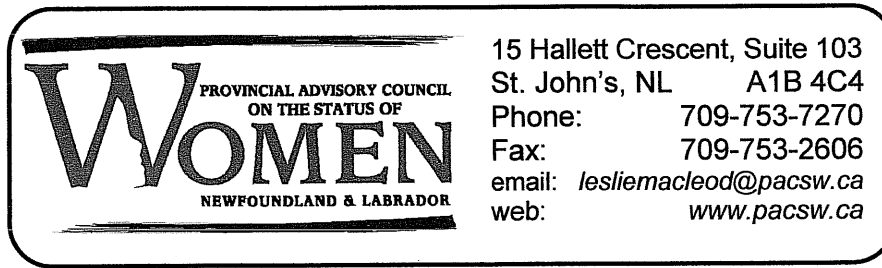


Submitted by

Provincial Advisory Council on the
Status of Women Newfoundland and Labrador



June 12, 2008

Mr. Robert Thompson, Chair
The Task Force on Adverse Health Events
P.O. Box 8700
Confederation Building
St. John's, NL A1B 4J6

Dear Mr. Thompson:

Re: Submission to the Task Force on Adverse Health Events

The Provincial Advisory Council on the Status of Women is concerned with all issues which impact women in Newfoundland and Labrador. The Commission of Inquiry into Hormone Receptor Testing has revealed many shortcomings in our province's health-care system and raises serious concerns about the service women are receiving.

Our submission to the Task Force on Adverse Health Events addresses two areas:

1. The need for a transparent and accountable disclosure policy.
2. The need for patient involvement in development of policy and practice.

Requirement for Full Disclosure

There is no doubt health-care providers have both an ethical obligation and legal duty to disclose health information fully, honestly and in a timely manner to their patients. Whether the rationale is patient autonomy or for the purpose of therapeutic decision-making, truth telling is required. Full disclosure is essential, whether the information relates to general health concerns or an adverse event which causes death.

Research has shown patients want as much information as possible about their health condition. They want to be involved in all decision making affecting their health. This is not possible if information is withheld. In her testimony before the Commission of Inquiry on Hormone Receptor Testing on March 24, 2008, Rosalind Jardine expressed what is required:

"The ultimate would be a top-notch, efficient, effective, transparent system whereby everybody affected with a disease such as cancer would be privy and would be a part of that communication system openly, because that's so important. That gives the patient, like just speaking from me, that gives us a power that we still have input and somewhat, though very limited, control on this disease process that's happening, and when you're not informed and it's happening kind of outside of you, you feel so insignificant. You feel that our life doesn't count at all. You don't feel that you're a team."

Historically, health care has not been based in a philosophy which includes notions of "patient autonomy" and "patient safety." From today's vantage point, it is surprising non-disclosure was the accepted practice until the recent past. "A 1961 survey of 219 physicians in the USA found that 90% would not disclose a diagnosis of cancer to a patient." In the 1990's, the Ontario court, "failed to find fault with a neurologist and a family physician who, for more than 7 years, did not tell a patient that she likely had multiple sclerosis." (Symaniw v. Zajac and Bimbaum, 1996). (Extracts from a paper, Disclosure: Ethical and Policy Considerations, pp 4-5, prepared by Philip C. Hebert for the Commission of Inquiry on Hormone Receptor Testing, Newfoundland and Labrador 2007-2008).

Surprising or not, we fear this outdated attitude of paternalism continues to influence health care providers both individually and systemically. We hear many stories of patronizing attitudes and information being withheld from patients and their families.

We also worry that stereotypical notions about women increase the likelihood of non-disclosure "for her own good." Ethnicity, class, race, age and disability may exacerbate the perception that the truth will cause worry and stress and, therefore, will be withheld.

Gerry Rogers provided a very clear example of medical paternalism, including its effects on patients, during her testimony to the Commission of Inquiry into Hormone Receptor Testing on March 25, 2008:

"...and then I asked her...why did Eastern Health never call me back and why didn't Eastern Health speak directly to the women who were involved, because there was so much confusion. There was so much fear, and I think mistrust grew out of that as well, and she said "well, we don't want to frighten women," and I said again...it makes no sense...we're adults who take part in our health care, and that, in fact what they did was exactly the opposite. They caused fear. They caused confusion. They caused mistrust. They caused unnecessary anxiety..."

Patient Involvement in Decision Making

One way to address this shortcoming is by the involvement of patients and their advocacy groups in the development of appropriate disclosure guidelines. It is not acceptable for these to be developed and sanctioned exclusively by health-care providers. Community agencies and advocates represent patients' rights and interests; they know what is needed and are well placed to provide this advice.

In addition, the patient's voice must be directly represented on the proposed health quality council in Newfoundland and Labrador.

It is possible our health-care systems will make the shift to a blame-free environment, one which encourages and supports the reporting of errors, including adverse health events. It is our understanding this culture shift would require accountability for errors and systemic problems in health care delivery. It would also create an avenue to improve patient safety, which must become paramount. As part of this culture shift, it will be essential for the public to be made fully aware of the intent, scope and impact of the new environment.

Recommendations

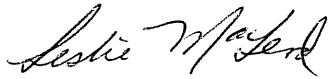
The provincial health-care system must:

1. Commit to full disclosure in regard to response and communication of adverse events within the health system.
2. Presume complete information sharing is required unless the patient has indicated otherwise or is legally incompetent.
3. Consider age, geography, socio-economic status, gender, race, disability and ethnicity and cultural norms in the manner of communication but these factors must not influence whether information is shared.
4. Provide mandatory training in gender sensitivity and communication skills for all health-care providers.
5. Educate all health-care providers about disclosure policy and procedure. It is vital this education is provided at both the entry level and to those presently working in the system.
6. Include community members with knowledge of equality issues in the development and monitoring of health-care disclosure policy.

7. Include patient representation on the proposed health quality council in Newfoundland and Labrador.
8. Inform and educate the general public about the scope and impact of a blame-free health care environment.

We hope the Task Force is successful in paving the way for a more accountable and responsible health-care system which maintains patient safety and full disclosure as primary values.

Sincerely,



Leslie MacLeod
President/CEO