



Welcome

Hello,

Thank you for your interest in being a Parent Mentor at St. Jude Children's Research Hospital. This workbook has been prepared by several St. Jude Staff members in multiple departments and is intended to be interactive as well as thought provoking. Please be aware, there may be some sections that will allow you to reflect back to the depths of your St. Jude journey. I recommend that you to take your time in completing this workbook and encourage you to break it up into sections; try not to rush through it. This may bring about feelings, emotions and memories that you may not expect. Please complete each question and exercise in this workbook as it will provide you with insight and prepare you for the upcoming mentor training. If at any time you feel that you need to process your feelings or thoughts, don't hesitate to contact me.

Thank you for the time you are putting into the program.
I look forward to meeting you at training,
Brittany

Brittany Barnett, MS, NCC, CAVS
Patient Family-Centered Care Manager
St. Jude Children's Research Hospital
262 Danny Thomas Place, MS102
Memphis, TN 38105
Brittany.Barnett@stjude.org
Office: 901-595-7560
Cell: 901-493-5993

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Logistics of Mentoring

There is a lot to cover in discussing how the mentor program works. This section will help you understand the “ins and outs” as well as your role in mentoring families.

The mission of the program is to provide the families of St. Jude Children’s Research Hospital with the unique understanding, encouragement, and support which only another parent who has walked a similar path can provide. Mentors are St. Jude parents who have been referred by a staff member, family at St. Jude or self-referred as someone who would like to give back to St. Jude by providing peer support and information on “navigating the journey” of treatment and medical care. Mentors provide a unique understanding, encouragement and support throughout the trajectory of care even into palliative care and end-of-life situations.

Parents who are being mentored are called mentees. Mentees can be referred by anyone at the hospital but are typically referred by the clinical staff and the psychosocial teams of each service. Following a referral, our lead parent, Betsy Lambert or a staff member personally extends the offer of a mentor to the potential mentee. Once the mentee accepts, Brittany will match the mentee with an available mentor per the parent’s specific concerns, needs and/or experiences. Typically, the match is based on the age of the patient in relation to the age of the mentor’s child when treated at St. Jude.

Preferably, specific diagnosis matching will be avoided in order to lower the risk of the mentor giving medical advice to the mentee based on their own past experience. This will also eliminate the risk of mentee comparing their medical team to that of the mentor’s. However, if a specific diagnosis match is made due to circumstances (lack of available mentor, specific parent request), it may be allowed. Preferably, BMT, QoL and H Clinic matches will occur within the same clinic if a mentor is available. In these cases, mentors must understand that giving any kind of advice regarding medical care, treatments or physicians is strictly prohibited and is grounds for termination.

After the match has been made, the family’s information will be sent to you through your St. Jude email address. In order to keep the patient and family’s information secure, this is the only way the information can legally be sent. Below is an example of a PAIR and QoL match form. Both forms are virtually the same but may have more or less information.

Note: The information below is used only as an example and does not represent actual families or patients.

PAIR Match Form

Patient Information

Patient Section

Patient MRN: 12345

Patient First Name: Jane

Patient Last Name: Doe

Preferred Name: Janie

Patient Gender: Female

Race: White

DOB: 1/1/2015

Age: 2 yo

Interpreting Services Needed: No

Housing Info: Tri Delta Place

Address: 1234 Street Ave. [This will be their home address. Not housing]

City: Denver

State: CO

Zip Code: 1234

Medical Information Section

Primary Medical Service: A Clinic

Primary Diagnosis: ALL

Date of Arrival: 11/19/16 [This is the approximate date the patient arrives at St. Jude.]

On Quality of Life Service? Yes [This does not mean that the patient is on palliative care, it simply means they are being followed by the service which can be due to many reasons.]

Care Team Section

Primary Doctor: Dr. Smith

Social Worker: Lois Lane

Mentee Information

Primary - Mentee Details Section

Relationship to Patient (Primary Mentee): Mother

Mentee First Name (Primary): Joan

Mentee Last Name (Primary): Doe

Preferred Phone Number (Primary): (123) 456-7890

Secondary - Mentee Details Section [This is only included if the other parent or another caregiver is involved. This is usually for information only.]

Relationship to Patient (Primary Mentee): Father

Mentee First Name (Primary): John

Mentee Last Name (Primary): Doe

Preferred Phone Number (Primary): (123) 456-7899

Recruitment Information

Concerns and Comments Section

Notes from Coordinator: [This information included in this section typically comes from the psychosocial rounds or from a staff member who is referring the family as a mentor.]

12/1/16- A Clinic Rounds: 2 year old with ALL. Intact family. Mom was overwhelmed during the assessment as her husband is at home with their 2 other children. She is feeling guilty about not being there for their upcoming Christmas programs at school and said that her oldest one is acting out. She reported feeling stressed about all the medical care and being here by herself. She relies on her faith heavily and has a good support system but she may be open to a mentor as well.

Recruitment Status Section

Referral Date: 12/1/2016

Referral Source: A Clinic Psychosocial Rounds

Recruitment Status: Accepted

Acceptance Date: 12/6/2016

Status Notes: [The information in this section is documenting who talked with the parent and when they said yes to a mentor.]

12/1/16- Betsy Lambert: I just called Mom and she said it was not a good time to talk. They were being discharged from being inpatient. I told her I would call her next week.

12/6/16- Betsy Lambert: I called to follow up with Mom and left a voicemail. She called me back and said she would like a mentor.

Enrollment Information

Enrollment Section

Enrollment Status: Active – PAIR

Enrollment Notes: 12/9/16- Brittany sent a note to mom along with the personal parent mentor card of her mentor.

Program Progression Section

Date of Match: 12/9/2016

First 12 Week Mark: 3/3/2017 [This is the date that the family would become inactive or re-enroll.]

QOL Match Form

Patient Information

Patient Section

Patient MRN: 12346

Patient First Name: Victoria

Patient Last Name: Wash

Preferred Name: Tori

Patient Gender: Female

Race: Black

DOB: 3/2/02

Date of Death: 12/15/16

Age: 15 yo

Interpreting Services Needed: No

Housing Info: Tri Delta Place

Address: 1234 Street Ave. [This will be their home address. Not housing]

City: Memphis

State: TN

Zip Code: 38102

Medical Information Section

Primary Medical Service: E Clinic

Primary Diagnosis: Medulloblastoma

Date of Arrival: 5/11/16 [This is the approximate date the patient arrives at St. Jude.]

On Quality of Life Service? Yes [This does not mean that the patient is on palliative care, it simply means they are being followed by the service which can be due to many reasons.]

Care Team Section

Primary Doctor: Dr. Smith

Social Worker: Lois Lane

Mentee Information

Primary - Mentee Details Section

Relationship to Patient (Primary Mentee): Mother

Mentee First Name (Primary): Tonya

Mentee Last Name (Primary): Wash

Preferred Phone Number (Primary): (123) 456-7890

Recruitment Information

Concerns and Comments Section

Notes from Coordinator: [This information included in this section typically comes from the psychosocial rounds or from a staff member who is referring the family as a mentor. For QoL families, I will typically put in notes from diagnosis if they were presented previously in rounds.]

5/25/16- E Clinic Rounds: Major pain issues; QoL has been consulted. Poor prognosis as the cancer has metastasized. Mom is a single parent as dad is not involved. There are several older siblings and one younger sibling. Mom is a caregiver for elderly and makes little money. There will be financial issues. Mom is using prayer to cope. She seems to be struggling with understanding how serious the diagnosis is and seems to still be in shock. Tori loves band and is always listening even when her eyes are closed. Social Worker referred mom for a mentor.

12/22/16: Tori passed away in the hospital surrounded by her mom and siblings. Throughout treatment, it was made aware that there were more social issues than we knew about at the beginning. Mom struggled to cope and on several occasions would leave St. Jude as she could not handle it. She stopped communication with her mentor and did not respond to any text messages or cards. Referred for a QoL mentor.

Recruitment Status Section

Referral Date: 12/22/2016

Referral Source: A Clinic Psychosocial Rounds

Recruitment Status: Accepted

Acceptance Date: 12/23/2016

Status Notes: [The information in this section is documenting who talked with the parent and when they said yes to a mentor. In this case, the mom was matched with a PAIR mentor previously.]

5/26/16- Betsy Lambert: I called and left a voicemail. Mom said she would like a mentor. She would like to talk to another mom who had a teenager during treatment.

12/23/16- Lizzie Barnwell: I just spoke to Mom. She is doing ok, but would like to talk with a bereaved parent mentor. She has very little support and she still feels very connected to St. Jude. She is expecting phone call soon.

Enrollment Information

Enrollment Section

Enrollment Status: Active – QoL

Enrollment Notes: [This section has notes about the mentee's enrollment. Often this has the reason why the mentee has become inactive and no longer being mentored.]

5/26/16- Brittany sent a note to mom along with the personal parent mentor card of her mentor.

Due to little response from mom, she was rolled off the program after her second enrollment on 10/3/16.

12/22/16- Brittany Cochran - Patient passed away. Mentor was made aware by phone call and plans to reach out by a "Thinking of you Card".

12/23/16- Brittany sent a note of condolences to mom along with the personal parent mentor card of her QoL mentor.

Program Progression Section

Date of Match: 12/23/2016

First 12 Week Mark: 3/17/2017 [This is the date that the family would become inactive or re-enroll.]

H Clinic Match Form

Patient Information

Patient Section

Patient MRN: 12347

Patient First Name: Jane

Patient Last Name: Doe

Preferred Name: Jane

Patient Gender: Female

Race: Black

DOB: 12/20/2016

Age: 3 weeks old

Interpreting Services Needed: No

Housing Info: Local

Address: [This will be their home address. Not housing]

City: 1234 West St.

State: TN
Zip Code: 38116

Medical Information Section

Primary Medical Service: H Clinic

Primary Diagnosis: Sickle Cell Disease

Date of Arrival: 1/10/17 [This is the approximate date the patient arrives at St. Jude.]

On Quality of Life Service? No [This does not mean that the patient is on palliative care, it simply means they are being followed by the service which can be due to many reasons.]

Care Team Section

Primary Doctor: Dr. Estepp

Social Worker: Margery Johnson

Mentee Information

Primary - Mentee Details Section

Relationship to Patient (Primary Mentee): Mother

Mentee First Name (Primary): Janet

Mentee Last Name (Primary): Doe

Preferred Phone Number (Primary): 901-123-4567

Secondary - Mentee Details Section [This is only included if the other parent or another caregiver is involved. This is usually for information only.]

Relationship to Patient (Primary Mentee): Maternal Grandmother

Mentee First Name (Primary): Dorothy

Mentee Last Name (Primary): Smith

Preferred Phone Number (Primary): 901-555-7890

Recruitment Information

Concerns and Comments Section

Notes from Coordinator: Social Worker and RN Case Manager met with the family for their confirmatory visit where parents learned that the patient does have Sickle Cell Disease. Both were very tearful and overwhelmed by the diagnosis. They indicated that they wish they could talk to another parent who has been through this process. At this time, mother is fearful that the patient is going to die early in life after all she has read on the internet. [This information included in this section will come from the staff member who is referring the family as a mentor.]

Recruitment Status Section

Referral Date: 1/12/17

Referral Source: Social Work- Margery Johnson

Recruitment Status: Accepted

Acceptance Date: 1/13/17

Status Notes: 1/13/17- Betsy Lambert: I called mom and she is open to a mentor.[The information in this section is documenting who talked with the parent and when they said yes to a mentor.]

Enrollment Information

Enrollment Section

Enrollment Status: Active H Clinic

Enrollment Notes: 1/14/17- Brittany Barnett: I sent a card with information about the mentor to mom.

Program Progression Section

Date of Match: 1/14/17

First 15 Month Mark: 4/14/18 [This is the date that the family would become inactive or re-enroll.]

Once you are matched, make the initial contact within 24 – 48 hours of referral unless you are requested to wait. PAIR Mentors, please contact your mentee family at least once a week. QoL and H Clinic Mentors, please contact your families once a month to once every other month. Each family is different and will need a different amount of support from you. Keep this in mind if they don't answer you back. You may be supporting your mentee family in the right amount for them, while other families may want more consistent weekly or monthly contact.

There are many ways to support your mentees beyond face-to-face interaction. In fact, the majority of mentoring is done by phone. Mentors often use their personal cell phones for texting and calling the mentee, depending on their preferred method of communication. We do have several "Go Phones" if you feel more comfortable using a St. Jude phone rather than your own. You will also receive a St. Jude email address which should be checked at least once a week for new matches as well as updated information regarding the families enrolled (past and/or present) under you. You also have the option to send St. Jude "Thinking of You" cards as another way to communicate with your mentee.

The goal of the first encounter is to identify who you are, explain your relationship to the care team and your boundaries such as your availability and restrictions from giving medical advice. We will talk more about boundaries later in the workbook. An example of a first text may sound something like this:

"Hi, my name is (insert your name) and I am a Parent Mentor at St. Jude. My son/daughter is also a patient and is doing well. I remember how overwhelmed and scared I felt at the very beginning. Though I may not completely understand what you are going through, I can certainly relate. I would love to set up a time to talk with you, either a phone call or text if that works better for you. When would be a good time to chat?"

For QoL, if you are contacting a family after the death of their child, yours might sound something like this:

"Hi, my name is (insert your name) and I am a Parent Mentor at St. Jude. I am so sorry for your loss of (insert name). I also lost my son/daughter and though I may not completely understand what you are going through, I can certainly relate. I would love to set up a time to talk with you, either a phone call or text if that works better for you. When would be a good time to chat?"

Note, there may be times that a QoL Mentor will be matched with a family whose child has a poor prognosis and/or is terminal. In some cases such as these, you may change your wording to reflect that you have been in a similar situation and had to make tough decisions while your child was there. You will be made aware of these circumstances.

After you make contact, or attempt to make contact with your mentee, you will complete an Encounter Form. The encounter form is a way to document the content of the mentoring session and is used to communicate any concerns regarding your mentee. This is one of the *most* important pieces of the program and should be filled out within 24 hours after you talk with or attempt to contact your mentee. The encounter form is available for the patient's care team to view in order to provide the family with the resources they may need. It is important, when filling out the forms, to put as much information and detail as possible. If you report the parent is in need of support or additional resources, staff members will assess the best way of approaching that family in a way that will keep your trust with the mentee intact and still address the need at hand.

There may be times when a parent tells you something that is concerning. We call these pink and red flags. Examples of pink flag concerns would be excessive parental worry, extreme financial concerns and/or family conflict. These do not immediately affect the physical or mental safety of the mentee or another person but are of concern and need attention. Red flags are concerns that require immediate action such as suicidal thoughts or actions, child or domestic abuse and/or significant complaints against staff. In a red flag concern, you can contact Brittany by phone or call the Social Worker on call. In these cases, you will openly explain to the mentee that what they are talking about is concerning and you have to report it to your supervisor. You can say something like this:

"Due to my position at the hospital, there are certain things that I have to report to my supervisor and your Social Worker. I think you are starting to talk about things in this category. I am happy to listen to what you have to say but the social worker can really help in these types of situations. I will call right now and see if she is available to talk."

Encounter forms and flags will be discussed in more detail during orientation. Below is an example of an encounter form along with a few helpful hints.

Parent Mentor Encounter

Asterisk (*) indicates a required field.

General Information

Mentor Name *

Please Select Primary Patient Medical Service *

- Leukemia (A)
- BMT (B)
- Solid Tumor (D)
- Brain Tumor (E)
- Hematology (H)
- Leukemia - Off Therapy (A)
- Radiation Oncology (RO)
- ACT



This information will be on your Match form that is initially provided for each mentee.

Make sure to spell all names correctly and capitalize names appropriately.

Patient Name *

MRN

Mentee Name *

Social Worker *

Date (of encounter or attempt to contact) *

Amount of time spent *

Type of encounter *

- Phone call
- Text
- St. Jude email
- Face-to-face
- Other

If face-to-face, please specify location

- Inpatient
- Clinic
- Common area
- Tri Delta Place
- Ronald McDonald House
- Target House
- Other

Please make sure to submit the form within 24-48 hours of contact or attempt to contact to ensure accurate data.

- Inpatient: Inpatient room, waiting rooms for surgery, ICU, 2nd floor, inpatient playroom, etc.
- Clinic: Any outpatient clinic waiting room, hallway or exam room.
- Common Area: ABC wall, Kay Kafe area, any lobby or hallway.
- Housing Facilities: Please make sure to choose the location in which you meet with them. This may not always be the same as listed on the Match form.
- Other: Anything that is not listed above or any location that is not on St. Jude grounds (McDonalds, Starbucks, etc.)

Referrals Made *

(Check all that apply.)

- Medical Staff
- Social Work
- Spiritual Care
- Child Life
- Psychology
- School Program
- Rehab
- Helping Hands
- None
- Other

→ If you made and/or suggested a referral to any of the listed programs/staff
Please check "none" if you do not make a referral

Please describe your encounter or attempt to contact * →

Please use this space to document your encounter. Use details when appropriate but know that many other people will be looking at this form as well. This information will be used for reporting back to the psychosocial team. If there is something that you would like to address over the phone, please call my office number at 901-595-7560 or if it is urgent, call my cell at 901-493-5993.

I have a pink flag concern

Choose ▾

I have a red flag concern

Choose ▾

→ When you flag an encounter, I will contact the patient's social worker. From there, they will take the appropriate steps (be sure to describe your concerns in the comments section above). Once there is resolution, you will be informed by email.

- All is ok, no need for further follow up.
- I have a personal issue or concern and need to discuss.

Submit

Reset

The Encounter Form can be found online at the web address below:
<https://hospital.stjude.org/apps/forms/fb/parent-mentor-encounter>

You may be wondering how you are to keep the patient's protected health information (PHI) safe and confidential when you are sending in encounter forms. As a volunteer, you are considered a "workforce member", therefore, you have access to need to know information. This allows me to send you information about the patient and the family to you in the match form. It also allows you to send us information through the encounter forms. In the brochure and personal parent mentor card, it is explained to the parent that their mentor will collaborate with their care team. The encounter form is that collaboration in action.

Any information that you gain from being a mentor at St. Jude is considered confidential. You have probably heard of HIPAA at some point prior to this orientation. HIPAA stands for the Health Insurance Portability and Accountability act of 1996. This act requires that everyone, including volunteers, safeguard and protect patient information. This information can be oral, written, or electronic. It includes medical records, conversations, emails and texts. To safeguard patient information, shred any notes regarding your mentee after you are finished. Lock your cell phone with a 6 digit passcode and do not discuss private information regarding the patient or their medical status via text unless the mentee brings it up first. Only use your St. Jude email when discussing patient information and type [Encrypt] in the subject line to ensure the utmost security.

Do not share patient information with your friends, family, St. Jude staff members or mentors that do not need to know information about the family you are mentoring. You are not to talk with your own care team regarding another patient and should be never give out information about one of your mentees to another mentee.

There will come a time when you will “graduate” your mentee from the program. You will receive the date of graduation when you receive your match form. Brittany will also remind you when the date is getting close and can help determine if a family is ready to roll off or in need of another enrollment. There are many reasons mentees are required to graduate from the mentor program. One reason is because, if no family graduated, you would be mentoring every family you’ve been matched with indefinitely. This could cause a real burden to you the longer you mentor and the more families you are matched with. Another reason is the goal of this program is to “walk with” a family during a critical time. You are helping to support them and help them to advocate for themselves. The longer you stay with the family, the more likely they are to depend on you. Inadvertently, you may be keeping them from being autonomous.

PAIR mentors will evaluate their mentees when approaching the 12 week mark of the relationship. If the mentee seems to be doing well then they will graduate from the program. You may say something like, “You’ve reached your 12 week mark in the program. At this point, I will no longer be contacting you each week but you are more than welcome to reach out at any time you want to talk.” If you do not feel like the mentee is ready to graduate, the mentee can be re-enrolled for another 12 weeks. This will be discussed in more detail during training. The same applies to H Clinic and QoL mentors except graduation occurs at 15 months instead of 12 weeks. If the family does not seem ready to roll off, they can be enrolled for another 6 months.

More time will be spent discussing the logistics of the program during training. Please feel free to use this space to write down your thoughts and/or questions.

Mentoring Skills

There are 6 basic mentoring skills that we teach during the Parent Mentor training: 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 are a tool that you probably already possess, and they are things that you may use 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 presence and your role during the mentoring session itself. Learning these skills will hopefully help you feel more prepared to enter into the mentoring relationship.

1. Active Listening

Let's begin with active listening, or reflective listening, which can be the bread and butter of a good mentoring relationship and session. What is it? Carl Rogers, a famous psychologist who is known for his work with person-centered therapy, first defined active listening as "a way of listening that focuses entirely on what the other person is saying and confirms understanding of both the content of the message and the emotions and feelings underlying the message to ensure that understanding is accurate." In other words, active listening involves listening for meaning and it consists of three actions or skills: focusing, confirming and understanding content and emotion.

Why should you use active listening? Not only is it an opportunity for the mentee to explore aloud about what he or she is experiencing, thinking, and feeling, it 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.

If active listening is so therapeutic and helpful in building relationships, why don't we use it more often? Frequently, we are so busy trying to formulate our response to something someone is saying, or we are waiting for them to pause for a breath so that we can speak, that we don't actively listen. 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 mentee within the hospital environment. Rarely are parents given the opportunity to talk to professionals about whatever is on their minds without receiving advice or directions.

Active listening is completely selfless and has no agenda. You, as a mentor, do not come into the conversation with a topic in mind that you would like to discuss, unlike a physician who has a new chemotherapy to introduce or who has three questions he needs to ask during a clinic visit. When you engage in active listening, you add no content to the discussion. The entire conversation is directed by the mentee and you make no presumptions about what the mentee is thinking or feeling.

So, *how* is active listening achieved?

- Focus and listen for total meaning. Try to gain a good grasp of what the mentee is saying (the content) and how they are saying it (the emotion or attitude behind the words).
- Avoid interrupting and allow the mentee to lead the discussion. Ask "Is there more?" or "Is that all?" to make sure they are finished with their thought.
- 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 did everything they could for your child while they were there.
 - "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.

- Get confirmation that you understand. After reflecting or repeating what you heard and understood, ask *"Did I get it?"* and *"Is there any part I didn't seem to understand?"*.

Finally, attend to body language (if you are face to face), both your own and that of your mentee. 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 from the mentee and be relaxed and open. Sit down with them and use head nods, facial expressions, and gestures to convey understanding without interrupting.

Exercise: Practice active listening with your spouse, a family member or friend. Afterwards, ask for feedback as to how the experience was for them. Did they feel heard? What feelings did they experience? Note your own feelings as you engage in the exercise.

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 your mentee 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 your mentee. 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."

You may be wondering how to start a mentoring session. After introductions, open-ended questions and intro statements are your best bet. Below are some suggestions:

"Tell me about your experience at St. Jude so far."

"Tell me about your cancer journey with your child to this point."

"What is your understanding of the mentoring process?"

"What have you been struggling with since we last spoke?"

"How are you staying strong for your child?"

3. Being Comfortable with Silence

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

Your silence:

- communicates to your mentee that they control the direction of the conversation
- allows your mentee the opportunity to reflect on content in conversation and to process thoughts and feelings more deeply

- conveys interest and acceptance
- acknowledges that sometimes there are no good answers to the problems that we face
- provides your mentee the chance to decide if they want to tell you more about a particular issue
- may help your mentee to feel more comfortable opening up solely because you aren't rushing them to do so and are giving them the gift of time

Exercise: Practice using silence with your spouse, a family member or friend. Ask that person to talk to you about a change he or she is considering making within the next six months. As the individual shares with you, do not respond verbally. Your only communication is through your body language; that is, nodding your head, smiling, etc. Allow silence to be present and note your feelings when it occurs. When the other person has finished sharing, discuss how the experience was for each of you.

4. Using What You Know

Anyone can implement the mentoring skills that we've discussed so far, but parent mentors have a perspective that other professionals will likely never have. "Using what you know" involves taking that unique perspective and applying it in constructive ways with your mentee. 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 to family, friends, neighbors, other parents, priests, pastors, ALSAC representatives, potential donors to St. Jude, etc. but sharing your story within the context of a parent mentoring 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.

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.

Sometime mentees feel guilty or 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 that 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 or tends to always have a negative experience when you talk with them, try redirecting the conversation and/or refer them to their Social Worker. Please make Brittany aware of this as well.

Effective mentoring stories have 5 characteristics:

- They have a beginning, middle and an end. They are easy to follow and have a basic story line.
- They are brief, focused and relevant. Thus, they are individually tailored to your mentee's current situation, and they don't take away from the time you could be spending engaging in active listening.

- 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, as a mentor, more approachable. However, if you find yourself eliciting support and comfort from your mentee, this should be a sign that you may need to reach out for support.
- 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 your mentee to learn from them.
- They end with an explanation of how your experience relates to theirs and provide a cue for the mentee to resume the lead in the discussion.

Consider practicing sharing stories that meet these characteristics. Think about your experience related to the following topics and briefly write an example of each:

Talking with medical staff—when and how did you approach them?

Researching and gathering information—how did you find the answers to questions?

Networking—who knows what around St. Jude?

Navigating the “system”—how did you manage hurdles?

Defining the parent role in care—how did you see yourself fitting in as a parent?

What was important to you as a parent and what was helpful for you?

What did you do to practice self-care?

How did you interact/cope with your external support system?

What was the hardest part about treatment or going home?

Each time you use a story during a mentoring session, or while practicing, take the time to evaluate how effective it was. Ask yourself these questions:

- Is my story relevant to the topic of discussion?
- Is the length of my story appropriate? Am I giving too much information?
- Am I complaining or gossiping?
- Does my story help to develop partnership?
- Am I aware of my own emotional reactions to my story?
- How is the parent responding to my story?

Our stories are what define us as human beings and allow us to connect with each other. We all have a choice to approach the lives of other people face to face or to keep our distance. Take the risk, treat it as the gift that it is, and share your story well. During your training, you will be given the opportunity to share your story. **Please take some time to think about and/or write out your story ahead of time. Keep in mind you will be given about 5 minutes to share your story.** Please read the 2 examples below that may help you as you prepare to share your story in training.

PAIR Mentor Example :

When my son, Thomas, was 4 years old, I had to take him to the pediatrician 3 different times in that one week due to high fevers and pain in his legs. On the third visit, his doctor suspected it could be Leukemia. We had an appointment at St. Jude the very next morning. On April 10th, 2007 Thomas was diagnosed with ALL. That day our family's world, as we knew it, stopped. While still trying to process that my child had cancer, Dr. Pui and nurse Stephanie were going over names of chemo's that I couldn't even pronounce, road maps that were completely foreign to me and consent forms that needed to be signed. I was completely overwhelmed and in shock that this was even happening to our

family. In my mind, I was thinking that he might be on chemo for six weeks, so I was so sad to learn his treatment would last for three years. I remember saying, “YEARS??!”

Being a local family, we had so much support from friends, family, church, and school, but I still felt very alone. I had never stepped foot in St. Jude until Thomas’ diagnosis. I quickly learned what an incredible place St. Jude was. Everyone was so warm and friendly, and I knew they would take the best care of my son. I also learned to take everything day by day and sometimes hour by hour. Throughout his three year treatment, I met other moms that I could talk with since we all had a child going through treatment at St. Jude. The hospital became a second family to us. Thomas completed his treatment in May of 2010. He comes for his yearly checkups and will continue until he is 18. At that time, he has expressed interest in the St. Jude Life study. Many blessings have come from his experience and it has changed our family for the better.

QoL Mentor Example:

My daughter Heather was 11 when she was diagnosed with medulloblastoma in 2008. She had a complete resection in Orlando, Florida and we went to St Jude in January as part of SJMB03 protocol. Heather had a very rough time throughout her treatment. She developed chemical meningitis before treatment even started. She continued to throw up 10-15 times a day throughout radiation. She missed being at home but became very comfortable at St Jude and made several friends. We were able to be home for a couple weeks between radiation and high dose chemo. She did not tolerate the chemo well at all. After many adjustments they had to stop treatment completely during her third round. She continued to have complications once chemo ended but we were finally cleared to come home in September, 2008.

Heather remained cancer free and learned to deal with the many side effects of treatment. She was eventually able to return to school and able to get her driver’s license. We returned to St Jude in June 2013 for her 5 ½ year appt. Her appts for the first time ever were all on one day. They found the tumor in the exact same spot. She had no symptoms at all. The decision was made to have surgery of which they were not able to get all the cancer and so she needed to have radiation again. This round she tolerated much better and we were able to enjoy Memphis. However, the radiation did not kill the cancer. In January, 2014, there was nothing else St. Jude could do and she was placed on hospice. Since she was 17, she played a big part in the decision making. St Jude was amazing. Knowing that she could not be cured, she opted to come home and live life to the fullest. We found a trial in Houston that our neurooncologist at St Jude thought was very promising. Dr. Armstrong took time to call and speak with Dr. Sandberg (the principal investigator on this trial) to get a feel for it. In March we went to Houston and had a week-long of tests and she had surgery. The surgery went well and we were coming home for about 10 days before treatment would start. Heather wanted to drive, not fly. My husband flew back to Orlando and my sister and I drove Heather to Tallahassee where she loved to visit with grandparents. It was there that things deteriorated pretty quickly. We ended up in the ICU where she died on March 25, 2014. My family and I will be forever grateful to St Jude. Heather’s final donation to St Jude was her brain. Her relapse was very unusual for medulloblastoma and surprised all of her doctors at St Jude. This was her final gift she gave to St Jude to help other children.

Another way you can use what you know is to offer direct suggestions to your mentee. Parent mentors can be particularly helpful when referring parents back to hospital resources and encouraging communication with staff. When offering suggestions, be certain that your mentee 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, 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. When in doubt, refer them to their social worker. Be cautious about offering suggestions or advice too often, as you don’t want to shift the balance of the relationship from a partnership to one of you being “the expert” and the mentee being “the novice.”

As a St. Jude parent, you are well aware of how having a child diagnosed with cancer disrupts family life. As a mentor, it will be important to remain mindful of how families “typically” adjust to the news that their child has cancer. The same can be said for QoL mentors. Make sure to use the resources given to you at training to identify appropriate adjustment

after the death of a child. Families differ in terms of how they cope and one way is not necessarily more “normal” than the next. Many families appear overwhelmed when they first come to St. Jude, and this is completely normal. You can often spot those new families in the halls or in the waiting rooms. It takes a few weeks for families to settle into a routine here in Memphis. Families need time to figure out how their system fits in with the hospital system. In the early stages of treatment, parents often benefit from just being able to talk about how they ended up here at St. Jude. They may be ready for problem solving discussions later.

5. Differences in Parent Perspectives

When working as a parent mentor, it is important to remember that you are walking in similar, but still different shoes than your mentee. Be mindful of how your values and family culture may differ from that of your mentee 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 sessions 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 your mentee 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” your mentee if you find them operating under a perspective, value, or belief with which you disagree. If you ever feel uncomfortable or unable to relate to a mentee due to these differences, don't hesitate to contact Brittany.

Can you think of any beliefs, values or perspectives a mentee could potentially have that would make it especially difficult for you to mentor them?

6. Recognizing Your Limits and Influence

The final mentoring skill involves some discussion of boundaries and the power differential that is inherently present within the mentoring relationship. Be mindful of your own personal limits and influence on your mentee. Session discussions may elicit unexpected and powerful emotions within you. Regardless of whether these emotions are positive or negative, they can catch you off guard. When this occurs, it is important to take time out to reflect on how and why you responded in such a way. Please call Brittany or a St. Jude staff member on the Steering Council about your reaction and take care of your own needs so that you can be more fully present with your mentee.

When evaluating your performance as a mentor, consider the amount of time you spent speaking in a session. When you talk too much, your mentee may begin to feel less accepted and less comfortable. You may be more likely to give unsolicited advice or to make assumptions about what your mentee is thinking or feeling. You may have more influence on your mentee than you realize. You are the “expert” in their eyes and they put trust in you. Focus on developing a partnership and continuing to allow your mentee to experience St. Jude or their grief in their own way, as their situation will be different from yours. If you do find that you have talked too much in a session, it is important to reflect on the reason.

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

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

In summary, there are multiple skills that you can use as a parent mentor to facilitate the development of a healthy, positive relationship and to provide a valuable service to a new St. Jude parent or one going through insurmountable

grief. While practice makes perfect, you will serve your mentee 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 ever in doubt, call Brittany to discuss, debrief or seek advice about how to handle a specific situation.

Boundaries

In working with fellow St. Jude parents as a mentor, you will be taking on a role which is not professional nor that of a peer. This work requires great capacity to maintain balance. You are being asked to journey with another to a place you have already experienced intensely and help them find their own way and their own strengths to live in their new normal. This work as a mentor can provide tremendous benefit to others, personal satisfaction and at the same time, take an emotional toll. Boundaries are essential to maintaining balance, supporting good self-care and avoiding burnout.

Boundaries are with us throughout our life's journey, serving to protect and define us individually and in relationship with others. Think about your own boundaries and how they work in your life. Consider relationships in which you are more open or more closed with your boundaries. Perhaps you have a trusted friend to whom you can tell anything—and know your confidences are secure. You are comfortable with having them at your home any hour of the day regardless of the condition of your home. Your boundaries with this friend might be very open. Perhaps you have another friend who cannot keep anything to themselves and is critical of everyone and everything. You may be much more selective in what you share with this person.

Please take a few moments to answer the following questions.

When are you rigid with your boundaries and when are you flexible?

How do you balance the demands of your life and self-care now?

How do you balance the interests of you and your family?

In taking on the role of a mentor, you are stepping outside the bounds of previous parent to parent relationships you may have had at St. Jude. From this point forward, you will not be allowed to informally mentor other families not enrolled in the program. This will be discussed in more detail when you attend training. Furthermore, mentors are required to report any conflict of interest that could lead to a dual relationship with the mentee (i.e. involvement with a bleeding disorder industry, third party company, home health company or clotting factor manufacturing company).

While you will not be in a professional role, you will need to adhere to the key elements of professional boundaries. Many professions have ethical codes which address boundaries between care providers and care recipients. Common themes of those codes, which also fit for the mentor/mentee relationship, are:

- Protection of the mentee
- Mentee needs come first
- Promotion of mentee’s independence
- Respect for dignity of the mentee
- No personal gain at expense of mentee
- No inappropriate relationships

A first step toward good boundaries in mentor/mentee relationships is to define your role. Clarity regarding limits of the mentor’s role helps the parent being mentored have clearer expectations of how you can help as well as the limits. For example, one part of the mentor role is to serve as an experienced companion on the journey. A mentee may express confusion about their eligibility for patient housing. Assisting them with how to get that information, perhaps accompanying them to Patient Services, rather than making a call on their behalf to “fix” the problem is one way of being responsive, respectful and supporting independence and dignity. Being mindful of role boundaries such as this supports the autonomy of the mentee by supporting them in finding their way in this new world of catastrophic illness or death of a child. It also supports the maintenance and development of other supportive relationships for the mentee. Giving a parent your full attention, helping them clarify a concern and redirecting them to a member of their care team for more help on a need helps them in utilizing staff resources effectively and confidently.

Boundaries support the parent in maintaining their own identity and role. Parents often describe how it feels to be thrust into the strange world of medical care with a new language, complicated procedures and perceived threats coming from all directions. Parents express feeling lost and even incompetent at times. Guiding a parent, linking them to resources, and yet not taking over, helps them maintain their identity as a good parent and promotes confidence in the mentee that they can parent and cope in this new world with a seriously ill child.

When a child has a life threatening illness, the primary focus and energy of the family shifts to that child. Demands and stress on the parent increase tremendously. Boundaries in the relationship with the mentee aid in providing the mentee a safe haven where their needs come first. It may be hard to see this as necessary, but boundaries also protect against exploitation of both mentee and mentor.

Can you think of an example of an inappropriate mentor relationship?

What would be an example of personal gain at the expense of a mentee?

What is an example of an action that would promote a mentee’s independence?

What is an example of an action that would promote a mentee's dependence on you?

How were your personal and family boundaries affected by your child's diagnosis and treatment?

What actions by caregivers and support system helped you feel more confident in your ability to cope?

What actions made you feel respected?

What actions made you feel diminished, incapable?

Consider what makes a good mentor. Key characteristics include:

- The capacity to be fully present with the mentee
- Listening actively with compassion
- The ability to companion and guide without taking over, and
- Consistently demonstrating respect.

These characteristics also look a lot like what we might want in a good friend and yet there are important differences in the nature of the relationships. The *motivation* for friendship is an instinctive connection that evolves over time. A mentoring relationship is intentional, offered by the mentor and the institution and generally time-limited and contextual. The *structure* of a friendship is spontaneous, while a mentoring relationship is scheduled and goal-oriented, if only in subtle ways. The *power balance* of a friendship is generally shared; however, in a mentoring relationship, the mentor is empowered by prior experience and training. *Location* of a friendship has no boundaries; a mentoring relationship generally occurs within the boundaries of the hospital (public housing areas, phone, email, text).

Most people help others in difficult times out of great compassion, with a desire to ease suffering, to support, to inspire and encourage, and to assist. It can be these very noble motivations that also provide the impulse to cross or violate boundaries. In exploring the difference between a boundary crossing and a boundary violation, the nature of the action, the intent, the impact, the frequency and the motivation are all points for consideration. One example of a boundary crossing could be accepting a small gift when declining would cause emotional or relational harm or violate cultural norms. Boundary violations are more serious, damaging autonomy and trust. Some examples can include using or sharing confidential information for your benefit, attempting to influence a parent’s decisions based on your beliefs and/or forcing your influence in any way.

If you find yourself considering crossing a boundary, there are some things you should consider:

- What is my intent?
- Who does this action benefit?
- What are the implications of my actions for this parent, patient and family?
- What are the implications for other parents, patients and families (present and future)?
- What are the implications for staff and for me and my role?
- What are the potential negative consequences?

Boundary violations usually occur because:

- We try to please others at our expense and possibly the expense of others.
- We desire to solve problems rather than empower.
- We act as super-caregivers and deny our needs.
- We begin to feel more special than others.
- We think we know better than others.
- Our need to be needed is too great.
- We can’t separate our lives from theirs—we believe their problems are ours.
- We don’t recognize our own secondary pain and suffering and take refuge in activity.

Scenario: You are mentoring a Mom who is here by herself with the patient who is 5 years old as well as the 2 year old sibling. Dad is unable to be here as he is keeping the 10 year old sibling in school at home and has their only car as he needs it for work. Mom tells you that she is feeling overwhelmed and stir crazy. The 2 year old is in full toddler mode throwing fits often. The patient has been very sick due to chemo and has been tearful and anxious. Mom tells you they have moved to Target House which is great but she has no idea how she is going to get to the grocery store with the patient throwing up so often and the 2 year old who is insisting on being held at all times. Mom explains there is little family support and doesn’t think anyone will be able to take off work to help.

How would you handle this?

What would be the intent of your actions?

Who would benefit from your actions?

What would be the implications of your actions for your mentee, patient and family?

What would the implications be for other parents, patients and families (present and future)?

What would be the implications for staff and for you and your role?

What are the potential negative consequences?

If you aren't sure if you are crossing a boundary, ask yourself the questions you just answered above:

- What is my intent?
- Who does this action benefit?
- What are implications of my action for the patient and family, other patients and families (present and future), staff, myself and my role ?
- Are there any potential negative consequences?

The following list of actions are all examples of actual scenarios that mentors have been faced with. Please indicate whether you think the behavior by a parent mentor would be Always OK, Sometimes OK or Never OK. We don't expect you to know all the answers but do ask that you attempt to complete each one, marking those that you cause you distress or that you have questions about. Feel free to fill in any other boundaries you can think of in the empty spaces below that you may want to discuss during training. "Family" or "Family Member" refers to a member of the family you are mentoring.

Action	Always OK	Sometimes OK	Never OK	Why?
1. Accepting personal gifts from a family.				
2. Buying gifts for or loaning money to a family.				
3. Providing the name of a babysitter for a family.				
4. Setting up a family with a local realtor to help them find a place to live.				
5. Giving a family a doctor's pager number or email address given to you by the doctor for use during your child's medical care.				
6. Referring a family not already enrolled to the mentor program.				
7. Referring a family to a counselor in their home town or at St. Jude.				
8. Accepting a friend request from a family or writing on a blog if initiated by the mentee.				
9. Inviting a patient or family to attend religious services with you.				
10. Asking for time off from mentoring due to things going on with your personal/family life.				
11. Giving a family a ride home or to the grocery store.				
12. Mentoring a St. Jude family who is not enrolled in the mentor program but that you know personally.				
13. Attending a special event (wedding, birthday, graduation) of a family member.				

14. Attending the funeral of a family member you are mentoring.				
15. Offering to meet your mentor family at the park so your kids can meet and play.				
16. Sitting with a family during a medical conversation.				
17. Offering the name of the home health organization that you use.				
18.				
19.				
20.				

It may have seemed difficult to evaluate these actions. There will be time during training to discuss your answers.

In summary, good boundaries are essential in a mentor/mentee relationship. Developing them requires self-awareness which enables you to monitor your own emotional reactions and listen to your intuition. Establishing trust, while avoiding over involvement, is crucial for both mentor and mentee. Having mutually agreed upon goals with your mentee for each session and keeping focus on the goals can help. Take time to reflect on each interaction with a mentee and debrief as needed with the Parent Mentor Steering Council or other trained mentors. If you are ever in a situation and in doubt, proceed with caution and call Brittany to discuss.

Critical Times for Families

The life of a St. Jude family is filled with pivotal moments and critical times. During a crisis or significant change in status the family may need a lot of support.

Especially difficult times may include:

- Initial Diagnosis
- Adjustment to separation from family, friends, and community
- Recognition of physical changes and limitations
- Admission to the ICU
- The end of treatment and return home
- Relapse
- Multiple Grief events in a short period of time
- End of Life Decisions
- End of Life Conversations
- Surgery
- Going home for the first time
- Hospital to Housing
- Unexpected complications

Think back to your own journey at St. Jude. **Place a check** by the critical times in the list above that were most difficult for your family.

Were there other critical times for your family that are not on the list?

What emotions do you remember experiencing at those times?

What support did you need at those times? What was helpful?

Mentor Support

Although we will try to inform and prepare you as soon as we know of a change in status, you may be thrown into a new situation without warning. Keep in mind, you are not alone in any of this. Brittany, or any Steering Council member, can and will help you in ways such as:

- Processing and Debriefing: help in deciding what to do in certain situations, when to make referrals, flag encounters, etc.
- After-hours and weekend support is also available via the hospital operator by asking to page the on-call social worker or chaplain. You may call or text Brittany on her cell phone when outside of normal work hours as well
- Supporting your personal grief with the loss of a patient
- Processing and supporting you through any other emotional distress that may occur
- Providing reading materials about loss, grief and bereavement free of charge

Spiritual Conversations

It is inevitable that, sooner or later, a family will say something to you of a spiritual or religious nature. That may feel ok or it may feel uncomfortable. It may leave you wondering about an appropriate response. Religion and spirituality are very personal so it is likely the person making the statement is extending an invitation to you based on trust. Often our immediate response is to want to fix or help them resolve their spiritual dilemma. But the illness process is not the best time to “do” theology. They are looking for someone with whom they can share their struggle, a companion, to suffer with them.

As the grief process merges with spiritual or religious beliefs, it can cause *spiritual distress*. Spiritual distress is an invasion of innocence that disturbs our belief system. We suddenly come face to face with tragedy in a personal way. Our belief in personal safety and family protection is exposed for what it is, an illusion. Symptoms of *spiritual distress* include questioning the meaning of the event, fear and loss of control. Some people are afraid to go to sleep. Many feel anger at God and at others including friends and family. It may cause a person to question their beliefs. Some may regard their child’s illness as a punishment or burden placed upon them by God. People often try to conjure up an extra measure of faith as if their child’s cure depends on their level of faith. While it might seem logical for someone in *spiritual distress* to seek spiritual counsel and support, some do while others avoid it like the plague. So how do we help?

In order to be helpful we must understand our own need to fix things. We must realize that most people understand that we cannot fix their suffering and pain nor do they want us to. They simply want us to become vulnerable, listen, and sit with them in silence. They want us to listen as they think out loud. They want a shoulder upon which to cry and a safe place to voice their greatest fears and concerns. It goes without saying that as mentors, a primary responsibility is to respect the mentees family values and belief systems. During *spiritual distress* a person’s belief system has been shaken to the core. They are not able to entertain complex changes to the way they believe. While it is uncomfortable to see them suffer, it is necessary that they do so as they move toward healing. Families want us to hope with them. Hope isn’t denial. Hope is essential. Something has to keep them moving forward, getting up in the morning and taking care of their child’s needs. Hope is the duty of every parent. Hope is the duty of every employee and volunteer at St. Jude.

When a person makes a spiritual comment like, “I can’t understand why God allows children to suffer”, it is sometimes helpful to risk being vulnerable. A way to respond might be, “I don’t understand that myself. I struggle with the same question.” It is helpful t they feel that you struggle with them rather than try to solve their spiritual problem.

It is necessary to always approach prayer with caution. If a family asks you to pray with them, you have at least two options. If you are a person who feels comfortable saying a prayer out loud with a family you are welcome to do so. Anytime you are about to pray it is always helpful to ask the family exactly what they want to pray about. They will usually give you specifics which will help you frame your prayer. If you are uncomfortable praying with people it is perfectly acceptable to tell them so and offer to refer them to a chaplain. It is never appropriate to initiate prayer without your mentee asking you directly to do so.

Another helpful technique for those in *spiritual distress* is to point to their faith in action. Faith is more than belief, it is active. As you observe parents pushing uphill and against the wind, let them know what a great job they are doing in expressing their faith. Remember two things; your experience and courage are the greatest gifts you can give to other parents. Also, keep in mind that you can always refer the family to a chaplain, one is always available via the hospital operator.

The Importance of Self-Awareness while Mentoring

To companion parents and patients who are going through cancer treatment means to be an active participant in their grief journeys. Doing so requires tremendous energy and focus and can be physically, emotionally, and spiritually draining. As a parent mentor, you have “walked the walk” and the families you serve will touch the depths of your heart and soul. Because of your personal experience, chances are slim that you can avoid the stress of emotional involvement. However, being involved does not mean that “burn out” is inevitable. Working within appropriate boundaries, having self-awareness and implementing a deliberate plan for self-care will enable you to be present with other families and still lead your own healthy and separate life.

Working within appropriate boundaries

Becoming a parent mentor will be a journey. It will not happen overnight. It will involve adapting to a new role and an adjustment period to “take it all in.” In some ways, you are also being asked to do the impossible! What you do not want to lose in the process is you!

- You are being asked to form a trusting relationship--but not to get “too close.”
- You are being asked to work alongside hospital staff--but you are not staff.
- You will be hearing many personal expressions of grief--but you’re not a counselor.
- You will be many things and do many things--but none completely defined.

In life we often use fences to establish physical boundaries. You can open the gate to your fence and welcome visitors when you want company and close it when you need privacy. As a parent mentor you will need to establish mental fences as well; opening and closing them to preserve a healthy lifestyle. Although some of these were discussed previously in the “Boundaries” section, it’s worth repeating - boundary violations usually occur when:

1. You try to please others at the expense of yourself.
2. You desire to “solve” problems for others rather than create conditions that allow them to solve their own problems.
3. You do things for people that they are capable of doing themselves.
4. You deny your own need for support and understanding and instead try to be “a super-caregiver” or “all things to all people.”
5. As a caregiver you need to feel more special or important than others in your mentee’s life.
6. You engage in “24-hour care” for your assigned families.
7. You can’t engage in your own normal activities without stopping to “check on” those in your care.
8. You desire to be “in control” and believe that you know how best to make things turn out well for others.
9. You have a tendency to need your patients and families as much as, if not more, than they need you.
10. You have a tendency to neglect your own personal relationships in favor of helping others.

In addition to these warning signs, there are clearly defined guidelines for professional boundaries in patient/family relationships. Know them and follow them. The best way to avoid burnout is to monitor your mentee relationships, identify your feelings, be honest with yourself, accept feedback from those you trust, and maintain healthy boundaries.

Self-Awareness

As a parent mentor, you will be in a new role that requires personal awareness and evaluation. Why? Because being with families who are grieving will cause you to grieve. It may even bring up unresolved grief from your own experience that may catch you by surprise. If you feel grief, it will not mean that you are “weak” or that you “can’t handle” being a mentor. It simply means you are human and emotional feelings are a normal part of caring for others. The task is being able to identify concerns, evaluate their severity, and be honest about them. One of the first steps in self-awareness as a mentor is to understand your motivation for mentoring.

What motivated you to become a parent mentor?

One sign that a person is not self-aware or being honest with themselves is when they confuse caregiving with caretaking. Caretakers are known as rescuers and often become over-attached to the people they attempt to help. This happens because they place all their energy on people and problems outside of themselves, leaving little time for self-understanding. At the end of each day the mentor should process each visit and each relationship. What am I doing for this patient/family? Why am I doing it? Am I doing this for them or myself? Who is this patient/family to me? Who am I to this patient/family? Asking these questions can lead to greater self-awareness, healthier choices, and better care for the patients and families.

To protect yourself from burnout or caregiver distress, it is important to know what to look for. Child psychologist, Dr. Alan Wolfelt, has identified the following as warning signs:

- Exhaustion and loss of energy. These are usually among the first signs of caregiver distress.
- Irritability and impatience. As caregivers we typically feel a sense of accomplishment and reward for our efforts. As stress increases, our ability to feel reward diminishes while our irritability and impatience become heightened. A real sign to watch for: You have more compassion and sensitivity for those you care for than you have for your own family.
- Cynicism and detachment. Repeated exposure to suffering makes us question life. At St. Jude the stakes are higher because our patients are children. Where is fairness? Where is justice? Struggling with these issues can be overwhelming and may cause us to become highly cynical or detach from others as a way to preserve some of ourselves.
- Physical complaints and depression. It is often easier to acknowledge physical symptoms than emotional ones. The process of consciously or unconsciously ignoring emotional conflicts may result in a variety of somatic symptoms like headaches, stomach aches, back aches and long-lasting colds. Generalized feelings of depression are also common for caregivers. Loss of appetite, difficulty sleeping, sudden changes in mood and lethargy suggest you may be dealing with depression.

Self-Care

To embrace the deep appreciation for the role you have assumed, you must stay grounded. To do so means caring for you as well as for others. Here are a few suggestions which seem to be common among caregivers.

- Embrace supervision/support. You will have the opportunity to process your encounters with staff. During those sessions you may be asked questions that feel somewhat personal, perhaps intrusive. That is the perfect opportunity to honestly talk about the various feelings and emotions generated by your role as mentor. No matter how much we try to practice self-awareness we can't truly know ourselves without the help of another. Staff must process their feelings with other staff members and mentors will need to as well.
- Associate and celebrate with people who are not connected to St. Jude. When St. Jude people gather together they often talk about St. Jude! You need friends who are not connected to St. Jude. They will become a safe haven that will become more important the longer you do this type of work.
- Engage in a hobby that is not connected to St. Jude. Every caregiver needs something about which they are passionate. Hobbies are very individual and what works for one may not work for another. The important thing is that you identify that which meets your needs and engage!

Dr. Alan Wolfelt has published a Self-Care Manifesto which provides a healthy way to think about parent mentoring. Adapted for the parent mentor model, it reads as follows:

1. I deserve to lead a joyful, whole life. No matter how much I enjoy being a parent mentor, I also deserve time and attention.
2. My work does not define me. Sometimes I need to stop “doing” and focus on “being”.
3. I am not the only person who can help St. Jude patients and families. You will be surrounded with others who can help. Use them!
4. I must develop healthy eating, sleeping and exercise patterns.
5. If I’ve been overinvolved in my caregiving for too long, I may have forgotten how to take care of myself.
6. I must maintain healthy boundaries in my helping relationships. As a mentor, I cannot avoid getting emotionally involved with the patients and families. Nor would I want to. However, I must remember I am responsible *to* others, not *for* others.
7. I am not perfect and I must not expect myself to be. When I do make mistakes, I should see them as an integral part of learning and growth, not as measurements of my self-worth.
8. I must practice effective time-management skills.
9. I must practice setting limits and alleviating stresses I can do something about.
10. I must listen to my inner voice. At times I will become grief overloaded. When my inner voice begins to whisper its fatigue, I must listen carefully and allow myself some grief down-time.
11. I should express the personal me in both my work and play.
12. I am a spiritual being. I must spend alone time focusing on self-understanding and self-love. To be present to the patients and families I must appreciate the beauty of life and living.

Self-care involves knowing our motives and making deliberate efforts to remain healthy but it could possibly mean a need for personal counseling. If you ever feel overwhelmed by the work you do as a mentor, you are encouraged to share this information with the Parent Mentor Coordinator, Brittany, or any Steering Council member. They will make sure you receive the support and resources you need in order to maintain a balanced and healthy life.



Conclusion

Congratulations! You have finished the Parent Mentor Training Workbook. You may be experiencing feelings such as excitement, anxiety, motivation and maybe even a little overwhelmed. This is very normal. This workbook has required you to think back to the times during treatment that you may have wanted to forget and look at things from a different perspective. I hope, most of all, you feel a sense of accomplishment and are ready to attend training. During our time together, we will connect all of these concepts together and have open and honest discussions.

If you have any questions, concerns and/or would like to talk before training, please don't hesitate to contact me. See you soon!

Brittany Barnett, MS, NCC, CAVS
Patient Family-Centered Care Manager
St. Jude Children's Research Hospital
262 Danny Thomas Place, MS102
Memphis, TN 38105
Brittany.Barnett@stjude.org
Office: 901-595-7560
Cell: 901-493-5993