

Parents Supporting Parents IBD Parent Mentor Handbook



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Riley Hospital for Children
Indiana University Health

Dear Fellow Parent,

Caring for a child with IBD can be tough. We know and we are here to help. The Riley IBD Parent Mentor Group is a team of parents who have children living with IBD. We recognize that with diagnosis, comes a potentially overwhelming world of new symptoms, medications, tests, appointments, and vocabulary. We have come together to support newly diagnosed and current IBD patients. Our goal is to be a resource for families dealing with pediatric IBD and the doctors and nurses who care for them. Most importantly, we aim to be a source of support and information for parents of kids living with IBD.

Having gone through many of the stages of IBD including: the initial diagnosis, treatment decision-making, hospitalization, surgery and the transition to adult care, we have been there and can support families as they navigate through these challenges. As parents, we understand how important it is to see our kids feeling well and living a normal life, in spite of IBD.

This mentoring program, along with our other projects, has been set up to answer the questions and be the support that we wished we had along our child's IBD journey. We are excited and blessed to have you as a part of our team. Thank you in advance for your time, talents and energy. Together we can make a difference.

Liz Dapp, Kathy Lazzara, and Stephanie Gottschalk
Parent Mentoring Group Parents

WELCOME TO IBD PARENT MENTORING GROUP

Thank you for volunteering to be a Parent Mentor for our IBD Parent Mentor Group (PMG). You bring a unique perspective to a family living through a life changing medical experience because you have been there! You can understand issues and feelings that nobody else can.

There are three key people involved with connecting parents to other parents for support. The *Parent Mentor*, the parent who has experience with the situation, the *Current Parent* just starting on their journey, and the *Program Coordinator*.

Parent Mentor

A Parent Mentor is a parent or other family member who has had experience with the health care system and volunteers to be matched to another parent new to the system. Parent Mentors will share experiences, practical information, and peer support. They will also encourage parents to utilize the resources offered by Riley Hospital for Children. Parent Mentors will receive training to provide support in positive ways.

Current Parent

The Current Parent is looking for information and/or support from someone who understands what they are going through. They might be a new parent, a parent whose child has just been diagnosed or someone who is going through a difficult time as a result of repeated hospitalizations or continued IBD flare ups.

Program Coordinator(s)

The Program Coordinators are Riley Hospital for Children employees. The Coordinators are responsible for recruiting and training Parent Mentors and facilitating the assignment with families in need of support. They maintain the confidential database of trained Parent Mentors as well as parents receiving support. Coordinators educate Riley Hospital staff and families about parent-to-parent support opportunities and provide support to Parent Mentors.

PROGRAM CONTACTS

Medical Team

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PARENT MENTOR

Volunteer Position Description

Coordinators: Director of Pediatric Gastroenterology **Phone:** 317-944-3774

Location: (Steven Steiner, M.D./Pediatric Gastroenterology) 705 Riley Hospital Drive, ROC 4210, Indianapolis, IN 46202

Purpose: To offer supplemental peer-to-peer support to parents and guardians of children with special healthcare need(s) receiving services from Riley Hospital for Children.

Qualifications:

- Have experience as a parent of a Riley patient at least one year post diagnosis
- Strong communication and listening skills (with special sensitivity to parent concerns)
- Willing to accept training and supervision
- Have working knowledge of Riley Hospital for Children and programs as well as available community and state resources
- Possess the emotional stability and maturity to address difficult/stressful situations
- Have a positive attitude in working with diverse populations
- Able to accept differences in perspective and choices that others may make

Training Requirements: Parent Mentor orientation provided by hospital staff with additional training or coaching as needed.

Description of Duties:

1. Attend recommended training and in-services related to your position
2. Initiate contact with referred family within 24 hours of referral
3. Offer peer support as appropriate and needed:
 - Listen and offer peer support to families
 - Facilitate interactions within the hospital system
 - Withhold judgment about family's decisions and/or choices
 - Provide support for families after discharge if mutually agreed upon
4. Complete and submit Contact Log and any other requested reports to Program Coordinator
5. Maintain appropriate confidentiality and boundary guidelines
6. Contact a Program Coordinator should any situation/concern arise that may be too difficult to handle

PARENT MENTOR

Roles and Responsibilities

Obligation of Parent Mentors:

Parent Mentors agree to follow all guidelines established in this manual. Any questions regarding policies or procedures should be directed to a Parent Mentoring Program Coordinator.

Code of Ethics:

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

Matching/Termination of Support:

- Every effort will be made to see that the family is referred to the appropriate Parent Mentor.
- If a match is not beneficial to the person requesting a Parent Mentor, or if the match is not comfortable for either party, the Program Coordinator should be contacted, and the match will end.
- Support may also be terminated when the issues of the current family go beyond the scope of the program. The decision to end support will be made by the Parent Mentor and the Program Coordinator.

PARENT MENTORS

What is Next?

- Complete an application providing information about their child's medical condition/experience. This information is maintained in a confidential database protected at Riley Hospital for Children.
- Receive specialized training before being asked to serve as a Parent Mentor to another parent.
- Will be called and asked to support a current family and if they agree, will be given the family's contact information.
- May share your contact information (email address/phone number) with the Current Parent if you choose, but the hospital will not give your contact information out.
- Agree to make a contact with the Current Parent within 24 hours of the referral. If contact is not made after 48 hours, notify the Program Coordinator.
- Maintain the parent-to parent relationship for a mutually agreed upon time.
- Maintain appropriate confidentiality and boundary guidelines.
- Contact a Program Coordinator should any situation/concern arise that may be too difficult to handle or is beyond the scope of the IBD Mentoring program.

GUIDE TO PATIENT CONFIDENTIALITY

What is confidentiality?

Respect for the secret or private matters of patients, families and staff members.

What is HIPAA? *Health Insurance Portability and Accountability Act*

- A set of rules established by the Federal Government that must be followed by health care providers
- Provides a way to increase privacy and security of individual health information

What is confidential information or *Protected Health Information (PHI)*

- Names and Addresses
- Phone Numbers
- Insurance information
- Patient ID bracelets
- Medical history and any other medical information
- Computer passwords and e-mail addresses
- Admission status and/or condition of patient(s)
- Census sheets and/or appointment lists w/patient information

Why is confidentiality important?

At Riley Hospital for Children, we promise patients and families that their private information will stay private unless it is important to their care and safety. We make the same promise to all staff members and volunteers. We want to keep our promises.

If I leave out the patient's name when I talk about someone, isn't that enough?

No. Sometimes so much information is shared the name can be identified later.

We break our confidentiality promise:

1) When a conversation with confidential information is overheard by someone who does not need to know. This can happen while talking:

- on the telephone
- in a hallway
- in elevators
- on the shuttle bus
- in the Cafeteria or Gift Shop
- anywhere in the unit or clinic
- in an office with the door open
- in the lobbies

2) When patient ***census sheets, patient appointment schedules***, memos, interoffice mail or printed e-mails with confidential information are left where someone who does not need to know can read them:

- on countertops
- in lounge areas
- in the trash
- in computer printers
- in copy machines

- 3) When an e-mail or Internet web-site includes confidential information that can be seen by someone who does not need to know.
- 4) When a famous person has a child in our hospital and we visit their room, go along on a tour, or ask for personal autographs or favors without permission.
- 5) When a Riley employee or volunteer has a child in our hospital and we visit their room or read their child's medical record without permission.
- 6) Any time gossip or rumors are started or shared with others.
- 7) Deliberate breach of patient confidentiality is grounds for immediate termination.

HOSPITAL CONFIDENTIALITY

Hospital Volunteers shall strive to maintain the confidentiality of patient and other confidential information in accordance with applicable legal and ethical standards.

Hospital Volunteers come in contact with a broad variety of confidential, sensitive and proprietary information. Inappropriate release of this information could be injurious to individuals, the Hospital's business partners and the Hospital itself. Every Hospital Volunteer has an obligation to protect and safeguard confidential, sensitive and proprietary information in a manner designed to prevent the unauthorized disclosure of information.

Patient/Family Information

All Hospital Volunteers have an obligation to conduct themselves in accordance with the principle of maintaining the confidentiality of patient and family information in accordance with all applicable laws and regulations. Access to patient care information is limited to physicians and other healthcare providers directly involved in providing services to that patient. Hospital Volunteers shall refrain from revealing any personal or confidential information concerning patients or family members unless legally required or there is a valid release for patient care purposes. If questions arise regarding an obligation to maintain the confidentiality of information or the appropriateness of releasing information, Hospital Volunteers should seek guidance from the Mentoring Program Coordinators.

Proprietary Information

Information, ideas and intellectual property assets of the Hospital are important to organizational success. Hospital Volunteers should exercise care to ensure that intellectual property rights, including patents, trademarks, copyrights and software are carefully maintained and managed to preserve and protect their value.

Confidentiality of Information

As providers of health care, Hospital Volunteers who have access to confidential information concerning patients or confidential information regarding other Hospital employees, must conduct themselves in a manner which will maintain the confidentiality of such information. Hospital Volunteers will only access information that they need to know in order to perform their duties and responsibilities as set forth in their position description. Hospital Volunteers will not reveal any personal or confidential information concerning patients, employees, Medical Staff members or others unless it is done pursuant to proper written consent or through other appropriate legal channels.

PROFESSIONAL CONDUCT¹

Parents who volunteer their time to help other parents are expected to act in a professional manner whenever they are representing the hospital in person or on the phone. When visiting another family in person at the hospital:

- Wear clothes designated by the hospital as appropriate.
- Observe hospital policy, signs, and any patient specific instructions.
- Do not bring anyone else with you to the visit.
- Do not give gifts or money to the family/patient.
- Do not accept gifts of any kind. If any are offered, thank the family and explain that gifts are not permitted by the program.
- Avoid eating, drinking or chewing gum during the visit.
- Do not use your cell phone while you are with the family. Keep your phone on 'silent' or 'vibrate', do not accept calls and do not take any pictures.
- Wash hands when entering or exiting an exam room or patient room.
- Leave the room if a doctor or medical professional comes in to speak with the family.
- Use names rather than "mom" or "patient" when speaking with a family and always introduce yourself.
- Be considerate of the family's emotions. Every situation is unique as are the family's reactions.
- Arrive for your visit a little early so you appear ready for the family.
- Share with the family how long you will visit with them and be respectful of that timeframe.

¹ *Volunteer/Visitor Handbook: Center for Pediatric and Adolescent Inflammatory Bowel Disease (IBD Center)*. 2013. Nationwide Children's Hospital. Columbus, OH: 2-3.

WHAT A PARENT MENTOR DOES

- ✓ Respects the confidentiality of the relationship.
- ✓ Provides a listening ear, allowing the family to express honest emotions.
- ✓ Listens with acceptance, remaining open-minded and non-judgmental.
- ✓ Answers questions honestly.
- ✓ Offers encouragement, emotional support and information.
- ✓ Guides the family in learning how to make informed responsible choices. A Parent Mentor offers guidance and direction as needed, but allows the person to make his/her own decisions.
- ✓ Keeps the conversation focused on the family's feelings and perception of their situation.
- ✓ Urges the family to discuss any concerns about quality of care or services with the professional(s) providing the care.
- ✓ Shares examples of coping skills.
- ✓ Calls a Program Coordinator if there are concerns about any aspect of the parent-to-parent relationship.
- ✓ Informs a Program Coordinator if it is not convenient or a good time to serve as a Parent Mentor.

WHAT A PARENT MENTOR DOES NOT DO

- ✘ Does not give medical advice.
- ✘ Does not give advice regarding diet, treatment, and any other personal choices.
- ✘ Does not provide:
 - Personal services (babysitting, transportation, etc.)
 - Money or tangible items (gifts, food, clothing, etc.)
- ✘ Does not give opinions on specific doctors, nurses, hospitals or other professionals. Remember that different people interpret the same professional differently.
- ✘ Does not refer to other families by name and should never discuss the identity of another Parent Mentor or IBD Family with anyone other than the Program Coordinators.
- ✘ Does not serve as a psychologist, social worker, or crisis counselor.
- ✘ Does not agree to be available 24 hours a day, 7 days a week. The Parent Mentor should set limits on their time and availability.
- ✘ Does not accompany the family to any doctor's appointments.
- ✘ Does not offer to set up medical appointments.
- ✘ Does not suggest or arrange for second opinions.

SUPPORTING THE WHOLE FAMILY

Support can come from many different kinds of sources:

- *Family Supports* - partner, spouse, members of family
- *Social, Community Supports* - neighbors, friends
- *Peer Supports* - those with similar experiences
- *Spiritual Supports* - religious-based supports
- *Medical Professional Supports* - physicians, nurses, social workers, teachers, therapists, counselors

Supporting Mothers

Often, mothers simply need opportunities to verbalize their thoughts. As a mentor you can help them by:

- Letting them share their feelings with someone in a non-judgmental atmosphere.
- Give them the opportunity to discuss things with a peer rather than a spouse.
- Provide information about resources in how to handle their concerns.
- Reassure mothers everyone copes in a different way and all of them are appropriate.

Supporting Fathers

On the surface, it may seem hard to offer specific support for fathers. As a mentor you can help them by:

- Offer them resources to read about their child's condition.
- Connect them to another father for some peer support. Fathers often do well with other fathers who have been through similar situations.
- Ask what they would find helpful.

Supporting Single Parents

Single parents often do not have a partner to offer support and share decision-making. You can help them best by:

- Acknowledging the situation and how stressful it may be.
- Help them identify people or groups who might provide additional support.
- Connect them to social service resources if appropriate.

Supporting Grandparents

Grandparents often need much support, but have few opportunities to receive any. Help them by:

- Tell them their feelings about their grandchild and their child are normal and expected.
- Give them an opportunity to share any crisis experiences of their own.
- Give them permission to take care of themselves, for they may try to do it all.

Supporting Siblings²

Siblings need support on their own developmental level. They need information about what is happening offered in ways they can understand and process.

Preschool Age Children (3-5 years old)

Perceptions

- This age is egocentric and may feel that their sibling's illness is a result of something that they did, a thought they had, or a punishment
- May be fearful that they will catch the disease
- Have a very active imagination and will have own ideas of what they see and hear about their sibling and hospital environment
- Children this age are unable to express their feelings verbally but will express them with changes in their behavior

Behaviors

- Regression
- Bed wetting or wetting pants during the day
- Changes in sleep patterns or routines, bad dreams
- May ask same question many times
- May appear detached or unaffected
- Clinging behavior
- Whining
- Acting out/anger toward primary caregivers
- Physical and verbal aggression

School Age Children (5-11 years old)

Perceptions

- Children this age may hide their feelings to avoid appearing "babyish"
- May appear able to restate complicated medical terms related to the patient's condition and ask concrete questions but may have misconceptions about their sibling's illness
- Children this age want to protect others from feeling sad
- May think they have caused their sibling's illness because of something they did, said, or thought
- May express their feelings through behaviors rather than words
- Understand order of actions and sequencing
- Fears of the unknown

Behaviors

- Regression
- School problems, unable to concentrate, forgetfulness
- May act like nothing is wrong with their sibling

² *Volunteer/Visitor Handbook: Center for Pediatric and Adolescent Inflammatory Bowel Disease (IBD Center)*. 2013. Nationwide Children's Hospital. Columbus, OH: 12-15.

- Nightmares
- Anger expressed in a variety of ways; may seem to be expressed at a time that seems unrelated or out of place
- May express jealousy about special treatment, attention or gift the ill child is receiving

How Can You Help?

Family members may need guidance in giving explanations to siblings that are age-appropriate and consistent. Suggestions on how to cope with behavior problems related to the crisis may be useful. Here are some suggestions that you can provide the parent or caregiver:

- Try to maintain as much of the child's normal routine as possible.
- Provide reassurance that just because their sibling is ill, they won't necessarily become ill.
- Let the child know that it is not their fault that their sibling is sick. Nothing that they did, said or thought caused the illness.
- Identify other family members who can provide extra attention to the child while the parents are at the hospital.
- Provide some consistency. Use tools like a calendar for the child to see the schedule and who will be caring for them.
- Provide play opportunities, physical outlets, or even play with medical equipment.
- Make special time for the child with all attention focused on them; can be as simple as reading a book together, playing a game, or eating a meal together.
- Keep communication open within the family and encourage open expression of feelings.
- Please refer to information in the resource section about community and hospital resources available for siblings.

LISTENING TECHNIQUES

Listening is a skill, not a natural art. It is 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.

Common listening mistakes:

- Long windedness
- Asking too many questions
- Inaccurate empathy
- Ignoring or discounting parent's feelings
- Pretending to understand
- Moving too fast or not moving along at all
- Making value judgments

How to be a better listener:

In order to understand the speaker it is necessary to pay attention and hear what they are saying. A good listener will pay attention to the words being spoken and the non-verbal cues. There are a number of strategies to help you listen effectively.

Paraphrase

Paraphrasing involves restating or rewording another person's verbal communication. It is a way to convey we are listening and understanding.

Reflect Emotions

When you reflect the emotions of the speaker you convey understanding of his emotional state. Body posture, vocal inflection, facial expression, all can reflect emotion.

Use open ended questions

Asking a question that requires more than a one word response will give you a more informative answer. Open ended questions usually begin with why or how. Closed

ended questions (beginning with who what when where or did) only require a one word answer.

Silence

Allowing for brief silences or pauses in conversations give the listener and speaker time to reflect on what is being said. It encourages the speaker to continue talking even when the topic is emotional. When in doubt use the 80/20 rule, let the parent talk for 80% of the time while you talk for 20%.

Clarification

Ask the speaker for clarification when you do not understand what is being said or you are not sure of the intended meaning. One way to get clarification is to ask them to repeat their statement. Another is to ask them to give you an example. Pay attention to the intensity of the words used and the non-verbal cues. Show you are engaged with the speaker. Maintain eye contact and an open posture, do not try to multi-task, nod to acknowledge you have heard them.

Summarize

Briefly highlight the main topics that the speaker discussed with you. This gives you the opportunity to point out the main issues, ensure you understand and show the speaker you were listening.

Things to avoid

- Interrupting
- Being defensive
- Focusing on yourself
- Giving advice
- Noise and distractions
- Jumping to conclusions (making assumptions)
- Trying to convince the speaker of your point of view
- Negative feelings toward the speaker, or the views being expressed

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

- Richard Moss

QUESTIONS ABOUT BEING A SUPPORTIVE LISTENER

As a Parent Mentor, you have something unique to offer other parents. You have experienced the fears, concerns, and ups and downs of a parent in crisis. This section addresses some question you may ask yourself.

What is my role as a listener?

Healthcare professionals provide medical supports and as a Parent Mentor, you provide support through empathy. Some things you might empathize with:

- the tension of not knowing how their child will be
- the stress of being physically separated from their child
- the feelings of being overwhelmed by the hospital environment
- the exhaustion from making trips back and forth to the hospital or the discomfort of staying in the hospital for long periods of time
- the possible feelings of isolation from others
- the difficulties of juggling the care for other siblings
- the possible stress of not feeling in control of their child's care

Being an effective listener so that a parent can express their feelings freely is all that is needed from you. An important benefit of good listening is that it can help the person get to the heart of the problem, instead of focusing only on one part. Finally, by actually voicing a concern, the parent may be in a better position to solve the problem. "Just" listening can be the most valuable service you perform.

Should I share my own experiences?

When a parent voices a concern, the listener may include some of their own ideas. There is a fine line between sharing experience and giving advice. The exploration of ideas is not the same as giving advice; in the exploration of ideas, you are on equal footing with the parent. The parent suggests some options and you may suggest some others. You are neither assuming responsibility for the problems nor are you the one who receives credit when the solution is found. The key is that once available options are explored, the parent makes the final decision. You listen and encourage, but don't give advice.

Some examples of the difference between giving advice versus sharing experience:

1. **Situation:** It has been recommended to the parent that their child begin a biologic medication.
Giving Advice – "This is a "last resort" treatment. If the doctor recommended this medication, you better start your child on it as soon as possible."
Sharing Experience – "I understand that this is a difficult decision. When we started a biologic, I had a lot of questions too."

2. **Situation:** The parent is questioning whether they should receive a second opinion from a different doctor.
Giving Advice – “You should go to see Dr. Smith. She is the best IBD doctor in the area.”
Shared Experience – “You are your child’s best advocate. You are certainly entitled to seek out a second opinion and have every right to do so.”

3. **Situation:** Relatives have told the parent that just by changing the child’s diet, it can cure their IBD.
Giving Advice – “The Specific Carbohydrate Diet is amazing. You should definitely put your child on it. I can guarantee you will see an improvement.”
Shared Experience - “Sometimes eating particular foods or even eating in general may result in increased symptoms, but this is different for every patient. We found it helpful to keep a food journal to understand the connection between how our child was feeling and what food he/she was eating.”

How do I keep the focus on the parents’ concerns and needs?

As much as you might want to talk about your child and your experiences, it is important to keep the focus on the parent and their child. Try to determine if it would be more helpful for them to listen or to talk. It will vary from parent to parent and from situation to situation. Be sure to give each parent ample opportunities to talk through his/her concerns. Always remember the 80/20 Rule, let the parent talk 80% of the time.

How do I deal with feelings and memories that may arise?

You may find that old memories and feelings surface by talking with parents. You may have anticipated some of these feelings or you may be taken by surprise. Regardless, you may feel a real need to talk with someone about memories and feelings. It is more appropriate to talk with another Parent Mentor or the Program Coordinators regarding these feelings. If these experiences are too difficult and you feel that you cannot continue as a Parent Mentor, tell a Program Coordinator.

SOCIAL MEDIA

There has been an explosion of technological options for people to connect and communicate with one another. When using the internet and social networks there are some common courtesies and guidelines to follow.

- You are responsible for the content you personally publish. Be mindful that what you publish will be public for an indefinite but lengthy amount of time.
- Take steps to protect your privacy and the privacy of those you connect with.
- Identify yourself.
- Clarify you are not a spokesperson for an organization (IU Health/Riley Hospital for Children).
- Maintain the confidentiality of patients and families.
- Respect copyright, fair use and financial disclosure laws.
- Do not provide another's confidential or proprietary information.
- Don't cite or reference patients, families, providers or suppliers without prior written permission.
- Respect your audience.
- Maintain professionalism.
- Avoid participating in inflammatory discussions.
- Do not give medical advice.
- Try to add value.

CULTURAL AWARENESS

Culture has been defined as a set of learned beliefs and behaviors shared by a group of people. More accurately, culture includes shared values about living with and reacting to others. It encompasses communication and language, customs and rituals, ways of interacting and relationships, status in terms of economics, gender, education, occupation and practices concerning health and wellbeing.

As the population in the United States becomes more and more diverse ethnically, racially, socially, economically and educationally, being aware and respectful of the variations in culture becomes more important. In health care especially, an understanding of families' cultural beliefs and practices is crucial.

How do we become culturally competent?

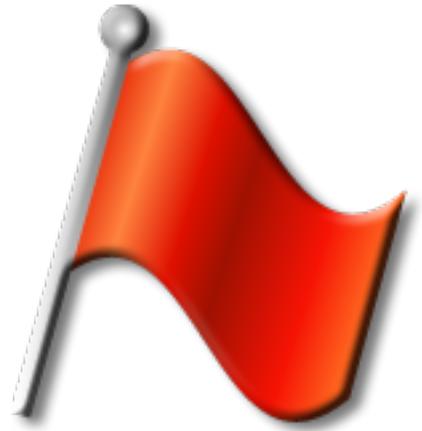
It may not be possible to be truly 'culturally competent'. We can strive to be culturally aware. Either way, it is an ongoing process unique for each person. First and foremost, we must understand our own cultural, ethnic and language background. What beliefs do we hold about those who are different than we are? Next, we must appreciate each individual is unique. People cannot be defined only by their cultural group. Stereotyping is ineffective and even harmful to the development of positive relationships. Finally, in order to work effectively with families, we must be respectful of the differences of others rather than judgmental.

The single most effective strategy for working with those of different backgrounds is simply to ask them what would be helpful to them at this point in time. It may not be what we would find helpful. Accepting their choice is the beginning of cultural competence.

CRISIS SITUATIONS

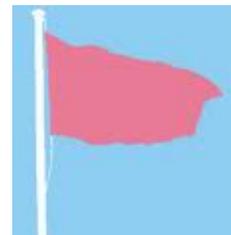
RED FLAGS

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, "These concerns are very serious and I will need to share them with my Program Coordinator." Then call a Program Coordinator!



PINK FLAGS

These situations can be handled differently, but will need to be monitored as well. This might include conversations indicating spousal conflict, depression, disconnection of utilities, etc. In this case, we can help you direct the family to necessary support services at Riley Hospital for Children.



EMERGENCY HELP

In rare circumstances, you may want to contact Riley Hospital professionals for assistance. Social Workers and Chaplains have a professional on call 24 hours a day, 7 days a week for such emergency situations. In these situations, contact a Program Coordinator who will contact the appropriate resources (chaplaincy, social work, etc.).

SUPPORTING FAMILIES IN CRISIS

Our biggest job as Parent Mentors is finding ways to support families in crisis. Crisis is defined as a point when a person has experienced a significant loss and must find a way to recover and adjust to that loss. The loss does not have to be a death; loss can be anything a person plans for, dreams about, or deeply wants.

Support is needed in times of crisis to accomplish five tasks:

- to provide a non-threatening avenue to receive information, and ask needed questions
- to allow communication of thoughts and feelings
- to “normalize” the experience
- to offer solace and comfort during painful periods
- to provide a socially-acceptable link between the family and community

STAGES OF CRISIS

Shock and Numbness

This is characterized by a general haze, a dulling of the senses, inability to articulate needs and make decisions.

- This is a time when family members need much physical support for their own health and safety needs. They may need someone to remind them to eat and get enough rest. They may also need transportation assistance, from a family member or friend, because they may be too preoccupied to drive safely. However, this assistance should not come from you.
- Communication needs to be simple and direct. Questions may need to be easy to answer, yes/no types of questions. They may not be able to carry on conversations. Decision-making may be difficult, for the family may not be able to process the information to make strong decisions. Sometimes an interested party, such as a friend or family member, can help by listening to doctor’s explanations with the family, and helping the family later to digest the information. Written information may also be helpful, so the family can review it on their own time frame.
- It is important that family members know the emptiness that they feel is a normal part of crisis; that is the body’s way of protecting them from overwhelming emotions until they are ready. It is also essential to point out that this numbness will subside soon.

Searching and Yearning

This stage is characterized by increased emotions, especially anger, guilt, and confusion, and much questioning in order to define reality.

- A nonjudgmental “listening ear” is a most important support at this time. Those involved in the crisis need someone they can talk to in order to verbalize new emotions, especially someone who can relate to those feelings and reassure them that they are in a normal process of coping.
- Parents still need help in formulating the questions they have and in finding sources to get their questions answered. They may need encouragement to talk with hospital personnel about their concerns and feelings. Support persons can also help families in this period by guiding them to other kinds of informational resources such as books and other parent groups.

Disorientation

This is a time of increasing awareness of reality, related stresses in other areas of their life, and occasional depression.

- Especially in the disorientation period, parents need reassurance that this confusing period is a normal part of coping.
- Those involved may feel very frustrated about the amount of stress in their lives, and may not see it as relating to their current crisis. They need help at times to see the connection, and understand that it will improve. They may need encouragement at this time to maintain supportive relationships with those around them, especially with their partner.
- Families may need additional support in sorting out and handling other kinds of conflicts, such as marital, child behavior, substance abuse, depression, etc. For some families, this may mean seeking out professional counseling.

Reorganization

This is a period of renewed energy, calm and control in their lives once again.

- The need for support gradually decreases at this time. Families need continued reassurance that during stressful times, when feelings and discomfort may reoccur, supports will still be there.

PARENT MENTORING PROCESS

Families who wish to be mentored are required to complete a consent form, giving personal contact information, at the time they receive a Parents Helping Parents binder from their GI doctor. A Riley GI doctor can also contact the Parent Mentor Coordinator and directly request that the family be contacted. The patient's name, age, sex, and diagnosis are confidentially passed along to the Riley Program Coordinator. Patient details allow us to make the best match between a family and a Parent Mentor whenever possible. In the event of a specific request, a flare up, or medical emergency, it may become necessary for a mentor to meet with the parent/guardian at a clinic visit, infusion center, hospital, or another agreed upon public place.

The Riley Parent Mentor Group is a team of volunteers that are training to provide these services. We welcome participation in one or both of the following services;

Referral Mentoring

- Riley Program Coordinator sends confidential referral to Parent Mentor Coordinator
- Parent Mentor Coordinator assigns new referral to a Parent Mentor
- Parent Mentor makes contact by phone or email, whichever is most effective at reaching new referral
- Parent Mentor uses contact log form in binder to track conversations with referral family
- Parent Mentor reports contact dates on Google Doc spreadsheet
- Status of new referrals discussed at Parent Mentor Group monthly meetings

Clinic Mentoring

- Clinic Mentor Coordinator assigns date for clinic mentoring to a Parent Mentor
- Clinic Mentor Coordinator relays number of IBD patients to Parent Mentor prior to clinic
- Parent Mentor arrives on time wearing Riley Identification Nametag
- Parent Mentor volunteers from a designated area giving support and resources to IBD patient family
- Parent Mentor distributes Parent Helping Parents binder, binder survey, and mentor survey when applicable

Mentoring Resources

- Parents Supporting Parents IBD Parent Mentor Handbook
- Patient Binder – Patient Helping Parents
- Google Docs – link sent when referral assigned
- Survey Monkey – Used to get parent mentor and binder feedback
- ibdpmg@iupui.edu – general Parent Mentor Group email address
- List of Program Contacts – provided in this binder

PARENT MENTORING

Things to Remember

Things to think about before accepting a match

- Do you have time to support another parent at this time?
- Do you have emotional energy to devote to another parent at this time?
- If your values are different from those of the referred parent, will you be able to set aside those differences to address the concerns of the referred parent?

Things to keep in mind when calling on the phone

- Make your calls when you have plenty of time and are not distracted.
- Introduce yourself as a Parent Mentor from Riley Hospital for Children.
- Ask if it is a good time. If not, ask when would be a good time to call again.
- Prepare some brief non-threatening conversation starters just in case.
- Keep the focus on the referred parent.
- Use sensitive, person first language.
- Use the correct terms for the diagnosis.
- Ask for clarification for terms that are unfamiliar to you.
- Refer to child by name.
- Remember to focus on positive attributes of their child.
- Ask about other family members.
- Ask open-ended questions.
- Plan to spend more time listening than talking.
- Validate the other person's feelings.
- Avoid giving advice.
- Suspend judgment.
- Help parents feel good about what they are doing well.
- Summarize or paraphrase what you think was said
- Ask if you can call the parent back and establish a date and time.
- MAINTAIN CONFIDENTIALITY!

Things to avoid

- Don't feel that you should have all the answers.
- Don't say that you know how a parent feels.
- Don't compare children.
- Don't encourage dependence by doing everything for the referred parent.
- Don't use incorrect or insensitive terminology.
- Don't give false hope.
- Don't be critical.
- Don't overload the parent with too much information.
- Avoid asking questions about sensitive topics.

When to call for help

- If personality or value differences interfere with your effectiveness.
- If the referred parent's negative emotions are directed toward you making it too difficult to provide support.
- If you feel the referred parent's needs would be better met by a different Parent Mentor.
- If you feel unable to cope with the issues brought up.
- If you feel the new parent needs professional counseling.
- If you need additional information.
- If you no longer have time to devote to the match.

Who to call

Kim Shelly, R.N.

Quality Improvement and Clinical Research Coordinator

Pediatric Gastroenterology

Riley Hospital for Children

Phone: 317-944-3774

PHONE CALL TIPS

Introducing yourself over the phone:

Example - "Hello, This is *Mary* from the Parent Mentoring Group at Riley Hospital for Children. Your name and number was given to me by the GI Clinic. I understand that your child was recently diagnosed with Crohn's/UC. I have a son/daughter with Crohn's/UC as well. I'm calling to see how things are going and if you have any questions or concerns. Is this a good time?"

Make a total of 3 attempts to reach the parent:

1st call – should be made within 24-48 hours of receiving the referral. If the parent does not answer, leave a brief message as follows, "Hello, this is *Mary* from the Parent Mentoring Group at Riley Hospital for Children. Your name and number was given to me by the GI Clinic. I'm calling as a parent of a child with IBD to see how things are going and if you have any questions or concerns. My phone number is xxx-xxx-xxxx."

2nd call – If you do not hear from the parent, a second call should be made 3-5 days later. If there is no answer again, leave the following message, "Hello, this is *Mary* from the Parent Mentoring Group at Riley Hospital for Children. I'm following up to see if you have any questions or concerns that you would like to discuss. My phone number is xxx-xxx-xxxx and my email is name@email.com."

3rd call – should be made 2 weeks after the initial call. If no answer again, there is no need to leave a message.

When and How to Call

- Call when you can give the parent your undivided attention and can be relaxed and free to talk at length, if necessary.
- Call at your earliest convenience after receiving a referral (within 24 hours).
- If you feel cautious at first, remind yourself that this person has **REQUESTED** your call! He/She will be looking forward to the contact.
- If you have difficulty reaching the parent, try calling at different times of the day. If contact cannot be made within 48 hours, notify a Program Coordinator.

How to Close a Call

- Give parent your name again as well as any contact information (i.e. email or phone numbers) that you feel comfortable sharing.
- Establish a time to follow up. If no specific timeframe presents itself, ask permission to follow up in six months.
- Let them know that they can contact you if they need support.
- Some parents don't respond well – don't take it personally – they may be more open next time.

- Document calls, make notes, and schedule a date to make a follow-up call. The IBD PMG used a Google document to track contacts. Please update your call information on that site as well.

Future Contact - Conversation Starters

Review any topics that were discussed in the initial call that seemed to concern the parent. This is where your call log can be helpful for your own use.

Focus on parent

- How have things changed since we last talked?
- How are you feeling and coping with the current situation?
- Are you taking care of yourself and your needs

Focus on other family members

- How is your spouse doing now?
- How are siblings coping with the experience?
- What is helping/not helping?
- How are parents arranging working and hospital visits?

Focus on hospital/clinic situation

- Are parents comfortable with hospital staff and routine? If not, have they expressed concerns to the hospital?
- Do parents understand the treatment/medication protocol? Encourage parents to ask questions.
- Is there a tool or information that would make their experience easier?

Focus on child (always use name)

- How are they feeling (both mentally and physically)?
- How are they functioning at school?
- Do they have any question about their diagnosis that you are unable to answer?



Riley Hospital for Children

Indiana University Health

PARENT MENTORING CONTACT LOG

Date _____ Mentor Name _____

Child's Name(s) _____

Child's Age _____

Parent(s)/Caregiver(s) Name _____

Siblings _____

Phone _____

Email: _____

Best Time to Contact _____

Special concerns:

Tips for phone contact (refer to script):

Introduce yourself

Is this a good time talk? If not, when can you call back?

(1st call) Briefly explain your role

Conversation starters:

How are you feeling today?

How is _____ (child's name) doing?

Conclusion:

Share your name and phone number or email (optional)

Remind parent that you aren't a social worker, just another parent

Make a date for a follow up contact and preferred method (phone/email)

Date _____ Type of Contact _____ Number of minutes _____
Notes:

Date _____ Type of Contact _____ Number of minutes _____
Notes:

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Notes:



Riley Hospital for Children

Indiana University Health

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Phone _____

Email: _____

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Date _____ Type of Contact _____ Number of minutes _____
Notes:

RILEY HOSPITAL RESOURCES

Parking

Patient drop off and pick up for both the Simon Family Tower inpatients and the Riley Outpatient Center patients are at Riley Hospital Drive. Garages are located adjacent to each. The Riley Outpatient Garage is owned and operated by Indiana University Purdue University Indianapolis. The Simon Family Tower Garage is owned by IU Health. All garages are accessible to people with special parking needs including wheelchair and over-sized van accommodations. Parking fees are posted at each garage. IUPUI garages are fully automated with payment by cash or credit card required at automated pay stations.

Each inpatient family receives two free passes to the Simon Family Tower parking garage. There are unlimited in and out privileges. Passes cannot be replaced if lost and are renewed every Monday at hospital information desks. Riley Outpatients may park in the Simon Family Tower for a flat rate of \$2 per visit if they have their parking ticket validated in the clinic they are visiting. IU Health cannot validate any parking for University owned garages (Riley Outpatient Center Garage and Wilson Street Garage).

Volunteers at Riley Hospital are provided one parking voucher each time they volunteer at the hospital. The voucher allows them to park at no charge in the Riley Outpatient Center or Wilson Street Garages.

There is free valet parking available to families who bring a child to the Riley Hospital Emergency Room.

More information about parking can be found at <http://iuhealth.org/riley/for-patients-and-families/parking/>

Child Life

As part of Riley Hospital for Children at Indiana University Health's health care team, the Riley Child Life Program at IU Health seeks to minimize the stress and anxiety children often experience by using therapeutic activities that address patient and families social, emotional, and educational needs during hospitalization. They can help children learn about their upcoming procedure and correct misconceptions children may have about procedures by using medical equipment. Through different distraction techniques Child Life Specialists are able to divert the child's attention from their pain and lessen anxiety.

Art therapy is a natural form of expression for children and adolescents. Creating art helps people of all ages make sense of and express their thoughts and feelings in a non-threatening way. A session with an art therapist can offer a patient the opportunity to make choices and gain control in an environment where they don't always have those

options. In a pediatric hospital setting art therapy is used to treat anxiety about medical procedures, depression, and psychosocial and emotional difficulties related to medical illness, trauma, and loss.

Contact the Riley Child Life Department for additional information at **317-944-8723**.

Child Life Zone

"A Child Life Zone is a state-of-the-art, therapeutic play area inside a hospital where pediatric patients and their families can play, learn, laugh, and relax. A sanctuary. A place to learn. A hang-out. A game center. A place to be the star of your own show. A place to connect. A place where a kid can be a kid."

Child Life Zones are created and funded by the Teammates for Kids Foundation, with Garth Brooks and Troy Aikman. The Child Life Zone at Riley Hospital for Children at IU Health is the 10th in the nation and is set to be the largest Child Life Zone to date! All Riley inpatients and outpatients are welcome in the space together: adults need to have a child and children need to have an adult when playing in the Zone. Hours of operation are Monday through Friday 10:00 AM-7:30 PM. (317) 948-0506.

Child Life Specialists are available in some outpatient clinics.

Family Resource Center

The Family Resource Center is designed to meet the needs of families whose children are patients at Riley Hospital for Children at IU Health. The Family Resource Center has a Ronald McDonald House, library, chapel and Family Education Center to support patients and families. It is located on the first floor, behind the atrium lobby.

Ronald McDonald House (inside Riley)

The Ronald McDonald House inside the hospital is open to inpatient families from 9 am – 9 pm, seven days a week. Its mission is to provide a home-away-from-home. Any parent, grandparent or legal guardian of an inpatient or outpatient with special circumstances is welcome. Passes for the house can be requested from the outpatient social worker. Because it is an area designed for respite and relaxation, patients are not allowed in the house. Within the house you will find a kitchen, food pantry, laundry, living area, books, toys, a quiet room, and six sleeping rooms. Meals are provided to families at no charge.

Block Family Library

The library is located on the first floor with entrances off Savannah Ave and from within the Family Resource Center. Patients and families can get materials and services like those at a public library. A librarian is available to help you find the information you need. Hours vary. Call (317) 944-1149 for more information. At the library, you can check out books for all ages, G/PG movies, CDs, Wii games and board games, access the Internet with print capability, watch closed-circuit

television or movies, find resources and information on medical conditions or support services.

Chapel

The chapel is located on the first floor within the Family Resource Center. Open 24 hours seven days a week. Non-denominational chaplains are available to anyone at Riley. Call (317)944-7415.

Education

The Family Education Center is located on the first floor near the library and chapel, classrooms 1504 and 1505. Trained educators help families learn new skills. It offers a quiet place away from interruptions at the patient's bedside. You can focus on what you need to know to care for your child at home.

As you practice and review, you feel more comfortable with the new skills and information, you gain confidence. Our goal is to help patients and families become independent. Education helps make that goal a reality.

Riley Labyrinth in a Garden

The Labyrinth in a Garden is located outdoors on the north-east side corner of the hospital near the Wilson Street Garage. A labyrinth is a single lane path that leads the walker to the center and back out again. Walking a Labyrinth can often calm people in the midst of crisis. The experience is different for every person because each one brings unique hopes, fears, concerns and celebrations to that moment in time. It is a reflective activity to renew the spirit.

Children with Special Health Care Needs (CSHCN)

The Children with Special Health Care Needs (CSHCN) Services Program provides supplemental medical coverage to families of children who have serious, chronic medical conditions. There are both financial and medical eligibility requirements for children birth to 21 years of age. On-site representatives are available to help families complete the necessary applications. Call (317) 944-3153.

Riley Safety Store at IU Health

Riley Safety Store at IU Health has more than 150 low-cost safety and family health products. Smoke detectors, bike helmets, outlet plug covers and sleep sacks are just some of the items available. The store's team members can show you products, teach you how to use them, and answer questions. The Safety Store is located on the first floor of the Riley Outpatient Center at IU Health (next to the Over the Rainbow gift shop) (317) 944-6565 or (888) 365-2022 (toll free).