releasing the pain without forgetting the accompanying stories.

The recognition and acceptance of your own vulnerability, your own feelings, and your response to the pain of others, will help you cope with the experience. Some people also find peer consultation, journaling, meditation, exercise, music, crying, self-nurturing activities, or counseling helpful. Ultimately, the capacity to accept and release the pain of others is something you must discover on your own.
Sharing Pain

As you listen to the stories of grieving people it is important to develop the capacity to absorb some of their pain. This is accomplished through using your active listening skills and your capacity for empathy. Remaining open to the emotional pain of others and really listening to what they are saying, allows people the often unique experience of being able to heap their hurt upon you and have it be received without judgment, or without your expecting anything in return. This is a rare experience for many people and it can be a powerful tool to help them cope with their experience, even if only for a moment. Most people shy away from pain and by opening yourself to the painful experiences of another you form an immensely meaningful connection (even if for a short time).

In listening to people’s stories and absorbing part of their pain, it is important to remember to be receptive to their pain, to take it in, to connect with the person, and then to breathe it out and let it go. You do not make their pain your pain; you just alleviate their burden for a time.

Trying to avoid taking in the full emotional impact of painful stories quickly leads to a lack of empathy, connection, and understanding. The secret is developing the ability to let the pain of others in and then let it go again.

It is important to acknowledge that hearing painful stories will

- Remember your personal competence level and refer the family elsewhere if you feel in over your head.
- Do say:
  - I’m sorry this happened to your child.
  - Your reactions are normal.
  - Your reactions/feelings are okay.
  - It is understandable that you feel this way.
  - It is okay to talk to me about it; I’m here for that purpose.
  - You are not going crazy.
  - It wasn’t your fault; you did the best you could.
  - Encourage memory sharing—likes, dislikes, child’s personality, favorite stories/memories, etc. (use questions like: “What would you like to tell me about your child?”).

Of special importance for formal helpers (people who are not friends or family members):

- Remember boundaries! Operate within the parameter of the agency with which you are involved.
  
  **Don’t**

  - Tell the family how or what they “should” be doing, feeling, believing, or thinking.
  - Take control from the family by trying to make decisions for them.
  - Deny, discourage, or ignore expressions of grief, anger, or other feelings.
Control the family’s time. Be responsive to cues that they may not want to talk to you.

Encourage the family to take on your personal values, attitudes, beliefs, or feelings.

Make small talk to avoid silence.

Take on a larger or more involved role than you feel comfortable with.

Focus on your own past experiences with loss or grief.

Avoid laughter. There is enjoyment in the memories the family shares and it can be very healing to share a laugh together.

Don’t say:

- It could be worse.
- You can always have another baby; or, At least you have other children.
- It is God’s will.
- It is best if you just keep busy.
- I know just how you feel; or, I understand how you feel (saying “your feelings are understandable,” is okay).
- You need to get on with your life.
- You’ll get over it.

Of special importance for formal helpers (people who are not friends or family members):

Avoid over-engaging and enabling (i.e. offering to talk to doctors for the family, calling other family members, giving personal money or gifts).

A Note About Empathy and the “Don’t” List:

As noted previously, forming empathetic connections with people involves communicating understanding of their feelings. This may seem in conflict with the advice not to tell someone that you, “know just how you feel.” The explanation for this is that, while you can understand how people might feel, you are not the one experiencing the emotion at the time. Since each person’s experience of grief and loss is different, it is impossible for you to fully understand another person’s distinctive, subjective feelings. Telling someone you “understand” frequently rings hollow and causes a shut-off in communication, as the person you are talking to has a unique experience and does not feel like you have truly “been there.” Using empathy involves the capacity to understand how someone is feeling and how it might be possible to feel that way, not saying that you feel or have felt the same way.