



**A Volunteer's Guide  
To  
Communicating with  
Patients and Caregivers**

**KINDNESS IS A LANGUAGE  
WHICH THE DEAF CAN HEAR  
AND THE BLIND CAN SEE**

*Mark Twain*

## What is real Communication?

- Talking without building walls
- Hearing what is said and knowing what is meant
- Sometimes looking, touching—perhaps not talking
- Allowing silence
- Sharing information in such a way that the other person really understands what is being said
- Active listening—the hardest part

As family therapist Virginia Satir wrote in her book, **Peoplemaking**, “Communication covers the whole range of ways people pass information back and forth; it includes the information they give and receive, and the ways that information is used.” In the communication process, the sender uses words to communicate their message. The receiver must then interpret the words, digest the message and finally respond with a message.

In addition to the verbal communication, an individual also sends any number of nonverbal messages. These are expressed by tone of voice, gestures, facial expressions, posture, silence and so forth. The receiver also picks up and interprets these nonverbal signals.

The goal of communication is to be sure that the verbal and nonverbal match; that they are congruent; that they enhance each other and make sense together. If this is not the case, the receiver cannot know which message is the real one. The receiver cannot know how to respond until further clarification is received. An example would be a person crying or looking sad but saying that nothing is wrong.

## Feelings

In our society, we’ve learned to hide or ignore feelings, but this does not make them go away. The more feelings are denied, the stronger they become and the longer they stay. By accepting the feelings of other people as well as our own, we recognize feelings, and deal with them. By accepting a patient or parent’s feelings, volunteers communicate respect and acceptance of the person.

The concept of “**acceptance without agreement**” is built into the support role. Volunteers may not agree with what is being said but understand that the person needs to say it. In addition, volunteers are good listeners who:

- Are not easily shocked or embarrassed by a parent’s tears.

- Remain warm and friendly even if a parent seems distant or aloof.
- Neither judge nor condemn.
- Respect confidentiality.
- Don't give advice or interrupt as a parent is speaking.
- Take time to listen to the feelings expressed in the message.

Feelings or thoughts volunteers may encounter run the full range of human emotion. Parents or caregivers may feel angry with staff if their patient is not doing well. Parents/caregivers may even feel anger toward the patient for being sick, for not being "perfect", for generally "causing so much trouble" in their lives.

It is okay for parents/caregivers to have these thoughts. However, their response, their actions or behaviors, may need to be changed if they are causing dysfunction for the family. Specifically, help parents/caregivers deal with angry feelings in ways that don't harm themselves or others. Cleaning house, taking deep breaths, counting to ten, going for a walk, and dancing are healthy outlets that might be suggested for releasing pent-up anger.

Guilt is another feeling that parents/caregivers might express. Volunteers should acknowledge rather than deny the existence of guilt and allow the person to seek relief through expression of the feeling. Give nonjudgmental support and encouragement by saying, "The important thing is that you are here for your patient now."

## **Open-Ended Listening With Reflection**

An essential communication method in the relationship is open-ended listening. This simply means keeping the communication channels open as a result of listening attentively for what the parent/caregiver is feeling and attempting to determine the "message behind the message." Then reflect back the feeling to the parent/caregiver, asking for clarification. The value of open-ended listening with reflection, lies in letting parents/caregivers know that their feelings are okay to express. Let parents/caregivers know that you are a safe person to whom they can voice their private thoughts or fears. Offer them comfort and a nonjudgmental listening ear.

## **Tips for Volunteers**

- Opportunities for open-ended listening with reflection arise when parents or caregivers exhibit strong feelings:
  - either verbally or non-verbally; when parents/caregivers want to talk over a problem

- when you suspect that the parents/caregivers have a problem, but are reluctant to take the initiative in discussing it
- when you feel that parents/caregivers need help in sorting through their feelings and thoughts.
- **Volunteers should not** use the process to send a message of their own, voice an opinion, give advice, preach, show pity, lecture, judge or condemn.
- Open-ended listening with reflection does not mean “parroting back” a person’s words. To do so could be interpreted as patronizing, even though this was not intended.
- Never fake understanding. Continue to ask for clarification if you don’t understand the message or feelings being expressed. Simply say, “I’m not sure what you meant. Is it that...?”
- Avoid saying “I know how you feel” even if you sincerely believe this to be the case. Instead, explore the meaning behind the nonverbal message and search for the most accurate word to express what you think the parent or caregiver is feeling. He or she can then agree or disagree: “Yeah, I really feel down today” or “No, that’s not it exactly. It’s hard for me to put into words. It’s more like...”
- Be sure to vary the communication techniques. Don’t use reflective listening in the same exact way every time.
- This communication technique should not be used if you:
  - are unable to be accepting
  - if you yourself feel pressured and don’t have adequate time to listen to the parent
  - if you think that you know exactly what the parent is feeling

Volunteers may use this formula for open-ended listening with reflection.

State what you think the parent might be feeling	Your voice sounds... It sounds like you’re feeling...
State what you think might be the source of the feeling	I’m wondering if maybe...
If appropriate, you might want to connect your experience to the one that you think the parent/caregiver is having	I remember feeling a lot like this at one point...
Ask for clarification to make sure that you’re on the right track	How is it for you?.....

### **Specific Examples:**

- “Your voice sounds sad today.”
- “I’m wondering if maybe you’re more worried than you’re saying.”
- “I remember at this point, with my patient in the hospital for so long, that I wondered if he’d ever be well enough to come home.”
- “How is it for you right now?”

Note how natural, non-threatening and compassionate this sounds. Notice how the parent/caregiver is offered a chance to respond and give clarification. The volunteer let the parent/caregiver know that he/she is not alone in his/her worries. By concluding with the open-ended question, “How is it for you right now?” the parent/caregiver is encouraged to explore his/her own feelings. At the same time, the volunteer gives the message, “I really care about you and what you’re going through, and I’m really interested in knowing what you’re feeling and thinking.”

### **Family Resources and Strengths**

Use the following list when assessing resources and strengths that families or caregivers can call upon to help them cope and point them out to the parent/caregiver.

Sense of humor	Appreciation of other family members
Supportive family and friends	Trusting relationships
Positive attitude	Support from other parents/caregivers
Ability to solve problems	Ability to ask for help
Competence	Compassion
Confidence	Ability to relax
Desire to learn	Family commitment
Resourcefulness	Spiritual framework

### **“I” Messages**

One strategy that patient advisor volunteers can use to teach parents/caregivers how to deal with difficult situations involving family members or friends is the “I” message. This is a non-threatening, non-defensive way of communication that allows a person to share concerns or frustrations without blaming or accusing.

“I” messages are best used by the one who “owns” the problem. It focuses on how that individual feels, what behavior is causing the feeling, how that behavior affects the person’s ability to satisfy a need, and what someone can do to help.

The “You” messages that are often used in difficult or frustrating situations are ineffective because they fail to identify the sender’s feelings. They usually come across as “put downs” that can cause resentment or defensive behavior, resulting in guilt, anger or lowered self-esteem.

In contrast, “I” messages are direct, clear and specific. Here is how I am feeling. This is the behavior that is contributing to that feeling. This is how the behavior is affecting me. This is what I need now.

The formula for the “I” message is as follow:

<b>State the feeling you are having</b>	I feel.....
<b>State the behavior that makes you have these feelings----</b>	When someone....
<b>State how the behavior affects you</b>	Because....
<b>State a way the offending person Could be more helpful</b>	I need...

Here is an example drawn from an actual parent-to-parent experience.

**A mom shares with you that she feels upset because a friend said to her one day, “If only you had put your feet up more when you were pregnant. Maybe you would have kept the baby inside you a little longer.”**

Suggest that she respond using the “I” message technique. “I feel very hurt and upset when someone tells me that the baby’s premature birth was my fault. It makes me feel that others see me as a bad mother. What I really need now is support, not blame.”

## **Nonverbal Communication**

Of the total impact of a message, 7 percent is verbal or word choice; 38 percent is vocal, or how you say it; and 55 percent is facial. Nonverbal communication includes the use of time and space, the distance between people, use of color, dress, walking behavior, standing, seating arrangements, and many other things.

Nonverbal communication often speaks louder than words. You can easily say one thing but actually tell a person something else. Volunteers must be extremely alert to the message they’re sending to NICU parents. It is important to convey an attitude of caring, understanding and empathy. Remember, volunteers are

strangers who appeared during a potentially unprecedented stressful time in the lives of parents and caregivers.

## **Nonverbal Signals**

**Distance**—Putting yourself far away from the person while speaking can imply unfriendliness, dislike, or superiority. Stand or sit near the person while you talk. That conveys warmth and a positive attitude. Don't be too close, however, or you'll invade that personal area reserved for intimate friends.

**Posture**—A person's posture can convey any number of messages: energy or fatigue; interest or boredom; approval or disgust; anxiety or confidence; like or dislike; approachable or unapproachable.

**Gestures**—Both the frequency and the type of gestures convey attitudes toward the other person. Frequent gestures are generally positive, as are relaxed, open palms. Some gestures can send a negative signal, such as clenched fists. Touching can convey warmth and sensitivity, although you need to be careful not to invade a person's personal space.

**Facial Expressions**—Head and facial expressions are the clearest indicators of your attitude. Nodding the head is positive; shaking the head can be negative. Cocking your head over to one side can indicate skepticism. Your face mirrors your attitude. Fear is usually clear in the eyes. Anger is apparent in the lower face, brows and forehead.

**Eye Contact**—Eye contact indicates a desire for communication and friendliness. Lack of eye contact can indicate disinterest or dislike; however, be aware of potential cultural, family or personal differences in this area.

**Hands and Feet**—Frequent nervous hand actions and restless action by legs and feet indicate, "I want to get out of here." Calm hands and feet indicates acceptance and friendliness.

**Silence**—Silence can speak volumes. Powerful emotions can be communicated with silence during periods of extreme joy or grief. It can show genuine concern and encourages additional talk. In every situation, there is a time to talk, and a time to listen and be silent.

### References:

1 Hartman, Ann, (October, 1978). Diagrammatic Assessment of Family Relationships. Social Casework.

**Adapted from Training Manual – NICUPPP, Helen Devos Children's Hospital Neonatal Parent-to-Parent Partnership**

## Differing Personality Types

### 1. Some people need to be dependent.

- a. Encourage them to do things for themselves – starting with the little things.
- b. Encourage them to make their own decisions.
- c. Some people may need more support or contact.
- d. Find a balance between support and independence.

### 2. Counterdependent (afraid to be dependent)

- a. These people may be more anxious to know what they can do for themselves.
- b. Be careful not to get too “situation oriented” and ignore parent’s feelings – they still have them!
- c. Sharing experiences and feelings may enable a parent to open up.
- d. Enabling her to help herself may free her to express herself and trust you more.
- e. Don’t be pushy. Allow her to have her own feelings and personality.
- f. Don’t take it personally.

### 3. Quiet

- a. This may be a personality, or a relatively long-term response to a situation or an isolated incident. The next call you make to him/her may be different.
- b. Don’t be afraid of periods of silence
- c. Let a parent know that you are not a social worker, just another parent. What difference might this make?
- d. Let a parent know you would like to share his/her feelings, but don’t be pushy.
- e. Try to accept their feelings and accept them as is.
- f. Don’t take it personally.
- g. To start conversation, this is a good time to briefly share your experience as an icebreaker.

### 4. Talkative

- a. This parent may have less trouble in expressing and releasing emotions or may just like to talk.
- b. Control conversation by turning to issues relating directly to the situation. Be tactful.
- c. Remember to try not to let the parent take advantage of you. Cut the person off when necessary (politely, or course). “My baby

awoke from nap.” Or “I have to pick up the boys from school.”  
Etc.

- d. To wrap up visit, summarize what you’ve heard and set up future visit or reiterate what the parent says they’ll do next.

## Trigger Words and Phrases

It is probably more important that you know what not to say than what to say in supporting another parent/caregiver. Here we have compiled some phrases to be careful not to use when supporting.

**If I were you...** because you are not them.

**Should or shouldn't phrases...** "You should be happy," or "Your husband shouldn't be so negative," imply judgment. **Could and couldn't** phrases **work better** in any situation, they imply the family has options.

**Don't phrases...** "Don't worry," or "Don't feel guilty," are again judgmental.

**Be realistic and Face reality...** Your opinion is not what they need. Remember to support them where they are in their grieving.

**It's going to be okay and Everything will be okay...** These are phrases that imply you think they are not normal in feeling they way that they do and they may **not** be ok.

**I know how you feel...** You don't know how they feel, only how you felt. You might say, "I remember how I felt when they told me," or "If they told you that, no wonder you are feeling so bad." Validate **their** feelings.

**Oh, you don't mean that...** They may very well mean exactly that. All of us have had terrible feelings at one time or another. It is all a part of grieving and should be respected as that. They may have anger, loss of faith, etc .... Meet them where they are in the grief process.

**Because you worked so hard, the child's come so far...** This makes the parent feel they will have to work harder and can't take a rest, for fear the child will lose ground.

**You're so strong...** Don't put that kind of burden on a parent. Other people do enough of that. We are all just doing the best we can, no better or worse than any other parent.

## **DO's and DON'Ts for Supporting Parents/Caregivers**

### **DOs**

#### **1. Listen to what the referred parent has to say.**

Allow the referred parents to express their feelings and ask questions. Do not overwhelm them with your experience, suggestions and general information. Let the new parents express their emotion

#### **2. Visit and take pictures with you.**

At some time during your contact with the referred parents, have a few pictures of your child from birth to the present with you. Have pictures of you before and after treatment. Referred parents/caregivers may be anxious to see how other patients with the same diagnosis or special needs look when they are older or have finished treatment.

#### **3. Be sure to relate to the baby or child when visiting a family.**

Hold and play with the child. If the child has an obvious special need, you may be the first to relate positively other than the family. Also acknowledge the spouse and siblings.

#### **4. Encourage parents/caregivers to take pictures of their child or patient.**

An opportunity once lost can never be regained. Regardless of what they think their child/patient looks like, encourage parents/caregivers to take pictures from the beginning.

#### **5. Supporting parents/caregivers need to be aware that transportation to services may be an issue.**

A referred parent/caregiver may need transportation to a service, or perhaps may need moral support to get there. If necessary, accompany them rather than have them miss an appointment.

#### **6. Be a support for your referred family.**

A referred parent/caregiver may need support until they are able to cope with the situation. However, care should be taken to avoid dependency.

#### **7. Supporting parents help new families to make new friends.**

Many times friends will stop associating with families with a child diagnosed with a special need. Through the supporting parents and the Parent to Parent program, new friendships can be developed.

**8. Encourage parents to take time out for themselves.**

**9. Remember to do #8 for yourself.**

## **DON'Ts**

**1. Do not be critical or judgmental.**

Supporting parents should not be critical or make a judgment of a family's home, furniture, housekeeping or personal appearance. The only thing to be concerned with is the family's adjustment to their child and the obtaining of services for their child.

**2. Do not give advice, particularly medical or legal advice.**

Supporting parents are not professionals. Do not give specific instructions; give several suggestions and resources. This will empower parents to make their own informed decisions.

**3. Do not allow yourself to become emotionally overwhelmed.**

If the situation becomes difficult, discuss confidentially with the family support coordinator.

**4. Don't be too positive in your attitudes when a family has just learned that their child has a special need.**

When talking to a referred family, be reassuring but do not be too enthusiastic about your child. It may be some time before they will be able to accept the thought that raising a child with a special need has its pleasures and rewards.

**5. Don't be too positive about specific services. Try to keep an open mind about the services.**

If the supporting parent is too positive about a specific service, the parent may be made to feel they have made a poor choice if their experience is not the same. There may be unknown reasons why they cannot select the same service as the supporting parent.

**6. Don't use a lot of "alphabet soup"; i.e., IEP, ARC, HAB, DD.**

Supporting parents help referred parents with new medical educational terms and vocabulary. Assure new parents they will learn the terms in time.

### **7. Don't overload parents with too much reading material.**

Overload is different for everyone. Offer the referred parents the materials but explain to them you do not expect them to read everything.

### **8. Don't worry about delay in obtaining referrals.**

Supporting parents are matched with referred families. This occasionally results in some supporting parents receiving several referrals while others have yet to be assigned one. Be patient. Your time will come. Get involved in other aspects of the program.

## **DOs AND DON'Ts**

1. **DO** respect feelings, attitudes and opinions that are different from your own.  
**DO NOT** project your feelings and opinions onto other parents.
2. **DO** suggest that they get another opinion if they are unhappy with the services provided.  
**DO NOT** argue what other parents' physicians or professionals recommend.
3. **DO** use your experiences in a constructive way.  
**DO NOT** discourage anyone simply because of your bad experiences.
4. **DO** share goals, successes and failures you have had with your child.  
**DO NOT** compare children, yours or anyone else's.
5. **DO** share hints of methods that have worked with your child.  
**DO NOT** make suggestions that are obviously inappropriate or are in contradiction with professional recommendations.
6. **DO** share personal experiences as a parent.  
**DO NOT** take the role of an infallible expert (which new parents may see you as).
7. **DO** alert someone if a parent appears to need professional help.  
**DO NOT** try to play the role of a therapist.
8. **DO** be empathetic.  
**DO NOT** be overly sympathetic.

9. **DO** be a listener.  
**DO NOT** be an advice-giver.

10. **DO** be supportive.  
**DO NOT** be officious.