

## Alternative medicine, but to insurers, no alternative

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Cari Hadac, 9, loves jokes, dancing and her pet fish, "except for the bully who eats the others," she says.

On Aug. 10, the Mount Horeb fourth-grader was diagnosed with a rare form of inoperable brain cancer, diffuse intrinsic pontine glioma. DIPG affects between 150 to 300 children a year in the United States. It is terminal, usually within 18 months. Cari's parents, Jim and Shannon, spent the weeks after that devastating diagnosis searching for help and hope. Doctors at UW Health told them radiation and steroids might buy Cari some time. But the treatments left the little girl bloated, nauseated and exhausted.

"It was horrible. She just lay in bed and turned her face to the wall," recalls her dad. "She was losing her spirit."

So the Hadacs made the gut-wrenching decision to stop radiation and try alternative therapies, including chiropractic adjustments, massage, acupuncture, essential oils, herbal supplements and an organic diet. Within days, Cari was riding her bike to school again and playing with her two younger sisters, Ellie and Maddie. "It wasn't until we switched to the alternatives that she got her health and her spirit back," her mom says. Nobody knows how long the reprieve will last.

Now the Hadacs face another hurdle: how to pay for her care.

In one of the many paradoxes of our troubled health care system, the family's health insurance covered Cari's radiation treatments - around \$2,200 a day - though the treatments made her sick and offered no real cure. Yet like most health insurance policies in this country, [Blue Cross and Blue Shield of Minnesota](#) will not cover the less expensive holistic treatments that are now helping her live more comfortably. The Hadacs have organized spaghetti dinner fundraisers to pay their bills. Advocates for alternative therapies, who include growing numbers of mainstream doctors, say this is absurd.

"All this family is asking for is what their daughter, who may not have long on this planet, needs to be at peace and reduce her suffering," says Dr. David Rakel, medical director of [UW Health's Integrative Medicine](#) clinic, which combines conventional and holistic approaches to patient care. "If we have evidence of a treatment that can do some good with very little harm, it should be covered. We can improve quality of life and health even if someone cannot be cured."

Rakel is not Cari's doctor, but he says her case is a tragic example of what he calls the "perverse incentives" and imbalances of a medical system in which health care providers are too often paid for treating disease but not for promoting wellness. "We see ironies like this every day," he says, citing as another example patients with high blood pressure and cholesterol prescribed costly statin drugs with potentially dangerous side effects instead of simple lifestyle changes.

"It's a backward system," agrees Dr. Brenda Trudell, co-owner of [New Beginnings Chiropractic](#) in Mount Horeb. She treats back pain in patients who she believes might have been spared years of surgeries, steroid injections and narcotics if they had been sent earlier for adjustments, massages and acupuncture. "It would be a lot cheaper if we were funneling them to conservative treatments first," she says. "People should at least be given the choice."

By the time Trudell treats some of these patients, she says, their anatomy has been so disfigured by the removal or fusion of bones and the accumulation of scar tissue that sometimes there's not much she can do. Advocates of alternative medicine contend that in our mad rush to high-tech surgeries and drugs - which, not coincidentally, are giant moneymakers in this country's for-profit health care system - our country has overlooked ancient holistic therapies that could relieve suffering and help curb the country's \$2.3 trillion annual health care tab.

"It's just crazy that insurance companies will pay to amputate a diabetic's foot, but they won't pay for treatments that might have prevented that disease in the first place," says Bonnie Horrigan, a spokeswoman for the [Bravewell Collaborative](#), a national research organization for integrative medicine. "This is a system set up to support itself rather than the patient."

Insurance officials admit that in cases like Cari's, their industry can seem cruel. The business gives them little choice, they say. "Look, it's heartbreaking," says J.P. Wieske, state affairs director for the [Council for Affordable Health Insurance](#). "But the simple reality is that insurance companies need to rely on studies to see what on a population basis will be effective. Right now, radiation is the only treatment that has been shown to be effective for cancer. When you have a third-party payment system, you have to make decisions on effective treatments. You cannot make them on a case-by-case basis. I understand that it doesn't feel like a good decision, and yet when you look at the system, this is what you get."

Until very recently, much of the medical establishment dismissed alternative medicine as wacky and downright dangerous: In 1963, the American Medical Association even formed a "Committee on Quackery" aimed at shutting down chiropractors. But times have changed. Alternative therapies are gaining converts, even among the doctors who once shunned them, as evidenced by new names that reflect this new partnership: complementary and alternative medicine (CAM), and integrative medicine. The Midwest lags behind the coasts, but Madison's Yellow Pages lists close to 20 acupuncture providers - up from a handful just a decade ago - and more than 50 massage providers.

The once-scorned chiropractors are abundant, too, with more than 150 in the Madison area. Cari's hometown, Mount Horeb, is much better known around the world for chiropractic care than trolls, thanks to the [Gonstead Clinic](#), founded in 1939 by chiropractic pioneer Dr. Clarence Gonstead. The area's biggest clinics, including UW Health, Meriter, and Dean, now proudly tout their various alternative services.

In 2006, nearly four out of 10 Americans used CAM treatments, spending \$33.9 billion on them, according to a survey conducted by the [National Center for Complementary and Alternative Medicine](#), an arm of the National Institutes of Health. Some seek relief from such life-threatening illnesses as cancer and HIV. Others use the treatments as preventive medicine. But many rely on holistic treatments to manage chronic conditions - including diabetes, obesity, infertility, back pain and headaches - that their regular doctors and Western medicine can't fix.

"I was driven to try acupuncture out of desperation. I went to 16 doctors and specialists, and none of them knew how to help me," says Holly Fentress, 62, a Madison social worker who suffered from fibromyalgia. Fentress says this soft tissue pain condition kept her from sitting down, walking in the mall or lifting her arms to change a light bulb. She scraped together \$65 once or twice a week for acupuncture sessions. Today, she says, she is cured. "I would have gotten better a lot sooner if my insurance had just paid for it instead of wasting money on me floundering around," she says. "I don't know why they don't pay for it - it's one of the oldest medicines in the world."

Senator Tom Harkin, D-Iowa, a longtime supporter of nontraditional medicine, co-sponsored a proposal during the health care debate this summer that would have required health care plans across the country to cover licensed alternative medical providers, but the amendment died in the sound and fury of the health care debate. Washington is the only state to pioneer a parity bill on its own. Around a dozen states, mostly on the coasts, also mandate coverage of acupuncture, and a handful mandate benefits for massage treatments, according to research published in the *Nutrition Business Journal*.

But patients in Wisconsin are out of luck. Chiropractors, who have a stronger lobby than the other providers, are guaranteed insurance coverage under state law. Otherwise, carriers can decide if they want to cover complementary and alternative therapies. In the Madison area, only Group Health Cooperative has decided to cover [alternative medicine as a regular benefit](#). Other health plans in the area offer discounts on the treatments as part of their wellness packages, along with coupons to restaurants and gyms, but they are little more than "marketing tools," complains David Bock, board president of the [Wisconsin Society of Certified Acupuncturists](#).

Access to insurance coverage affects much more than a patient's pocketbook. Frequently, experts say, doctors won't even tell patients about available treatments if they're not covered by insurance. As a result, many patients are stuck discovering, investigating and paying for alternative medicine on their own.

And that can be a lonely, expensive and controversial place to be.

The Hadacs spent sleepless nights scouring the Internet for information and support. They found out about some of the holistic approaches they use with Cari from parents of other children with brainstem tumors. (Their treatment team at UW recommended against [holistic care](#), say the Hadacs.) When they decided to stop Cari's radiation treatments last month after only 13 of the 30 prescribed sessions, Jim says, the radiologist told them Cari would probably die within two months. Cari's oncologist declined to comment on this story, saying she did not want to make the family's life any more "difficult" than it already is. But other physicians say that the world of alternative medicine is still largely unregulated, and that the Internet, in particular, is rife with so-called cures and hoaxes that can mislead and exploit desperate parents.

Jim and Shannon say Cari receives only safe holistic therapies from providers they either know personally, or have carefully screened through friends. "You can't hurt a 9-year-old girl by giving her green tea," says Ray Yingling, the owner of the vitamin store on Monroe Street that provides the family herbal supplements and vitamins.

The Hadacs believe that prayer can help Cari, too, yet while they pray for a miracle, they also talk about how to make their daughter's last days as happy and comfortable as possible. They say the natural treatments are safer and healthier for her than radiation and steroids, which were "poisoning" her body and which the doctors said offered no real hope for a cure. And they say a brain scan two weeks ago showing Cari's tumor had shrunk by 10 percent is proof they are doing the right thing, though doctors

might argue it is proof the radiation had been working. "They handed us a death sentence," Jim says. "We chose a path of health and hope."

As for Cari, she complains she is sick and tired of "all the cancer stuff." She feared the radiation treatments at first, especially the part where she had to put on a mask and be bolted into a machine. But she's not crazy about her new dietary regimen, either. She misses potato chips and doughnuts, and demands a straw so she doesn't gag on her daily dose of what she calls "green juice," a powder of vitamins and extracts from fruits and vegetables that her parents mix with purified water. She doesn't mind her weekly appointments with a Mount Horeb chiropractor. She likes the peppermint oil Susan Ludington, who owns Blue Mounds Essential Oils and calls herself a "healer," rubs on her feet to help her relax. And, though she can be a bit ticklish, she loves her massage therapy sessions with Shelley Ferguson, owner of Madison's [Bodyworks Massage and Nutrition](#).

Turning off the beaten path prescribed by doctors and insurance coverage means the Hadacs will need to come up with close to \$500 a month to pay for all of Cari's treatments. They also have switched to an expensive organic diet, staying away from processed foods and sugars they fear "feed" the cancer. The Mount Horeb spaghetti fundraiser raised close to \$28,000, they say, and what money they don't use they plan to donate to other families like their own struggling to pay for alternative treatments not covered by insurance. "Good for them," says Tami Wahl, legislative director for the [Alliance for Natural Health](#), a coalition that advocates for "health freedom" - access to both natural and mainstream medicine. "A lot of people just stick to what their insurance pays for."

A lot of people are trapped. Karla Meyer, 39, has suffered from debilitating migraine headaches for years. They wreak havoc on her personal life and force her to call in sick to her job with the state one week a month. Her neurologist thinks acupuncture and craniosacral therapy - a gentle form of bodywork - would help, but her insurance won't pay. Yet it will pay thousands of dollars for 12 different prescription drugs that don't do her any good, she says. How would she make her case to the insurance company if she could? "I'd say, 'Look at my medical records. Look at all the work I'm missing,'" she says. "If you are truly there to help me get better, in the long run it would help me the most and be cheaper to pay for these treatments. But maybe you'd rather have me drugged out for the rest of my life."

Her neurologist is frustrated, too. Dr. Douglas Dulli, a neurologist with [UW Health's Pain and Headache Clinic](#), says that many of his chronic patients would fare much better with acupuncture or massage than with what he can do for them. "As a doctor, I have a limited repertoire," he says. "I can just give pills, and frankly, a lot of the medicine I give is hazardous. But the problem with these much more innocent and helpful therapies is that patients have no access to them because insurance won't pay for them."

Dulli is a believer in the power of alternative medicine: He once tried massage for a running injury. It worked so well, he said, he now goes regularly. "I can afford to pay out of pocket," he says. "What about all the people who can't?"

Insurance representatives say it is as unreasonable to expect a health policy to cover these kinds of treatments as it would be to expect an auto policy to pay for regular car washes. "Wellness is not something insurance typically pays for," says Wieske. "It's sort of like a car insurer doesn't cover routine maintenance. If an insurance policy covered every brake job and made sure the car was conspicuously clean so you don't have a smeared-up windshield, you could limit the number of accidents. But it would be prohibitively expensive."

Some agents consider these treatments a luxury and say footing the bill for them would lead to what the industry calls overutilization, or abuse, of services. Costs would spiral out of control for everybody, they say, just as they did when prescription drugs began to be routinely covered. "It's human nature that when you pay for something yourself, you're going to be sure you need it," says Dan Schwartz, a lobbyist with the Wisconsin Association of Health Underwriters. "But when a third party starts paying for it, you'll do it even if you don't really need it. Who doesn't like to have a massage?"

Even if there is anecdotal evidence that these therapies truly help some people, insurance officials say they need proof. One problem with holistic medicine and the whole concept of wellness, says Wieske, is that it is very difficult to talk about objectively and to measure its results. Underwriters like to be able to plug costs and benefits into actuarial tables, and executives need to protect their companies from liability and malpractice claims. "I totally understand that there is a strong relationship between the mind and the body," says Dr. Ron Parton, vice president and chief medical officer of [Physicians Plus Insurance Corp.](#) "But what is covered by insurance still needs to be driven by safety and scientific evidence."

More research is needed. But who will fund it? "There's a reason drug companies and medical device companies pay for research," Peyton says, alluding to the tremendous profits they make as a result. "Who's going to make enough money selling massages?"

Advocates see the barrier, too. "There's not a great profit potential in health and healing. Many of these therapies can't be

patented," UW's Rakel says. "Once you attach a for-profit motive to human health, we're lost."

Advocates say efforts to enact insurance parity also will be blocked by the drug industry and other powerful players who profit from the sick and view natural cures as competition.

But practitioners of alternative medicine are too fragmented and too stubbornly independent, at least right now, to organize and fight back. Many are ambivalent about becoming part of mainstream medicine anyway.

Dr. Susan Padberg quit her family practice at a local HMO and went to school to become a licensed acupuncturist because she "burned out" working within the system, she says. She had a caseload of several thousand patients and felt constrained by the 15-minute limit on patient visits imposed by insurance reimbursements. Today, she sees a few hundred patients a year and spends at least an hour with each one. While she earns much less than she used to, she is happier, she says.

CAM providers say that while they hope insurance coverage one day becomes standard for their clients' sakes, many say they want nothing to do with it. Most earn between \$55 and \$125 an hour before taxes - too little, they say, to compensate them for wasting time battling insurance companies. Many require the few patients who have coverage to pay up front and take care of the paperwork themselves. "On the rare occasions when patients do file for coverage, it's an absolute nightmare," acupuncturist Bock says. "I have to refile it three times, and it ends up taking two or three of my hours to get reimbursed."

Massage therapist Shelley Ferguson balks at being controlled by insurance policies, too. She can spend time with her clients that mainstream providers on a tight schedule regulated by insurance reimbursements rarely have. The personal side of healing is more important than anything else, she says.

There are scientific reasons for how and why the massages she gives Cari help her relax. The gentle strokes not only release the tension in Cari's neck and head, but restore circulation, blood, and oxygen to the area of the brain invaded by the tumor, she says. But it is the art of what she does that matters much more, Ferguson says - the time she takes to help heal, though not cure, a little girl with a scary diagnosis.

"I don't see Cari when she's angry, wondering, 'Why me?' Or scared, wondering what's going to happen next," Ferguson says. "I don't bombard her with questions or advice or procedures. I don't invade her body. We just enjoy our sessions together. She can relax and talk about the little funny things she's doing, like the Halloween party and what she's dressing up as. For one hour, she can be just a 9-year-old girl."