

**Storyteller Toolkit**

*The purpose of this document is to help you to think about, write and share your personal experiences of positive or negative examples of patient and family-centred care. The purpose of your story is to share your experiences with medical student learners in a way that would help them to realize what it was like to be a patient, family member or caregiver and the positive impact or negative impact certain interactions or care experiences may have had on you.*

**Core Concepts of Patient- and Family-Centered Care**

*Patient and family centered care is working "****with****" patients and families, rather than just doing "****to****" or "****for****" them. – Institute for Patient & Family Centred Care*

**Participation & Empowerment**

**Dignity &   
Respect**

**Communication   
& Information Sharing**

**Collaboration**

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, families and caregivers. It redefines the relationships in health care by placing an emphasis on collaborating with people of all ages, at all levels of care, and in all health care settings.

* This perspective is based on the recognition that patients and families are essential allies for quality and safety—not only in direct care interactions, but also in quality improvement, safety initiatives, education of health professionals, research, facility design, and policy development.
* Patient- and family-centered care leads to better health outcomes, improved patient and family experience of care, better clinician and staff satisfaction, and wiser allocation of resources.

**Patient and Family Centred Care**

Principles, Definitions and Vital Behaviors

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| **Principle and Definition** | **Proposed Behaviors, Actions & Attitudes of Health Care Providers** |
| **Dignity & Respect**  Patient and family perspectives and choices are heard and honored.  Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into care planning and decision making. | Ask patients to define their “family” understanding that it may include friends and others from their community. Discuss with each patient to ensure that whomever the patient defines as “family” is considered to be “a partner in care.”  Acknowledge patients and families as the experts of their own experience, with information that needs to be heard and acted upon. |
| **Communication & Information Sharing**  Health care providers share complete and unbiased information with patients and families in ways that are clear, complete, timely, accurate and useful in helping patients and families effectively participate in care and decision making.  Patients and families also share all necessary and relevant information with members of their care team. | Introduce yourself, what your role is and what they can expect from you. Ask patients and families how else you can assist them.  Inquire to find out from patients/families about how to share information/education. What they want in terms of the amount, how often, what format, when?  Tell patients/families what the diagnosis is and the seriousness as soon as possible. Don’t hold back the truth. Be open, upfront and realistic about the treatment, appointments, process, options and side effects etc.  Encourage questions, answer questions. In conversations with patients and families, use appreciative inquiry, be attentive with reflective listening to ensure two-way communication and full understanding – use a “teach back” technique. |
| **Participation, Empowerment & Collaboration**  Patients, families and health care providers collaborate in policy and program development, in professional education, in research and evaluation, and in the delivery of care.  Patients are empowered to participate in experiences that enhance control and independence. | Educate patients and families about their important role in ensuring their safety and welcome them to ask questions and voice concerns. Ensure that patients and families know who and how to call for help.  Ensure that patients and families always know who different staff are, and what they are doing; staff should state their name, occupation and explain what they are doing. |
| **Comprehensive & Coordinated Care**  Patients and families receive care that provides physical and emotional comfort and is safe.  Patient and families experience care that has continuity and smooth transitions. | Show caring, compassion and empathy through: eye contact, listening, taking time, giving your full attention – be present in the moment.  Provide supports for patients/families: be knowledgeable of what is available to them, suggest and refer to social work, spiritual care, and dietician for example.  Prepare well for transitions (hospital – home), between different providers and phases of care. |

**The Power of Storytelling**

Stories told by patients, families and caregivers can be powerful tools for bringing about constructive change and is recognized as the most effective way to communicate a message. Simpley telling your story in your own words with sincerity is what matters.

* Think about your journey as a patient - specifically those times that stand out for you when you experienced a positive, negative or mixed experience.
* Ask yourself:
  + What am I willing to share and what do I feel is too private to share?
  + 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?
* Write out examples of each experience – if you are not comfortable writing the story, write down some key points that you can expand upon. Start by just writing your story as if you were talking to a friend – including all your normal expressions, thoughts and words you usually use. Do not worry about grammar.
* Details are important including: What were you thinking? How did you feel? What fears did you have? What was the impact of the experience on you or your family?

***Remember:*** *Do not include the entire patient story history or specific dates – just focus on the key events or experiences that impacted you most.*

# Storytelling Activity

## Step 1:

To help you get started, the following chart (pg. 3) provides some questions to help you think and write about your experiences that relate to patient and family-centred care. Only respond to the questions that are meaningful to your experience and skip the questions that are not meaningful to you.

## Step 2:

Once you have listed different examples from your many experiences using the questions/prompts – look over the examples that came up for you and pick one positive experience and one negative experience that you feel passionate about and would be open to talking about.

## Step 3:

Write out the positive story example – including all the details that bring it to life.

## Step 4:

Write out the negative story example – including all the details that bring it to life.

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| **Questions for you to think about when writing**  **your story** | **Use this space for notes to help develop**  **your story** |
| **1. Dignity & Respect**   1. Can you think of a time when you felt like you were **really heard and listened to**? What did they do that made you feel positive about this? If not, what could have been done better or differently? 2. Can you think of an incident where **YOUR** knowledge, values, beliefs and cultural backgrounds were incorporated into care planning and decision making? What did the providers do or say that made this so effective? If not, what could have been done better or differently? 3. Can you think of a moment when your providers acknowledged **you as an expert** in your own experience, who had information that needed to be heard and acted upon by the providers? If not, what could have been done better or differently? |  |
| **2. Communication & Information Sharing**   1. When you received your diagnosis, was the physician **sensitive** to your emotions? Did the physician ensure you had resources available to answer questions once you’d had a chance to absorb your diagnosis? If not, what could have been done better or differently? 2. Was there ever a time in your care journey when **the providers took the time to find out from you** what you wanted in terms of the amount of information, how often you wanted to be informed, or they took the time to discover what format you preferred to receive the information in? If not, what could have been done better or differently? |  |
| **3. Participation & Empowerment**   1. Can you think of a time when you were encouraged to ask questions and voice concerns and the providers were open to this – what did they do so well? If not, what could have been done better or differently? 2. Was there a time when the providers did an exceptional job of ensuring that you and your family knew who and how to call for help? If not, what could have been done better or differently? |  |

**Helpful Tips for Sharing Patient and Family Experiences**

# Preparation:

1. Emotions. Be aware that speaking about health care experiences is emotional. This is a sensitive subject matter.
2. Prepare written notes. This will alleviate anxiety. First, write what you want to say, then organize your thoughts and edit them down.
3. Terms. Create your story keeping these terms in mind: Respect, Dignity, Information Sharing, Communication, Participation, Empowerment, Collaboration, Comprehensive and Coordinated Care.
4. Collaborate. Speaking with the staff liaison of the audience you are presenting to is important. Often, they can act as a coach, review your talk, help you narrow focus and give feedback prior to the presentation.
5. Rehearse. Practice in front of a mirror. You can practice looking up and making eye contact and use a timer to determine whether you are speaking too fast.
6. Engage a partner or child to be your audience. Time your story so you know if you have too much or too little information. Time. Plan to speak for less time, as opposed to more. Most people go on too long when speaking.
7. Rehearse the content. This helps make it more ‘formal’ and less emotional.

# Content:

1. Sharing information. Think about what you are willing to share, and what you consider too private.
2. Collaborate with family members to ensure you have their permission to share their story.
3. Know your audience. It is important to connect with your audience in some way. People listen best when they identify with the speaker.
4. Do not generalize (e.g. “all patients/families think”). Speak form the “I” and be sure to be specific and use examples.
5. Honesty. Make sure the facts are true. Admitting mistakes, failures or weaknesses is useful.
6. Tell a positive story. An example of a positive patient experience and how that made you feel and why. When telling a negative health care story consider first telling the strengths and the positive no matter how small. After the negative story, ensure that you have time for analysis or reflection to discuss the obstacles that may be in place to change. An uplifting tone will help drive your message across.

# Delivery:

1. Stress. Public speaking can be stressful. It is good to acknowledge that what you are doing is important, and those health care providers and other patients and families will benefit from hearing you speak. Everyone has anxiety before public speaking, even the most accomplished speakers.
2. Slow Down! Have you ever heard a speaker speak too slowly? Slow down. Count to three at the end of every sentence. Breathe long at every comma. You cannot go too slowly. Think about especially slowing down at the end of your talk so people can digest what you’ve said.
3. Emotions. Speaking about our own or our medical experiences can be difficult. If you feel like you are getting too emotional, pause and take some deep breaths. Don’t force yourself to continue right away. Let the audience know you just have to compose yourself before you can move on. If you cannot contain your emotions, ask for another presenter to speak, or even opt out of the session. There is no shame in admitting that the speaking is too much for you. You are human.
4. Energy! Be energetic! Lackluster speakers lose audience interest.
5. Smile!
6. Notes. Bring your prepared notes, but try to rehearse so you don’t have to read directly from them. There’s nothing wrong with referring to them if you get lost, but still try to pause and look up often to make eye contact.
7. Look around the room. It can be helpful to choose one person in each part of the room, and alternate who you look at each time. Looking around the room and not just at one spot makes everyone feel included..
8. Remember:
   1. Not everybody will like you or your message.
   2. There will inevitably be one person in the front row fast asleep, don’t let that sway you.
9. Questions and answers. Be accepting and non-judgmental. Even if the question is convoluted, try to reframe it into what you think the person is saying. If you don’t know, or have to think about it more, just say so.
10. No Fear! Be present with your audience. Do not fear them. They are there because they want to hear what you have to say – consider them friendly.
11. After. Concentrate on the positive feedback, and use negatives only to improve your next presentation.