



Spinal stenosis
Dancing with the Stars judge Carrie Ann Inaba shares her story



Interstitial cystitis
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**MEDIA
PLANET**

September 2012

CHRONIC PAIN

FINDING POWER OVER PAIN

Singer Paula Abdul
opens up about life with
**Reflex Sympathetic
Dystrophy Syndrome**



PHOTO: FOX



"As an athlete, pain is inevitable." **NFL Wide Receiver Laurent Robinson** tackles a discussion on concussions.

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CHALLENGES

In 2011, the Institute of Medicine released a report on a medical condition that affects **100 million Americans and costs more than \$600 billion dollars annually**, more than heart disease, cancer, and diabetes combined. Yet few Americans are aware of this condition and medical professionals receive little training in its treatment.

The invisible medical disorder

The condition is chronic pain, defined as pain that persists beyond the expected healing period for an illness or injury or pain from any source that goes on for three or more months. One of the most misunderstood health care issues today in spite of its prevalence and cost, pain is invisible, undetectable on x-rays, blood tests, or any other measure.

Living with pain
Pain may be invisible, but its impact on the person is overwhelming. It affects one’s ability to think clearly, complete the basic tasks of daily life, hold down a job, or have any quality of life. People with pain are stigmatized and isolated. Left untreated, pain will not only destroy the person with pain, but too often the family, as well.
During the month of September, we work to raise awareness and understanding of chronic



PENNEY COWAN
Founder, Executive Director,
American Chronic Pain Association

“Unlike most medical conditions with specific causes, chronic pain does not lend itself to a ‘cure.’”

pain. Unlike most medical conditions with specific causes, chronic pain does not lend itself to a “cure.”
Rather, chronic pain must be managed using an interdisciplinary approach that includes medication, physical therapy, counseling, stress management, coping

skills, and much more. The goal of pain management is to restore quality of life and level of functioning while reducing the sense of suffering.
Raising awareness
Unfortunately, most health care professionals have little knowledge in pain management because it is rarely part of their training. People too often are left to their own devices to manage their pain.
The good news is that it is possible to live with chronic pain. It requires a coordinated approach drawing on the skills of a multi-disciplinary team on which the person with pain plays a vital role. With more awareness and education about chronic pain among professionals, people with pain, and the public, we can reduce the economic impact of this invisible epidemic and help to restore the lives of the millions who suffer daily.
PENNEY COWAN
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WE RECOMMEND

Bill Walton talks about managing chronic back pain

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Barby Ingle
Executive Director
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INSPIRATION

Patient education: Filling your toolbox

My Pain Diary

CHRONIC PAIN MANAGEMENT



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I live with Ehlers-Danlos Syndrome (EDS), a genetic connective tissue disorder that causes painful joint dislocations.

As a child, I relied on adults to speak for me to access medical care. Health care providers did not believe me when I said I hurt because I didn't have the words or knowledge to adequately describe the pain. As I grew older, it became clear that I needed to learn anatomy, medical jargon and much more to advocate for myself.

Sadness, anger, calm... emotions alone don't make the point that EDS causes pain. Just saying, "I'm in pain," is not enough. To fully understand, health care providers need to know where it hurts, how long it lasts, what causes pain to flare, and how the pain feels (burning, aching, heavy). Advocating for me means saying, "Moving my body feels like I'm walking through a tropical storm on a listing ship with bags of pebbles strapped to my feet while wearing a jacket hooked with a thousand



"Keep a pain journal to help you gather information to share; where it hurts, when it hurts and what makes it feel better."

Maggie Buckley
Volunteer Patient Advocate

dangling hammers. I am battered and aching all over." That is the language it takes for others to understand.

Working with health care pro-

viders respectfully and communicating clearly has helped me fill my pain management toolbox with treatment options and coping techniques, including exercise,

sleep hygiene, nutrition, massage, meditation, distraction, acupuncture and prescription pain medications. Combining these tools provides the most powerful pain relief because each one chips away at the pain a little bit.

Your first tool in advocating for yourself is communication. You are the expert on your unique body. Always be respectful and clear in your descriptions, expectations and requests for treatment. Keep a pain journal to help you gather information to share; where it hurts, when it hurts and what makes it feel better. Chronic (persistent) pain is a multi-faceted condition that requires a multi-modal approach. Use a pain scale and define what each level means to you. Be patient as you try different treatments on your journey to identify which combination of options work for you. Eventually, your toolbox will be filled with various pain management tools too.

MAGGIE BUCKLEY
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TIPS

- Create a **daily activity checklist** to help you to see where you are having difficulties with everyday activities.
- Prepare for each healthcare visit by **tracking any new symptoms** or improvements since your last visit.
- Create a **pain log**. Many things can affect your pain. These can include stress,

sleep, money worries, and even the weather. A pain log can help you track the everyday things that have an impact on your pain.

■ **Follow-up from your visit.** It is important that after your appointment with your doctor you follow through with what was discussed during your visit.

SOURCE: AMERICAN CHRONIC PAIN ASSOCIATION

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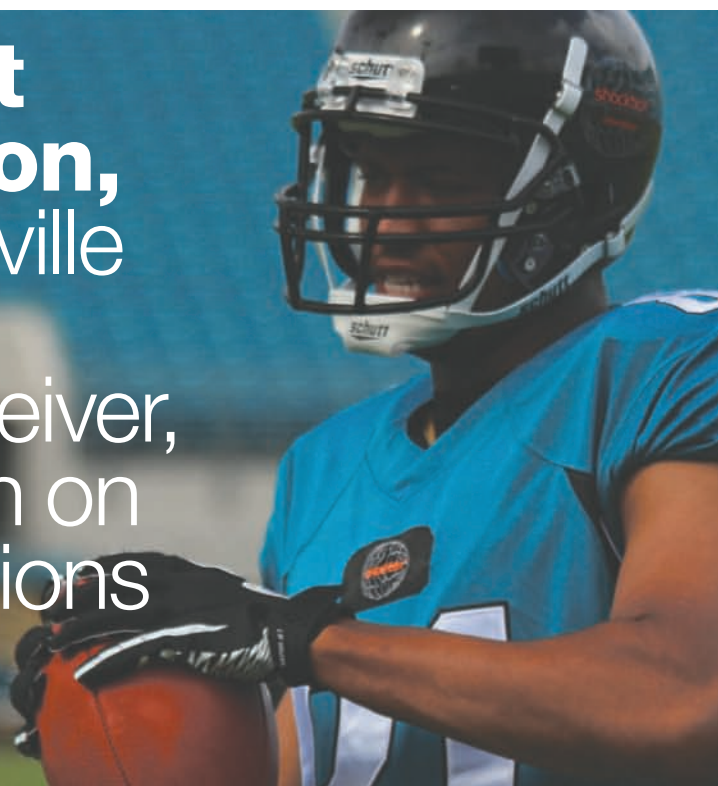
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INSPIRATION

Laurent Robinson, Jacksonville Jaguars' wide receiver, weighs in on concussions



■ **Question:** As an athlete, how do you manage pain?
 ■ **Answer:** As an athlete, pain is inevitable. The game of football is a contact sport and you are going to get hit and pushed around. You have to continue to get up and line up for the next play.
 ■ **Q:** What is your experience with concussions?
 ■ **A:** I have had a few concussions throughout my football playing career. My first one in the NFL was my rookie year versus the Colts on a slant pattern where the corner hit me so hard, the ball flew up, and the pass was intercepted. I had to go to the sidelines and perform all the necessary tests. After a quarter, I was able to go back in.

■ **Q:** What pain did you experience due to your concussion?
 ■ **A:** It felt like I was dreaming at first — I didn't know where I was. A few days after that concussion, I had some headaches and mild neck pain.
 ■ **Q:** Why is it important to you that people learn to take concussions seriously?
 ■ **A:** It is important for players to take concussions seriously because of the long-term effects after our playing careers are over. The more you know about concussions and safety now, the better your life will be in the long run.

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NEWS



FACTS

Certified Registered Nurse Anesthetists (CRNAs) at a Glance

- Nurse anesthetists have been providing anesthesia care to patients in the United States for 150 years.
- CRNAs are anesthesia professionals who safely administer more than 33 million anesthetics to patients each year in the United States.
- CRNAs are the primary providers of anesthesia care in rural America, enabling healthcare facilities in these medically underserved areas to offer obstetrical, surgical, pain management and trauma stabilization services. In some states, CRNAs are the sole providers in nearly 100 percent of the rural hospitals.
- According to a 1999 report from the Institute of Medicine, anesthesia care is nearly 50 times safer than it was in the early 1980s.
- Managed care plans recognize CRNAs for providing high-quality anesthesia care with reduced expense to patients and insurance companies. The cost-efficiency of CRNAs helps control escalating healthcare costs.
- According to a recent survey, nine out of 10 Americans believe it is crucial that Medicare protect patient access to pain management delivered by CRNAs.
- A minimum of 7-8 years of education and experience are required to become a CRNA, and 40 hours of continuing education is required every two years for recertification.

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For Certified Registered Nurse Anesthetist Jackie Rowles, **developing a comprehensive treatment program** for pain management is crucial, no matter the patient.

Pain knows no boundaries



“I care for teens, students, executives, farmers, construction workers, professional athletes, mothers, fathers, retirees, nursing home patients, and disabled patients. Pain knows no boundaries.”

Rowles, a longtime registered nurse, works at Meridian Health Group in Carmel, Indiana and has specialized in chronic pain management care for 10 years. As a trained CRNA, Rowles can provide

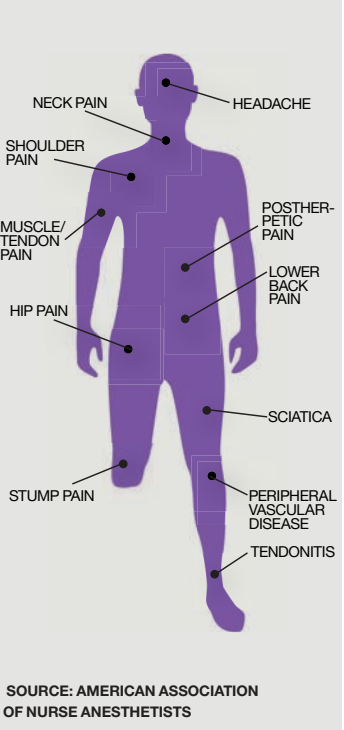
diagnostic and therapeutic injections which are sometimes done using fluoroscopy or ultrasound visualization.

“To watch someone’s pain lessen to where he/she can become more active and involved in life again because their pain has been managed enough to get them back to work, or allow them to play with their children or exercise again, is just amazing.”

“CRNAs administer more than 32 million anesthetics to patients each year in the U.S. and are the primary provider of anesthesia care in rural America, according to Janice Izlar, President of the American Association of Nurse Anesthetists. In fact, nurses were the first professional group to provide anesthesia services, as far back as the 1800’s.

CRNA John Kane runs a pain office in Wolfeboro, New Hampshire and has the authority to

TYPES OF PAIN TREATED BY CRNAs



SOURCE: AMERICAN ASSOCIATION OF NURSE ANESTHETISTS

CINDY RILEY

editorial@mediaplanet.com

write prescriptions in his state. He points out, “In the 30 years I’ve been doing anesthesia, I’ve seen the profession go from a certificate program to doctorate level. We’re taught techniques in placing epidural catheters to take mom’s pain away during labor and delivery or post-op pain in a patient having abdominal or joint replacements.”

Kane adds “These homegrown New Englanders are blind when it comes to the letters after my name. They live in a world where doctors are few, and to get their care they see Physician Assistants and Advanced Registered Nurse Practitioners.”

MANAGING PAIN, BUILDING RELATIONSHIPS

■ **Question:** How can a nurse anesthetist make a difference in a patient’s life?

■ **Answer:** By providing pain relief while also forming a personal relationship.

It was a Good Friday Dan Flachmeyer will never forget. Just 14-years-old, he was trying to remove a fish hook from a power line using a stack of aluminum tent poles.

“The pole hit the line and I lost both my arms and some toes,” explains the 46-year-old Montana native. “I was smoldering on the

ground, with smoke coming out of my clothes. It was extremely painful.”

Flachmeyer spent nearly a year recovering, and was fitted with prosthetic arms. He eventually found work in the security field, married and raised three children. But in 1999 he fell on a job site and suffered a serious neck injury. It wasn’t until he met CRNA Brian Bradley, years later, that he truly found relief from the pain.

Bradley explains, “Dan wears a prosthesis that crosses his neck. The pressure on his neck broke down some of the spinal seg-

ments, resulting in considerable pain. We’ve been treating him with cervical epidurals with good success.”

Bradley, who works at a practice focusing on disc herniations, spinal stenosis and facet disease, says most of his patients are referred to him for treatment from local orthopedic spine surgeons and neurosurgeons.

“The work is very rewarding. Chronic pain management provides me with the ability to establish relationships. I get to know the patients and their families on a much more intimate level.”

CINDY RILEY

editorial@mediaplanet.com

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NEWS

DOCTORS SAY NEW GENETIC TEST COULD
REVOLUTIONIZE PAIN MANAGEMENT



One doctor calls it the “Holy Grail” of patient drug therapy: a genetic test that can tell physicians why some patients react poorly or differently to opioid prescriptions.

Some believe it could revolutionize the field of pain management and result in more effective care of chronic pain patients. Millennium Laboratories announced the launch of its pharmacogenetic test (PGT) during PAINWeek in Las Vegas, a national conference attended by nearly 2,000 frontline practitioners in the field of pain management.

PGT testing Millennium is one of the nation’s largest urine drug screening companies, but PGT is a saliva-based test — designed to detect genetic variations in enzymes that influence how a patient’s metabolism processes opioids. That information will help physicians modify dosages, anticipate side effects or change medications for patients who don’t respond well to opioid therapy.

The company first introduced PGT to a select group of physicians in June and is now expanding its use to other healthcare professionals who want to incorporate the emerging science of pharmacogenetics into their practices.

“I’ve been waiting 30 years to do this kind of testing,” said Forrest Tennant, MD, a longtime pain physician in the Los Angeles area. Tennant has long suspected that genetic differences in patients influence how patients respond to opioid treatment.

“A few years ago, I became aware that there was something different about patients. You take two

patients who seem to have the same back problem. One patient would need 50 mg of morphine a day and the other would only need 10 mg. It didn’t make any sense, really.”

Pharmacogenetics Tennant believes PGT testing will give physicians an extra tool that will help them prescribe opioids



more effectively. “Right now I’ve got an awful lot of questions that I don’t have answers for. But at least we’re starting,” said Tennant. Last month, Millennium announced the start of a large clinical study examining the use of

pharmacogenetics in pain management. The study, which will encompass more than 30 trial sites in the United States, will evaluate the relationship between a patient’s genetic variations and clinical outcomes.

“Individual genetic differences in medication metabolism can significantly impact the efficacy of

“By identifying patient-specific drug metabolism, pharmacogenetic testing can potentially pave the way for personalized medicine in the field of pain management...”

medication therapy in pain care. By identifying patient-specific drug metabolism, pharmacogenetic testing can potentially pave the way for personalized medicine in the field of pain management,” said Angela Huskey, associate vice-president of Clinical Affairs at Millennium.

Helping patients “I think we’re still very early in the game in understanding which genes you should test for that will make a difference,” said Harry Leider, MD, chief medical officer of Ameritox. “There aren’t many studies out there that will really support that if you test for this gene, it will help you make a decision about how to tailor therapy for a patient.”

But Forrest Tennant is convinced the time has come for genetic testing.

“This is going to be a godsend. For the first time, we have scientific, objective tools at our hands that we can use to justify regimens that are odd and to help our patients,” Tennant says.

READ MORE
National Pain Report
nationalpainreport.com

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The art and science of
pain management

Three years ago following a stroke, Rick Fraum experienced excruciating pain in his wrist. After consulting with his family practitioner who couldn’t solve the issue, Fraum sought treatment at a pain management clinic.

Of the 100 million Americans suffering from some form of pain, estimates are that at least half are living with chronic pain that, like Fraum, halt them from enjoying daily activities.

According to research from Peter D. Hart Research Associates, 40 percent of those with severe pain have made appointments with specialists and seven in 10 Americans feel pain research and management should be one of the medical community’s top few or top priority. The pain clinics are often off-

shoots of major medical centers and are staffed by physicians uniquely qualified to treat issues such as chronic back pain — one of the biggest maladies. “Typically you find a group of physicians coming from different specialties such as anesthesiologists or spine and back specialists,” said Stuart Bogema, Jr. a toxicologist who consults to pain management providers. “Pain treatment has grown into a specialty.”

Pain management clinics fuse art and science. The art is the knowledge of the physicians to prescribe a mixture of treatment ranging from meeting with psychologists, physical therapists, massage therapists and even acupuncturists. The team puts together a pain management plan that also involves strict monitoring of pain medications since many of these — specifically opioids — can be addictive.

The line has to be found between those who need the medications and those abusing them, added Bogema. That’s where monitoring comes in. But the screening and testing must be done with experts and with the right tools since even tiny variations can yield false results.

Pain management clinics are also becoming a great choice for those in need since more and more are taking all of the services in house, according to Michael Bartlett, director global financial services at Thermo Fisher who said clinics now have the cutting edge equipment and have brought testing in house to keep costs down and provide speedy monitoring and treatment.

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INSIGHT

Physicians at the forefront



Lynn R. Webster, MD,
President-Elect, American Academy
of Pain Medicine

One third of Americans suffer from the debilitating effects of chronic pain which not only prevents them from working, but also from engaging in the normal activities of daily life. This number includes patients who suffer from spine, headache, facial and arthritis pain, as well as members of our returning military, over half of whom report suffering chronic and persistent pain.

Physicians from a variety of specialties, including anesthesiology, internal medicine, neurology, neurological surgery, ortho-

pedic surgery, physiatry, and psychiatry are at the forefront of treating these patients. But no matter the specialty, we have the same goal, to provide patients in pain with a safe and comprehensive yet individualized treatment program.

Chronic pain not only debilitates each individual sufferer, but also significantly affects our society and our economy. The medical cost of pain care and the economic loss related to disability and lost wages and productivity ranges from \$560 billion and \$635 billion, excluding military service members and older adults living in long-term care such as nursing homes, where the known presence of painful conditions is very high.

Physicians should be dedicated to their patients, but also advocate on their behalf for better care and more research so that their quality of life can be enhanced. We owe them nothing less.

LYNN R. WEBSTER, MD
editorial@mediaplanet.com



monitoring tools

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INSPIRATION

Q & A



S. Tim Yoon
MD/PhD
Associate Profes-
sor, Director of
Clinical Research,
Department
of Orthopedic
Surgery, Emory
University

Q: What exactly is minimally invasive surgery?

A: Minimally invasive spinal surgery is a cutting-edge technology that is a potential treatment option for spinal disorders, as well as chronic back and neck pain. The goal is very much the same as any traditional spinal surgery, which is to decompress pinched nerves and remove bone spurs that can press on the nerves or to fuse painful spinal segments.

Q: What are some of the advantages of minimally invasive spine surgery versus other traditional surgical options?

A: Minimally invasive surgery is a way of making the surgery less destructive to the soft tissues of the patient. It also reduces the overall time for the patient to recover, as well as reduces the amount of pain the patient experiences post-surgery. Some of the other benefits include: reduced blood loss and scarring, improved function, and smaller surgical incisions.

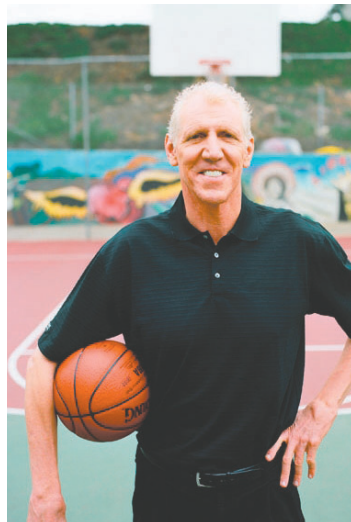
editorial@mediaplanet.com

Q: Who are the best candidates for this, and what would you warn against?

A: It is extremely important to note that the vast majority of patients with chronic low back pain should not have spinal surgery. In fact, I spend a great of time counseling patients against spinal surgery especially for chronic low back pain. However, patients with low back pain need to be evaluated by non-surgical specialists (primary care physicians, physiatrists, neurologists, etc.) who should determine whether the cause of the low back pain is correctable with surgery. These causes include isthmic spondylolisthesis (a slippage of the vertebra), severe forward bend of the spine (typically due to previous surgery), severe scoliosis, and some spinal stenosis (nerve root pinch). Patients with these diagnosis could become candidates for surgery but only after failing other conservative treatment modalities. Minimally invasive spinal surgery techniques can be used to reduce the recovery period in many patients who need surgery, but not all patients. Each case will need to be evaluated by an experienced surgeon.

Bill Walton, the basketball great who played under John Wooden at UCLA has never forgotten the game that wrecked his back — and changed his basketball career and life.

BACK IN THE GAME



Bill Walton
PHOTO: BARRY GRIMES

In January 1974 when playing Washington State, Bill was “low-bridged” by an opposing player that flipped him upside down on his back, sending him falling hard to the wooden floor.

“I broke two bones in my spine that night, and things were never the same for me again,” he recalled.

Bill received treatment but was still not his best. “It was always there,” he said. “That pain. That discomfort. That limitation. That

“I had lost everything. But now I’m back in the game. There is hope.”

restriction.”

He eventually transitioned into a broadcasting career, where the constant travel (200 nights a year on the road) compounded the problems with his aching back.

“I lived in this increasingly unbearable world of pain and disability,” he said. “I ate my meals on the floor, face down. I couldn’t get sleep. I couldn’t get dressed.”

At one point, feeling like there was no hope, Bill stood atop a tall bridge and contemplated jumping.

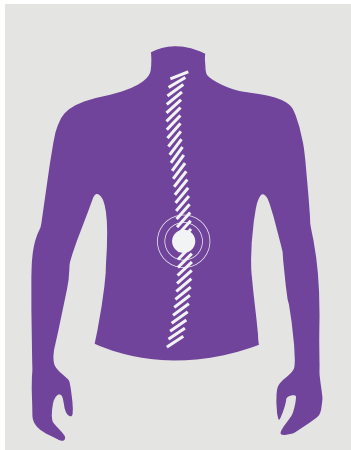
At least his troubles would be over.

Finally, at the age of 56, Bill submitted to back surgery after trying various non-surgical treatment options. In February 2009, he underwent a minimally invasive surgery.

“I just wanted my life—any life—back,” said Walton. After his surgery, he was amazed by the relief he experienced from his excruciating nerve pain.

“I began to do things again I hadn’t been able to do in years, like put on my own shoes and socks and bend over and pet the dogs,” says Walton.

Today, the basketball great has a message for anyone contemplating minimally disruptive spine surgery. “I had lost everything. But now I’m back in the game. There is hope.”



NELLY NITRAM

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INSIGHT

Overcoming spinal stenosis



Carrie Ann Inaba
Judge, Dancing with the Stars

■ Question: What are some unique challenges you have faced as a dancer with spinal stenosis?

■ Answer: Because of where my spinal stenosis is, it’s up high in my neck, I have been told not to dance, punch, or get into a car accident because I could easily become paralyzed. Because of the whiplash element being so dangerous for me, I don’t do any partnering dancing. So I hope that people are not offended when I decline a request to dance with them. It’s because I don’t want to end up paralyzed.

■ Q: What advice would you give to others who also want to pursue their dreams but suffer from pain?

■ A: You know your body best, you have to listen to it when it speaks to you. Don’t wait until it’s yelling at you. Hear the whisper of pain first, then go easy, slow it down a bit, don’t push yourself into a pain situation. If you want relief and want to continue doing what you love the most, you have to seek out the remedies that work for you.

■ Q: Did you ever have moments where you felt you needed to defend yourself because others didn’t understand your invisible illness?

■ A: ALL THE TIME! People don’t

understand what it’s like to be in pain. As a dancer, I loved my body. I don’t mean the way it looked, but the way it worked. It was my engine, my base, my source of everything. When I found myself in pain 100 percent of the day, unable to even go for car rides without excruciating pain, I hated my body. It was a terrible feeling and it caused a bit of depression I think. I was sad that my body was letting me down. And I could tell people got bored of having to leave places early if they were with me because I was hurting so badly. Or I could see they just thought I was overacting.

■ Q: Why did you decide to tell the world about your spinal stenosis?

■ A: I decided to share it because I don’t think a lot of people know what spinal stenosis is. And I think they suffer needlessly because they don’t know about it. If I help make people aware of it, and it helps ease the pain of one person, I have helped and that’s important to me.

■ Q: How do you empower yourself as a patient?

■ A: I ask tons of questions. I also take notes. Words I don’t understand, I write them down and I Google them. I also go to chat boards and read blogs of people who have similar conditions. If they suggest a medication, I read all the side effects and check to make sure it’s the right medication for me. The doctor doesn’t know everything about me so it’s my job to inform him of everything I think is important. And then double check. It’s my health and my body—not theirs. They are experts but I’m the one who has the ultimate say on what I am going to do for treatments.



NEWS IN BRIEF

Understanding TENS Devices for lower back pain

In basic terms, electrotherapy uses electrical energy to address medical conditions ranging from edema to incontinence. It is also used as a method of pain management, and can be delivered via a transcutaneous electrical nerve stimulation (TENS) device.

Simply put, TENS distracts patients from pain by causing a tingling, pulsing sensation. James W. Matheson, PT, MS, says, “A TENS unit utilizes a counter stimulus of electrical stimulation to interfere or mask painful stimuli.”

Uses

According to Christopher Proulx, DC, MS, TENS can be used to address both acute and chronic pain. And while it does not treat the mechanism of pain, it can help patients undertake other therapies.

“For some chronic patients, it may be uncomfortable to perform therapeutic exercise due to pain,” says Proulx. “But with the use of TENS, they may be able to perform therapeutic exercise to progress their condition.”

Advances

TENS is evolving to become more user friendly and cost effective. Proulx says if technology and accessibility advances continue, its usefulness will increase. “It’s not a magic bullet, but can be used to improve movement, which in turn improves therapy, activities of daily living, and quality of life.”

JILL SMITS

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NEWS

DON'T MISS



The journey through pain

My journey with Interstitial Cystitis (IC) began in 1995. I woke up one day feeling like I had a very bad bladder infection. The terrible burning felt like my bladder was filled with acid or broken glass. Tests at my doctor's office showed no signs of an infection. I was baffled asking my doctor how I could be in such pain and not have an infection. The pain continued and my urinary frequency increased. I was going to the bathroom at least 40 times a day. Halfway through a less than 20 minute commute to work, I had to stop at a hotel and run in to use their restroom. Road trips meant stopping at every rest stop. Going to a concert meant standing by the doorway so that I could use the restroom as often as needed without climbing across a row of people. Over the next five years, I saw many urologists and tried numerous different treatments. During this time my condi-

tion continued to worsen, and I quit working for a year due to the severity of my symptoms. I rarely talked about my condition, even to my husband. He was shocked to hear that I was in pain every single day. This disease was negatively impacting every aspect of my life

Finally, a diagnosis
One day my internist recommended that I make an appointment with a urogynecologist, who formally diagnosed me with interstitial cystitis. Though getting diagnosed didn't relieve my pain, I felt relieved to finally have a name for what I was going through. I have not been cured, but my symptoms continue to be helped with medication, dietary restrictions and yoga. Physical therapy and cauterization of ulcers have also been very helpful. I have learned to advocate for myself and to talk with others about my condition.

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Some have compared it to a urinary tract infection that never goes away. **Interstitial Cystitis (IC) is a debilitating medical condition** that can go untreated for years.

Finding hope:
Living with Interstitial Cystitis (IC)

"Patients often state it feels like they have ground glass or a hot poker in the bladder," says Robert Evans, M.D., Associate Professor of Urology at Wake Forest Baptist Medical Center. "The symptoms of pain, urgency and frequency don't improve with antibiotic or over-active bladder therapy. It's more commonly seen in women than men, but can occur in all ages." The chronic bladder condition affects 4 to 12 million Americans and might be caused by a deficit in the bladder lining layer. "There are many options available, and most patients can find a treatment that will help them get

back to living a productive life," Evans explains. "While there's no clear cut way to cure this disease, it can often be controlled." Unfortunately, only 50 percent of IC sufferers tell their doctors, and many health care providers don't ask," says Kristene Whitmore, M.D., Medical Director of the Pelvic and Sexual Health Institute at Drexel University College of Medicine in Philadelphia. "The quality of life is worse than diabetes, and the pain is worse than arthritis. Thirty percent have neuropathic pain, which is a more severe type of pain, and can become incapacitating."

Dr. Whitmore points to a 42-year-old female, with 20 voids a day, five trips to the bathroom at night and discomfort with a full bladder. Her pain was severe, she feared for her job, and had sexual secondary pain. Through stress management, bladder instillations, physical therapy and trigger point injections, she improved dramatically. She was eventually promoted and is sexually active. According to physical therapist Bernadette Kamin, "Most IC sufferers are in pain 24/7. IC patients are frustrated, sleep-deprived, depressed and some have contemplated suicide." Kamin says it's important to empower patients with tools to gain control and better manage their symptoms on a daily basis. They may include a home exercise program, relaxation and breathing techniques, proper posture and body mechanics, along with bladder retraining.

CINDY RILEY
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FACTS

■ 100 million = number of Americans who suffer from chronic pain, of those 12 million may have interstitial cystitis.	■ In the US, the mean yearly costs for treating IC are more than double those of other patients.
■ IC can affect anyone. Women, men, and children of any age or race can develop IC.	■ Pelvic pain resulting from IC can be so severe that many people with IC abstain from all sexual activity.
■ On average, it may take up to five years to receive a correct diagnosis of IC.	

So You Have IC, Now What?

Newly Diagnosed Tool Kit:

Top Questions IC Patients Ask • Top Treatments for IC

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Interstitial Cystitis Association

THE INTERSTITIAL CYSTITIS ASSOCIATION

100 MILLION
Number of Americans who suffer from chronic pain, of those 12 million may have interstitial cystitis

advocates for IC research dedicated to discovery of a cure and better treatments, raises awareness, and serves as a central hub for the healthcare providers, researchers and millions of patients who suffer with constant urinary urgency and frequency and extreme bladder pain called IC.

Go-to website: www.ichelp.org
Weekly e-newsletter: ICA eNews
Quarterly magazine: ICA Update
Short clips with IC experts: YouTube/ichelp
Meeting updates: twitter/ichelp

IC Facebook community:
www.facebook.com/interstitialcystitisassociation
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Conquering IC. Changing Lives.

INSIGHT



DON'T MISS

Turning Pain into POWER

Ten years ago, I was in a minor car accident. Those eight seconds changed my life trajectory and has brought me to a place in life I never saw for myself. I learned motivational skills as a cheerleader growing up, but never knew how much more I would learn after developing Reflex Sympathetic Dystrophy Syndrome (RSD).

Through my motivation for a cure, I am turning pain to POWER! How am I doing it? I am taking life moment by moment. I believe in myself. I have a goal of motivating others through my actions. I know firsthand how hard it is to continue looking for relief, perfect answers, and then coming up against healthcare professionals who blow you off or do not believe what you are saying could actually be what you are experiencing.

As I search for a cure, I have become my own best advocate. I feel strongly about sharing the knowledge I have learned so that everyone can be their own best advocate. Even after seeing over 100 healthcare professionals, having major surgeries I did not need, complications such as internal bleeding, medication interactions, kidney stones, tumors, and so much more — I did not give up or give in! I was tested to my limits and realized they are past the boundaries I placed on myself. I had to become the *Chief of Staff* of my own medical team. If I can do it, anyone can.

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Paula Abdul talks pain, support, and hanging in there.

BETTER DAYS
AHEAD

Question: What are some unique challenges you have faced as a celebrity with Reflex Sympathetic Dystrophy Syndrome (RSD)?

Answer: Regardless of my “celebrity” status, I faced two major challenges: isolation, and the quest for knowledge about what was happening with my body. The truth is, it’s a complicated disease to explain to people. At the end of the day, the people who really love you hang in there, and I’m so grateful for the people that hung in there with me.

Q: You continue to do what you love every day, despite the challenges posed by your chronic pain. What advice would you give to others who also want to pursue their dreams but suffer from pain?

A: Look, I can only speak from my own place of pain. It was imperative for me to constantly check in with myself, and to be clear on what pain I was feeling. Of course, I encourage people to do as much research as much as possible. That has been invaluable to me. Really take the time to inform yourself, and try to connect with what’s going on in your body.

Q: How important is having a support network to you?

A: Before I actually learned what the correct medical diagnosis was for what I was experiencing, it was very difficult for people to fully understand and accept the severity

of the pain I was dealing with at the time. Honestly, there were some very dark days; however, the people that loved me unconditionally are still in my life supporting me today.

Why did you decide to tell the world about your RSD?

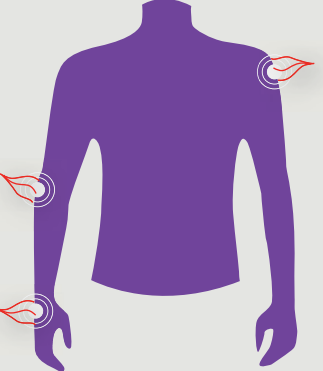
A: The assumptions being made about me were just so off the mark. I felt like I was already fighting the pain... did I want to start fighting people’s perceptions, too? My appearance on Dr. Oz was so freeing—for the first time I felt like I was understood. The whole experience of sharing that with the world was truly liberating for me. I felt like I could give back to all the people who so generously shared a wealth of information with me. I felt like I could help give them a voice, and create more awareness. I want to encourage people that there really are better days ahead, and to hang in there.

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RSD FACTS

- Burning pain is the hallmark symptom of RSD. Feeling as if you are fire and can’t put out it out.
- Anyone can get RSD (all ages, races, and both men and women). It affects females 3 to 1 over males.
- One limb will be a few degrees different then the other.
- There are approximately 10

- million Americans with RSD.
- RSD was first diagnosed over 150 years ago by Dr Weir Mitchel a military surgeon in the civil war.
- There have been over 20 names for this condition including RSD, CRPS, Causalgia, Polytrama Neuropathy. It is most commonly known as RSD, Reflex Sympathetic Dystrophy.



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NEWS



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www.headaches.org



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www.fibrocoalition.org



National Vulvodynia Association

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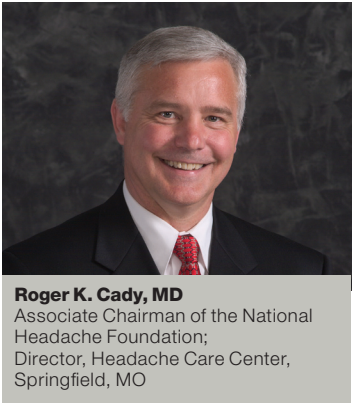


campaign to end chronic pain in women

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www.EndWomensPain.org

Managing chronic migraines



Roger K. Cady, MD
Associate Chairman of the National Headache Foundation;
Director, Headache Care Center, Springfield, MO

Migraine is divided into episodic or chronic based on frequency of attacks. Chronic migraine (CM) lasts 15 or more days a month; moderate to severe in intensity, headaches last at least 4 hours. The chronic migraineur has little or no time for recovery, making the headache and other migraine symptoms more intense, lasting longer, and more disabling.

Even on a “good day,” individuals feel as if they are on the verge of the next migraine. As a complication of episodic migraine, chronic migraine may be prevented by effectively treating episodic migraine.


Management is an art
Chronic migraine (CM) is rarely just about migraine. Patients

with CM are often afflicted with other medical problems associated with migraine such as back pain, irritable bowel syndrome, sleep difficulties, anxiety, and depression. Additionally, there are often established patterns of medication misuse and overuse, and counterproductive learned pain behaviors. This is understandable given that a patient has often endured years with ineffective control of migraine and multiple failed attempts to find successful care. Attention to the multifactorial nature of CM is essential to creating a comprehensive individualized treatment plan.

The management of patients with CM is as much an art as it is a science. Only recently has the scientific underpinning of chronic migraine been identified. The first formal definition of CM was provided by the International Headache Society (IHS) in 2004 and revised in 2006. Consequently, no acute medications and only onabotulinumtoxinA (Botox) is approved by the FDA specifically for CM although many medications are successfully used in clinical practice. Complicating matters further is that by overusing medications that treat episodic migraine, chronic migraineurs are inadvertently worsening their pattern of migraines, a

condition called medication overuse headache. While most clinicians find it understandable that someone experiencing 15 to 30 days of headache a month desire medications to treat migraines, they also know that successful management of CM is very difficult unless the medication causing the problem is discontinued. Medications implicated as causing medication overuse headache are

TIPS



- See a headache specialist or neurologist if your pain changes or you have a headache lasting more than 72 hours.
- Keep a headache diary. Tracking changes in diet, hydration, and sleep can help identify your triggers.
- Try complimentary therapies. Many people find yoga or massage therapy help reduce the frequency of their headaches.

pain medications such as opioids, butalbital combinations, triptans, and ergotamines when used more than 10 days per month and many over-the-counter (OTC) products when used more than 15 days per month.

Recovery is the goal
Neurological recovery from the enduring presence of migraine is the foremost goal when managing CM. Instead of the control of acute attacks, the emphasis of treatment shifts to altering the nervous system’s vulnerability for persistent and sustained generation of migraine. While control of disabling attacks of migraine remains critical, the more global emphasis is to reduce migraine frequency and ideally reverse chronic into episodic migraine. This change in therapeutic emphasis ideally begins before a patient has evolved into a protracted state of CM. Successful management of CM ultimately requires a sustained collaborative relationship between patients and healthcare professionals that emphasizes the physical, psychological, and social needs of the “whole” patient. With active participation in their care, most patients with CM achieve significant improvement.

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