



Patient Family- Centered Care

Quality of Life Parent Educator Training Manual

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Dear Adviser,

Welcome to the St. Jude Quality of Life Parent Educator Program. We value your time and efforts and thank you for your willingness to take part. Throughout the reading, “parent” and “caregiver” will be used interchangeably and can be seen as one in the same.

In a children’s hospital, it is crucial for staff to understand the parents’ perspective. It helps us continue to improve the way we care for patients and their families. Today, just about every major children’s hospital has a parent advisory council. They help drive policies and procedures for patient and family care, facility design, and governance. As a *bereaved* parent, you have an important viewpoint. You have walked with your child through illness and treatment to the end of life and beyond.

As a bereaved parent educator, your perspective is a gift you offer to the health care staff you will meet. They include nurses, doctors, psychosocial clinicians, rehab therapists, and others. Your role as an educator is to put your unique point of view into words and to improve the quality of patient care and experience at the end of life.

The QoL team offers several educational events each year for health care staff. These events include, but may not be limited to, the Pediatric Palliative Oncology Symposium (PPOS), End-of-Life Nursing Education Consortium (ELNEC), Fellows Communication Training, and Schwartz Rounds. There may also be opportunities for engagement outside of these St. Jude offerings. Our parent educators are vital to improving patient care.

Your role as an educator may take many forms. Depending on your comfort level,

- You may be asked to sit on a panel led by a faculty member. This typically follows a question-answer format.
- If you are willing, you may be asked to participate in a lecture highlighting a caregiver’s viewpoint on an issue. Topics might include managing pain and symptoms, spirituality, or delivering difficult news.
- Along with other educators and faculty members, you will be taught to lead roleplay activities with doctors in training, facilitate small group discussion, as well as listening to their experiences and offering them guidance.

In short, you will teach what we cannot: the thoughts and concerns of a parent. You are not expected to be a scientific expert, but you are an expert on being a St. Jude parent.

We are so grateful you are willing to be vulnerable, to share, and to step outside your comfort zone. We look forward to working with you!

Gratefully,

The Patient and Family Centered Care Team & The Quality-of-Life Steering Council

Quality of Life Parent Educators

Parent educators take part in St. Jude Quality of Life education events for health care staff. They are supervised by the St. Jude bereavement coordinator.

The Basics

- ***What is a parent educator?***
Parent educators are formally trained in communication and presentation skills. They offer their unique perspectives as bereaved parents to help health care staff improve their approach to care. The story of their journey with their child from diagnosis to bereavement is the platform for their teaching.
- ***Why do we have this role?***
You are uniquely qualified to provide insight to caregivers. By listening and learning from your story, health care staff can improve the quality of care they offer to patients.
- ***What is the time commitment?***
Your time commitment will vary based upon the number of educational events you decide to attend. These events are typically 1–2 days long. You will need to prepare before each event, including reviewing materials. Prep time will vary from educator to educator, event to event. You are the best judge of how much time you need to spend to feel prepared. Parent educators are required to take part in at least one event per calendar year. The staff will provide ample time for planning and preparing for educational events.
- ***What accommodations are made for attending meetings?***
As a parent educator, you may be asked to participate in on-campus education events several times a year. If you live within 50 miles of St. Jude, no travel accommodations are made. If you live more than 50 miles from St. Jude, your travel costs for a car, train, or plane will be covered. St. Jude also covers the cost of a hotel room if you need to spend the night and any associated travel costs (Uber, taxi, parking, etc.). All parent educators will have their meals provided or reimbursed during in-person educational events and travel. For additional information about travel and accommodations, visit the QoL training webpage or contact brin.schaechtel@stjude.org.
- ***What training is needed for this position?***
 - After you complete the onboarding process through Patient Family-Centered Care (PFCC), we will send you a link to the PFCC volunteer training webpage, www.stjude.org/pfcc-training. All parent advisers should review this training. It is filled with resources that will help you throughout your time as a volunteer.
 - You will also receive a link to the QoL parent educator training. There, you will find the position description, this training manual, and more resources.

- The QoL bereavement coordinator will train you in skills needed for the events and provide opportunities to practice.
- Shadowing to observe skills will be mandatory for new educators prior to solo education efforts.
- Please log into your St. Jude email and Microsoft Teams before your first meeting.

If you have any trouble logging in, please contact brin.schaechtel@stjude.org. For technical issues please contact the St. Jude Helpdesk at 901.595.2000 or helpdesk@stjude.org.

- ***How am I prepared for educational events?***

Pre-work will be needed for each event, usually discussed in WebEx and email format.

- For lecture format events, the staff will give you slide show templates with guiding questions and general information. You can use this to help prepare your portion of the lecture. The QoL bereavement coordinator will also be available to provide needed support.
- For small group work, parents will receive a general leader's guide as well as information for any case studies to be discussed.
- For panel events, the staff will provide a discussion guide.
- Be prepared to introduce yourself and relevant points of your St. Jude story for the event. Faculty will offer guidance as to which aspects of your story to emphasize.

- ***How are staff members prepared for these educational events?***

- All health care staff attending your event will have a good understanding of the event's purpose. They may even have questions, experiences, and information prepared to share with you.
- You likely will be introduced ahead of time to any staff taking part in the event, usually by email. Depending on the event, you may work with staff beforehand to prepare for the event.

- ***What are the different education events?***

- **Global Academy/Pediatric Palliative Oncology Symposium** – Timeframe is usually 3–4 days on campus, depending on travel. May include a one-day pre-conference session, followed by small group sessions and parent panel activities during the main two-day conference. (See Appendix 1)
- **End-of-Life Nursing Education Consortium (ELNEC)** – Two-day format that involves taking part in lectures and small group discussions. (See Appendix 2)
- **Fellows Communication Training** – Typically a half day event that occurs twice a year. Includes parent-led, small-group roleplay and follow up one-on-one meetings with fellows. (See Appendix 3)
- **Schwartz Rounds** – Parent educators take part in panel format. Typically occurs with the annual Day of Remembrance event on a Friday and does not exceed an hour. (See Appendix 4)

Participation

Every education event will be a new experience. We are always learning, creating, and adapting our parent educator role to best meet your needs and the needs of the hospital. However, here are some simple ways to be sure you are prepared and engaged for every event.

- **Before: Preparing for an event**

Check-in often with the QoL team electronically.

- Check Microsoft Teams – Under the team “Quality of Life Steering Council,” look for the channel called “Parent Educator.” There, you will find training materials and documents you may review before an event.
- Check your St. Jude email – Your St. Jude email address will likely be your firstname.lastname@stjude.org. The staff will give you your email address during the onboarding process. Meeting planners, agendas, and other important communications will be sent to this email address. You can even get the Outlook app to check your St. Jude email on your smart phone.
- Use your Outlook Meeting Calendar – You can access the calendar through your St. Jude email. Any event request sent to your email that you accept will show up here.
- Keep an eye on your text alerts for any last-minute room changes etc.

It is also a good idea to check in with the QoL team to see if you need to do any special preparation before an event.

- **During: Taking part in the event**

- Come prepared: Be ready to discuss the topics at hand. If possible, keep cell phones put away during the event to avoid distractions.
- Practice active listening: Engaged listening during discussions, panels, and presentations can help you fully take part. See tips on active listening later in this manual.
- Use your story: As a bereaved caregiver, the St. Jude staff knows that you see the hospital in a way we cannot. Using your own experiences to share your input can be a powerful tool. When telling your story, use it to help guide St. Jude toward better outcomes. Construct your message to encourage movement in a positive direction. Just hearing your story can be helpful, but you can increase the impact of your message by explaining why you are sharing it and how you think it affects the discussion at hand.
- Represent the bereaved family viewpoint: During your time at St. Jude and your time as a parent educator, you meet many families, hear their stories, and witness the changing culture. You are now a voice for many of these families. So, consider their perspectives as you represent them.

- **After: Outside the events**

- Right after each event, the leader should conduct a debriefing session with you. As a parent educator, you will be sharing memories tied to some powerful emotions. The primary purpose of the debrief is to talk through any troubling thoughts, images, or

emotions that may have arisen as a result of taking part in the event. We want to ensure that no one is emotionally harmed by sharing sensitive information. We also want to know how we can better support and prepare parent educators and how we can improve every aspect of our education events. Below are some questions you might expect to hear during a debriefing session.

Debrief Questions:

- Could you briefly describe your overall impression of the event?
- What are the thoughts and images that will stick with you?
- Have any thoughts or images from the event upset or disturbed you? If so, would you please describe them?
- What were some of the event's rewarding or uplifting moments for you?
- Were there any moments in which your emotions surprised you? If so, would you describe one or two?
- Do you think any healing occurred for you from preparing for or taking part in this event? If so, how?
- As you reflect on the event, did you think it was worthwhile? Do you think you made a positive impact? If so, how?
- Are there ways we could improve the event in the future?
- Are there ways we could better prepare or support you in the future?

Time between events can be productive. You can stay engaged through email and Microsoft Teams. Some projects may need work or research outside of meetings depending on what events are coming next. If you are unsure what your involvement outside of meetings should look like, you can check in with fellow council members to learn from their experiences.

Skills to Foster

This section reviews helpful skills for your volunteer position. You already possess many of these skills. To improve your skills, practice with family members, friends, and other QoL parent advisers.

- **Introduction/Telling Your Story**

"Telling Your Story" is a wonderful way to build rapport quickly, and hopefully help you connect with your audience.

Open with your child's name, age, and their diagnosis. You may wish to make a brief statement about challenges you faced during treatment, life lessons you learned along your journey and where you find hope. Wrapping up by sharing what motivated you to do this work can also be very inspirational.

- **Boundaries**

Everyone at St. Jude has boundaries: staff, patients, caregivers, and even you as a St. Jude volunteer. Anytime you enter a discussion, take a moment to consider the boundaries others might have and the boundaries you would like to set for yourself.

- Boundaries are put in place to help us separate our work, home life, and emotions.
- People may have personal boundaries about discussing their personal experiences, medical experiences, home, personal beliefs, work, family, money, or many other areas of their life.
- It's important to build trust when you enter a conversation, while respecting others boundaries.
- Respecting boundaries includes accepting that someone may not be open to hearing your story; this includes not asking questions or sparking a conversation around a boundary topic.

Questions for evaluating your boundaries:

- Did the discussion leave you feeling sad, angry, embarrassed, vulnerable, or confused?
- Did I share something before I was ready, or wish that I hadn't?
- What do I gain from sharing? Does this help me? Does it help the listener?
- How would my family feel about me sharing their perspective/experiences?
- Did listening to the perspectives of other parents cause me any unexpected distress?

- **Conversation Skills**

- **Active Listening**

Active listening involves listening for the meaning of what someone else is saying. It consists of three actions: focusing, confirming, and understanding content and emotion. Active listening is a skill because we must put our own opinions aside and delay our responses to accomplish its three components.

- **Focus** and listen for total meaning. Try to gain a good grasp of what the person is saying (the content) and how they are saying it (the emotion or attitude behind the words).
- Use reflection or repetition to show you are listening and **confirm** accurate understanding. Summarize what someone else is saying or ask follow-up questions.
- Seek to **understand** emotion and attend to body language, both your own and that of the other person you are speaking to. Be aware of nonverbal cues, such as head nods, facial expressions, and gestures which help convey understanding. Maintain a comfortable distance and be mindful of your body posture (e.g., try to be relaxed and open).

- **Creating an Inclusive Environment:**

Do:

- Allow everyone in the conversation to introduce themselves.
- Be clear and up front about what is expected of the leader and those taking part.

- Treat everyone with respect and consideration.
- Be aware of learning barriers (cultural; social; based on past experience, etc).
- Provide time and space for people to gather their thoughts and contribute to the discussion.

Don't:

- Assume those taking part all expect the same things from the discussion when the group first convenes.
- Convey a sense of self-importance or superiority.
- Allow only the dominant or more verbal people to take over the conversation.
- Discourage alternate views or counterarguments.
- Try to be someone else. Be yourself.

● **Establishing Ground Rules:**

- Clarify the goals of each session to the group
- Keep discussions constructive and positive
- Share personal experiences rather than making general statements about groups of people (stereotyping).
- Ask those who are more verbal to allow others to speak.
- Give each person a voice. At the start, highlight the value of diverse viewpoints as an essential part of the process.
- Request that if someone challenges another person's ideas, they back it up with evidence or related logic or experiences.
- Try to keep the group on task without rushing them.
- If the group starts to veer in a negative direction or toward pointless venting, ask them how they would like to address this.
- Step back when a group is functioning well. Help those in the discussion take control of their own learning.

● **Encouraging Participation:**

- Ask follow-up questions and paraphrase the comments for everyone to ponder.
- Use open-ended questions to bring out further ideas from those taking part.
- Ask contributors to clarify or elaborate.
- Re-visit past contributions and incorporate them into the current discussions.
- Encourage others to add their reactions or ideas to build on someone's comment.
- Do not be afraid to admit when you don't know something.
- Discomfort and silence are OK, but balance it with clearly stated context and purpose.

Review the debate vs dialogue guide at www.stjude.org/pfcc-training under the section for "preparing for meetings."

Confidentiality – HIPAA Reminder:

We want to ensure that we respect the privacy of all St. Jude patients, families, and staff. Do not share any information with others outside of QoL meetings. Use your St. Jude email to communicate information with staff and fellow parent educators to ensure all remains confidential. Please accept this as a friendly reminder of what we expect of parent educators and why it matters to us and the families we serve.

Thank you! The Quality-of-Life Team welcomes you to this new role.

Contact Info:

Bereavement Coordinator
Joanna A. Lyman
Joanna.Lyman2@stjude.org -
901-595-2658

Patient Family Centered Care (PFCC) Offices
pfcc@stjude.org

Appendix

Pediatric Palliative Oncology Symposium (PPOS)

PPOS is an international pediatric palliative oncology conference. First held in 2017, PPOS is the only symposium of its kind, specifically addressing pediatric palliative needs of the oncology patient. The week-long symposium begins with a two-day global workshop with an audience from more than 20 countries around the world.

This symposium is typically followed by a day of pre-conference workshops that address medical, spiritual, and psychosocial aspects of pediatric palliative care in the oncology setting. Parent educators typically host a pre-conference workshop. It is designed to expose other institutions to the concept of developing a bereaved parent advisory council and integrating the council into institutional practice. Parent educators also are involved in a parent panel discussion, as well as various breakout sessions throughout the week. These sessions are likely to change from year to year as our speakers and topics vary each year.

The two-day main conference focuses on pediatric palliative care topics in the oncology setting. It features speakers who are internationally renowned experts in the field.

The audience of 300–400 attendees includes physicians, advanced practice providers, nurses, social workers, psychologists, spiritual care providers, and child life specialists.

Teaching Objectives: Will be defined by the faculty lead for each session

Teaching Methods: Is dependent on educator preferences ie. Lecture, panel, discussions, small group leader

Tools: PowerPoint (PPT) guides, leader guides will be provided by faculty and can be found on the TEAMS site (Teams Parent Educator Channel)

End-of-Life Nursing Education Consortium (ELNEC)

ELNEC is a national nursing curriculum for educating nurses in end-of-life care with a specific track for pediatric end-of-life care. The curriculum is written by a national certifying organization. The organization requires that every ELNEC slide in the PowerPoint curriculum be included in the presentation.

When teaching ELNEC, the staff instructor may supplement but may not remove or replace any ELNEC-produced material. For our St. Jude purposes, we add oncology-specific information and weave in the bereaved parent perspective throughout the course.

Parent Educators lead small-group discussions using case studies to further explore the concepts being taught. Some of the subject matter covered includes pain and symptom management, ethics, care of the dying child, spirituality, and bereavement.

Teaching Objectives: Reinforce the basic concepts presented in each module and share the parent perspective re: module topic i.e., spirituality.

Teaching Methods: small group discussion

Tools: PowerPoint (PPT) guides, leader guides will be provided by faculty and can be found on the TEAMS site (Teams Parent Educator Channel)

Fellows Communication Training

At St. Jude, we have an extensive number of medical trainees who are at the Fellow level in hematology, oncology, surgery, psychology, infectious disease, etc. We understand that no matter what specialty these doctors choose, communication is a key skill all must master. Our fellows take a two-part Advanced Communications Skills workshop using VitalTalk curriculum, led by a St. Jude faculty member. During this workshop, roleplay is used to teach communication skills. Bereaved parents help create these roleplay scripts, participate in the roleplay scenario, and will assist in facilitating the discussion/feedback session.

This workshop is followed up six months later by one-on-one sessions with bereaved parent educators. The fellows have a chance to talk through a patient communication experience that might have gone well or poorly. The bereaved parent educator serves as a guide for the fellow, offering feedback and discussion as only an experienced St. Jude parent can.

Teaching Objectives: Encourage the direct use of new communication tools (SPIKES & NURSE etc.) and offer feedback.

Teaching Methods: small group discussion, role play, parent panel

Tools: PowerPoint (PPT) guides, leader guides will be provided by faculty and can be found on the TEAMS site (Teams Parent Educator Channel)

Schwartz Rounds

Annually, at the St. Jude Day of Remembrance event, parent educators take part in a parent panel during Schwartz Rounds to our St. Jude faculty and staff. The Schwartz Rounds are a method of staff support modeled by The Schwartz Center for Healthcare Compassion. The goal is to support relationships and interactions between health care workers and their patients.

Teaching Methods: Parent Panel, Question & Answer Session

Tools: Guidance will be provided by staff on which part of your story should be the focus