

Treating women who have disabilities



Jennifer Howell's first — and only — visit to a local obstetrician/gynecologist was one she'll never forget.

Howell, 32, who uses a wheelchair because of spastic cerebral palsy, started having spasms on the treatment table.

When her caregiver told the nurses Howell needed pillows and blankets to make her more comfortable, they were "baffled," she said. So the aide began rifling fruitlessly through drawers.

Howell, of Manheim, eventually left without undergoing an exam. "I was very embarrassed," she said of the episode, which occurred about three years ago.

"It was a horrible experience."

To eliminate this kind of mistreatment, United Disabilities Services of Lancaster County is ready to work to improve the delivery of medical care to women and girls with handicaps.

Among the hurdles they typically encounter are lack of transportation; a shortage of movable exam tables and other accessible equipment; physicians' offices that don't take Medicaid patients; and medical professionals not used to treating persons with disabilities.

Marybeth Tearpock, chief financial officer of UDS, said the local initiative views the Center for Women With Disabilities at Pittsburgh's Magee-Women's Hospital as a model. "We don't need to reinvent the wheel."

The center provides a spectrum of services, from OB/GYN and primary care to screenings and mammograms. "It's been very successful," Tearpock said.

There are approximately 27 million women with disabilities in the U.S., and Tearpock said they "are no different": They go through menopause and develop osteoporosis just like other females.

But in many cases, medical professionals don't see women with disabilities "as women first," Tearpock said, and that creates a barrier. "They mean well," yet don't feel comfortable treating females with handicaps, she said.

There has to be "a willingness to change the way you think and operate." And awareness needs to be accompanied by education and training, she added.

The next step is to approach hospitals and clinics about their interest in this issue and what opportunities exist to move forward, she said.

Karl Gross, administrative director of diagnostic imaging for Lancaster General Health, said in an email that LGH is always open to suggestions on how to improve care for patients with

disabilities.

"We image handicapped patients all the time, and they typically stay seated in their wheelchairs for the mammography exam," he wrote.

"All mammography units are flexible enough for positioning to get good images for most all handicapped patients.

"Imaging professionals have been imaging handicapped patients with standard equipment for years and make accommodations as needed," Gross said. That includes lowering tables, allowing people to stay in their wheelchairs for many exams, and adapting X-ray and mammography units to patients' needs.

"So we do have handicapped-accessible tables and equipment across the system [and] all rooms are wheelchair accessible as required by the Americans with Disabilities Act," he wrote.

Tearpock noted that grant money is available to help defray the costs of buying portable mammography machines, special exam tables or other equipment. Many people with disabilities are afraid of falling when they transfer from a wheelchair to an exam table, so it's important to have tables they can get on to easily and securely, she noted.

Tearpock would like to see local women with disabilities surveyed about where they go for medical care, "what worked and what hasn't."

She also wants UDS to pair with other agencies on the project.

A solutions forum on the subject — sponsored by the ACHIEVA Disability Healthcare Initiative with the support of the FISA Foundation — was held in March at Penn State Milton S. Hershey Medical Center.

ACHIEVA, a nonprofit organization based in Pittsburgh, provides services in western Pennsylvania to people with disabilities and their families.

ACHIEVA's Disability Healthcare Initiative started in 2005 with a focus on dental care.

The next step was targeting health care for women and girls with disabilities, an effort that began a year ago, said Mary Hartley, manager of the initiative.

"In western Pennsylvania, we're pretty pleased with our resources [such as Magee-Women's Hospital], but it's still not enough," Hartley said.

And access is even worse elsewhere in the state, she said.

"It's great that you're doing a dental initiative," people would tell her, "but can you find me a gynecologist?"

"That concerned me," said Hartley, who knows individuals with disabilities who travel from Erie to Pittsburgh — a distance of approximately 120 miles — just to see a doctor.

The lack of gynecological care is probably the biggest problem, she said. "They're going to a GP [general practitioner]" but not getting mammograms, Hartley said.

The Hershey forum, "Access to Healthcare for Women & Girls With Disabilities," featured a number of speakers, including two UDS employees who served as panelists.

Jennifer Howell, a transition coordinator who assists young adults facing handicaps, was one of them.

Persons with disabilities are often reluctant to go to doctors because of "the fear of being honest about their limitations," Howell told the audience. For example, they may be embarrassed about incontinence, she said.

And it's hard for young adults to navigate the system, she said, because finding a new physician once you're too old for a pediatrician can be very difficult.

Doctors don't always listen, either, when dealing with handicapped patients, she said.

Panel member Kathy Wolff, a consumer quality-assurance specialist with UDS who relies on a wheelchair because of paralysis, said some medical facilities are accommodating. The imaging center she goes to is aware of her needs and treats her with respect, Wolff said.

But in other situations, she's had to get X-rays done in her chair, because there was no help to lift her on to the X-ray table.

Medical professionals need to be compassionate and listen to patients with disabilities, Wolff said. At the same time, patients should "speak up" and be their own advocates, she said.

But several barriers make it hard even to get in the door, Wolff said.

One is a shortage of handicapped parking, she said, which is a pet peeve of hers. And accessible ramps can be too steep and entry doors too heavy to manage, Wolff said.

Speaking at the forum, Suzanne C. Smeltzer, professor and director of the Center for Nursing Research at Villanova University's College of Nursing, said females with handicaps exhibit a high incidence of osteoporosis and low bone density, and follow-up care is often lacking.

Fear of hospitalization also is worse among people with disabilities than the general population, she said.

Nursing education must cover the treatment of persons with handicaps, Smeltzer said. There's virtually nothing about this in nursing textbooks, she said, and the solution is to "develop teaching strategies without major disruption to the existing curriculum."

A grant has been given to integrate this content into graduate-level nursing education, and she'd like to see one go toward undergraduate training, Smeltzer said.

Another speaker, Dr. Rick Rader, director of the Morton J. Kent Habilitation Center in Chattanooga, Tenn., said medical professionals who treat those with handicaps still get little encouragement from peers and colleagues.

People with intellectual and developmental disabilities are a medically underserved demographic, but that's not even acknowledged the way it should be, he said.

There's no reason for a 54-year-old woman with Down syndrome to be getting an exam

from a pediatrician, Rader said.

Young medical students are the population that needs to be reached, he said. Early contact is what's required to change attitudes.

The challenge, Rader said, is getting a curriculum in medical schools that will do that.

WEBSITES

For more information on health care for women with disabilities:

- nurseweb.villanova.edu/womenwithdisabilities/
- bhawd.org/sitefiles/Policy.html
- bcm.edu/crowd/health_wellness/health_wellness.html

Contact Sunday News staff writer Paula Wolf at pwolf@lnpnews.com.

Read more: http://lancasteronline.com/article/local/407730_Treating-women-who-have-disabilities.html#ixzz1Pum4mZUK