

Patients for Patient Safety Canada Disclosure

Highlights from the May 27, 2014 Knowledge Transfer Session on 'Disclosure'

The Crucial Elements of Disclosure

- Disclosure is a process and not a 'one-time meeting'.
- Disclosure is a continuation of the relationship between health care providers and the patient/ family-compassion and effective communication are required to re-build trust.
- In disclosure families want to know what happened, how it happened and what can be done to prevent this happening again.
- Health Care providers have an ethical and professional obligation to disclose which is required by accreditation, professional associations and health care organization policies.
- Factors that affect disclosure are 'willingness to disclose' as well as 'ability to disclose'.
- Health Care Providers require support and training to be able to engage in disclosure conversations.
- When disclosure is not done well it can create secondary harm for patients, families and health care providers.

How Disclosure Has Evolved

- Disclosure policies started to evolve after 2004.
- A steady inclusion of the 'patient voice' in disclosure guidelines occurred following the original Canadian Disclosure Guidelines (2008) and the re-drafting of these guidelines in 2011.
- Initially there was fear on the part of health care providers and organizations.
- The cultural shift from a 'blame and shame' environment has helped the evolution of disclosure. There is still much work to be done.
- Five key challenges to disclosure: challenge of large scale implementation, balance of patient safety theory with expectations of patients for transparency, confidentiality concerns, disclosure vs. liability and the challenge of measurement.

What Families Can Do to Support Full Disclosure

- In advance of care ask what will happen if 'something goes wrong' – support the normalization of disclosure.
- Be involved in your own care.
- Routinely ask for copies of your health reports (i.e. lab tests, report etc).
- When a harmful incident has occurred-
 - Be clear and respectful about what you expect and what you need.
 - Work hard to keep emotions in check.
 - Be prepared to be persistent.
 - Have an advocate to coach and advise as to best next steps.
 - Be part of the solutions.
 - Recognize the discomfort of health care providers and help to create a 'safe place' for disclosure conversations.
 - Ask for a written summary after a disclosure conversation and /or write your own summary, including further questions. This informs health care providers as to what the patient/ family heard and works to make disclosure an on-going conversation.

Closing comments

- Disclosure requires transparent processes that re-build trust.
- Disclosure depends on reporting in a safe and supportive environment.
- Disclosure can lead to change.