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# Custom Orthotic Seating: A Hot Technology Gets a Cold Shoulder from Medicare

Barry Corbet

You get out of rehab, and you're a flash on wheels. But you're no fool--you know pressure sores can become a problem, so you use the best cushions money can buy and you do your weight shifts religiously. Ten or 20 years later, you've got your first sore.

You nurse it. You spend a lot of time down, maybe cut back on work and definitely on play. The sore heals, but it keeps coming back. You change to another cushion, work on your posture and rip the back pockets off your Levi's.

One time the sore comes back and doesn't go away. A doctor suggests a "definitive closure," meaning a flap surgery. You're tired of messing around, so you take the fall. You spend six weeks flat and the problem is solved.

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Until the nightmare recurs. And recurs. You're battling cumulative history now, and every new surgery adds to your risk. o does worsening scoliosis and pelvic tilt. The plastic surgeon has to look farther from the wound to find replacement tissue, so he starts robbing shark bites from Peter (your legs, usually) to pay Paul (your butt). And the older you get, the more vulnerable your skin becomes.

Then the bone mass becomes infected, so you scorch your veins with vancomycin for six weeks. Each hospitalization now costs about $70,000 and a big chunk of your life. I know whereof I speak: I own a $400,000 butt myself, or at least the co-paid part of it. Blue Cross holds title to the other 80 percent, and it seems like it's been that way forever.

**Butt Tales**
It's been 20 years since Angela Lodmell's car accident. She's still only 30 years old, but she's seen it all.

As a teenager, she was as active as a T5 para can be. She couldn't abide being told that she always had to be sitting on a good cushion, because it meant staying in her wheelchair. If it came to a choice between doing more and pampering her skin, she usually opted for doing more. Sometimes that called for riding a horse, not a chair.

"When I was 17," she says, "I thought that because I hadn't had a pressure sore, I wouldn't ever get one. But just because there isn't one today doesn't mean there won't be one tomorrow." One day there was one. And many more. "After the first one, it was never the same. I had scar tissue and it just kept getting worse."

Lodmell can't remember how many pressure sores she's had, or even the number of flap surgeries. "At least a half-dozen muscle flaps," she estimates. She progressed from foam

cushions to gel to air, and the sores kept coming. In 1989, an infection that came with a sore cost her a leg. In 1995, she lost the other leg and part of her pelvis. What next?

"If I get another pressure sore," Lodmell says, "there's nothing left to fix it with."

It should be said that while off-the-shelf wheelchair cushions didn't work for Lodmell, they do work for most people--at least for a number of years. But what do you do when they don't, when surgery follows surgery like the marching seasons, when your life's work becomes protecting your skin? Butt transplants are not currently feasible.

Here's what some people living in Minnesota did.
William Spann is 48. He's had a C5-6 spinal cord injury for 29 years, and no end of pressure sores. One of them kept him in bed for two years. He's had six flap surgeries. But three years ago, he paid a visit to Tamarack Habilitation Technologies in St. Paul, and his skin has been problem-free ever since. "It's given me the opportunity to be up 12 to 15 hours every day and it's just great," Spann says.

Stephen Felton, 32, became a C4-5 quad in 1983, and got a pressure sore right off. A flap surgery followed, then two more, all on the right ischium. He tried different cushions, but the outcome was the same. "For awhile," he says, "I was in and out of bed all the time and going downhill." After Tamarack custom-designed his seating, he says, "I haven't had a breakdown. It's changed my life."

Alice Ruch is 70, and has been an L6 para since 1968. Pressure sores? "My backside looks like railroad tracks," she says. She's had nine skin surgeries, with another needed every year. Her surgeon told her she was at the end of the line--he couldn't do any more cut-and-paste. Ruch, too, has had problem-free skin since Tamarack built her seating. "Not that I can feel it," she says, "but I can't tell you how much I enjoy this seat."

Rick Cardenas, after 37 years as C4-5 quad, had his first skin breakdown two years ago. He had sores on his tailbone and hips, and they got worse until the bone was infected. For Cardenas, Tamarack's molded seat has made all the difference. "It gives you a whole lot of confidence in what you can do," he says. "It removes a huge area of concern."

Steven McKeever, 44, a C5-6 quad, didn't have sores because he couldn't sit long enough to get them. "They were a concern," he says, "but I had severe low back pain. I had to limit the hours I sat up so that limited the pressure sores." McKeever got relief with a molded seat that removes pressure from his lower spine. "It works for both the pain and the pressure sores," he says. "I still have pain, but it's nothing like what it was. It doesn't limit my quality of life at all"

Paul Walsh, 41, a T8 para for 12 years, also had back pain. Until he got to Tamarack, he says, "I just endured the pain." Afterward? "It really was a dramatic difference. To go this long without major skin or back problems is just a real positive thing."

Don Bania Jr., 45, a C3-4 quad for 27 years, says he's had hundreds of sores over the years, although he has avoided surgery through vigilance. "I've had this cushion about three years, and I have not even had a pink spot," he says. "I feel like I've been born again."

Robert Fenn, 36, after 16 years as a C5-6 quad, was just beginning to develop skin problems. They went away when he changed to Tamarack's seating. "I kind of feel bad for anyone who doesn't have one of these," he says.

And Angela Lodmell? She required very different answers, but she also got them from Tamarack. Because of her amputations, her seating is a bucket that distributes pressure. But it works for her, and she's actively raising her 8-year-old daughter and planning to go back to school. The tragedy? If she'd had--and used--custom seating from the beginning, she would probably still have her legs. "If I had known years ago what they can do," she says, "I might have been in there designing it with them. They probably could have accommodated my need for mobility and my need for saving my skin."

**Basics**

The solution for all these people has been orthotic seating. "Orthotic" just means that it's used to brace or assist a part of the body, and is custom-designed by definition. If you want to spitshine the ortho-talk, they're all using a "spinal orthosis."

There's nothing startling about the technology. Its key elements have been applied for years to upper- and lower-limb bracing, and even to pediatric seating. What has not been done traditionally is to extend custom orthotic design and fabrication methods to the seating problems of adults with spinal cord injury and other neurological impairments.

Marty Carlson, president of Tamarack, has been building seating for children since 1974, and for adults since the early '80s. Applying orthotic techniques in new ways, he and his colleagues have come up with seating that often prevents skin breakdown when conventional cushions don't.

The basic principles are simple: Fit the device to the person with custom contouring. Shift pressure from areas that can't handle it to areas that can. Improve and stabilize sitting posture. Avoid shear, moisture and heat buildup. Design for functional considerations, such as transferring, driving stability and clearance under tables and work surfaces.

Basic materials: plastic and foam, sometimes a little leather and Velcro. Basic technology: contact molding, elbow grease and a boundless willingness to fine-tune the product.

The concept of molded seating might conjure up images of restricted motion, and Tamarack's Sherry Rovig acknowledges that some people--paras more than quads--initially do feel more constrained. Yet with the expected exception of Lodmell, the wheelers I talked to all feel their movement is unrestricted. And, uniformly, they're thankful they no longer slide forward in their chairs.

"You're pretty planted, and that's what you need," says Fenn. "I used to have to stop wheeling every five strokes or so to slide my butt back in the chair. I don't have to worry about that now." Fenn, in fact, thinks the technology should be used for athletic seating in kayaks, water-skis or four-wheelers--anywhere there's a need for stability and skin protection.

The beauty of any custom-designed device is that it can be tailored to the customer's needs. Both Fenn and Felton are unusually tall, and have long fought one-size-fits-all merchandising. Tamarack easily accommodated them. Lodmell's seating is attached to her, not her wheelchair, so she finally can sit safely anyplace she can transfer. Fenn's was designed to accept a portable chemical toilet--a boon on camping trips, he says--and Felton's has a quick-release attachment that allows him to use the seating on both his manual chair and his power recliner. Although Tamarack much prefers tilt-in-space to reclining because it minimizes shear, Felton is delighted that he no longer *needs* to recline for weight shifts.

The flexibility of custom seating encourages hybrid designs. Many of Tamarack's systems integrate a custom-contoured cushion with a ready-made gel component. The back can be integrated with the base, or made as a separate piece. Or a base can be--and frequently is--combined with a custom corset. A removable urinal block can be incorporated, or supports can be

added for stability while driving. The seating can be integrated with computers, environmental controls or augmentative communications devices. Or the molded cushion can be interchangeable with a conventional cushion. It's a design intended to ease the break-in period, but Fenn still appreciates the option. "It's like having more than one pair of shoes," he says.

**Caveats**

There is an inherent flaw in all wheelchair seating, including custom orthotic systems. A change in one part of the system affects the others. If you raise your footrests, you'll add pressure. If you change the back angle, you'll change your posture. And if your body changes, the seating should follow suit.

For Beverly Barfknecht, 47, a T7 para since 1962, a sebaceous cyst erupted into a large pressure sore and the familiar story began. She healed the first sore on a conventional cushion, but several more followed.

It wasn't a smooth transition to orthotic seating. Hers has built-up sides for support, and hitting the side during transfers has given her a sore. Her scoliosis has increased, and that's not helping. Because she had a rash, she switched back to her old cushion for awhile. That's what did her in, she says. She's having new skin problems, yet she remains a believer in orthotic seating.

"If I were not sitting in this cushion," she says, "I'd have to lie down every two or three hours to get off my butt. I'd be miserable. I'm going back in July, and we'll work out the bugs."

George Reeder III, 40, a C5-6 quad since 1977, had an ischial sore that required flap surgery three years ago. It didn't take, so he had another. During his 90-day stay in the hospital, Tamarack was brought in to make a body mold.

"What happened," Reeder says, "is they took all the weight off that area and spread it to everywhere else. I ended up getting a sore on the other ischium. It just blew out of nowhere last September. I'm trying to adjust [the seating] myself, but it's not healing right, so I've got to go back in."

But Reeder puts in prodigious days--up by 8 in the morning, to bed at midnight with no time down during the day. "I push my luck," he concedes, "but I can't stand lying in bed."

Brian Shaughnessy, 38, a C5 quad, began getting sores 10 years ago. "For every day I was up," he says, "I would have to spend two in bed. I got a seating system from Tamarack that's worked really well for the last five years." But last year, a sore started to come back. The problem was increased scoliosis, and the solution was to add lateral support. He's had another recurrence since then, but it's minor and he still thinks he's got the right seating. "I don't spend months in bed any more," he says. "It's not a forced exile."
Rovig warns that people can come to trust orthotic seating *too* much, and Carlson notes that it requires a willingness to change. Of Tamarack's few failures, he says, most were a result of his clients being unable to give up behavior that no longer works. "As you get marginalized functionally," he says, "you have to depend on what works or you get into trouble. But sometimes that stops people from making the changes they need to make."

Yet Paul Walsh sees his transition to orthotic seating as an investment that has already paid off: "I've had several fusions, Harrington rods put in, and a rib graft on my spine. I looked at the seating as a way to prevent further surgery, and that's so far been the case."

"I don't understand why insurance companies wouldn't want to spend a little more money on this,"adds 40-year-old Steve Burrill, C5-6, another convert to orthotic seating."I know from the six weeks I spent in the hospital after my first sore that that's more expensive."

Not all insurers see it that way. "I'm in limbo," says Shaughnessy. "I have Medicare, and they would rather pay for surgery and hospitalization than spend a fraction of that for preventive seating."

Orthotic seating might seem like an answered prayer for anyone with a history of pressure sores--and any insurer that wants to save money--but during the last three years, getting paid for the technology has been like pulling teeth. For people who rely on Medicare and Medicaid--and even for many with private insurance--custom orthotic seating is effectively out of sight and out of reach (see sidebar).

Until that changes, people with recurrent pressure sores will continue to face spending the rest of their lives in bed, and rehab professionals will continue to proclaim that decubitus ulcers are uniformly preventable.

Marty Carlson is a measured man, but he responds passionately to that quasi-medical dictum. "Sure they're preventable, *if* you remember to do weight shifts and do everything else right for your whole damn life. It's like the pope saying pregnancy is prevented by the rhythm method. It's like saying a plastic surgery didn't work because the patient was noncompliant. It's often bullshit, because the skin condition may not allow a single lapse, not a single mistake. You can't expect real people to lead perfect, error-free lives."

Carlson knows he can't make any absolute claims for his seating systems, but he insists they can allow us to live in less jeopardy. "They're not the answer for everybody," he says, "but we do widen the margin of safety so you can make some real-life mistakes."

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**Where's the Orthotic Seating?**
With all the success stories and the proven technology, why aren't people with intractable pressure sores--and their doctors and therapists--demanding custom orthotic seating? Why aren't orthotists everywhere offering it?

Orthotic seating is expensive, admits Marty Carlson, president of Tamarack Habilitation Technologies in St. Paul. The time and skilled labor required can drive the cost to $5,000 and more. Compared to a $400 cushion, it's a lot. Compared to repeated hospitalizations, loss of income and disrupted quality of life, it's peanuts.

Some insurance carriers see custom orthotic seating as a good investment. But in 1994, Medicare threw up a roadblock that cut off most reimbursement for orthotic seating and denied people with disabilities what may be their best shot at preventing skin breakdown.

In the early 1990s, Medicare changed its reimbursement codes to exclude a flood of junk positioning products being aggressively marketed as "spinal orthoses" to nursing homes. "They were nothing but cushions," Carlson says. "The prices were outrageous and the efficacy was nil."

The changed codes still left three categories for "orthotic" or "custom-fabricated" seating reimbursable under the "brace benefit," and Carlson didn't expect the good orthotics to be thrown out with the bad. But in 1994, Medicare began interpreting the codes to exclude from the brace benefit all orthotic devices intended for use on a wheelchair. If it's used on a wheelchair, Medicare decreed, then it's not an orthosis. Since that ruling, Medicare has put all custom orthotic seating into a category officially labeled as "inexpensive, routinely purchased." In effect, that means only off-the-shelf cushions are adequately reimbursed.

In addition, Medicare has imposed maximum allowables that cap payment at absurdly low levels. Together, these actions have ruled out custom orthotic seating for anyone insured by Medicare or Medicaid or by any of the many private insurers that use Medicare's coverage policy and reimbursement rates to guide their own. As goes Medicare, so goes much of the industry.

And as went Medicare, so went the spread of orthotic seating beyond its birthplace in Minnesota. Because reimbursement is denied, orthotists haven't learned how to design it. "If they're not going to be paid for it," says Carlson, "they've got other things to do." Doctors and therapists haven't learned when to prescribe orthotic seating, and people with disabilities don't even know it exists. Carlson is a tireless advocate, but Tamarack's seating may become an orphan technology. Orthotist meets Godzilla.

There is hope for improvement. Medicare's reimbursement policy is set by the Health Care Financing Administration. HCFA Ruling 96-1, preventing full reimbursement for orthotic seating, was recently challenged in court by several orthotists. On May 19, Judge Morris Lasker of the U.S. District Court in Massachusetts declared HCFA Ruling 96-1 void and issued an injunction against its enforcement.

Will it solve the problem? Time will tell. "The government frequently ignores court orders unless there's a public outcry," says Carlson. Want to help? Become part of that outcry. HCFA and Medicare need to hear from the butts at risk. Contact Thomas E. Hoyer, Director, Chronic Care Purchasing Policy Group, HCFA National Headquarters, 7500 Security Blvd., Baltimore, MD 21244 410.786.5661.
THoyer@HCFA.gov.**

** This address is updated from the original listing in the article, and was accurate as of Jan. 1999.

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