



Patient Family- Centered Care

Quality of Life Steering Council Training Manual

Quality of Life Steering Council

Role Description

As a Quality of Life (QoL) Steering Council member, your role is to take the knowledge you gained from your St. Jude journey and share that perspective and insight to facilitate positive change in St. Jude policies, practices, standards of care, and patient experiences. The steering council hosts regular in-person meetings to discuss the needs of QoL, upcoming QoL events, and to meet with staff interested in receiving parent feedback or sharing information with members. The QoL Steering Council also guides the strategy, goals, and direction for other QoL volunteer opportunities. All strategies are based on the institutional strategic plan and the 8 recommendations put forth by QoL advisers.

These documents can be found on the QoL Steering Council webpage, Teams, and stjude.org.

The Basics

- ***What is the QoL Steering Council?***

The council is comprised of bereaved parents, a staff representative from each of the psychosocial departments, Quality of Life division leadership, the bereavement coordinator, and several at-large members.

- ***Who can be a member of the council?***

To become a member of the council, you must be two years past the date of your child's passing and have completed the parent adviser application, interview, and onboarding process with Patient Family-Centered Care. The steering council requires a commitment of at least two years of service. Members should also have access to email, internet, and phone as the role requires active participation outside of meetings and good communication.

- ***How often are meetings held and what is the time commitment for this position?***

Meetings are usually held on the St. Jude campus in a meeting room facilitated by QoL Staff and attended by council members as well as St. Jude staff representing various departments. Meetings occur bi-monthly with some communication taking place via email and conference call(s) between meetings. Meetings typically start between 8-9 am and continue until 2-4 pm depending on the meeting agenda. You can expect to spend approximately 12-20 hrs per month volunteering for the council. These hours can include activities such as monthly teleconferences, checking emails, and reviewing materials in addition to the bi-monthly QOL Steering Council meetings.

- ***What accommodations are made for attending meetings?***

If you live within 50 miles of St. Jude, no travel accommodations are made. If you live over 50 miles from St. Jude, St. Jude will cover your travel cost for car, train, or plane. 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 council members will have their meals provided or reimbursed during council meetings 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?***

Once you have completed the onboarding process through Patient Family-Centered Care, we will send you a link to the QoL webpage. There, you will find a list of training materials to review. Before your first meeting, be sure to review:

_QoL 8 Recommendations

_QoL Bylaws

_QoL SC Training Manual

_Debate vs Dialogue Guide

_Preparing for a Meeting Guide

In addition to reviewing these materials, be sure you have completed your onboarding paperwork with Patient Family-Centered Care. Please log into your St. Jude email and Microsoft Teams before your first meeting. If you have any trouble logging in, call the helpdesk at **901.595.2000**.

- **How are staff members prepared to work with me?**

- A staff member serving on the steering council will be familiar with the council and your role. These members are there to provide you with information, answer your questions, and bring information back to their departments.
- Staff members presenting to the council have worked with QoL staff to prepare a presentation or discussion and likely have specific feedback they need from you.
- Staff on a QoL subcommittee may receive a checklist explaining what a parent adviser is and how they can be of assistance.

Participation:

Every QoL Steering Council meeting is unique; reviewing different topics and needs with a variety of people. However, there are some simple ways to be sure you are prepared and engaged for every meeting.

- ***Before: Preparing for a meeting***

In addition to reading the document “How to prepare for a meeting” that can be found on the QoL webpage, you will also want to actively check-in electronically.

- Check Microsoft Teams – Meeting agendas, annual calendars, informational documents, and presentations will be posted here so you can review them before the meeting.
- Check your St. Jude Email – Meeting planners, agendas, and other important communications will be sent to this email address. Check your email frequently. You can even get an app on your phone!
- Use your Outlook Meeting Calendar – Your calendar can be accessed through your St. Jude Email. Any meeting request sent to your email that you accept will be shown here.

It is also a good idea to review the 8 recommendations, bylaws, and strategic plan periodically to help remind yourself of your role and the steering council’s goals.

- ***During: Participating in the meeting***

- Come prepared: Be ready to discuss the topics on the agenda.
- Takes notes: A lot gets discussed in these meetings so having a way to review information later can be helpful.
- Practice active listening: Engaged listening during discussions and presentations from speakers can help you participate to the fullest ([see tips below](#)).
- Ask Questions: Being sure you understand the need and the goals of others can help you provide your best insight. Asking questions also shows you are engaged.
- Use your Story: You are part of the steering council because St. Jude acknowledges that as a bereaved caregiver, you see the hospital in a way we cannot. Using your own experiences to explain your input can be a powerful tool. When using your story, you want to use it to help

guide St. Jude toward better outcomes, so construct your message to encourage movement in a positive direction. Though just hearing your story can be helpful, taking a moment to explain to others why you are sharing it at this time and how you think it affects the discussion at hand can increase the impact of your message.

- Represent the Bereaved Family Perspective: During your time at St. Jude and your time on the council, you meet many St. Jude families, hear their stories, and witness the changing culture at St. Jude. You are now a voice for many of these families so consider their perspective as you represent them.

- ***After: Participation outside of the meeting***

Time between meetings can be a time of high productivity. Staying engaged through email and Teams means discussions and decisions can take place virtually. There may also be projects that need work or research outside of meetings depending on your role. In some cases, you may serve as a member or liaison to other councils where you will need to represent the Steering Council and bring information back to your fellow members at a future meeting. If you are unsure what your involvement outside of meetings should look like, you can always check in with fellow council members to learn from their experiences.

Skills to Foster:

- **Active Listening**

Active listening involves listening for the meaning in what someone else is saying. It consists of three actions or skills: focusing, confirming and understanding content and emotion.

- Focus and listen for total meaning. Try to gain a good grasp of what the parent is saying (the content) and how they are saying it (the emotion or attitude behind the words).
- Use reflection or repetition to show that you are listening. Do this by summarizing what someone else is saying or by asking them questions using their statements as the question's foundation.
- Attend to body language, both your own and that of the other person you are speaking to. Be aware of nonverbal cues. Maintain a comfortable distance and be relaxed and open. Use head nods, facial expressions, and gestures to convey understanding without interrupting.

- **Help others solve problems for themselves**

If someone comes to you with a need or a question, you do not have to resolve things for them. We wouldn't want that pressure on you as you don't have to know all the answers and you should not have to. Instead, help them figure out what department or person can address their problem, empower them to seek help from staff, and share any information that will help them connect to the needed resource. If you don't know a specific person or resource to direct them to, encourage them to speak with their social worker or a QoL staff member if that person is a parent. If that person is a staff member, connect them with a QoL staff member or a PFCC staff member. Our contact information is at the end of the manual and on all QoL webpages.

- **Boundaries**

Everyone at St. Jude has boundaries: staff, patients, caregivers, and even you. 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. Review the examples below and use the questions to help you practice setting boundaries.

Boundary Examples:

- Staff: Every staff member loves our patients and their families, but this is also their job; some staff may have different boundaries in place to help them separate their work, homelife, emotions, or their personal lives.
- Patients, Parents and Caregivers: Everyone is at a different place in their St. Jude journey and everyone lives a diverse life outside of St. Jude. 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. By entering a conversation acknowledging you will need to look for and respect someone's boundaries, you are building trust. Part of respecting boundaries is not asking questions or sparking a conversation around a boundary topic. Another part of respecting boundaries is accepting someone may not be open to hearing your story around a boundary topic. Practicing active listening, observing, and asking someone about their boundaries are all great ways to learn about someone else's needs.

Questions for setting your boundaries:

- How do I feel after discussing X? Do I feel sad, angry, embarrassed, or disappointed?
- What happened the last time I discussed X? How did it affect me and/or others?
- What do I gain from sharing X? Does this help me? Does it help the listener?
- How would my family feel about me sharing X? Am I respecting the boundaries of people not directly involved in this conversation?

Confidentiality/HIPAA reminder:

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

Resources (QoL website and links will go here)

Thank you! The Quality of Life Steering Council welcomes you to this new role.

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If you are not sure who to contact, email our group email, pfcc@stjude.org.