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advancing care



MASSACHUSETTS
GENERAL HOSPITAL

PATIENT CARE SERVICES



TAKING CENTER STAGE

Advancing Patient- and Family-Centered Care

Susan and Phil Geary are invaluable members of the Heart Center Patient and Family Advisory Council. Throughout the course of several decades, the couple has amassed a truly unique body of healthcare knowledge and experience. We believe that no one, no matter how skilled or empathetic, commands a more informed perspective on all that is involved in the delivery of patient care — *their own care.*

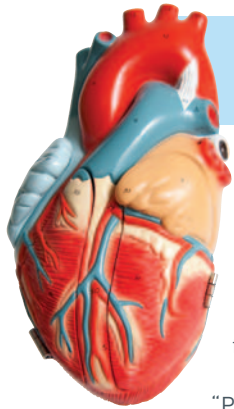
Susan is a lifelong high-risk cardiac patient, and for the past 47 years of her personal journey through the healthcare system, her husband Phil has been by her side. Together, they have undergone countless checkups, appointments, diagnostic procedures, treatments, and interventions, and multiple open-heart surgeries, all the while grappling with a roller-coaster ride of emotions. They have benefited from the very best of care and weathered the associated and often predictable complications.

Born in 1946 with aortic stenosis — an abnormal narrowing of the aortic valve, which impedes the flow of blood to the arteries — Susan has battled heart disease ever since. She has suffered through bacterial endocarditis, an infection of the heart valves that can result in serious illness, damage to the heart or even death. She has survived a growing descending aortic aneurysm. And she has undergone multiple open-heart surgeries — including one to implant what was, at the time, a state-of-the-art mechanical heart valve, the Starr-Edwards. She and her husband have repeatedly endured the post-op recovery process with its ice chips, blood tests and continuous cardiac monitoring; getting out of bed for the first time post-op; performing coughing and deep-breathing exercises while protecting the breastbone; and learning about atrial fibrillation, a heart-healthy diet



The Heart Center Patient and Family Advisory Council (PFAC) meets regularly to help inform and shape the delivery of care at Mass General.

Opposite page: Susan and Phil Geary



and various medications, including warfarin, a blood-thinning agent designed to reduce the likelihood of clots forming in the blood.

“People who learn about my medical history seem completely amazed,” says Susan. “I tend to take it all one hurdle at a time, but when I look back at it all together, Phil and I really have been through a lot.”

In the summer of 2008, when Susan noticed she was increasingly short of breath and feeling tired after even a modest amount of activity, her diagnosis and plan of care came quickly. She had developed an aortic aneurysm that was beginning to grow, and she would have to undergo her third open-heart surgery. The cardiac surgical team would repair the aneurysm and replace her long-functioning mechanical valve with a now more commonly used cow valve. At this point, Susan had lived longer on warfarin and with a Starr-Edwards implant than virtually any other known patient.

The culmination of her medical history meant she would enter the hospital as the highest of high-risk patients. And as Susan underwent a pre-op cardiac catheterization procedure, the possibility

of internal bleeding was ever present. A 39-year history of taking blood thinners multiplied those odds, which turned out not to be in her favor on that day. Susan developed a bad bleed and was immediately admitted to Mass General, her open heart surgery canceled.

“For the next few days, the clinical team worked night and day to identify the source of the bleed and keep Susan’s vital signs as stable as possible,” says Phil. “But it was clear her condition was extremely fragile, her lungs and kidneys were starting to fail, and I was afraid we might lose her.”

Finally, on day three, the team was able to identify and stop the source of the tricky bleed, located in a hard-to-visualize area toward her back. Susan quickly began to regain her strength, and her surgery was back on. And despite her high-risk status, she came through beautifully. From that point on, her recovery moved along as expected.

“The staff was phenomenal,” says Phil. “We knew we were in the best of hands, and with a tough case like Susan’s that meant everything. But from the vantage point of ‘husband’ and ‘advocate,’ it was also an incredibly tense, frustrating and emotionally charged several days. We went through a lot.”

Throughout the many twists and turns in Susan’s health and the many hospitalizations, the Gearys have learned more than they ever imagined about patient care delivery. Since 2007, they have brought voice to their experiences by serving as members of the MGH Heart Center Patient and Family Advisory Council (PFAC). Here, along with fellow patient and family participants, they help inform and shape the delivery of care to the many other patients and families within the Mass General community and beyond.

“The care we’ve received from Mass General has been nothing less than exceptional in our eyes, the best in the world,” says Phil. “But maybe even more impressive is their commitment to raising the bar even higher by tapping into the patient and family experience.”

Patient and family advisory councils are grounded in the belief that often the most informed voices on the care team are those of the patient and family. Ultimately, they alone can confirm whether a plan of care was explained thoroughly; the clinical information provided was fully understood; their questions and fears were appropriately addressed; care was tailored to their specific needs; they felt safe; systems worked efficiently and effectively; and each was treated as a person — a whole person — and not simply as a chart or a medical record. PFACs at Mass General include the MGH Heart Center, MGH Cancer Center and MassGeneral Hospital for Children (MGHfC).



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Front row (l. to r.): Lin-Ti Chang, RN, MSN, staff specialist and Heart Center PFAC facilitator; Susan Geary; Theresa Fryer; Michael C. Bider, III; Theresa Gallivan, RN, MS, associate chief nurse; Sara Strobe
Back row (l. to r.): Phil Geary; Lora Wooster; Sister Jon Julie Sullivan; David Wooster; Thomas Fryer; Michael Montgomery, administrative director, Noninvasive Cardiology, MGH Heart Center [Not pictured: Claudia Chae, MD; Denise Mallen; and Christine Rice]



The pathway document was originally developed by the clinical staff as a way to help surgical patients and family members better understand what they could expect as they recovered in the weeks immediately following surgery.

Along with fellow PFAC members, the Gearys have been hard at work. They have provided input into a draft of the hospital's revised mission statement and reviewed an MGH Office of Patient Advocacy proposal to increase public awareness and access to an array of expanded services. They made recommendations to broaden the hospital's Patient Experience Survey Questionnaire to better monitor the voice of the patient. And, according to Lin-Ti Chang, RN, MSN, facilitator of the MGH Heart Center PFAC, their direct participation in the redesign of the Cardiac Surgery Post Operative Patient Care Pathway perhaps best illustrates the impact that a patient and family advisory committee can have on direct care.

"The pathway document was originally developed by the clinical staff as a way to help cardiac surgical patients and family members better understand what they could expect as they recovered in the weeks immediately following surgery," says Chang. "The primary goal was to reduce anxiety and hasten recovery."

PFAC members thought this was a valuable concept, but one that could benefit from a stronger patient and family perspective. "It needed to reflect the patient and family's 'lived' experience," says Susan. "After all, who knows better what it's really like to be on the receiving end of that care?"

The group assumed the task of redrafting the pathway, transforming it into something to

which patients and families could better relate. The ultimate product was reviewed and approved for use by the Nursing Practice Committee and the Cardiac Surgical Team, and then immediately distributed for use with patients and families. They are currently collaborating with staff from the Cardiac Catheterization Lab and the Heart Failure Service to develop similar tools for those areas.

The Heart Center PFAC has also provided input into the development of many other direct-care interventions. One particular patient favorite is a simple heart-shaped pillow: one side features the MGH Heart Center logo with instructions for its use, the other depicts the anatomy of the human heart. Patients are coached to cough and do deep breathing following their procedures as a way to clear the lungs and decrease the risk of pulmonary complications such as pneumonia. The pillow provides a soft object to hug and hold at the incision site to help minimize pain and add support.

"It's extremely rewarding for all of us to see the ideas we discuss in Council meetings come to life within the hospital," says Susan. "We can see that our own perspectives as patients and family members are having a very real impact on the delivery of care."



Lin-Ti Chang, RN, MSN, is a staff specialist within the MGH Department of Nursing who serves as the facilitator of the MGH Heart Center Patient and Family Advisory Council.

Opposite page: PFAC members Denise Mallen and Susan Geary

For Susan, when her clinicians began coaching her through the early stages of post-op recovery, that meant giving her a heart-shaped pillow with its Mass General logo a little extra hug.

Similar input from cancer patients and their family members has proven invaluable within the oncology setting. Formed in 2001, the Cancer Center Patient and Family Advisory Council has, since its inception, made many significant contributions toward advancing care. Members of the Council have participated in the orientation program for residents and fellows and provided feedback for the Cancer Center's guidebook, welcome letter and video for new patients. Along with PFAC members from other hospital services, they took part in a national Patient- and Family-Centered Care Symposium cosponsored by Mass General. Of particular significance, they participated in numerous discussions regarding the expansion of the Cancer Center into the Yawkey Center for Outpatient Care. Their suggestions were shared with the project architects, who repeatedly revised their plans to incorporate the PFAC's recommendations. Most recently, as Mass General began planning for its new Building for the Third Century, the group reviewed a mock-up of a proposed patient room, providing valuable insights into that design process as well.

The importance of patient- and family-centered care is also embedded in the mission of the

MassGeneral Hospital for Children. The service is "dedicated to providing outstanding, personalized, developmentally appropriate care for infants, children and adolescents within the context of their family and community." MGHfC Family Advisory Council (FAC) members have offered numerous insights into the development of personalized care approaches within Pediatrics. Members sit on key committees throughout the MGHfC, participating in critical quality and safety conversations and decisions. They created a video for staff that features vignettes of family-provider interactions. The goal of the project was to spark a dialogue around enhancing communications with families, a priority area for the group's work. The FAC has also contributed ideas to two design projects — the pediatric emergency room and pediatric family lounge — with an eye toward enhancing the environment for children and their families.

Last fall, as the Gearys faced the prospect of Susan's pending hospitalization and a third open heart surgery, they were well aware that she faced significant

associated risks. Still, they found great comfort in knowing that they were entrusting their care to a highly skilled, multidisciplinary team of clinicians that forms around the specific needs of each patient and family — cardiac physicians and surgeons, nurses, social workers, chaplains, respiratory therapists, speech-language pathologists, physical and occupational therapists, case managers, medical interpreters, and others.

Yet for all of the team's vast technical expertise, Susan and her husband found added comfort in the knowledge that they were entering a world in which they would continue to play a central role on the care team. The patient and family voice — their voice — would be reflected throughout the delivery of care.

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