Jeanette Ives Erickson, RN, senior vice president for Patient Care and chief nurse

Patient and family advisory councils

one more way to ensure the patient’s voice is heard

In my last column, “The patient experience: the driving force behind patient care,” (August 20, 2009) I spoke about the importance of listening to our patients to gain a deeper understanding of what they experience while in our care. It is implicit in our mission that our work, our care, and our decisions be guided by the needs of our patients. But to truly be guided by the needs of our patients, we must first listen to them.

Through a variety of tools and surveys, we have access to patient-satisfaction data and feedback from patients about what we’re doing and how we can improve. The H-CAHPS, for example (Hospital Consumer Assessment of Healthcare Providers and Systems) and other data-collection instruments help us tap into information about how patients perceive their experience of care. And this is helpful in informing our decisions about how to prioritize our time and resources.

Another way we ensure our patients’ voices are heard is by inviting them to participate in patient and family advisory councils. Patient and family advisory councils bring together clinical and administrative staff, patients, and family members to talk about issues relevant to the patient’s experience. These councils advise hospital leadership on matters relating to patient-provider relationships, safety, quality improvement, patient education, and other issues they may deem relevant to patient care.

Most patient and family advisory councils are comprised of some combination of direct caregivers, support staff, administrators, former patients or family members, parents of pediatric patients, and/or members of the community. Membership or length of participation on patient and family advisory councils varies, and members are not compensated or reimbursed for their participation.

MGH has long recognized the value of patient and family advisory councils, so we’re ahead of the curve in meeting the Massachusetts Department of Public Health’s directive for hospitals to establish patient and family advisory councils by October 1, 2010. The new regulation requires hospitals to report annually on the progress and accomplishments of their advisory councils and to make these reports available to the public and to the Health Department upon request.

continued on next page
One of the longest standing advisory councils at MGH is the MassGeneral Hospital for Children’s Family Advisory Council, which was formed in the fall of 1998 to foster alliance between parents, children, and professionals and to reinforce a spirit of responsiveness to the needs of pediatric patients and their families. Among its many accomplishments, the Family Advisory Council has established an on-line website for frequently asked questions; produced instructive videos for medical residents and inpatient staff; participated in pain initiatives and research studies; and consulted on the design of the pediatric emergency department.

In November, 2001, the MGH Cancer Center created an advisory council that is today comprised of six staff members, five family members, and 16 patients of diverse ages, diagnoses, socio-economic status, and life experience. The group meets an average of once a month for two hours with agenda items suggested by staff, patients, and family members alike. With a focus on learning and sharing information, the Cancer Center Patient and Family Advisory Council has helped to formally integrate the patient-family experience into teaching, training, building design and patient care, and serves as a model for other advisory councils both within and outside of MGH.

In 2007, the MGH Heart Center established a patient and family advisory council currently comprised of four MGH staff members and 11 patients and family members. The council has had input into patient-education initiatives, customer service and patient satisfaction projects, and efforts to enhance patient- and family-centered care. Their future work will focus on the creation of disease-specific support groups and providing input into patient-education tools, continuity of care initiatives, staff orientation, and multi-disciplinary education within the Heart Center.

Of note, the Maxwell & Eleanor Blum Patient & Family Learning Center makes use of a patient and family advisory council to provide feedback on its many services, to field-test educational materials, and to guide decisions around educational programs, information displays, and acquisition of new materials.

These are just some of the advisory councils at MGH that enlist the involvement of patients and family members. We applaud the new legislation encouraging the creation of patient and family advisory councils because we know first-hand the benefits of partnering with our patients. We are grateful for their participation and the positive impact their voice has had on care delivery and the patient experience.

**Update**

I’m pleased to announce that Karen Waak, PT, has assumed the position of inpatient physical therapy clinical specialist covering the Ellison 4 Surgical Intensive Care Unit, and the Ellison 7, White 7, and Bigelow 7 surgical patient care units.