



# Patient Family- Centered Care

## Family Talk Training Manual for Parent Advisers

# Family Talk

## Role Description

Parent advisers help to facilitate Family Talks by sharing stories and asking discussion questions of the parents/caregivers. The goal of the event is to ensure that families have a time to interact with other families during their time at St. Jude.

## The Basics

- ***What is Family Talk?***

Family Talk is an event where families are welcome to come and connect with other families at St. Jude in a casual setting. We provide a dedicated time and place to give caregivers the ability to meet with others to share their experiences or simply get to know one another.

- ***Why do we have Family Talks?***

We understand that being able to interact with other families can provide an irreplaceable source of support. Family Talk is a place to meet with other caregivers to discuss things related to a child's treatment, the stay at St. Jude, family, personal life, work, questions, concerns, etc.

- ***How often are Family Talks held?***

Family Talk tends to coincide with in person PFAC meetings but may be scheduled as needed.

- ***What is the time commitment?***

Approximately 2.5 hours. This includes the shift itself (2 hrs) plus the time needed to send a report and return supplies.

- ***Do I have to attend a Family Talk as a parent before attending/hosting one as a parent adviser?***

No, you are more than welcome to host a Family Talk whether or not you have attended one before. There will always be several parents signed up for each coffee talk. If it is your first time, feel free to sit back and listen to other parent advisers and then, jump in!

- ***Am I able to host a Family Talk if my child is still in active treatment?***

Yes, you are able to host a Family Talk no matter the status of your child

- ***How do we set up for a Family Talk event?***

*All supplies necessary for the program will be gathered by staff and ready to be picked up by you from the Family, Guest, and Volunteer Services office on the plaza level of the PCC the day of the event.*

In the supply cart provided, you will find a variety of items necessary for setting up the event.

- A large purple PFCC tablecloth is provided. Depending on the location, there may be additional smaller table cloths. Use them as you see fit.
- There is a confidential folder provided for you to place all completed E-Council applications in.
- Spread PFCC brochures and bookmarks out.
- Spread PFCC pens and mugs out on the table available for anyone to take.

*Some supplies may not be needed for every event depending on the event:*

- 2 Carafes of Coffee
- 1 Carafe of hot water for tea and/or hot chocolate
- Craft supplies may be provided to children to enjoy during the event at another table or area.

- **What duties are expected on the day of the event?**

- Review the Family Talk Manual to refresh yourself on the basics before the event. *Don't hesitate to contact us with questions! Our contact info is at the end of this manual.*
- Arrive at St. Jude at least 30 minutes before the event to pick up supplies from the Family, Guest, and Volunteer Services office. If the program is located off campus, allow additional time for the commute. Head to the designated location for set-up. Table and chairs should already be set-up for you at the site of the event.
- When the event begins, engage parents and explain Family Talk.
- Let potential participants know that all patient families are welcome. Families can come and go from the event as they like or stay for the entire length of the program.
- Be sure to introduce yourself and explain the purpose of Family Talk and parent advisers.
- Try and make sure parents walk away with some information about PFCC even if they do not participate.
- Let parents know about other upcoming events or services.
- If they are interested, you can invite caregivers to complete an E-Council application then place it in the confidential folder to give to the PFAC coordinator.
- Hand out Give-Aways to anyone who wants them including staff, children, and parents.
- Pack up the program supplies. If you are attending a parent meeting the next day, just bring the supplies with you and PFCC staff will return them to Family, Guest and Volunteer Services. You do not need to break down the table(s) or chairs.

## Hosting

The following are suggestions for encouraging conversations during a Family Talk event. Please feel free to refer to these as needed. You can spark conversations and allow them to flow organically. There is no set agenda for the event.

- **Introductions:**

- Include in your introduction, *"I am a St. Jude parent. I serve on the Patient Family Advisory Council. We ensure that the families' needs are included in the care of the patient."*

- **Opening Phrases:**

- *"Tell me about your St. Jude journey so far. How long have you been here?"*
- *"I am here to talk about whatever is on your mind. What you like to talk about today?"*
- *"Have you met any other families while you have been here?"*
- *"How are YOU doing? Are you getting rest and taking care of yourself? I know that is hard."*

- **Talking points for families:**

- Share information about PFCC Programs: St. Jude 101, PFAC, E-Council, etc.
- Ask them about their experience, where they are living, how things are going.
- Ask them about their child and their family, instead of focusing on their child's illness.
- As they are leaving, make sure to give parents some information about PFCC and how they can get involved.
- Invite them to complete an E-Council Application

- **Talking points for families of different cultures:**
  - Discuss how communication is going for them.
  - How has your experience here been? Is it what you expected?
- **Resetting the Conversation:**
  - Encourage dialogue, not debate with phrases like “*I understand you feel...*” and “*Let’s work together to think about this, maybe we can find a new perspective*”. **See Debate vs. Dialogue handout for details.**
  - “*I am hearing that you have a concern about... Have you tried talking to your care team about this?*” It’s important that we encourage families to advocate for themselves. Often times they have concerns that a staff member like social work or the medical team can address.
  - Another response could be, “*we actually have someone here that could help. Would you like to talk with them?*” You can then direct parents to someone (like Jim Mobley) from patient relations who will likely be attending the event. If you feel a parent needs to talk with someone, ask the parent if it is ok to bring someone over.
- **Closing Points:**
  - Thank them for coming (and for filling out an E-Council application if applicable).
  - Thank them for sharing with you. Tell them the impact their words have.
  - Provide giveaways when available.



***Jim Mobley, our patient relations coordinator, usually attends as a staff representative to listen to any major concerns. You can direct parents to him if they voice a concern.***

### **After the Event**

- We want to make sure to hear the family’s voice in these events. If a parent or caregiver you were talking with had concerns or things they appreciated, please write them down (manually or by email) and send them to [PFCC@stjude.org](mailto:PFCC@stjude.org)

### **Roles Limits**

- **Confidentiality/HIPAA reminder:**  
Family Talk is a time in which caregivers can share many things related to their child or themselves/their family, and we want to ensure that we respect their privacy and do not share any information with others outside of this meeting. Please take this as a friendly reminder of what we expect of parent advisers and why this matters to us and the families we serve.
- **Help others solve problems for themselves:**  
If you know what department or person can address an attendee’s problem, share that info. Otherwise, encourage the attendee to speak with their care team about problems they feel need addressing.

## Skills to Foster for Family Talk:

There are 6 basic skills one can implement during Family Talk conversations: active listening, using open ended questions, being comfortable with silence, using what you know, validating parent perspectives, and recognizing your limits and influence. Each of these skills is a tool that you probably already possess; you may already use them on a regular basis without ever knowing it. The purpose of teaching and reviewing these skills is to help you become more mindful of your impact during Family Talk. Applying these skills will help you feel prepared as you sit and chat with fellow parents.

### 1. Active Listening

Active listening involves listening for the meaning in what someone else is saying. It consists of three actions or skills: focusing, confirming and understanding content and emotion. It is an opportunity for the parent(s), to explore aloud what he or she is experiencing, thinking, and feeling, which can be therapeutic. Active listening is based on the premise that the best way to understand someone is to be fully present with them and to listen to their experiences. Active listening has been shown to create positive and strong relationships between people because it conveys acceptance for where they are in that moment.

\When someone else is speaking, their words often trigger thoughts about our own experiences and we are motivated to share those with the other person. However, when we engage in active listening, we try to grasp the other person's point of view and to show them that we understand what they are saying. We aren't trying to find a way to relate to them so that we can shift the conversation over to ourselves. We are simply trying to understand them and their feelings. When you think about it, active listening provides a unique experience for the caregiver within the hospital environment. Rarely are parents given the opportunity to talk to professionals about whatever is on their minds, and rarely are they allowed to talk without receiving advice or directions.

- Focus and listen for total meaning. Try to gain a good grasp of what the parent is saying (the content) and how they are saying it (the emotion or attitude behind the words).
- Use reflection or repetition to show that you are listening. Do this by summarizing, or paraphrasing what you've heard. Use statements like:
  - *"It seems/sounds as though"*...you've had a hard time organizing work and family after being inpatient unexpectedly.
  - *"From your point of view"*...St. Jude is doing everything they can for your child
  - *"From where you stand"*...you are feeling pretty confident about line care.
  - *"As you see it"*...your child has a pretty tough course of treatment ahead.
  - *"I can hear that you"*...are feeling frustrated that you have had to miss so much work lately.

Finally, attend to body language, both your own and that of the parent. Make good eye contact, be aware of nonverbal cues such as use of a cell phone, looking at a watch, crossing your arms as if you are closed off, etc. Maintain a comfortable distance and be relaxed and open. Use head nods, facial expressions, and gestures to convey understanding without interrupting.

### 2. Open-Ended Questions

Open-ended questions are one of the best ways to gain information from another person and add depth to the conversation. They also allow the fellow parent the freedom to provide as little or as much information as they see fit.

Open-ended questions also help you keep “assumptions” at bay because they are more objective and are less leading. Because of this, they result in meaningful answers that stem completely from the other person’s point of view, knowledge, and feelings.

Refrain from asking questions that can be answered with just a “yes,” “no,” or other one word response when you are trying to get information or start a conversation with a parent. Instead, use questions that begin with “why,” “what,” and “how” and intro phrases, such as “tell me about...”

*Here are some examples of open-ended questions you might ask:*

- *“How did you and your child end up at St. Jude?”*
- *“What has your experience been like so far in housing?”*
- *“Tell me about how you are coping with all of these changes in your life.”*
- *“Let me know more about your experience at St. Jude so far.”*
- *“What has been your cancer journey with your child to this point?”*

### **3. Being Comfortable with Silence**

This is perhaps the most difficult skill to master, but it can be the most important, particularly in times of significant distress and change. Sometimes doing nothing is your best option.

When you are silent, you:

- Communicate to the parent that they control the direction of the conversation
- Allow the opportunity to reflect on content in the conversation and to process things more deeply
- Convey interest and acceptance of what the parent is saying
- Acknowledge that sometimes there are no good answers to the problems that we face
- Provide the parent the chance to decide if they want to tell you more about a particular issue
- Help them to feel more comfortable opening up because you aren’t rushing them

*Some of the most common reasons we “over talk” are:*

- Discomfort with silence
- Fear that the parent won’t have anything to talk about
- Need to make a difference or to feel needed by the parent
- Need to “fix” an issue for a parent rather than empowering the parent to problem-solve

Even when being silent, validate what the other person is saying by using your body language to show you are engaged in the conversation

### **4. Using What You Know**

Parent advisers have a perspective that professionals will likely not have. “Using what you know” involves taking that unique perspective and applying it in constructive ways. You can do this by sharing stories, offering suggestions and recognizing patterns of “normal” adjustment.

Sharing stories in an effective way is more complicated than it sounds. Certainly, many parents become adept at telling their stories for many audiences but sharing your story within the context of a parent-to-parent relationship is fundamentally different, and it takes practice. Instead of “telling” your story, you are choosing to “use” your story. In doing this, you choose stories carefully and with purpose to help others.

Personal stories, when shared well and at the right time, can serve as a powerful tool to encourage and share hope with another person. They can be used to validate the other parents’ feelings and to provide concrete examples of how you solved a similar problem, how you might have solved it better or how working with various

hospital resources helped you and/or your child with a similar situation. It is important to clearly understand the purpose and intent of your message. Are you reassuring a newly diagnosed and frightened family? Are you providing encouragement to a nervous family as they prepare for their child's scans or surgery? Are you supporting a hurting family who is making difficult decisions about quality of life issues? Each of these circumstances requires a special understanding and sensitivity to know whether it is appropriate to share your story or not and what part of your story might be helpful to share.

Some parents may feel guilty as though they are being ungrateful if they are dissatisfied with something at St. Jude. To validate their feelings, you may want to share about a negative experience that you had while here as a parent. This is appropriate if you do so in a way where it is a constructive learning opportunity by emphasizing the positive. What did you learn from your negative experience that helped you or another person? If a parent starts to complain try redirecting the conversation and/or refer them to their Social Worker. Please make PFCC staff aware of this as well.

#### **Effective stories have 4 characteristics:**

1. They have a beginning, middle and end. They are easy to follow and have a basic story line.
2. They are brief, focused and relevant. They are individually tailored to the parent's current situation, and they don't take away from the time you could be spending engaging in active listening.
3. They are emotionally appropriate. When effectively sharing your story, you can expect that some people who hear it may be deeply moved. You may also feel emotional at times. Remember that emotions are an honest response to the reality of life circumstances. Vulnerability and openness make your story more powerful and you more approachable. They illustrate good problem-solving through partnering with staff OR they provide insight into how situations may have been resolved better. Your stories may help you redirect the parent to appropriate resources if and when needed. Your stories may also provide an opportunity to admit to your own mistakes and allow the parent to learn from them.
4. They end with an explanation of how your experience relates to theirs and provide a cue for the parent to resume the lead in the discussion.

Our stories are what define us as human beings and allow us to connect with each other. We encourage you to take some time to think about and/or write out your story before attending Family Talk.

Another way you can use what you know is to offer direct suggestions to the parent. Parent advisers can be particularly helpful when referring parents back to hospital resources and encouraging communication with staff. When offering suggestions, be certain that the parent feels empowered to make his/her own decisions. One way to ensure this happens is to ask permission before making a suggestion; for example, "May I suggest to you something that was helpful to me when we were going through something similar?" If the parent gives permission, offer the suggestion directly and clearly, and without placing demands or pressure. Steer clear of making suggestions or offering advice that references treatment protocols and medical care, specific staff members, breaking hospital or housing rules, or any issue that would be more appropriately handled by a trained staff member. If in doubt, refer them to their social worker.

#### **5. Differences in Parent Perspectives**

When serving as an adviser, it is important to remember that you are walking in similar, but still different shoes than the parents who may visit Family Talk. Be mindful of how your values and family culture may differ from that of the parent(s) and avoid judgment. Be respectful of differences in communication style, coping style, religion, family structure, parenting style, access to resources, beliefs about illness, etc. Notice when you feel uncomfortable during Family Talk or when you have the urge to interrupt. These are signs that you may have a

different perspective, value, or belief. Don't be afraid to ask the parent to explain his or her beliefs and values if it helps you to understand them better. However, it is extremely important that you resist the urge to "change" or "fix" if you find them operating under a perspective, value, or belief with which you disagree.

### **6. Recognizing Your Limits and Influence**

Discussions may elicit unexpected and powerful emotions for you. When this occurs, it is important to take time out to reflect on how and why you responded in that way. You may be more likely to give unsolicited advice or to make assumptions about what the parent is thinking or feeling. You may have more influence on the parent than you realize. They put trust in you in that moment. Focus on continuing to allow the parent to experience St. Jude as their situation will be different from yours

In summary, there are multiple skills that you can use as an adviser to facilitate the development of a healthy, positive interaction and to provide a valuable service to a St. Jude parent. While practice makes perfect, you will serve parents well by focusing on these key aspects: listening for meaning, conveying interest and acceptance, avoiding interruptions, using silence and stories and referring parents to appropriate St. Jude resources. If there are concerns, contact a PFCC staff person or Jim Mobley to debrief or seek advice about how to handle a specific situation.



## **Boundaries**

In working with fellow St. Jude parents, you will be taking on a role which is not professional nor that of a peer. As a parent adviser at Family Talk, parent participants will look to you to set the boundaries for the conversation. Lead by example and kindly redirect the conversation as needed.

### **Topics to avoid:**

- Medical advice-protocols, medications, etc.
- Stories or examples regarding another families' experiences.
- Advice that takes the form of a command rather than a suggestion.
- Do not share personal or social media contact information

### **Instead...**

- Try brainstorming questions parents can ask their care team or other staff instead of offering medical advice.
- Use your story and St. Jude experience rather than sharing the experience of others.
- Offer several options a parent can explore rather than dictating what they should do in a situation.
- Share an experience that you and your parent participant are both emotionally prepared for. You have emotional boundaries that you should respect. Your patient parent may have emotionally boundaries they have not shared. Mirror the level of sharing you see in the parent participant.
- Let the parent know how they can get a mentor or additional support rather than exchanging contact information.

***As a parent adviser facilitating Family Talk, you are stepping outside the bounds of previous parent to parent relationships you may have had at St. Jude. Consider what this may mean to you and what boundaries are important to you before your first encounter with another parent.***

Being mindful of role boundaries supports the autonomy of the parent. You are supporting them in finding their way in this new world of catastrophic illness. Boundaries also support the maintenance and development of other supportive relationships for the parent. Giving a parent your full attention, helping them clarify a concern, and redirecting them to a resource for assistance teaches them a procedure they can use repeatedly to utilize staff resources effectively and confidently.

### **Thank you!**

You have the skills to be successful as a parent adviser during Family Talk because you have lived this. Use this manual as a tool to help you but don't overthink things. We are thankful to have you and your expertise to help support our parents and caregivers during this time. Please don't hesitate to reach out if you have any questions or concerns.

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