

Helping You Tell Your Story

We know that the patient or family voice can influence healthcare providers and hospital staff to think differently about program design, clinical care, and communication with patients and families.

As BIDMC seeks to hear patient and family voices more often and bring patient and family advisors into more of the hospital's planning and educational activities, a number of advisors have been asked to share parts of their stories.

The guidelines below offer some things to consider at different junctures - before, during, and after telling your story.

Things to consider before telling your story

Some of the things that happen as part of your healthcare experience are private - you may not have shared them with anyone before. Once you tell your story, in a public audience or a one-on-one interview, your story becomes part of how BIDMC thinks about the way patients and families experience healthcare in our hospital.

This reality gives your story a lot of power, because through your story we learn how we might make things better for other patients and families. In order to work on improvement – especially to convince others of the value of making change – parts of your story may be retold by others, through the use of quotes or anecdotes. Please consider your comfort level with your story being shared in these ways.

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 decide whether or not to share your story. Ideally, the Patient and Family Engagement staff will come to you with some of this information. But, if you are approached by a provider or other BIDMC staff person directly, these questions will be helpful:

- 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?
- Will there be video- or audio-taping? Who will have access to the tape afterward?
- Who else will be speaking?
- 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 a larger context that would make my story more transferable to other situations?
- What is your presentation style? Do you tend to use a script?
- Is there reimbursement for child care, transportation, or parking?
- Is there an honorarium?
- Do you need an answer today?

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?

Sometimes telling your story can bring out emotions you thought you didn't have anymore, even if what happened was a long time ago.

Please think about what will help you feel supported through those emotions, so that you can have a plan in place. For example, having someone in mind who you can call to debrief afterward is one option. The Patient and Family Engagement staff are available to speak with you, should you need it.

It may be useful to practice telling your story with a BIDMC staff member so you can make sure the points you want to make are the ones coming through to others.

If you are invited to share your story and are not comfortable doing so in person, consider different ways you might share your story, such as in writing or via an audio or video recording, and feel free to suggest those options to staff.

Finally, it is always okay to respectfully decline the request if the opportunity does not feel comfortable.

Things to pay attention to while telling your story

If it becomes hard to tell your story, you can always stop. We invite you to tell your story because we know that there is nothing like hearing directly from you about your experience, but we want to respect that you know when you need a break.

Things to be aware of after telling your story

Those in the audience may approach you and ask you questions about your experience. You can choose whether or not you would like to answer their questions in the moment. If you'd like to talk further, but not immediately following your presentation, feel free to ask if you can follow up later.

Some advisors feel great after telling their stories, and some feel overwhelmed by being taken back to a difficult time in their lives and the lives of their families. If you have planned to check in with someone after telling your story, follow through on your plan.

You may also want to consider what went well and what felt uncomfortable, should you be asked to participate in a similar opportunity in the future.

Thank you for sharing your story to improve the patient and family experience at BIDMC.