

Parent to Parent Support:

A resource manual designed to support families in the NICU



*"I could not have gone through it without her support.
She helped me so much."*

Peer Support Parent Responsibilities

Adapted from the Parent Care Inc. Training Manual, 1993 (out of print)

a A Peer Support Parent Is:

1. Someone who uses their own experiences and personal qualities, enhanced by training to listen empathetically, support and assist with problem solving. They are specially trained to use their experience to inspire hope, comfort and help to navigate the NICU environment
 - Can empathize, not just sympathize
2. A Listening Ear
 - Listens carefully (“active listening”)
 - Validates what parent is saying
3. A Crying Shoulder
 - Allows parents to express honest emotions
 - Isn't afraid to express her own sadness or grief
4. Someone that is able to provide helpful information around community resources
5. Someone who will guide a parent in learning how to make decisions
 - Support a parent with problem solving and decision making
 - Support parent must learn to recognize when to refer parent to health care professional
6. Someone who will be responsible for keeping records for each referral parent
 - Touch base with coordinator to provide regular updates about parent to parent relationship and seek additional support when needed
7. Someone who will be responsible for maintaining confidentiality
 - Never share any information you receive about your parent buddy or the person you are supporting with anybody else other than the program coordinators
8. Someone who has concerns about child abuse, domestic violence or potential suicide must report it immediately to a Program Coordinator

A Peer Support Parent is:

Parent who has experienced a crisis involving her child and who can provide:

- Listening ear
- Crying shoulder
- Resources
- Guidance

*Joan Sturkie and Valerie Gibson
The Peer Counselor Pocket Book*

b A Peer Support Parent is NOT:

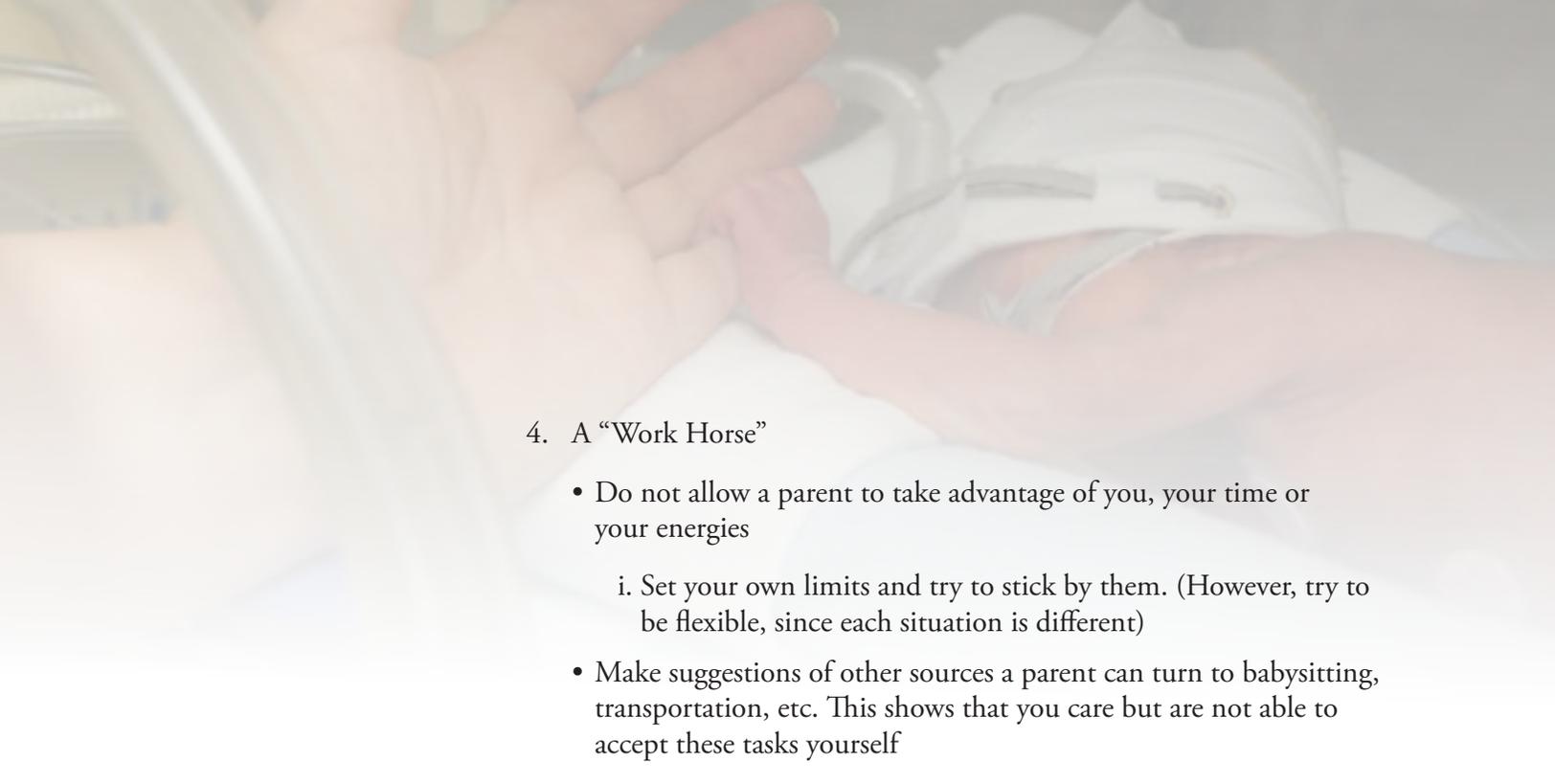
1. A Medical expert
 - NO MEDICAL INFORMATION SHOULD BE OFFERED
2. A psychologist
 - Stay out of parent's personal life if at all possible
 - Help parent to decide priorities for herself
3. A "Cure-all"
 - Even though you will want to, restrain yourself from saying "Everything will be all right." A parent will want to hear this and may try to force you to say it. Instead, help the parent to face reality in a positive way
 - Make suggestions, give other resources and encourage them to make their own phone call
 - i. Encourage discussion/conversation whenever possible so parent can make choices

This also demonstrates that there is no single "fix" and gives parent a more flexible, open-minded perspective

- You may have to repeat suggestions. The bottom line, however, is that you can lead a parent to the phone, but you can't make her dial. If she chooses not to follow your suggestions, let them drop. After all, you could be wrong about what is "right" for her, or at least in the timing

"Counselors are overdoing when they find they cannot leave their crisis work behind; they cannot let the person go on to the next stage of recovery; they find their own personal lives shrinking, with less time for creation, they have difficulty concentrating on other tasks; they feel anxiety developing over unresolved conflicts of their own; they feel themselves suffering from "contagious exhaustion," a reaction to too much exposure to the emotional reactions of people in life crises."

*Eugene Kennedy
Crisis Counseling*



**A Peer Support Parent
is NOT:**

- A Medical expert
- A psychologist
- A “Cure-all”
- A “Work Horse”

*Joan Sturkie and Valerie Gibson
The Peer Counselor Pocket Book*

4. A “Work Horse”

- Do not allow a parent to take advantage of you, your time or your energies
 - i. Set your own limits and try to stick by them. (However, try to be flexible, since each situation is different)
- Make suggestions of other sources a parent can turn to babysitting, transportation, etc. This shows that you care but are not able to accept these tasks yourself
- A parent may be looking for these limitations to know just how far you will go. Make them clear in a friendly way
- Place a time limit on phone calls. (not over an hour)
 - i. Do not accept a referral if you do not have the time
- Sometimes, something may come up after you have started talking with the parent. Continue working with her if you can, but if not, call the Program Coordinator and they will give the parent a new support parent

“The directly human response always works best. This is an abiding truth that should be a source of encouragement and strength for nonprofessionals who are involved in crisis situations ... There is a simplicity and lack of self-consciousness about ourselves that we either understand immediately or never will; we cannot pretend it.”

*Eugene Kennedy,
Crisis Counseling*

Developing a Relationship



"She understood. We went through the same things."

Developing a Relationship

a Developing Rapport (*building a positive relationship*)

1. Actively imagine the parent's present feeling
 - Listen and ask about parents experience
2. Attempt to subtly match parent's
 - Tone (note of voice)
 - Rate of speech (may be arrhythmic)
 - Intonation
 - Doing all three of these will enable you to have almost immediate rapport and allow the parent to feel free to express herself
3. Establish Trust
 - Use a warm tone to your voice; speak slowly
 - Lift your voice slightly at the end of a question
 - i. It makes it seem less cold and hurried
 - Ask, "Did I understand you?" "Is that how you feel right now?"
 - Seem sure of yourself. Your confidence may lessen the parent's anxiety
 - i. If you are not yet feeling confident about your support abilities, it is important to still accept what the other parent is feeling
 - Continually develop the capacity to have your own feelings and also allow a clear space to attend to what the other parent is feeling
 - i. You will learn the limits between your feelings and others'
 - ii. This perspective also helps you to formulate questions to help the parent understand and identify her own feelings





b Attitudes That Encourage Communication

1. Conveying warmth
 - Accept parent's responses to situation
 - Place no conditions on acceptance
 - Share in joys as well as sorrows
2. Showing empathy
 - Recognize existence of underlying emotions
 - i. Also recognize that though your experiences may have been similar, you still do not truly know what the parent is feeling
 - Communicate understandings of feelings
 - Allow parent to express her feelings (as hers, not yours)
3. Pacing
 - Monitor rate at which you speak
 - Be sensitive to "where parent is"
 - Allow periods of silence for reflection, regrouping
4. Conveying respect
 - Respect parent's privacy
 - Call when you say you will
 - Respect parent's own strength to cope
 - Respect parent's emotions
5. Offering hope
 - Let parent know you recognize her pain and despair
 - Support healing process

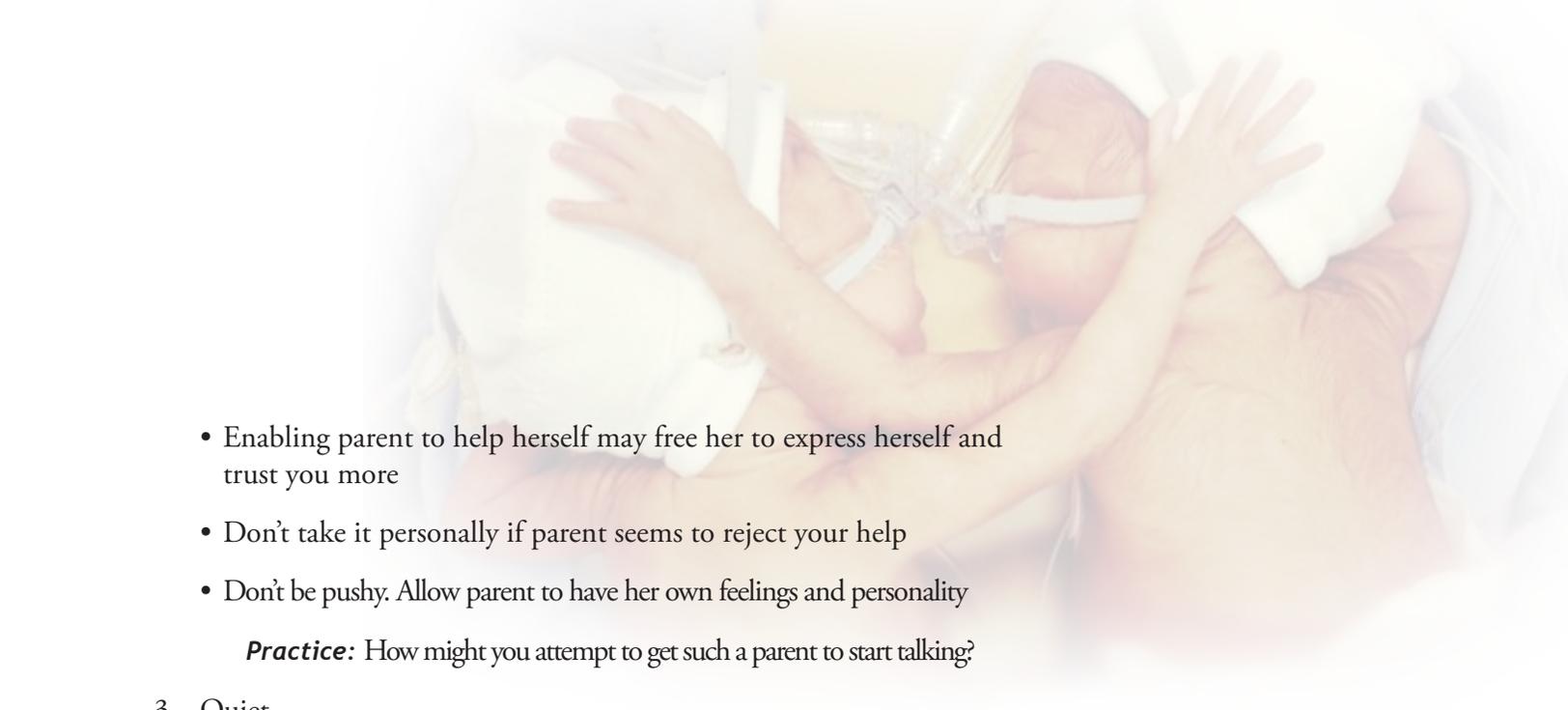
Recognize that though your experiences may have been similar, you still do not *truly know* all that the parent may be feeling

- Everyone needs the mental stabilizer of hope – believing that things will turn out all right and that the person will emerge safely from the experience is important
- Although you may recognize denial, allow it to happen. Denial is a way of maintaining mental health during a crisis and normally transitions into other feelings within a reasonable time

C

Qualities of a Relationship: Responses to Crisis

1. Some people need to be dependent
 - Respect this need
 - After listening to the parent, encourage her to do things for herself—starting with little things
 - They may need more support, or contact for a greater amount of time
 - Find a balance between support and independence
 - Practice:* How might you encourage a parent to become more involved with a baby in the NICU?
2. Counter-dependent (afraid to be dependent)
 - This parent may be more anxious to know what she can do for herself
 - Be careful not to get too “situation oriented” and ignore the parent’s feelings—she still has them!
 - Be careful not to take over; always stop to see how she is feeling
 - Sharing experiences and feelings may enable such a parent to open up

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- Enabling parent to help herself may free her to express herself and trust you more
 - Don't take it personally if parent seems to reject your help
 - Don't be pushy. Allow parent to have her own feelings and personality

Practice: How might you attempt to get such a parent to start talking?

3. Quiet

- This may be a personality, or a relatively long-term response to a situation, or an isolated incident. The next call you make to her may be different
- Don't be afraid of periods of silence
- Let a parent know that you are not a social worker, just another parent. What difference might this make?
- Let a parent know you would like to share her feelings, but don't be pushy
- Try to accept her feelings and accept her as she is
- Don't take it personally. If it becomes clear that a parent really doesn't want contact, don't be afraid to leave the responsibility of continuing the relationship with her

4. Talkative

- This parent may have less trouble expressing and releasing emotions, or may just like to talk
 - i. Remember to try not to let parent take advantage of you. Cut the person off when necessary (politely, of course—"My baby awoke from her nap," "I must pick my husband up at the train," etc.)
 - ii. Control the conversation by returning to issues related directly to the situation

Practice: What might you say to tactfully return to the situation at hand?

"This is the crux of establishing and nurturing a support relationship: being personally, humanly involved and empathizing through having shared a similar experience, and yet giving the parent the space and caring attention to be fully involved in her own experience."

Zack Boukydis

Developing a Relationship

5. Feeling helpless/ having no control

- This is a common feeling among parents of children in the hospital
- Allow parent to express her feelings
- After she has expressed her feelings, guide her in labeling them
 - i. This helps to make the feeling separate from her, and more able to be controlled and managed
- Help parent make a list of questions to ask doctor, or things she can actively do for the baby, or even things she can do in her home or for herself
 - i. Make the list short and the things small so that she can easily accomplish them

6. Feeling out of control/ panicked

- This parent may feel out of touch with reality. This is a common reaction, and does not indicate a mental problem—but the parent may feel frightened that she might be “going crazy”
 - i. Assure her that many parents have felt this way—this statement alone may begin to allay her fears
- Her thoughts may be scattered, so that she is unable to continue a conversation easily, or interrupts frequently
- Help her to focus on the main reason for her panic
 - i. Is she fearful about the baby’s condition?
 - ii. Is she wondering about paying the bills?
 - iii. Is she overwhelmed by the entire situation?
- If you can discover a single reason, encourage her to talk about it
 - i. If possible, label feelings so she feels separated and less “controlled” and overwhelmed by them

Before talking to a parent; release all personal conflicts, ongoing personal problems, breathe

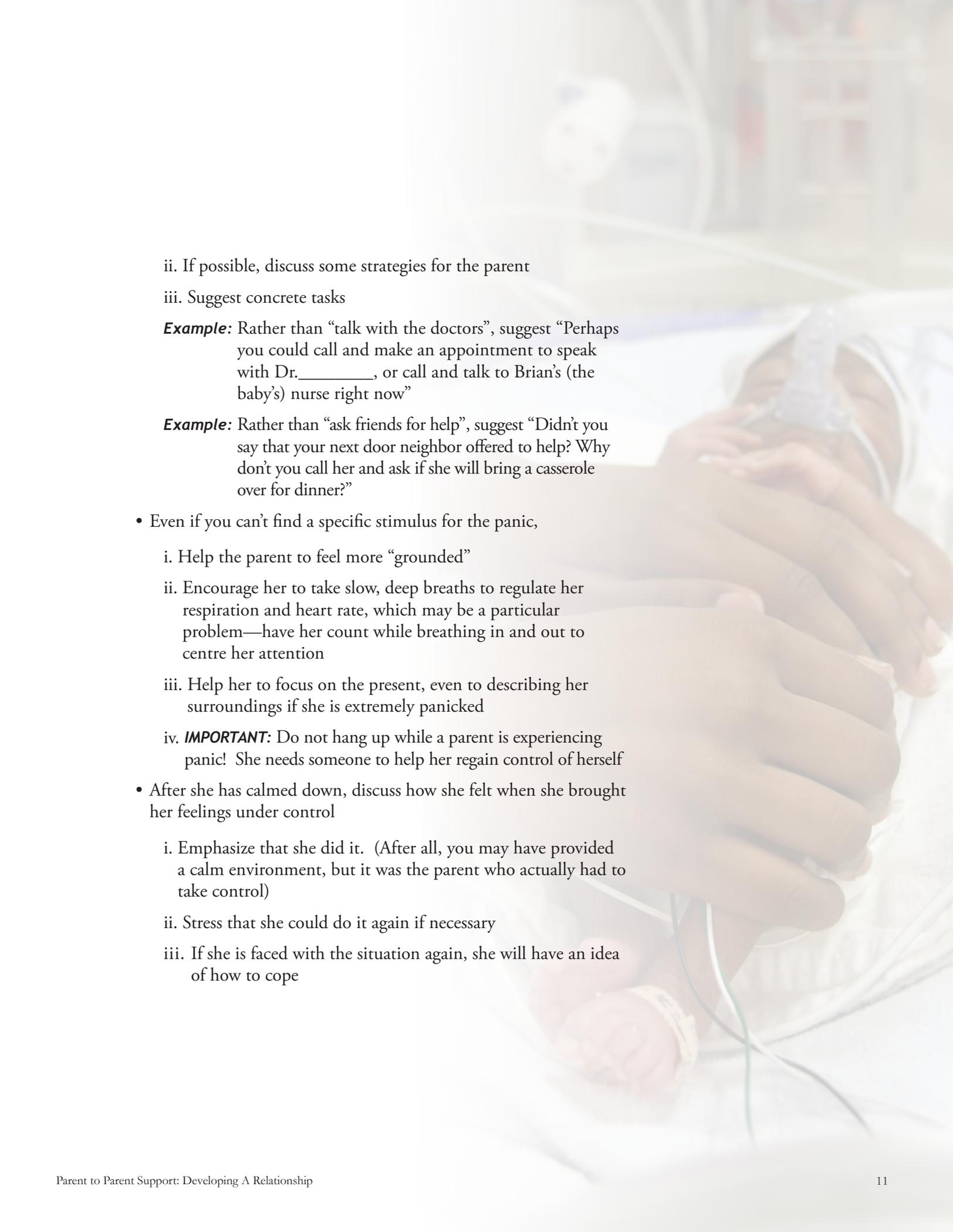
Define your role

State the kind of help you can offer, relate it to the problem she has

State your desire help and to be available to her

Establish trust; assure the person of confidentiality

*Joan Sturkie and Valerie Gibson,
The Peer Counselor Pocket Book*



ii. If possible, discuss some strategies for the parent

iii. Suggest concrete tasks

Example: Rather than “talk with the doctors”, suggest “Perhaps you could call and make an appointment to speak with Dr. _____, or call and talk to Brian’s (the baby’s) nurse right now”

Example: Rather than “ask friends for help”, suggest “Didn’t you say that your next door neighbor offered to help? Why don’t you call her and ask if she will bring a casserole over for dinner?”

- Even if you can’t find a specific stimulus for the panic,
 - i. Help the parent to feel more “grounded”
 - ii. Encourage her to take slow, deep breaths to regulate her respiration and heart rate, which may be a particular problem—have her count while breathing in and out to centre her attention
 - iii. Help her to focus on the present, even to describing her surroundings if she is extremely panicked
 - iv. **IMPORTANT:** Do not hang up while a parent is experiencing panic! She needs someone to help her regain control of herself
- After she has calmed down, discuss how she felt when she brought her feelings under control
 - i. Emphasize that she did it. (After all, you may have provided a calm environment, but it was the parent who actually had to take control)
 - ii. Stress that she could do it again if necessary
 - iii. If she is faced with the situation again, she will have an idea of how to cope