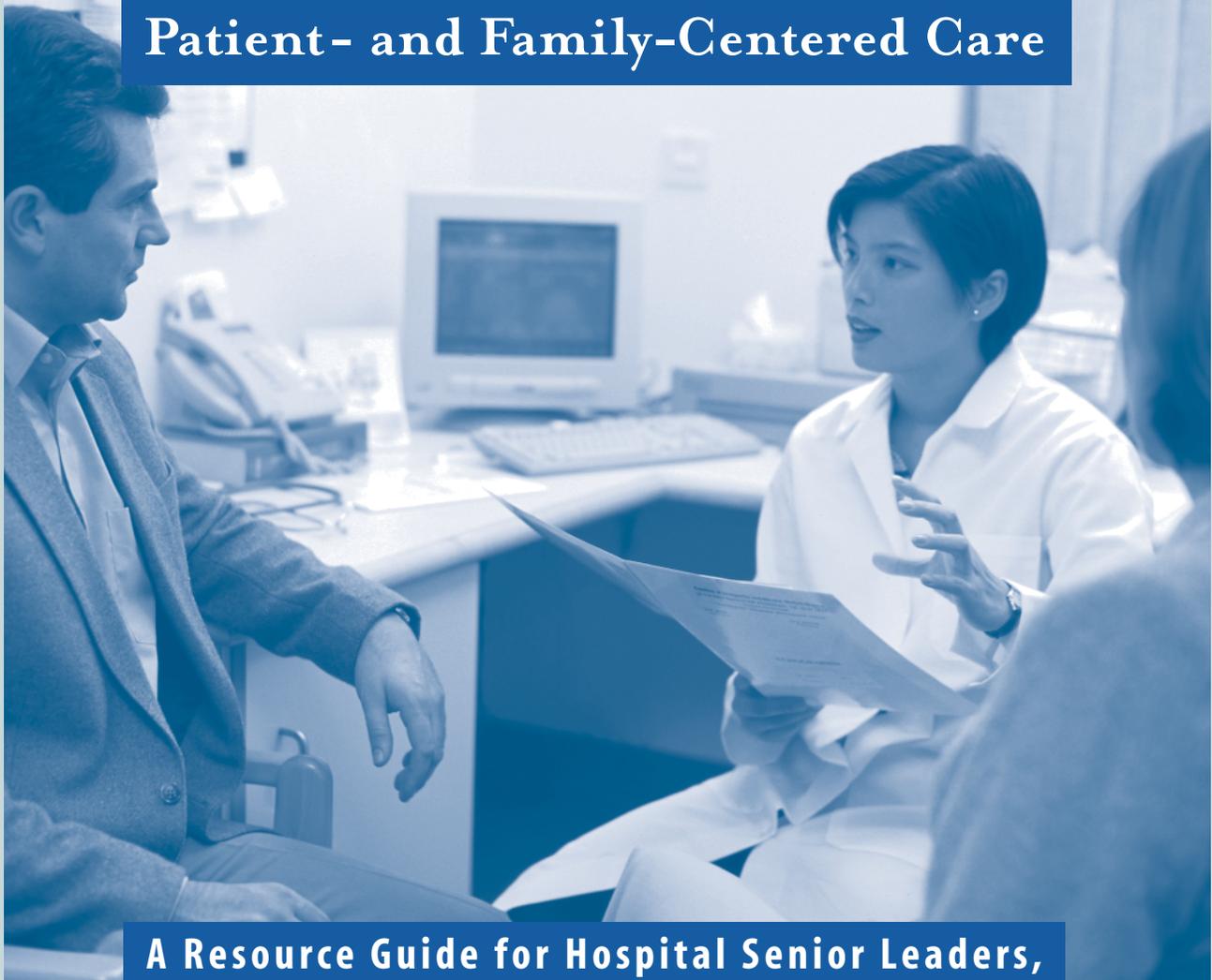


Strategies for
LEADERSHIP

**ADVANCING THE PRACTICE OF
Patient- and Family-Centered Care**



**A Resource Guide for Hospital Senior Leaders,
Medical Staff and Governing Boards**



**American Hospital
Association**



INSTITUTE FOR FAMILY-CENTERED CARE



American Hospital Association

The AHA is committed to working with hospitals and health systems to continually improve patient safety and quality of care. We know that while America's hospitals provide the best care in the world, we can and must do better. For the past several years, the AHA has undertaken a series of initiatives to bring national attention to improving patient care and safety. These initiatives have focused upon:

- Evaluating care as to being "patient-centered;"
- Narrowing the range in variation of care provided to patients, especially in regard to palliative care and care at the end-of-life;
- Involving patients in decisions concerning their health care;
- Utilizing the Malcolm Baldrige Quality Award criteria to assist hospitals in their efforts to improve care provided to patients; and
- Creating a "culture of safety" within hospitals and health systems that focuses upon the prevention and avoidance of harm to patients, visitors and staff.

In 2001, the Institute of Medicine report, *Crossing the Quality Chasm – A New Health System for the 21st Century*, articulated six critical aims for our health care system: patient safety, patient-centeredness, efficiency, effectiveness, timeliness and equity. All of the AHA's previous quality efforts are complementary to achieving these aims. However, recognizing the importance of the IOM's findings, the AHA's Quality Agenda now clearly focuses on the six aims, how they are integrated with one another and how by pursuing these aims, America's hospitals and health systems can continually "reduce the burden of illness, injury, and disability as well as improve the health and functioning of the people of the United States."



INSTITUTE FOR FAMILY-CENTERED CARE

The Institute for Family-Centered Care, a nonprofit organization, provides essential leadership to advance the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care providers, the Institute facilitates patient- and family-centered change in all settings where individuals and families receive care and support.

The Institute serves as a central resource for policy makers, administrators, program planners, direct service providers, educators, design professionals and patient and family leaders. Institute staff promotes change and enhance the quality of health and other human services through development of print and audiovisual resources, information dissemination, policy and research initiatives, training and technical assistance.

The Institute for Family-Centered Care gratefully acknowledges the financial assistance of the California HealthCare Foundation in producing this resource.

ADVANCING THE PRACTICE OF Patient- and Family-Centered Care

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FORWARD

Across the United States and beyond, many hospitals and health systems are discovering new and more effective ways to ensure optimal health outcomes, improve patient and staff satisfaction and provide high-quality, cost-effective care. These organizations have made a commitment to patient- and family-centered care. In these settings, members of health care governing boards, administrators, clinical staff and others engage in partnerships with patients and families not only in the delivery of care but also in health care planning and program development, facility design, quality and safety initiatives, and in the education, training and hiring of health care professionals.

Developed by the American Hospital Association (AHA) and the Institute for Family-Centered Care, this Strategies for Leadership toolkit provides an introduction to the concepts of patient- and family-centered care. In addition to this resource guide, the toolkit includes a video and discussion guide and a self-assessment inventory that will help hospitals advance patient- and family-centered approaches to care.

What is Patient- and Family-Centered Care?

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 patients, families, and health care practitioners. It is founded on the understanding that the family plays a vital role in ensuring the health and well being of patients of all ages.

The ultimate goal of patient- and family-centered care is to create partnerships among health care practitioners, patients and families that will lead to the best outcomes and enhance the quality and safety of health care.

If you don't open up and involve your patients and your families in your care system, then you're shortchanging yourself and, more than anything else, you're shortchanging your patients.

—Vice Chair, Board of Trustees,
Dana-Farber Cancer Institute

Principles of Patient- and Family-Centered Care

The practice of patient- and family-centered care is guided by four principles:

DIGNITY AND RESPECT

Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

INFORMATION SHARING

Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

PARTICIPATION

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

COLLABORATION

Patients, families, health care practitioners, and hospital leaders collaborate in policy and program development, implementation and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Although each of these four principles stands on its own, they become inseparable in the day-to-day practice of patient- and family-centered care. In some situations, however, one principle may have a more dominant role than the others.

For example, treating patients and families with *dignity* and *respect* is of key importance when discussing patient and family wishes concerning advance directives and end-of-life issues. Practitioners of patient- and family-centered care also show respect when they explore treatment options with patients and their families. Honoring patient choices is particularly important for patients with chronic illnesses, which have an ongoing effect on daily life of both the patient and their family.

Information sharing is an overriding issue. Health care practitioners practice this principle by creating an atmosphere where information is shared openly and candidly among patients, families and providers. Information flows in two directions: caregivers provide patients and families with information about their illness and treatment options, patients share their perspectives and ask questions, knowing that their input will be valued. When such information exchanges occur, patients, family members and health care practitioners learn from each other and make the best decisions concerning treatment and care plans. Organizations committed to this principle offer patients and families a range of options for obtaining information, such as patient and family resource centers, print and audiovisual materials, access to electronic resources, and participation in

Patient- and family-centered care is a change in thinking from serving patients and families to partnering with patients and families. And that's a very big difference.

—Senior Vice President,
Patient and Family Centered Care,
MCG Health System

peer support groups. In addition, these resources are available in languages and at an educational level appropriate to the populations served by the hospital.

To support patient and family *participation*, hospitals that practice patient- and family-centered care welcome and encourage patient and family member participation in care and care planning. They do not label family members as “visitors” and do not limit the hours they may

spend at the patient’s bedside. They encourage patients and family members to participate in rounds and other decision-making processes. Staff prepare and support patients and families to participate in care at a level they choose.

The outgrowth of participation is *collaboration*, which, in patient- and family-centered environments is a mutually beneficial process. Health care practitioners and hospital leaders gain insights from patient and family perspectives. Hospitals in which patient- and family centered care is part of the culture may, for example, have patient and family advisory councils. Patients and family members may serve on committees that help shape hospital policies and practices. They may also have patient and family faculty programs, in which patients and family members assume roles in training students and staff and interviewing potential staff and faculty.

The voice of the patient and family is everywhere in the institution. They teach us and teach us every day things that we don't know.

—Chief Operating Officer,
Dana-Farber Cancer Institute

Patient- and Family-Centered Care: Why Is It Needed?

“ . . . Care must be delivered by systems that are carefully and consciously designed to provide care that is safe, effective, patient-centered, timely, efficient, and equitable. Such systems must be designed to serve the needs of patients, and to ensure that they are fully informed, retain control and participate in care delivery whenever possible, and receive care that is respectful of their values and preferences. ”

—Institute of Medicine, *Crossing the Quality Chasm*

Health professionals are well-intentioned dedicated, competent individuals who assume they provide patient- and family-centered care as a matter of course. But that assumption lies at the heart of the problem. Far too often, health professionals see their interactions with patients

We've come to understand that as smart as we might be as physician leaders that they [patients and their families] contribute greatly to our understanding of how practices might better serve their needs. And we need them at our shoulder, at our side, every step of the way.

—Chief Medical Officer,
Dana-Farber Cancer Institute

and families only from their own perspectives—through their own eyes—they do not realize that patient- and family-centered caregiving is based on partnerships.

Partnership at the policy level and the clinical level is the distinctive feature of patient- and family-centered care. Patient- and family-centered leaders and practitioners are committed to working *with* patients and families at all levels of the organization, not simply doing things *to* or *for* them.

Survey after survey has shown that a majority of patients do not want to be passive recipients of care. They want to be engaged in decisions that affect their well-being. They want information that will help them understand and manage their care. They want to feel free to ask questions and voice concerns and to expect that these will be answered.

Results of a 1996 survey by the AHA and the Picker Institute revealed that consumers are concerned about their *experience* of health care, as well as about their health care outcomes. Respondents noted that caregivers do not provide enough information; that patients are not involved in decisions about their health care; and that caregivers are often not emotionally supportive. They also expressed dissatisfaction with the traditional “expert-driven” models of health care and excessive reliance on technology.

More recently, the Institute of Medicine’s 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century* (see page 6) reinforced the central nature of patients and their families in the care process. The report articulated six quality aims of which patient-centeredness was one. That report defined *patient centeredness* as follows:



Patient Centeredness. The real business of health care is about preventing illness, healing those who are ill, meeting the needs of people who must live their lives with disabilities or chronic disease, and helping people in our communities achieve better health. Patient-centered care includes respect for patients' values, preferences, and expressed needs; the coordination and integration of care; information, communication, and education; physical comfort; emotional support; and the involvement of family and friends.

In 2004, the Commonwealth Fund conducted a study that compared five English-speaking countries on how well they were meeting the IOM's six aims. The United States ranked lowest for "care coordination" and, along with the United

Kingdom, lowest for the "degree of patient involvement in their health care decisions."

Health care consumers have repeatedly voiced the desire for trustful, respectful relationships with their care providers. Moreover, the research increasingly shows that such relationships have a positive effect on outcomes. In 2001, the Agency for Healthcare Research and Quality noted, "...research has demonstrated that patients who are active participants in their care experience better outcomes than those who are not similarly engaged."

Hospitals where patient- and family-centered care is part of the culture invariably find that not only does patient, family and staff satisfaction significantly increase but also that clinical care outcomes improve. This becomes a win-win situation for all concerned.

Crossing the Quality Chasm: A New Health System for the 21st Century

QUALITY AIMS

1. **Safe** – avoiding injuries to patients from care that is intended to help them.
2. **Effective** – providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit.
3. **Patient-centered** – providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.
4. **Timely** – reducing waits and sometimes harmful delays for both those who receive and those who give care.
5. **Efficient** – avoiding waste, in particular waste of equipment, supplies, ideas, and energy.
6. **Equitable** – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographical location, and socioeconomic status.

RULES TO REDESIGN AND IMPROVE CARE

1. *Care based on continuous healing relationships.* Patients should receive care whenever they need it and in many forms, not just face-to-face visits.
2. *Customization based on patient needs and values.* The system of care should be designed to meet the most common types of needs, but have the capability to respond to individual patient choices and preferences.
3. *The patient as the source of control.* Patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision making.
4. *Shared knowledge and the free flow of information.* Patients should have unfettered access to their own medical information and to clinical knowledge. Clinicians and patients should communicate effectively and share information.
5. *Evidence-based decision making.* Patients should receive care based on the best available scientific knowledge.
6. *Safety as a system property.* Patients should be safe from injury caused by their care system.
7. *The need for transparency.* The health care system should make information available to patients and their families that allows them to make informed decisions when selecting a health plan, hospital, or clinical practice, or choosing among alternative treatments.
8. *Anticipation of needs.* The health system should anticipate patient needs, rather than simply reacting to events.
9. *Continuous decrease in waste.* The health system should not waste resources or patient time.
10. *Cooperation among clinicians.* Clinicians and institutions should actively collaborate and communicate to ensure an appropriate exchange of information and coordination of care.

Adapted from Institute of Medicine. *Crossing the Quality Chasm: A New Health Care System for the 21st Century*, 2001. Washington, DC: National Academy Press.

Frequently Asked Questions

Hospital and medical staff senior leaders who champion a new idea must be prepared to provide answers to key questions. The following are responses to some of the most commonly asked questions asked about patient- and family-centered care.

Does patient- and family-centered care take more time?

Yes and no. Implementing a patient- and family-centered approach does require an up-front investment in relationship building. Staff must have the opportunity to explore how they currently interact with patients and families and to discuss and reflect on the value of collaborative approaches. Patients and family members who will take key roles on hospital committees or task forces will need training and mentoring.

This initial investment in education, however, is eventually repaid several fold. When administrators, staff and patients and families have a shared understanding of, and respect for, what each brings to the health care experience, the stage is set for a mutually beneficial relationship. The possibility of misunderstanding, dissatisfaction and even medical error is greatly diminished.

Will patient- and family-centered care cost more?

Many aspects of patient- and family-centered care do not cost more money; they simply require a change in attitude and approach. Patient- and family-centered care improves the quality and effectiveness of communication. It is proactive, rather than reactive. As a result, many problems are prevented, and others are handled before they grow out of control.

Introducing patient- and family-centered care will entail some initial and ongoing education costs. But the costs of failed communication—often quantified in terms of poor patient outcomes and malpractice litigation—are much higher.

With respect to facility design, environments that support the presence and participation of families and ensure a healing environment with privacy for patients and families may be more expensive to build. These costs are quickly recouped, often in quantifiable terms, as demonstrated by lower infection rates, higher patient and staff satisfaction ratings and improved market share. A healing environment that offers appropriate space for families can also be more supportive of staff and thus enhance staff satisfaction and retention.

Health care literature offers a growing number of articles documenting the cost benefits of patient- and family-centered care. Examples are listed in the References, Resources and Self-Assessment Inventories section.

How do we engage board members in advancing the practice of patient- and family-centered care?

Board members should have a critical role in the discussions, self-assessments and decision-making processes that precede a hospital's commitment to incorporate patient- and family-centered concepts into its organizational culture. Their support is essential.

One way to begin to familiarize board members with key concepts of patient- and family-centered care is to invite patients and families to share their stories informally at a board meeting. A respected member of the medical staff who is well versed in the concepts of patient- and family-centered care should facilitate this session, and opportunities for discussion should be included. Some hospitals include patient and family presentations as part of annual board retreats and continuing education programs for board members.

The video in this toolkit illustrates the key principles and strategies of patient- and family-centered care. The accompanying discussion guide will help spark board discussions.

How do we ensure that all our staff are on board? How do we overcome staff resistance?

Begin by setting a positive example, by modeling collaboration with patients and families. Nursing and medical executives can encourage and support mid-level managers to involve patients and families in collaborative planning at the unit or departmental level. Other steps include ensuring that staff have the appropriate resources to practice patient- and family-centered care and rewarding exemplary practice.

Other effective strategies include offering forums at which staff can voice their concerns and then designing educational and support programs to address these concerns. Staff should be provided with the education, resources and support they need to effectively partner with patients and families. This includes programs that feature patients and families as faculty—programs where they present their personal stories of their experiences within the health care system. As part of these efforts, staff should be invited to think about their own health care experiences and how these experiences influence their own practices.

Another effective technique is to develop patient- and family-centered champions across the hospital by identifying staff (managers, direct care staff and support staff) that are already interested or knowledgeable in patient- and family-centered care and inviting them to serve on committees and task forces with patients and families. When possible, choose staff that are viewed as opinion leaders by their peers.

Finally, as the program proceeds, find ways to measure changes and improvements and provide timely feedback to staff. Give staff opportunities to share their positive experiences and engage in joint problem-solving discussions in areas of concern.

How can a hospital influence the voluntary medical staff, who are not employed by the hospital, to change their care patterns?

Educational opportunities, involvement and recognition are key to influencing the practice of community-based physicians.

With respect to educational opportunities, one possibility is to collaborate with local or state medical societies in offering continuing education programs that include patient- and family-centered content and practical ways to integrate these concepts in community-based physician practices. Educational programs also could be offered for physicians' office staff. The material should cover principles of patient- and family-centered care and offer specific suggestions on how to incorporate this approach to care in office systems and in activities related to the hospital such as arrangements for admissions, surgery, specialty ambulatory consultations, diagnostic tests, and discharge follow-up. By introducing patient- and family-centered concepts to office staff, they are then in a better position to support the physician in changing practices.

Hospitals should make intentional efforts to involve community physicians more closely in hospital operations. For example, when planning a major renovation or a new construction project, invite community-based physicians to meetings in order to give them opportunities to learn about innovations in design that may benefit his or her patients and families and his or her work at the hospital. Plan to include a social component in some of these meetings and invite spouses to become involved in various aspects of building a new hospital. Invite community-based physicians to serve on committees and task forces working on patient- and family-centered quality improvement initiatives such as the peri-operative experience, discharge planning, and patient safety.

When recruiting patient and family advisors, ask community physicians to nominate patients and families from their practices to serve on hospital committees and councils. Physicians will learn about patient- and family-centered care from their patients and then may choose to become more involved themselves.

Public recognition also can be a motivational force. Ask patients and families to nominate physicians who exhibit many of the qualities and skills associated with patient- and family-centered practice. Then invite these physicians as leaders to participate in further quality improvement initiatives that will benefit the hospital and their practices. List the names of any community physicians who are participating in patient- and family-centered committees or other activities in hospital publications and on its Web site.

How do we find patients and families who want to serve as advisors?

Ask staff and physicians to recommend patients and families whom they believe may be effective advisors. Contact peer support groups in the community or groups that are affiliated with the clinical programs at the hospital. Review satisfaction surveys for individuals who had constructive ideas to share for improving care experiences.

What qualities should we look for in recruiting and selecting patients and family members as committee members and advisors?

In choosing family and patient advisors, look for individuals who:

- Show concern for more than one issue or agenda.
- Listen well.
- Respect the perspectives of others.
- Speak comfortably and candidly in a group.
- Interact well with many different kinds of people.
- Work in partnerships with others.
- Share insights and information about their experiences in ways that others can learn from them.
- See beyond their own personal experience.

How do we begin to involve patient and family advisors?

Some hospitals invite patients and families to come to an exploratory meeting about serving as advisors to the hospital. Others begin by developing an informal workgroup of patients and families as a way of building mutual trust and understanding for this collaborative process. See previous questions for more specific ways to involve patients and families as advisors.

Profiles of Patient- and Family-Centered Care

MCG Health System, Augusta, Georgia

(MCG Medical Center and MCG Children's Medical Center)

The MCG Medical Center and the MCG Children's Medical Center are part of MCG Health System, which is affiliated with the Medical College of Georgia. The not-for-profit health system has 632 beds and more than 3,000 employees and staff. In 2003, MCG Health System cared for 22,217 inpatients and more than 455,000 outpatients. During the past 11 years, MCG has systematically integrated patients' and families' perspectives and involvement into all areas of operation.

The Foundation for Transformation

The transformation of MCG's organizational culture began in 1993, during discussions about the development of a new children's hospital facility. Accepting the suggestion of a group of pediatric nurses, administrators agreed to the implementation of family-centered care within the inpatient pediatric service. This commitment was followed four years later by efforts to apply these same concepts to care for patients of all ages.

The following initiatives were essential to implementation:

- **Assessment.** An assessment revealed that the care delivered at MCG, while excellent in many ways, reflected the needs of providers and did not adequately respond to the needs and concerns of patients and families.
- **Collaboration.** MCG established a Family-Centered Care Steering Committee in 1993, composed of staff members only. After educating themselves about family-centered care, staff asked families to join the committee. Training sessions

were held to help staff and families learn how to work collaboratively.

- **Definition of Core Values.** In 1993, hospital leaders convened a visioning retreat. Participants developed a philosophy of care and values statement for the new MCG Children's Medical Center and built a consensus for family-centered concepts and priorities. Attendees included hospital- and community-based physicians, other clinical staff, administrators and families.
- **Family Involvement.** Following the retreat, families were appointed to all the design planning committees. In 1993, a Family-Centered Services Committee, which included staff, faculty and families, was charged with exploring ways to integrate family-centered concepts and strategies into all aspects of the MCG Children's Medical Center. The committee evolved into the Family Advisory Council that continues through today to provide guidance for policy and program development.
- **Strategic Plan.** In 1997, MCG created a strategic plan to implement patient- and family-centered care throughout the institution.
- **Adult Family Forum.** MCG established an Adult Family Forum that later became the MCG Health Partners Advisory Council. The 35-member council consists of patients, families, hospital clinical staff and senior hospital leaders. The council meets monthly.
- **Paid Staff Position.** In 1998, the hospital created the position of Director of Family Services

Development and hired a family member of an MCG patient to fill this post. The Director is part of MCG's management team and is responsible for ensuring that patient and family perspectives are represented in all aspects of the health care experience for both children and adults.

- **Future Plans.** In July 2004, the President of the Medical College of Georgia and the President of the MCG Health System established the Center for Patient and Family Centered Care to advance cultural change in health care delivery toward models that serve as strong examples of patient, family, and provider partnerships. The Center will influence the curriculum of the health sciences university, conduct research and build on more than a decade of work integrating patient- and family-centered care into the health system.

Outcomes of MCG's Organizational Commitment Facility Design

- **The Augusta Multiple Sclerosis Center.** MCG Health System worked with the Walton Rehabilitation Hospital to create the Augusta Regional Multiple Sclerosis Center. The Multiple Sclerosis Family Advisory Council was created to ensure patient and family input in the development of this center.
- **The MCG Neurosciences Center of Excellence.** Three members of the MCG Health Partners Advisory Council, who have neurological conditions, were involved in developing the design of a new neurosciences center. The center is a model for patient- and family-centered care within the hospital. Along with other patients and families, advisory council members contributed to the

We've incorporated patient and family-centered care into our strategic planning. It's part of the process every time we update our plan. It's part of our core vision and our values, so it's part of the driver for the health system's overall goals and objectives.

—Senior Vice President,
Patient and Family Centered Care,
MCG Health System

design process, assisted in the development of the philosophy of care for the unit and participated in interviewing center staff and physicians prior to opening the unit.

Aspects of patient- and family-centered care are found throughout the neuroscience unit. For example, the unit has no visiting hours, and family members are provided a bed in the patient's room. Patients and families are welcome to participate in rounds. Ten rooms on this unit have a universal design, functioning as either an ICU, step down, or general medical/surgical room. This decreases the number of times patients and families must change rooms during a hospital stay. The unit also has a small resource room with Internet access, and written and audiovisual materials. Quiet areas throughout the unit provide space for private reflections or confidential conversations with providers.

- **Breast Health Suite.** A breast cancer patient served on the planning committee to design and build a new mammography suite. Her participation dramatically changed the way health care professionals viewed this center. It is now a place for women's health and wellness rather than just a diagnostic and treatment center.

Patient Safety

Three members of the MCG Health Partners Advisory Council are members of the hospital's Patient Safety Committee. They designed a "Speak Up!" campaign to encourage patients and families to become active and informed members of the health care team.

Professional Education

With the encouragement of the leadership of the medical centers and the deans of the five schools on the MCG campus, a Patient and Family Faculty Program has been developed. A Directory of Families profiles 25 families who have agreed to share their stories with students, trainees and others to help further their understanding of patient- and family-centered care and to help staff learn how to collaborate with patients and families. Family faculty have participated in educational sessions, including

the opening-day lecture made to first-year medical students. Members of the academic faculty participate on hospital committees to enhance the practice of patient- and family-centered care.

To learn more about MCG's journey, read "Developing Partnerships among Patients, Families and Staff at the Medical College of Georgia Hospital and Clinics," *Joint Commission Journal of Quality Improvement* (26(5), 268-276) by S. F. Hobbs and P. F. Sodomka. Web site: www.mcghealth.org

Dana-Farber Cancer Institute, Boston, Massachusetts

THE FOUNDATION FOR TRANSFORMATION

In 1997, Dana-Farber Cancer Institute (DFCI) embarked on a joint venture with neighboring Brigham and Women's Hospital (BWH) to merge cancer care services into a single program that would eventually become the Dana-Farber/Brigham and Women's Cancer Center. Patients and families expressed concern about the potential impact of this merger on quality of care.

The plans were announced at a time when the public trust in DFCI was being tested. In 1994, two medication errors had resulted in the death of one patient and the serious injury of another. The dual tragedies fostered a profoundly new awareness of the unique insights that patients and families can bring to organizational decision-making.

Senior hospital and clinical administrators responded to concerns about the joint venture by involving patients and families directly in the discussions and decision-making processes. A 50-member work group was formed, which soon became a forum where patients, families, executives, physicians, nurses and other clinical staff

The Patient and Family Advisory Council is a central focus of my work.

—Chief Nurse, Dana-Farber Cancer Institute

could discuss experiences of care and explore solutions. An atmosphere of mutual trust and respect soon developed among participants. They began to learn from one another in ways that previously would not have been possible. Encouraged by the results of the collaborative planning process they had initiated, the institutions' leaders created a permanent Adult Patient and Family Advisory Council in 1998, followed by its pediatric counterpart in 1999.

The Pediatric Patient and Family Advisory Council serves patients in the Jimmy Fund Clinic at Dana-Farber and the oncology units at partnering Children's Hospital Boston. This council is composed of parents whose children have or had cancer, and teen patients. Members have dealt with topics such as improving emergency department arrivals and expediting patient discharges.

OUTCOMES OF DFCI'S ORGANIZATIONAL COMMITMENT

Facility Design

Patients and families helped plan expansion and satellite sites for the Blum Patient and Family Resource Center. They participated in the design of all clinical facilities, including outpatient care,

infusion areas, radiology, and radiation treatment facilities. All capital projects require review by the councils before being approved by the Institute.

Family and Patient Participation on DFCI Councils

The councils comprise up to 15 patients and family members each and several staff members, including the chief nurse executive, the chief medical officer and the Advisory Council Director Liaison. Other clinical leaders are regularly invited to attend meetings and share their input. Goals are set each year that are integrated into the overall goals for the organization. In 2000, space was allocated for a council office, and in 2001, an administrative specialist was appointed to provide support to the council. The councils occupy a prominent spot in DFCI's organizational chart and are part of the DFCI's quality improvement program structure.

Patients and family members also serve on the board-level Joint Committee on Quality Improvement and Risk Management. In this capacity, they review a wide range of confidential reports including patient falls and accidents, system failures, medication errors, and patient survey results. They are involved in care improvement teams on the inpatient oncology units at BWH. In 2002, they participated in a visit of a Joint Commission on Accreditation of Healthcare Organizations survey team.

Program and Policy Development

- **Programs.** Patients and family members were integrally involved in the development of the patient representative program, the pain and symptom management team, the Leonard P. Zakim Center for Integrative Therapies, a hospice care program, and psychosocial programming for patients and families. Members of the councils also conduct "rounds" in clinical areas, gathering feed-

Patients and family members provide a unique perspective... It has transformed how we do the work; it has transformed how we approach specific problems.

—Director of Risk Management and Infection Control, Dana-Farber Cancer Institute

back from patients and families about their experiences.

- **Policies.** Patients and families were asked to help develop DFCI's vision statement, which describes the ideal experience for cancer care. They also participated in developing tools to measure patient perceptions of care.

Patients and families helped revise visiting policies to reflect patient- and family-centered principles. They participated in the redesign of the admissions process, contributed suggestions for a new approach to handling emergency care for immunocompromised patients, helped implement family participation in resuscitation practices, collaborated on a video that describes clinical trials, and provided advice for the development and use of a longitudinal medical record.

Staff Recruitment and Orientation

Patients and families are involved in the recruitment and orientation of staff, and participate in the interviews for hospital leadership positions.

Professional Education

Patients and families partnered with faculty and staff to develop a curriculum for oncology fellows that focuses on communication and information sharing. They also have conducted educational sessions for surgical residents and fellows, and participate in orientation for new employees.

To read more about Dana-Farber's journey, read "Making Patient-Centered Care Come Alive: Achieving Full Integration of the Patient's Perspective" in the *Journal of Nursing Administration* (33(2), 82-90) by P. Reid Ponte and others. Web site: www.dfci.org

Moving Forward with Patient- and Family-Centered Care: One Step at a Time

Establishing patient- and family-centered care or enhancing current approaches requires a long-term commitment. It entails transforming the organizational culture. This approach to care is a journey, not a destination—one that requires continual exploration of new ways to collaborate with patients and families.

The following 10 steps can help set a hospital or health system on its journey toward patient- and family-centered care. Although listed in numerical order, these steps do not generally occur in a pre-ordered sequence. The order in which they are accomplished depends on the resources, needs and priorities of each individual organization.

1. Implement a process for all senior leaders to learn about patient- and family- centered care.
 - Read the literature, visit Web sites, and review professional guidelines, standards of practice and accreditation standards. Attend relevant conferences or seminars.
 - Conduct site visits to hospitals with exemplary patient- and family-centered practices.
 - Include patients and families and staff from all disciplines in this process of continual learning from the beginning.
2. Appoint a patient- and family-centered steering committee comprised of formal and informal leaders of the organization and patients and families. This committee should provide guidance for the development and establishment of a patient and family advisory council or councils.
3. Conduct an assessment of how the concepts and principles of patient- and family-centered care are currently implemented within your hospital or health system and identify priorities for change and improvement (see *Patient and Family-Centered Care: A Hospital Self-Assessment Inventory* included in this toolkit). Use the findings from the assessment to develop an action plan.

4. Using the action plan as a guide, begin to incorporate patient- and family-centered concepts and strategies into the hospital's strategic priorities.
5. Ensure that your hospital or health system has a written philosophy of care that reflects the core concepts of patient- and family-centered care.
6. Provide education and support to patients, families and staff on patient- and family-centered care and on effective sharing of information, participation and collaboration.
7. Invite patients and families to serve as advisors in a variety of ways. Appoint some of these individuals to key committees and task forces.
8. Create the expectation that patient- and family-centered goals are included in the annual plans of clinical areas and relevant departments and that patients and families participate in developing these goals. Offer incentives for success.
9. Offer regular opportunities for all staff to hear patients and family members share stories of their health care experiences during orientation and continuing education programs. Create similar opportunities for organizational leadership (governing body, hospital and clinical staff), students, trainees and faculty for the health professions to learn from patients and families.
10. Monitor changes made, measure the impact, continue to advance practice, and celebrate and recognize success.



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GUIDANCE PUBLICATIONS AND VIDEOS

The following guidance publications and videos are available from the Institute for Family-Centered Care:

- Ahmann, E., & others. (2003). *Changing the Concept of Families as Visitors: Supporting Family Presence and Participation*. Bethesda, MD: Institute for Family-Centered Care.
- Ahmann, E., & others. (2000). *Creating and Expanding Patient and Family Resource Centers*. Bethesda, MD: Institute for Family-Centered Care.
- Blaylock, B.L., & others. (2002). *Creating Patient and Family Faculty Programs*. Bethesda, MD: Institute for Family-Centered Care.
- Blaylock, B. L. & Johnson, B. H. (2002). *Advancing the Practice of Patient- and Family-Centered Geriatric Care*. Bethesda, MD: Institute for Family-Centered Care.
- Webster, P.D., & Johnson, B. H. (2000). *Developing and Sustaining a Patient and Family Advisory Council*. Bethesda, MD: Institute for Family-Centered Care.

SELF-ASSESSMENT INVENTORIES

The following self-assessment inventories are available from the Institute for Family-Centered Care:

- Patient- and Family-Centered Care: A Hospital Self-Assessment Inventory (included in toolkit)
- Patient- and Family-Centered Hospital Design: A Self-Assessment Inventory
- Personnel Practices to Advance Patient- and Family-Centered Care: A Self-Assessment Inventory
- Moving Toward Patient- and Family-Centered Adult Oncology: A Self-Assessment Inventory
- Patient- and Family-Centered Care in the Emergency Department: A Self-Assessment Inventory
- Moving Toward Family-Centered Inpatient Maternity Care: A Self-Assessment Inventory
- Moving Toward Family-Centered Outpatient Prenatal Care: A Self-Assessment Inventory
- Family-Centered Pediatric Care in Hospitals: A Self-Assessment Inventory
- Family-Centered Care in Pediatric Intensive Care: A Self-Assessment Inventory
- Family-Centered Care in Newborn Intensive Care Units: A Self-Assessment Inventory
- Implementing Family-Centered Pediatric Care in the Emergency Department: A Self-Assessment Inventory

For information about other resources, visit www.familycenteredcare.org.



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