How to care for yourself when representing the patient voice

A knowledge transfer program designed by and for patients, family champions, advisors and/or advocates working to improve patient safety (Patient Champions) offered by the World Health Organization’s Patients for Patient Safety Programme, SickKids Hospital and Patients for Patient Safety Canada.

Date: Thursday May 7, 2015

Time: 7-8am MT/ 9-10am ET/ 1-2pm UTC/ 3-4pm CEST (click here for other time zones)

Cost: Free access, registration required (click here)

Topic description: This interactive session will discuss the journey of patient champions as partners in patient safety and ways they can care of themselves with the goal of:
- Providing examples, tools and guidance to help Patient Champions care for themselves
- Helping liaisons/coordinators of Patient Champion groups understand the needs of Champions

What to expect during the webinar: Each speaker will provide a short presentation that provides evidence, experience, examples and lessons learned. This will be an interactive session and participants are encouraged to contribute to the discussion (verbally or via chat). The session will be recorded in order to make it accessible to those who cannot attend however the chat conversation will only be available during the session. A short summary document with the key points shared will be made publicly available after the webinar.

Speakers
- Sharon Nettleton, co-author of Harm to Healing: Partnering with Patients who have been harmed.
- Martin J Hatlie, JD, CEO Project Patient Care
- Sabina Robin, Member, Patients for Patient Safety Canada
- Manvir Jesudasan, Chairman, Patients for Patient Safety Malaysia
- Sitara de Gagne, Family Advisor, Member of Family -Centred Care Advisory Council, SickKids Hospital

Click here to register. The login information, one week and one day reminders will be sent to those who registered.
How do You Know You are Ready to Assume an Active Role as a PS Champion?

Ask yourself:

1. Am I ready to partner with health care providers, or do I want to seek justice first?

1. What issues do I want to work on, specifically related to my experience or more general?
PS Champions in Action

Especially Focused on Particular Kinds of Harm

Sue Sheridan

Knitasha Washington

Working on Broader System Reform

Helen Haskell

Bob & Barb Malizzo
PS Champions in Action

Focused on Particular Kinds of Harm

• Tell your story
• Connect with others who have similar experiences
• Connect with experts
• Start or join a group
• Work with policymakers to give voice to the issue you are passionate about

Working on Broader System Reform

• Apply to be on advisory council
• Ask to be on a hospital board of directors or hospital committee
• Get involved in community groups or social media networks interested in patient safety or patient rights
How Do You Decide the Type of Tasks or the Level of Commitment You are Ready to Assume?

The Serenity Prayer

God grant me –
the Serenity to accept the things I cannot change --

Courage to change the things I can --

and the Wisdom to know the difference
How Does One Take Care of Body, Mind, Spirit?

• Find a family member or friend who will listen to you when you are discouraged
• When you are anxious, imagine throwing back the “anxiety ball” to those with whom you are uncomfortable
• Do not be afraid to bruise feelings when it’s important to speak up
• Remember, the health care system is supposed to work for you and your family. Make it so!
Harm to Healing Study

Sharon Nettleton, PFPSC
May 14, 2015

Trew, Nettleton, Flemons

http://www.patientsafetyinstitute.ca/English/research/commissionedResearch/HarmtoHealing/Documents/Harm%20to%20Healing.pdf
Feelings/emotions/activities

*The grief process is utterly exhausting.*

*It involves internal & external processes of coping.*
Dual Process Model

Distress Avoidance
- grief work
- intrusion of grief
- breaking bonds/ties/relocation
- denial avoidance of restoration changes

Restoration Oriented
- attending to life changes
- doing new things
- distraction from grief
- denial / avoidance of grief
- new roles/identities/relationships

Stroebe & Schut, 1999
Harm to Healing – Study

Patient/Family: Readiness for collaboration

Grief / Healing Cycle
- appropriate time for grieving has past
- signs of recovery (internal & external coping)
- right motivating factors