

Children's Mercy NICU

Family Support Program

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Welcome to Children's Mercy

Family Support Mentor Programs

Thank you for volunteering to be a Family Support Mentor. You bring a unique perspective to parents and caregivers who are living through a life changing medical experience because you have been there.

Family Support Mentors are interested, trained, and available for face to face interaction in the ICN with a parent or caregiver facing a NICU stay.

There are three key positions involved in the mentor program: the Family Support Mentor, the Parent/Caregiver, and the Program Coordinator.

Mentor

A mentor is an experienced parent or caregiver who volunteers to meet with current ICN inpatient families. Mentors will share experiences, practical information, and offer peer support. They will also encourage requestors to utilize the resources offered by Children's Mercy. Mentors undergo background checks and will receive training to provide support in positive ways.

Parent/Caregiver

A parent/caregiver of a patient who is inpatient in need of support and information.

Program Coordinator

The Program Coordinator is responsible for recruiting and training mentors, communicating with and supporting those mentors. They maintain the database of trained mentors and parents/caregivers currently inpatient while protecting the confidentiality of all of the participants. Coordinators educate Children's Mercy staff and families about mentor programs and provide support to mentors and parents/caregivers.

Program Coordinators are available to answer any questions or concerns about the program.

HOW DO Family Support MENTOR PROGRAMS WORK?

- You have given information about your experiences on the application. This information has been entered in a database which is protected at Children's Mercy.
- You will undergo a background check, have the appropriate vaccinations and will be interviewed before training will start.
- You will be trained before you are scheduled to be on the ICN unit providing support.
- Scheduling will be discussed upon the interview process and set up during training.
- You may **not** share your contact information with the parent or caregiver.
- You will be making rounds on the unit every shift and expected to update a report on the families that you meet.
- Maintain appropriate confidentiality and boundary guidelines.
- Contact the Program Coordinator should any situation/concern arise that may be too difficult to handle or is beyond the scope of the Peer to Peer Mentor.

If at any time you are unwilling or unable to mentor a particular family or fill your shift, please inform the coordinator as soon as possible. We understand that life and family concerns will arise. We neither want nor expect you to handle anything beyond the realm of just listening and being understanding! The following pages will give you more ideas of what to say and how to say it, as well as other tips for becoming a successful mentor.

VOLUNTEER POSITION DESCRIPTION

Family Support Program

Supervisor: Parent Support Program Coordinator

Purpose: To offer supplemental peer support to the parents and caregivers of children inpatient at Children's Mercy ICN.

Qualifications:

- Must be a parent or primary caregiver of a child that has been cared for in the ICN at Children's Mercy.
- Strong communication and listening skills.
- Emotional stability in dealing with difficult/stressful situations.
- General knowledge of Children's Mercy services and programs.
- Ability to maintain confidentiality.
- Positive attitude in working with diverse populations.
- Ability to accept differences in perspective and choices others may make.
- Ability to educate and share resources for parents and caregivers.

Training Requirements:

Complete recurring background checks

Complete annual on-line education and training as needed

Complete Family Support Mentor Training

Schedule:

After first on unit training is complete, you will be required to complete at minimum one shift that is shadowed by the Parent Support Program Coordinator. Self-scheduling will occur after the initial training is completed.

Description of Duties:

1. Offer peer support as appropriate and as needed.
2. Update report each shift.
3. Give parent education, unit materials and other resources to appropriate families.
4. Provide surveys to appropriate families.
5. Maintain appropriate confidentiality and boundary guidelines.
6. Contact Parent Support Program Coordinator should any situation/concern arise that may be too difficult to handle.

MENTOR RIGHTS AND RESPONSIBILITIES

Obligation of Family Support Mentors:

- Mentors must participate in mentor training session
- Mentors agree to follow all guidelines established in this manual. Any questions regarding policies or procedures should be directed to the Parent Support Program Coordinator.

Code of Ethics:

- Mentors must be sensitive to the issues of families who have a child with special health care needs, appreciate cultural differences, and be non-judgmental.
- Mentors will not use the parent to parent program as a source for self-promotion, sales or advertising of any product. Advancing your own religious, political or any other personal beliefs is inappropriate and not allowed.

Matching/Termination of Support:

- If a mentor visit is not beneficial to the parent/caregiver, or if a visit is not comfortable for either party, Parent Support Program Coordinator should be contacted, and the follow up visit will be redirected.
- Support may also be terminated when the issues of the parent/caregiver go beyond the scope of the Family Support Program. The decision to end support will be made by the mentor and/or the Parent Support Program Coordinator. Every effort will be made to see that the parent/caregiver is referred to the appropriate resources.

WHAT DOES A MENTOR DO?

- Respects the confidentiality of the relationship.
- Uses effective listening skills allowing the requestor to express honest emotions.
- Listens with acceptance, remaining open-minded and non-judgmental.
- Answers questions honestly as you feel comfortable. Use discretion as needed.
- Offers encouragement, emotional support and information on community and hospital resources.
- Encourages requestor to feel empowered to make informed, responsible choices. A mentor offers guidance and direction as needed, but allows the requestor to make his/her own decisions.
- Keeps the conversation focused on the parent/caregiver feelings and perception of their situation.
- Urges the parent/caregiver to discuss any concerns about quality of care or services with the healthcare providers and share effective communication strategies.
- Shares examples of healthy coping skills.
- Contacts the Parent Support Program Coordinator if there are concerns about any aspect of the interaction.
- Informs the Parent Support Program Coordinator if it is not convenient or a good time to serve as a mentor.

You never know when a moment and a few sincere words
can have an impact on a life. - Zig Zigler

WHAT A MENTOR DOES NOT DO...

- Does not give medical advice.
- Does not give advice regarding diet, treatment, religion and any other personal choices.
- Does not provide:
 - personal services (babysitting, transportation, etc.)
 - money or tangible items (food, clothing, etc.)
- Does not give opinions on specific doctors, nurses, hospitals or other professionals.
- Does not discuss the identity of another mentor or requestor with anyone other than the Mentor Program Coordinator.
- Does not serve as a psychologist, social worker, crisis counselor, or chaplain.
- Does not agree to be available 24 hours a day, 7 days a week. The mentor should set appropriate limits on their time and availability.
- Does not accompany the requestor to a doctor's appointment.
- Does not offer to set up medical appointments.
- Does not suggest or arrange for second opinions.
- Does not share information they are not comfortable sharing.

Visiting TIPS

First Visit

- First visits should happen within the first week of admission.
- Avoid visiting bedsides that are busy (meeting with another staff member other than bedside nurse, doing education, prepping for surgery, pumping, etc.) offer to circle back at a more convenient time.
- If you feel cautious at first, remind yourself that this person deserves to know they have people like you here to support them and share with them resources that will help them during their stay.
- Introduce yourself and explain you are with the Peer to Peer program and why you are visiting

What to Say

- Example Script: "Hi my name is _____ and I'm a Family Support Mentor here at Children's Mercy. My baby was up here in the NICU for a while and I'm here to support you as a peer that has experienced this place first hand. Our babies may not have the same journey but I know what it's like to have to sit in that chair and listen to the alarms and watch the monitors, having complete loss of control. I'm happy to share my story whenever you'd like but I know sometimes others stories can be a bit overwhelming. So feel free to ask questions whenever you are ready!"
- Introduce yourself by name, as an NICU Family Support mentor
- Ask if this is a good time to talk; if it isn't ask when a good time would be to come back
- Ask if there is a time of day that is most convenient for a mentor to come by
- Are there any other limitations, preferences, or requests?
- Mention your own experiences briefly (purpose is to help requestor feel less alone)

Conversation starter for introducing to parent/caregiver:

- How is the patient (use name) doing today and how is the parent doing today
- Tell me about your day
- Tell me about yourself
- Ask where they are from – this will prompt opportunities to share resources available to them depending on where they live
- Ask if parent/caregiver has any questions

Conclusion

- Give parent/caregiver your name again
- This visit doesn't have to be more than 5 – 10 minutes; play it by ear
- Some parents/caregivers don't respond well – don't take it personally – they may be more open next time

- Let the parent/caregiver know you are not a staff member, just another parent volunteering
- Document visit and make any notes important for next mentor or coordinator to know

Additional Thoughts

- The parent/caregiver's story may stir up emotional memories for you. Be prepared for this. It's okay to be moved by a family's story, but try to keep your responses in perspective. Take advantage of connecting with your own support network and/or the program coordinator to find support for you if needed.
- It is not your responsibility to solve the problems of the other family. Relating your own experiences when it's appropriate can validate the referred family's experience, or offer new ways of looking at the situation. When using you as an example, try qualifying by saying, "This approach worked for me. It may not be the best for your family, but it may be something to think about." It is also perfectly fine to say "I don't know but you might ask____" in answering to some questions.
- Most importantly, it is your role to listen with empathy and provide a safe, supportive environment for the parent/caregiver to express themselves. Be aware that some families may have other serious problems in their lives. Marital difficulties, depression, alcohol or substance abuse etc. that require the help of a trained professional. If people express these kinds of concerns to you or anything else that makes you feel uncomfortable, you can suggest they contact their social worker or if it is after 4pm they can contact the on call hospital Social Work Department **(816) 234-3000** and ask for the on call Social Worker.

LISTENING TECHNIQUES

Listening is a skill not a natural art, but something that is learned so it can be improved. Listening is when a person voluntarily and consciously gives his/her attention to another so he/she can hear what is being said.

Common barriers to hearing:

- The person's views are different from your own.
- The thoughts or feelings being expressed shock you or cause you anxiety.
- The environment is noisy or there are frequent interruptions.
- YOU are experiencing stress or discomfort in any way.

Often people will get caught up in one aspect of the message and begin to think of an answer before the speaker is finished or answers to problems that haven't been asked for.

Listening Tips:

- Avoid close ended (yes/no) questions.
Example: "I'll bet you're having some strong feelings."
Better: "Can you tell me about some of your feelings?"
- Center around concerns of the parent/caregiver, not your own.
Example: "I felt so guilty for putting my child through this."
Better: "What are you feeling right now?"
- Watch for "doors" (openings in conversations, pauses).
- Be alert for your own negative feelings and remain objective
- Avoid premature conclusions and interruptions.
- Control the conversation by returning to issues relating directly to the situation.
- Remember to try not to let the parent or requestor take advantage of you. Cut the person off when necessary (politely of course) "I have to get to work", "I have another call", "I apologize but I have to get going".

Active Listening:

- Above all, stop talking!
- Want to be helpful
- Ask appropriate questions
- Listen for more than just facts
- Empathize with the parent/caregiver (put yourself in his/her shoes)
- Accept the parent/caregiver feelings as his or hers – not yours
- Know that feelings change
- Trust in the parent/caregiver's capacity to handle their feelings, to work through them and to find solutions to their problems. You are there to help them, if they choose.
- Be patient
- Allow plenty of time
- Don't be in a hurry to give answers or everything you know
- Take notes

Strength Perspective Assumptions

Consider asking strength-focused questions such as:

"What has gotten you through so far?"

"It has been 2 weeks since your child was diagnosed...what has helped you through?"

"What resources/people/coping strategies help you get through the day?"

The greatest gift you can give another is the purity of your attention.

...Richard Moss



FLAGS

“Red Flags”

There will be times when you will need to stop the conversation and direct a person to other sources of support. Please be aware of any indication of abuse, suicide, etc. which would require professional intervention. Please tell the parent/caregiver, “These concerns are very serious and I will need to share them with the appropriate person.” Then call your coordinator, contact the charge nurse or call the on call Social Worker to determine next steps!

Parent Support Program Coordinator: **(816) 983-6918; (913)731-6834**

Charge Nurse from any Children’s Mercy phone: **15311**

OR

A CMH Social Worker: **(816) 234-3000 and ask for the**

On-call Social Worker

“Pink flags” can be handled differently, but will need to be monitored as well.

This might include conversations indicating conflict in the home, etc. In this case, please notify the Parent Support Program Coordinator and we can help you direct the family to necessary support services at Children’s Mercy.

EMERGENCY CONTACT NUMBERS:

In rare circumstances, you may want to contact Children’s Mercy professionals for assistance. Social Workers and Chaplains have a professional on call

24 hours a day, 7 days a week for such emergency situations. You may either call them and identify yourself as a Parent to Parent volunteer with a concern, or you may give the contact information directly to the patient.

To reach a Children’s Mercy Social Worker: **(816) 234-3000 and ask for the on call social worker.**

INTERVENTION

If the parent/caregiver makes suicidal statements such as “I don’t feel like doing this anymore” or “I don’t want to live anymore” these comments need to be taken seriously. The parent/caregiver needs to be assessed by a professional. Ask the following questions in a gentle, non-threatening manner:

1. Who else have you talked to about these feelings?
2. Where are you and who is with you?
3. Share with the parent/caregiver that you are so thankful they are sharing this information. You are concerned for their safety and need to share this information with someone who can support them.
4. Share the National Suicide Prevention Lifeline information listed below with the parent/caregiver.
 - a. Share your concerns and encourage them to:
 - i. if he/she has a plan or has an immediate threat, they should call 911 or go to the Emergency Department
 - ii. follow up with their mental health provider
 - iii. share the National Suicide Prevention Line information
5. Contact the Parent Support Program Coordinator

If you sense they are need additional help in coping with these feelings, please offer the suicide prevention hotline number which is: Dial **1-800-273-TALK (8255)** for the free 24-hour **National Suicide Prevention Lifeline**

If the person indicates a plan to hurt him/herself, CALL 911!!

In addition, if you need support for yourself, or if you are uncertain about the person’s ability to cope, feel free to call this same number at any time.

NOTES: