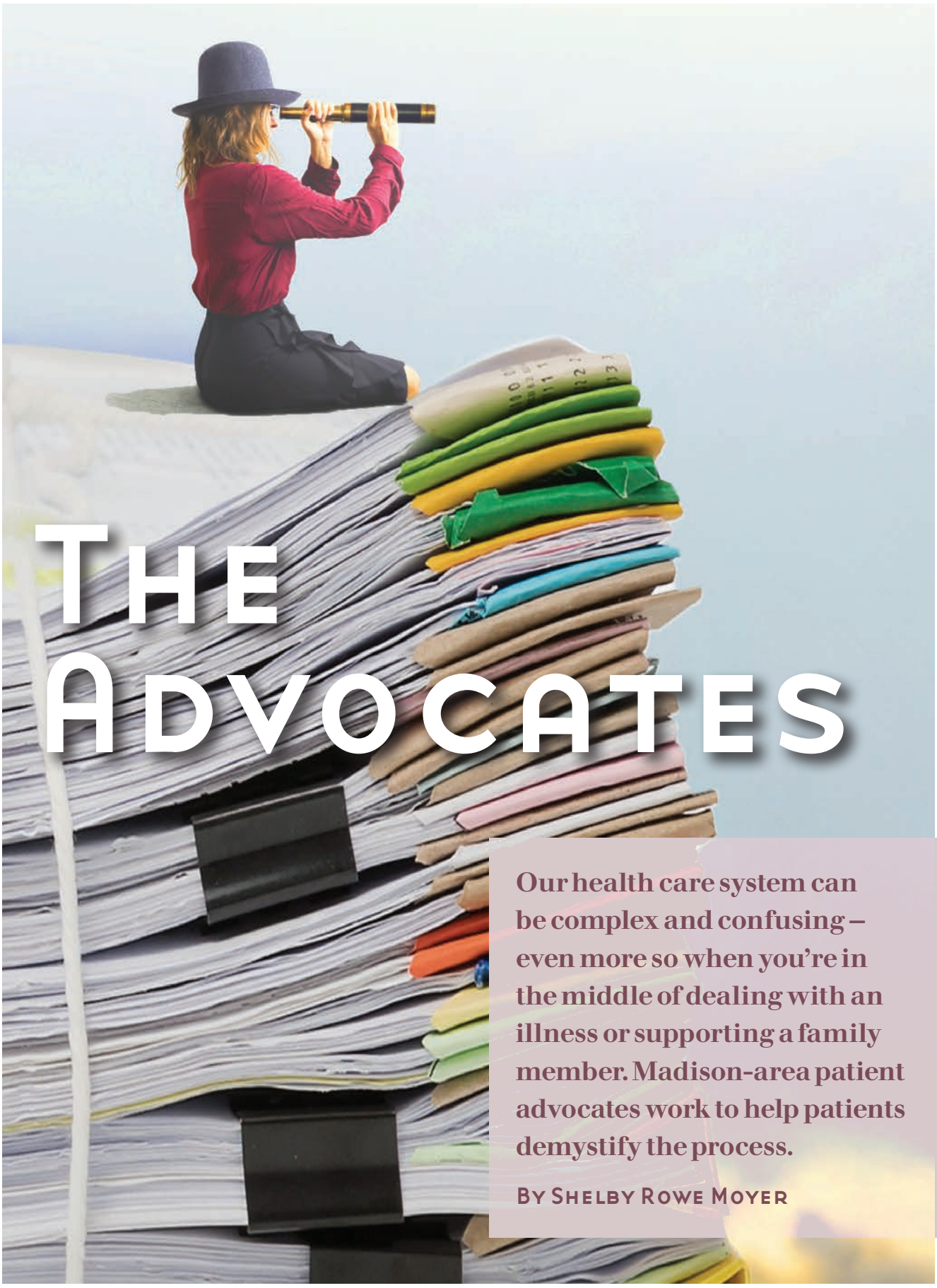


The Advocates

Our health care system can be complex and confusing – even more so when you're in the middle of dealing with an illness or supporting a family member. Madison-area patient advocates work to help patients demystify the process.

By Shelby Rowe Moyer

Debby Deutsch, founder of Patient Care Partners

Jill Jacklitz, co-director for the Center for Patient Partnerships

Kathy Saymer, former chief of organizational improvement at the Madison Veteran Affairs office

"I wish someone would just spend five minutes to explain what's going on."

Anyone who has entered the rabbit hole of our health care system – whether it was trying to interpret a bill, dealing with an insurance company, or finding the proper health care team – understands this simple sentiment from Debby Deutsch, who decided to become a patient advocate when her dad was hospitalized in 2015 and placed in a rehabilitation facility.

Even with her medical background, Deutsch (who had a long career in health care as a hospital chaplain and with hospice admissions) encountered numerous hurdles during her dad's illness, including finding a home health agency and a lack of communication with hospital staff that ultimately prevented him from getting the hospice support he needed in his final days.

Prior to her dad's illness, her mom also had a long hospital stay and rehabilitation in 2013 and 2014, and her sister was in the ICU for several weeks before passing away in 2013. All of these family members' situations presented their own challenges within facilities that felt chaotic and overworked – and resulted in an aftermath of enormous hospital bills.

After her father's passing in 2015, Deutsch wanted to help people avoid the painful health care experiences she'd gone through by becoming a patient advocate. Patient advocates can assist with insurance and billing claims; finding clinical trials; and understanding patient options, such as finding the appropriate doctors or facilities.

Deutsch came across the Center for Patient Partnerships program at the University of Wisconsin-Madison and decided to enroll. In 2018, she was one of about 140 people nationwide earning a board certification in patient advocacy – the first time a certification had ever been offered. As of July, the Patient Advocate Certification Board announced the fifth cohort of students were certified nationwide, bringing the certified advocate numbers to 686.

Where to Turn

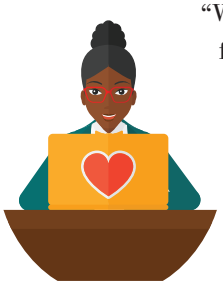
In Madison, there are several privately-owned patient advocacy organizations, as well as community resources like the Center for Patient Partnerships, the program Deutsch trained under. The CPP

offers advocacy services free of cost to patients who are dealing with a serious or life-threatening illness. All of its advocates are students going through its program under the supervision of faculty.

Private and public organizations with patient advocates have a similar thread of services that revolves around helping patients move through and understand the health care system.

"I think of us like tour guides," Deutsch says. "We've got the map and understand the native language, and these folks are in a foreign place, and they're lost."

Deutsch's advocacy firm, Patient Care Partners, contracts with independent advocates who have a history with the medical field – from nursing to social work to medical billing – that gives them an intimate knowledge and understanding of the industry. By the time clients get in touch with Deutsch's firm, she says they're often at a point of exasperation.



"What I often hear from folks is that they've been hospitalized, and they get bills they don't understand, or they have a sense that some of the bills are wrong," she says. "We take a look and dive in … patients will try to work with an insurance company or a heath care system's billing office, but often become frustrated. You're often going from person to person. Cases get assigned to different departments. You're on hold for long times. You have to be very tenacious."

The 37,000 Madison-area veterans – 2,800 of which are women – that are served by the Madison U.S. Department of Veterans Affairs also have access to VA-employed patient advocates. The VA's advocates can help veterans and their families navigate the system, resolve complaints and questions or simply help veterans secure timely appointments, says Kathy Saymer, former chief of organizational improvement at the Madison Veteran Affairs office. (She moved to a different facility prior to publication.)

"Primarily, communication tends to be an area that surfaces frequently," Saymer says. "[Patients] may have a question and they aren't sure who to call. They may have been notified that their appointment was cancelled, but they can't reach anyone. Sometimes it comes down to a test result, and they'd like to see those test results more quickly. We can advocate for them and close some of those gaps."

A Guiding Hand

In the case of Margaret – whose name has been changed to protect her privacy – she needed help getting detailed information from medical staff about her husband's illness, as well as moving him into a facility that would best suit his needs after he suffered a stroke this past January. After his hospital stay, he spent a few months in a rehabilitation facility.

"It was like I had to be on top of it all the time and asking questions and trying to figure out what we should be doing," Margaret says of the whole experience.

When he was moved to the rehabilitation facility at the end of January, Margaret says she could tell his health was declining, but it wasn't until a friend came to visit that she learned about the patient advocates with Patient Care Partners.

Madison Area Patient Advocacy Programs

Many private and public organizations facilitate patient advocacy in the Madison area and beyond.

ABC for Health

ABC stands for Advocacy & Benefits Counseling – a nonprofit law firm that works for children and families providing services and support to help them "navigate a complex health care financing system."

The nonprofit was founded in 1994 and, through the years, has made strides in making health care more accessible to Wisconsinites, facilitated the development of community programs, provided legal assistance for health care financing and much more.

safetyweb.org

Center for Patient Partnerships

The Center for Patient Partnerships began in 2000 and operates within UW-Madison's Law School as a training program for patient advocacy. It's primarily composed of UW undergraduate and graduate students who are entering the

Madison Area Patient Advocacy Programs (cont.)

field as medical doctors, attorneys, insurance agents or want to open a private patient advocacy firm. There is also a track for returning adult students, and the center offers tailored group trainings for businesses, health care organizations and more.

Students within the program gain experiential training as patient advocates. The CPP's services are free for anyone who has a serious or life-threatening illness, and are available to people nationwide. The center also informs policy makers and health care leadership about systematic problems patients encounter with research and analysis that aims to change systems for the betterment of patients.
patientpartnerships.org

Gilda's Club Madison

The Middleton-based nonprofit provides emotional support and education to adults and children living with cancer. Its patient advocate helps members with insurance coverage, medical billing, disability, ADA and employer accommodations, clinical trials, information about resources and conversations about advanced directives.
gildasclubmadison.org

She hired the firm not long after that and they immediately got to work reviewing his information. The advocates Margaret worked with had more than 30 years of experience in nursing, so they were able to read her husband's chart and explain what was going on. They also attended meetings alongside her to discuss his medical options. Once it was decided that hospice was the best fit for her husband, he was moved to a facility and his advocates helped get him situated.

He passed away not long after he was placed in hospice, and it gave Margaret solace that he had been moved just in time, and that his pain had been managed prior to his death. Even after his passing, her advocates remained in touch, even stopping by to visit and bring her meals.

Margaret says aside from their guidance, it was also soothing to have reassurance that the right decisions were being made. When you're in a health crisis with a loved one, it's hard to know if you're doing the right thing, she says, but the advocates were knowledgeable enough to confirm which path was the best.

An Industry Shift

Of course, every client case is different, Deutsch says. Clients are all ages, and advocates may work directly with the client, or with a family member on their behalf.

"Sometimes we work with families for a long time as things change," Deutsch says. "Sometimes patients are just on our radar, and we're poised to step up when needed. So, it's all kinds of things we see."

Lately, Deutsch has seen a shift in referrals, and is getting more clients directed to her from physicians who have noticed how advocacy work has helped their patients. She says that shift has really affirmed the vocation they do.

Jill Jacklitz, co-director for the Center for Patient Partnerships (which is under the purview of UW-Madison's Law School), says most people won't find their way to a patient advocate, so the center's programming also aims to educate and empower physicians, nursing and law students, and other health-adjacent professionals to advocate for their own patients.

The Center for Patient Partnerships also does policy work, Jacklitz says.

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