Amputee support group a bridge from hospital to home

Lacking Legs, Lending Ears

By Todd Neff

It could have happened to anyone.

Katy Page, RN, stepped quickly outside in PJs and flip flops to round up the dogs. It was an icy morning, but it would only take a minute. She slipped and badly broke her leg.

That was seven years ago. Infections and other complications led to her enduring 22 surgeries and a Taylor Spatial Frame, which strung wires through and pressed screws into flesh and bone to stretch and grow her lower leg more than seven inches. It all failed.

In early April, she had her 23rd and final surgery on her lower right leg. Surgeons amputated below the knee.

Last week, Page crutched into a conference room at University of Colorado Hospital. Although she works at UCH, she wasn’t working this day. A chorus of people, most of whom she had met for the first and only time a month ago, cheered her arrival. When she had made her way around the table, participants in the hospital’s monthly Amputee Support Group asked her how she was doing.

“T’m doing great on the great days and really crappy on the bad days,” Page said.

Page, the youngest here, is 36. Del Kehr, seated around the corner of the table, is twice her age and had leaned on a prosthetic right leg for 20 years before Page was born.

“You’re doing great,” he said.

Safe setting. The Amputee Support Group has met once a month for about a year and a half. The crowd on this Wednesday afternoon was thin – seven amputees, all but one with prostheses attached to one of their legs; a husband; and a significant other.

Typically about 20 amputees show up, but tornado warnings and hailstorms on this day suppressed the numbers.

Wendy Clyne, PsyD, facilitated; sitting in were Outpatient Physical Therapy Supervisor Guy Lev, PT, DPT; Bill Mramor, CRTS, a recreational therapist; and Cory Christiansen, PT, PhD, an assistant professor with CU’s Physical Therapy program.

Mramor described the environment as “safe and welcoming.” That’s essential for this group. At the beginning of the meeting, Lev brought up a study that showed that, psychologically speaking, losing a limb ranks somewhere between surviving the Holocaust and having served on the front lines in war.

Given that, Lev and Mramor had independently realized the need for a group that would help amputees transition from clinical care to everyday life. As Lev put it, for these patients, “There was this gap between what we do in the hospital and being in the community.”
Mramor had been looking for amputee support groups in town and realized that one had existed until 2008 but disbanded. Matthew Godleski, MD, a CU School of Medicine assistant professor of physical medicine and rehabilitation, saw what Lev and Mramor were doing and connected them. At first, the group was mostly UCH patients; now they come from elsewhere, too.

“They come here and people understand,” Mramor said. “And it has a strong focus on wellness. This is not a pity party.”

Ups and downs. Much of the discussion on this day was practical – how to handle phantom pain and phantom electrical storms, the potential pitfalls of switching prosthetists, the hierarchy of prosthetics based on providers’ and insurers’ perceptions of needs, and patient capabilities. But emotions were also on the table. Betty Jo Copeland, 69, who had driven down from Breckenridge with her husband of nearly 50 years, lost her leg above the knee to cancer in March 2013.

“I have ups and downs. I feel good when rehab’s doing well and I’m spending time with friends. But if I have a setback and I’m in my wheelchair, it’s hard for me to get going,” she said.

Lynn Gordon, who lost her left leg below the knee two years ago, said friends have a hard time understanding that it’s hard for an amputee to bounce back quickly from a health setback.

“They want to fix it. They’ll say, ‘Change your doctor.’ ‘Change your prosthetist.’ ‘Change the way you’re walking.’” she said. “They have no clue.”

The others laughed.

“I had been so healthy. I didn’t know how to navigate a hospital,” Gordon continued. “I’ve smart-mouthed [to others]: ‘Why aren’t you snowboarding in the Olympics with two limbs?’”

The others laughed again.

“But your friends care about you. They want to know how you’re doing,” Kehr said. He was the oldest one here, a big man who walked with a cane and said he can put his prosthetic leg on in about 10 seconds.

“They do. Your friends care about you,” fellow group member Kathryn Crawford said. “But they don’t know how to handle you.”

Honest talk. Jonathan Springer, 64, who lost his left knee below the leg to necrotizing fasciitis, said with good friends he started just taking off the prosthesis and the sleeve and showing them the residual limb – the polite word for “stump,” which these amputees seemed to prefer.

“They then don’t have to explain it again. You just show them to them, and they say, ‘It looks like a weird thumb with a scar,’ and that’s it,” Springer said, admitting that might not work as well for upper-leg amputations like Copeland’s. “Yours is a little more up-close-and-personal,” he said.

Page asked if their stumps get hot in the summer. Yes, they all said. You can use anti-perspirant, offered Crawford, who lost her left leg below the knee two years ago after a knee replacement gone wrong. Springer said he knew it was time to find a new sleeve when the old one got soaked and made farting sounds every time he took a step.

“My daughter thinks it’s hilarious,” he said.

The group listened with keen interest when Amy McCracken, 46, gave her update. She had walked into the meeting in April. But her lower-right leg, broken in a horseback-riding accident seven years ago, had by then required 12 operations and caused unremitting pain. She had begun thinking about having it amputated. She and Page, who battled similar ordeals, had hit it off when they met a couple of weeks after Page’s amputation.

Now, McCracken had arrived on crutches. Thick rolls of bandages wrapped around a leg that now ended mid-shin. The support group had tipped the scales as she struggled with the difficult question of whether or not to amputate, she said.

“I walked out thinking, ‘This will be a great choice,’” she said.

A month after the operation, she’s off pain meds and has been sleeping through the night for the first time in years.

Page said she never had trouble sleeping. Her big concern now is for insurance to allow the delivery of a better prosthetic leg so she can start doing physical therapy and get back to work as a
postsurgical nurse at the hospital’s Lone Tree Ambulatory Surgery Center.

“It’s just waiting to wait,” she said. “It sucks.”

The others all seemed to know exactly what she was talking about.