



INSTITUTE FOR FAMILY-CENTERED CARE

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SHARING YOUR STORY: TIPS FOR PATIENTS AND FAMILIES

Patient and family leaders are often asked to share their stories—these personal stories serve as powerful tools for bringing about constructive change in the health care system. The following tips will help those asked to share their story.

- ▼ The way you present your story can have a long-term effect on the way people view you and others in similar circumstances. Consider the following questions prior to agreeing to share your story:
 - What am I willing to share?
 - What do I feel is too private to share?
 - What does my family not want me to talk about?
 - What will my story teach those who are listening?
 - Have I had negative experiences that are still bothering me and will be difficult to share in a constructive manner?
- ▼ Plan ahead for what you will share and how you will share it. Your story is a precious resource, use it thoughtfully and wisely.
- ▼ Gather information, prior to sharing, about what is expected of you and what you can expect. Asking some of the following questions may help you to decide whether or not to share your story:
 - When do you want me to speak? What time? For how long?
 - Where do you want me to speak? What site or city?
 - Who is the audience? How many people will be there?
 - What is the theme or topic?
 - What part of my story do you want to hear?
 - Is there a message you want me to leave the audience with?
 - Is there reimbursement for child-care and transportation?
 - Is there an honorarium?
 - Do you need an answer today?

- ▼ After you accept an invitation to speak, remember to think carefully about the message you want your audience to remember. Try to focus on two or three main points and organize your thoughts. Speak from your heart—be authentic, respectful, and constructive. Remember the following tips when you tell your story:
- Know who your audience is and prepare with them in mind.
 - Practice ahead of time.
 - Use only two or three main points in your story.
 - Use your story to illustrate specific principles of patient- and family-centered care.
 - Use your own style.
 - Use people-first language.
 - Look at your audience.
 - If you are speaking as a family member and if you are comfortable doing so, share pictures of your child or family member.
 - If you don't know the answer to a question, say so.
 - Let the audience know your boundaries.
 - Be honest.
 - Try to avoid putting people on the defensive.
 - Remember that your negative experiences can be turned into constructive learning opportunities. Anger used ineffectively may not be the most powerful use of your story.
 - It may be helpful to put highlights of your story on note cards as a reference during the presentation— but avoid reading from them.
 - Expect that some people who hear your story may be deeply moved. Also remember that you may feel emotional when you tell your story.
 - Consider taking a friend, family member, or supporter with you. They can help with any problems that arise and sit up front so you can focus on a friendly face.

Adapted from: Thomas, J. & Jeppson, E. (1997). *Words of Advice: A Guidebook for Families Serving As Advisors*. Bethesda, MD: Institute for Family-Centered Care.