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**Canadian Premature Babies Foundation
Fondation pour Bébés Prématurés Canadiens**



Introduction to NICU Peer Support

The content for this workshop was adapted (with consent), from the Mount Sinai Parent Buddy Program, a pioneering peer support program based at Mount Sinai Hospital in Toronto, Ontario. We thank the team at Mount Sinai for graciously sharing their materials with us.

1. Peer support: what is it and why do we do it?

The Self Help Resource Association of BC defines peer support as:

- People who share a common problem, challenge or issue learning from and providing support to one another
- Opportunities to learn new coping skills and new means to approach or improve their personal situations
- Something that can be done one-on-one or in groups, in person, by telephone or online
- Unique, offering the kind of support that one can only get from others who share similar experiences

There is a growing body of evidence that shows peer support is an effective way of helping NICU parents manage the stress of hospitalization and discharge (Preyde, 2003). Connecting with peer parents can help NICU families:

- Experience the relief of talking with someone who understands
- Begin to deal with their own feelings about their experiences
- Feel less isolated and alone
- Begin to solve some of their own problems and find ways of coping
- Feel hope for the future

What a Peer Support Person Is	What a Peer Support Person Is Not
a listening ear	not a medical professional
a shoulder to cry on	not a friend
a valuable information resource	not a financial resource
a source of realistic optimism/hope	not a psychologist or counsellor
a safe person for someone in crisis	not a judge or a critic
part of a support system	not alone; can connect with others for help

2. Communication Skills

Empathic Listening is the most important skill for a peer parent to have. Empathy is the ability to understand another person's ideas and feelings. It is gaining an understanding through listening and demonstrating that understanding by responding. As parents of NICU children, peer parents have a unique capacity to listen, understand, and communicate that understanding to new parents of NICU babies.

The three elements in responding empathically are:

1. Identify the feeling
2. Identify the situation/content
3. Respond to the feelings and situation, letting the person know you understand

Empathy formula: "Do you feel _____ because _____?"

When listening empathically:

1. Focus on listening and give your undivided attention
2. Don't feel you need to solve the person's problem
3. Let person know if you don't understand what they are saying
4. Watch for non-verbal cues
5. Remember that just by listening empathically and responding you can help people gain more self-understanding and help them solve their problems

Pitfalls in Empathic Listening

1. Not really paying attention
2. Responding inappropriately (judging, joking, overly reassuring)
3. Doing all the talking yourself



Exercise: Empathic listening

A) Look at the sample one liners. Identify the feeling. Describe the situation.

B) Practice with a partner

FEEDBACK:

**Did you feel listened to?
What made you feel listened to (or not)?
How did it feel?**

Sample One Liners

I don't feel like a mother

Everyone tells me different things about breast pumping

The nurse last week let me hold my baby but the one today won't

There is nothing I can do for my baby

I feel like I'll be here forever

Why did this have to happen to me?

I feel like all of this is my fault.

I feel like if my doctor had listened to me everything would be okay right now

My family won't listen to any of the hospital rules

I don't feel close to my baby



Empathic Responses and Open Ended Questions

If you're unsure about how someone is feeling or what they are saying, you can use these following responses and open ended questions to build or direct the conversation

1. What I hear you saying (reframe their statements)
2. I'm not sure I'm following but ...
3. Correct me if I'm wrong ...
4. You mean ...?
5. You sound a little (frustrated, upset, sad)
6. As I hear it _____
7. Is it possible that...?
8. Where would you like to begin?
9. What's most important to you right now?
10. What would make tomorrow better?

3. Problem Solving/Decision Making

Parents with babies in the NICU are in crisis. Often they are overwhelmed by many concerns, they feel helpless, and they don't know what to do or where to start.

Parents feel better when they decide to do something or take action about one of their concerns.

This five-step decision making process can serve as a plan of action to assist parents in feeling and gaining some sense of control, and can help them make decisions.

1. Identify the central issue or problem
2. Explore the issue or problem (alternatives and consequences)
3. Choose a next step
4. Act upon your choice
5. Evaluate the results

Exercise:

Think of a problem a parent in the NICU might experience. Note down how you would work through the five stages, then share and debrief with a partner.

Role play. Help a parent with decision making. Each person takes a turn in each role. Discuss your reactions to the exercise.

Problem Solving Examples

I feel as if I'm in the way when I visit my baby

I find it really scary to go into the NICU.

I know my baby prefers his right side but I'm scared to tell the nurse.

My baby was born yesterday at 24 weeks and weighs 600 grams. I hope he makes it. I haven't bought any baby things. Should he be in our bedroom when he comes home?

4. Communication Roadblocks

Roadblocks are ineffective ways of responding to another person. They can block the communication process rather than facilitate it. The other person is likely to feel judged, misunderstood or not respected. They may not want to continue the conversation, or feel defensive, or lose self-confidence.

Examples:

1. Advising: "You shouldn't be at the hospital so much." The implication is the person can't solve her/his own problems.
2. Judging: "What did you do to cause the early birth?" Communication may be cut off because the parent feels judged. Parental feelings of guilt may be worsened.
3. False reassurance: "Don't worry - he'll be fine." A false promise promotes lack of trust and negates the reasonable worry a parent in the NICU feels.
4. Avoiding/changing subject. "I'm worried if my baby will ever come home." Response was: "So, do you have the baby's room ready yet?" Implication is that the parent's worries are either not worth discussing or you aren't capable of discussing them.
5. Asking too many questions. "Who? When? Why? How often?" A parent can lose track of his or her own feelings/goals when responding to a questioner's agenda.

Exercise:

With a partner, discuss the types of communication roadblocks you've experienced (either in the NICU or in regular life) and your response to them.

5. Confidentiality and Special Issues

Protecting personal information:

As a peer parent, you may hear personal information about families or patients. If you are working with an institution (such as a hospital or community agency), you are required to keep all such information private and confidential. Ask to see your partner institution's privacy policy; most institutions will also require you to go through orientation which will clarify policies on confidentiality and privacy.

If you are offering peer support in another context, such as in a group or an online forum, it is wise to encourage all participants to respect confidentiality and privacy. Set expectations early and reiterate them at every meeting, or post them in a visible area of the online group.

Dealing with conflict:

Parents may disclose to you feelings of anger, distrust or betrayal related to their experience in the health care system. Although it is very normal to want to agree and bond over any similarly challenging experiences, encouraging anger can actually cause harm to the parent because it disrupts a necessary trust relationship between the parent and the particular institution.

You can listen and sympathize with their feelings without validating those feelings or agreeing with them. For example, you can say, "That sounds like a tough situation. What do you think could make it better?", instead of "I know exactly what you mean - those doctors are terrible!"

Dealing with uncertainty:

One of the most challenging parts of the NICU experience is living with the uncertainty of what the future will bring. While it is very natural to want to encourage parents to think positively about the future, it is vital that you focus on encouraging realistic optimism.

At times you may wonder why the medical team is pursuing a particular course of treatment. It is important to remember that new practices and procedures are always being developed in the NICU, and that you do not know the entirety of a baby's or a family's story. Questioning medical decision-making has the potential to disrupt the trust relationship. If you are really concerned, speak with a medical team member who may be able to address the issue.

Understanding the boundaries:

You will be a vital resource for a family, but you are not the only resource. If a parent presents you with an issue that you feel you can't solve, reach out to a team member for help. Social workers and nurses can offer valuable support and can take the baton from you when the problems you have been presented with exceed your comfort or knowledge level. If you are in any doubt, consult with a relevant staff member.

Self Care

Offering peer support can be an amazing experience for a parent, but it can also be an emotional one. Sometimes the close proximity to the NICU can bring back feelings of stress and worry, and seeing people in crisis can revive memories of tough experiences. You may develop close attachments to families who experience loss and pain. Take the time to debrief with a staff member (such as a social worker) after challenging interactions. Also, if you are feeling stressed or anxious, never feel bad about taking a break from peer mentoring to focus on yourself or your own family.

6. Developing the Relationship with the Family

Crafting a letter or email of introduction

Parents will appreciate receiving a letter or email of introduction from a peer parent. The introduction can be shared with the parents as soon as you are connected to them as a peer parent.

The following are suggestions for inclusion in a letter of introduction.

- Introduction to your family
- Specific information about your premature child or children, or NICU experiences. This could include weight, gestational age, or specific issues you faced.
- What the experience meant for you and how you hope to be helpful to them.
- Your contact information and the best times to reach you.

NOTE: Remember to keep the note short, and include within it information about what is going to happen next.





Telephone tips

Before you call

- gather your information
- call when you don't expect too many interruptions

Reaching the parent

- goal is to connect soon after referral/introduction
- try different times of day

First call

- Introduce yourself as a peer parent who has had a baby in the NICU
- Ask if this is a good time to talk
- If not ask when would be a good time to call back
- If it is a good time to talk, tell the parent a little bit about you (very brief introduction) and ask parents about their NICU experience so far.
- A telephone conversation can be 5 minutes or 30. Even a short conversation can make a huge difference.

Ending the call

- End on a positive note if possible
- Arrange a follow up (email, meeting or call)

Note: Try to use the name of the baby in your conversations.

Connecting online

Research shows that online support groups can be immensely helpful to participants, especially to those who would not find it easy to attend an in-person session. Usually, a good online support group is:

- Private but not anonymous
- Moderated
- Governed by a clear set of guidelines that are posted in a visible and accessible place
- Made up of more active posters than passive posters (also known as lurkers)
- A place of acceptance, not judgement
- A place of respectful sharing, not arguments

"You can point with the sword of truth as well as slash."

7. Running a Group

In many instances, peer parents will be invited into hospitals or community settings to host peer support groups or community celebrations. A group setting is a wonderful opportunity to provide peer support, and also offers its own unique challenges and possibilities.

Some tips for running an effective group are:

1. For a recurring group, keep meeting times and dates consistent (ie. every Tuesday at 1pm, or the 1st Thursday of every month). Make it easy for people to remember when and where the group meets.
2. For both recurring and one-off meetings, invest time and effort into information sharing and publicity. Use multiple methods to spread the news about the group or event. Do posters, drop off small flyers, and use social media. If running an in-hospital group, enlist staff members to help you get the word out.
3. A co-hosted model (with two or more peer or staff facilitators) is ideal. If the group is particularly small (less than 5) you may be able to have just one facilitator, but if the group is larger than 5 or if you are meeting with people in particularly vulnerable states, a co-hosted model gives you more flexibility if a particular need has to be addressed in the moment. It is especially important for new facilitators to seek an experienced co-host when beginning a peer group; you learn so much so quickly from observing an experienced facilitator.
4. Give yourself time to set up for the meeting; ideally you would arrive at least 20 minutes before the beginning of the session to organize chairs, tables and refreshments.
5. Greet everyone who arrives, and start the meeting within 5 minutes of the stated start time. Your goal is to make everyone feel welcome and comfortable. Introduce yourself briefly and share any ground rules for the group. This introduction sets the tone for the meeting so it's important to keep the tone friendly, while being clear about the goals and rules for the session. Participants should understand that the group needs to be a safe place for everyone, that people who are not present in the group should not be discussed, and that anything that is discussed in the group should not be discussed outside of the group.
6. Depending on the nature of the group, starting with an ice-breaker can be effective (sharing something basic like names or home towns, or asking about why the person came, or asking a parent about his/her baby's name).
7. Some groups require active monitoring of the conversation. For example, a session with an education focus with particular educational goals will require the facilitator to focus more on keeping the discussion on track. A group that has a more open social focus might require less conversational guidance, but facilitators do still need to pay attention to the direction of discussion and be prepared to involve themselves if discussion seems to be going in an unproductive direction. A simple statement like "I hear what you're saying and let me follow up with you about this after our meeting. For now, let's stay focused on the question about NICU discharge" is often enough to reorient the discussion.
8. Close the group on time and give written or verbal reminders to participants about any next sessions. If any concerns have arisen during the session, make time to debrief with your co-host or a staff member before leaving.

8. Building a relationship with an Institution

If the institution you would like to work with does not already work with volunteers or graduate NICU parents in any capacity, it can be challenging to find a way in. You can ask to meet with volunteer services, who can sometimes serve as a link to an individual unit. However, without support from the actual unit you'd like to work with, volunteer services cannot place you.

Some units can be very receptive if you offer to organize a celebratory event for them or a fund-raising event. Examples of these sorts of events would be a pizza night, a special holiday event (like a Valentine's party), an activity like scrapbooking, or a celebration of World Prematurity Day. You will need a unit/institutional champion, both to make sure your offer gets heard by institutional leadership, and also to help get the word out to families.

If your institution has a Family Advisory Committee, it can be incredibly helpful to join this, to help but also to learn more about the institution.

If your motive for participating or volunteering is because you have grave concerns about care and wish to make change, this route may not be the best option for you. Institutions are often (and reasonably) cautious about the agendas of outside volunteers. While your concerns may be valid, airing them in the context of a unit event or a Family Advisory Committee meeting may well not serve your cause, and may make it more difficult for graduate parents to volunteer in the unit or institution. You also may need to make peace with the pace of change in large institutions. Even the best ideas take a long time to be accepted and implemented.

Of course, there is much to be done independently of institutions. You can find an organization that shares your perspective or whose cause you believe in, you can engage in online mentorship in preemie parent groups, or you can develop your own volunteer projects or organizations.

Before you meet with any organization, take the time to develop your "elevator story" (called this because it is the story you would tell an influential person if you only had a few moments with that person in an elevator). It focuses on only the most important details of your entire story, and is intended also to communicate your main goal and your passion. It needs to answer these questions: who, what and why.



References

M. Preyde, F. Ardal. Effectiveness of a parent “buddy” program for mothers of very preterm infants in a neonatal intensive care unit. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC152679/>
Self-Help Resource Association of BC (now PeerNetBC): <http://www.peernetbc.com/>

Resources for Peer Parents

The Canadian Premature Babies Foundation: <http://www.cpbf-fbpc.org>
NICU Peer Support Group Leaders: <https://www.facebook.com/groups/805696576230790/>
Hand to Hold: <http://handtohold.org/>
Ideas for NICU Crafts from Hand to Hold: <http://www.pinterest.com/handtohold/crafts-to-make-in-the-nicu/>
Peer Support Guide from the Canadian Mental Health Association: <http://2010.cmha.bc.ca/files/ParentPeerSupportGuide.pdf>
Peer Support Best Practices Toolkit: <http://hollandbloorview.ca/teachinglearning/evidencetocare/peersupportbestpracticestoolkit>
Graham’s Foundation: <http://www.grahamsfoundation.org/>
Share your Story (March of Dimes): <http://share.marchofdimes.com/>
Reaching In, Reaching out (Resiliency Building): <http://reachinginreachingout.com/index.htm>
Centre of Excellence in Peer Support: <http://www.peersupportvic.org/what-is-peer-support>
Miracle Babies (Australia): <http://www.miraclebabies.org.au/>
The Power of Peer Mentoring: <http://www.waisman.wisc.edu/hrtw/PPM.pdf>
“How not to say the wrong thing, or the Ring Theory of Support”, <http://articles.latimes.com/2013/apr/07/opinion/la-oe-0407-silk-ring-theory-20130407>

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