



Lean on me

Local agency provides support for parents of children with disabilities

By NICOLE DORN
World Staff Writer

For fathers Adam Paul and Jessie Barnett, raising a child with a disability is often very challenging. "I worry about her everyday," said Barnett, father of a 14-year-old daughter who suffered a traumatic brain injury at age 4 and was in a coma for two months.

"Even though there might not be anything wrong, sometimes I'll call her school three times a day."

As a single parent, Barnett said he is responsible for taking his daughter, Desiree, to all doctor appointments and school meetings.

"I do it because it's natural to me," he said. "It's hard, but after a while, you get used to it. Being a father raising a girl is different than being a father raising a boy."

Along with the help of his family, Barnett also receives some assistance from TARC, a network of programs advocating for the rights of those with developmental disabilities.

Sherilyn Walton, family support coordinator at TARC, says Barnett is very forceful and knows what he needs for his daughter.

"Recently he was trying to decide where to send her to high school because she was transitioning from middle school to high school," Walton said. "So I went to both schools with him to look at the facilities and just kind of consult with him. He's such an involved parent that he just asks me questions and he basically knows what to do."

As a father, Barnett is extremely pleased with TARC.

"They go out of their way to make sure you have the best for your child," he said.

Paul, a married father of 3-year-old daughter Taylor, who has Down syndrome, has the same appreciation for TARC.

"TARC is a great organization for people with disabilities," he said. "The thing that TARC does that is sort of the most intriguing to me,



STEPHEN HOLMAN / Tulsa World

Adam Paul holds his 3-year-old daughter Taylor.

personally, are their advocacy efforts."

Paul is the president of the Down Syndrome Association, an affiliate of TARC.

"We provide support for their newsletters," Walton said. "We print newsletters, maintain their database, send out their newsletter, copy it . . . all that."

Taylor was born with Down syn-

drome, and Paul and his wife still continue to have high expectations for their daughter.

"We worked hard with Taylor to get her to walk," he said. "Most kids with Down syndrome are able to walk; it's just the time frame."

According to Paul, when parents have a child with a disability, at the hospital they are often presented with the negative aspects up front.

"Then you're kind of left sitting there like, 'OK, what can they do?'"

For Paul, the easiest thing to do was "focus on what they can do and prove them wrong on what they can't do."

"People with disabilities are a lot more like people without disabilities than they are different," he said.

TARC has various support groups for parents of children with disabili-

ties, Spanish-speaking parents of children with disabilities, a social-skills group for children and adolescents with Asperger syndrome, and a group for parents of adult children with disabilities.

For more information about TARC or its support groups, call 582-8272.

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Fighting back

Chemotherapy doesn't have to be scary – especially with all of the facts



JAMES GIBBARD/Tulsa World

Rhonda Spencer hasn't let her cancer or chemotherapy prevent her from taking Tae Kwon Do.

By JASON ASHLEY WRIGHT
World Scene Writer

Rhonda Spencer found out she had cancer May 26.

On June 13, she decided to take chemotherapy, which she started July 14.

And on Saturday, she was at her Tae Kwon Do class at Beavin's Martial Arts in Claremore.

"I felt like I was going to stop my normal life," said Spencer, a local hair stylist currently undergoing chemo for breast cancer. She was so afraid to start it, she even told her doctors she wasn't going to take it.

David Curry and a two-hour class changed her mind.

"Chemotherapy doesn't kill people, cancer kills people," said Curry, a registered nurse with Cancer Care Associates. He leads classes during which patients about to undergo chemotherapy learn everything they need — and occasionally don't want to know — about chemo.

"I thought it was going to be a horrible, horrible experience," said Spencer, remembering her preconceived notions

of chemo. "I was afraid of the whole thing."

Her feelings aren't unusual, Curry said.

"Most patients are really anxious about their first chemotherapy experience," he said. "But it's usually very anti-climactic." In fact, chemo patients usually feel the same way right after the first treatment as they did immediately before it.

He explains all this in the class, for which he wrote the "Blue Book, Your Chemotherapy Resource," which is a thorough, patient-focused manual designed to teach patients about their chemo, and what to expect before, during and after treatment.

Spencer, who refers to Curry as "an encyclopedia," attended two classes recently — one with her mother-in-law and daughter, the next just by herself.

During class, Curry briskly but clearly leads patients through the steps of their chemo, beginning with a basic explanation of the therapy itself, how it works, its goals and how it's administered. For example, most chemo drugs are given intravenously (IV) — either directly into a vein (IV push), IV infu-

sion or continuous infusion, he said.

Curry also covers medications you can take during chemo, like over-the-counter aids for sinus problems, heartburn or constipation. Those you can't take, though, include aspirin, ibuprofen, naproxen sodium and antioxidant supplements.

"My 13-year-old was even able to understand and follow everything," Spencer said.

Side effects from chemo are also discussed, like fatigue, which usually hits about the fourth or fifth day after starting therapy, Curry said.

Curry also discusses complete blood counts (CBC), which give patients information about their white and red blood cells, as well as platelets. The CBC is regularly monitored during chemo. Each component of the CBC is explained in the class.

Curry also talks to patients about alopecia, or hair loss.

"It can be one of the most painful experiences you have," Curry said. It's a common side effect, but it's temporary and varies from slight thinning to complete baldness.

Patients might experience nausea, too, Curry said, but they will be given

premedications with their chemo to prevent or decrease it. Those medications will depend, of course, on the chemo drugs.

Other topics Curry broaches include loss of appetite, taste and smells, treating mouth sores, diarrhea, vision, potential sexual side effects and emotional changes.

"There will be days when you're so angry and so mad that this could happen to you," said Curry, who added that fear, anxiety and depression are normal. "The roller coaster is a very common place to be." When patients settle into their chemo treatments, though, the "roller coaster" slows down.

The class is designed to be as informative as possible, but patients shouldn't abandon their doctors' advice — always follow what they say, Curry said.

"By the time you leave his class, you are ready for everything that's going to happen," Spencer said.

For more information on chemotherapy education, call Cancer Care Associates at 499-2030.

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