Writing and Telling Your Story for Presentations

There are 3 basic questions to ask yourself when beginning to prepare for a presentation or to formally share your story.

1. Who is the audience?

- Consider your audience; who will you be speaking to, i.e. volunteers, staff, members of the community, donors, parents, patients
- Why would they be interested in your message?
- What experience or knowledge do they already have of Family-Centered Care, or FCC at St. Jude?

2. How long do you have to speak?

- This will give you boundaries as you develop the content and style of the presentation.
- Time your finished presentation and correct for over/under time.
- Practice speaking the presentation out loud vs. reciting it in your head.
- Practice until you can stick to your outline and stay within the allotted time
- Consider the style of presentation you will be giving. Will you be the primary speaker or is this a panel or shared presentation? Will there be only lecture or group interaction?

3. What content do they want to know or what do you need to share? What are your goals for the presentation or discussion?

- Consider the purpose of the presentation- informational, educational, scientific, fundraising, etc. and how this will affect the details you share
- Possibly pick a piece of your story or an emotion from your story and how that emotion evolved, i.e. hopeless to hopeful, isolated to supportive, what happened that wasn't anticipated and how it turned or could have turned into a positive outcome.
- Be careful of making suggestions or giving advice that seems self-serving or limited to select groups.
- Use honesty vs. negativity to be constructive
- Pick a theme and use your story to illustrate, i.e. supportive care, partnership, kindness, medical expertise, fear, challenges, family impact of illness, etc.
- Consider the impact of emotion and how that will affect the audience.
 - Is there a need to focus on your feelings or impressions of your experience, to educate about FCC, or is there a need for more clinical or technical details, or what is the balance? What type of talk are they expecting to hear?
- Develop goals based on the audience's needs. What do you expect they will learn or do after they hear your presentation?

Preparation

After you determine the goals and general content of the presentation, you will need to decide what information to share. You may choose to share your bio in part or in whole or, you may share information about a certain aspect of your experience.

Writing a bio

Writing a bio has a twofold purpose. First is to get you to be able to pull out the most important parts of your story so that you can share it briefly yet efficiently. Secondly, a bio allows presenters to get to know each other, such as when you prepare a presentation to give as a panel or other group style.

Start with writing a half page bio of you, your child, your family, and your St. Jude story. A half page doesn't seem like much but it is an exercise that will help you learn how to pull out the most important parts of your story and tell it well, in a short amount of time.

Writing for a Reason

Writing to address technical questions or personal perspective

Below is an example of different types of questions you may want to address in your presentation if you were for example, asked to share information about research and informed consent, each set having a different focus.

Technical Questions

Don't look for a right answer but simply and honestly share your experiences. If you don't know an answer, just be honest and say that you don't know. It's OK to not have all the answers!

- What was your child's diagnosis?
- What was the name of your child's treatment protocol?
- Was it a research protocol?
- What kind of therapy did that protocol include?
- Has that research protocol trial period ended?
- If so, do you know what the results were overall? If yes, what were they?

Personal Questions/Perspective Questions

- How and when were you given the consent to sign?
- What went well in that process? What could have gone better?
- Do you feel like you fully understood the consent process?
- What was that process like for you? What were you feeling and thinking?
- How did you make the decision to sign off on your child's research protocol?
- Did other family members agree with the decision?

Differences in telling one's story for ALSAC

Many parents work with ALSAC to share parts of their treatment journey at St. Jude. These experiences may be the same as the ones you share as a parent adviser, but the goals are usually different. Expressing gratitude and helping to raise funds for St. Jude are always most appreciated and we couldn't do the work we do without this support. However, expressing your experiences as a parent adviser is focused on continued improvement in quality patient care and in building partnerships between parents and staff. The content of the story may be similar but the goals are unique and generally a story expressed as a FCC adviser will differ based on this goal.

Telling a story

An effective story has:

- A beginning, middle and an end.
- Is concise, focused, and relative.
 - Speaking when caught off guard, or when you only have a couple of minutes
 necessitates your being able to make a quick decision about the amount of information
 you can share.
 - Know at what point to start your story so you can get the important points across and also know when it is time to end the story.
- Conveys emotional information in a non-emotionally charged manner
 - May chose to not share certain experiences but if chooses to share an emotional experiences, needs to <u>state</u> the emotion rather than display the emotion
- Illustrates problems resolved thru partnership or expresses what might have made the situation better
- Elements of one's personal experience, as well as is applicable to the larger parent population

Tips for Writing

- Consider what is motivating you to share information and that will affect your details and emotions. Are you sharing for reasons that promote FCC?
- For some people, it is helpful to just start writing and see where your thoughts take you
- Think through not only what you're willing to share, but also what you not willing to share.
 - o Establish boundaries including what content and amount of detail you're able to share
- Consider what you think would be an effective story to tell
- Recognize you may feel or experience strong emotions when your write or tell your experiences
- Include a current state for your child/family/self

Preparing for presenting

- Develop a timeline for completing the content based on the presentation type and date.
 - Plan specific goals and deadlines for completion. The preparation stage may be longer or shorter based on the number of presenters who need to coordinate and the type of presentation that you're giving
- Read the draft over many times and once the presentation is finalized, read it out loud many times
- Stand up to practice and time it to assure you can stay on track for completing the talk in the allotted time as well as sticking to your prepared outline
- Prepare for the emotions a personal story invokes; Practice telling your story until you can share
 it with others without reliving it
- Don't have to memorize but be very familiar with the content so you don't stray from the planned topics
- Consider what graphics or pictures need to be included if the presentation includes visuals; before and after photos make a big impact
- Coordinate with co-presenters in advance regarding order of presenting and key points each person will make
- Consider what questions the audience may have and allow for questions at the end if possible

Sharing Stories: Self-evaluation

- Is my story relevant to the topic of discussion?
- Is the length of my story appropriate?
- Am I complaining, gossiping or otherwise not being constructive?
- Am I representing my views solely and not applying details to the broader patient population?
 - At some point, either of these may be ok. It depends on the intent of the information being shared.
 - Too many "I" or "my child" can possibly be seen as self-focused if not appropriate to the situation.
- Does my story help to develop partnership?
- Am I remaining tolerant?
- Am I aware of my own emotional reaction to the story?
- How is the audience responding to my story?