FINDING POWER OVER PAIN

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

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

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.

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

As a child, I relied on adults to speak for me to access medical care. I knew that my symptoms didn’t make sense. I didn’t 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 I had to learn anatomy, medical jargon and much more to advocate for myself.

Insomnia, anger, and an inability to focus... I don’t believe that they aren’t listening... they are! For more information about how you can help prevent prescription drug abuse, visit www.PurduePharma.com

What can parents do?

Dispose of old or unused medications properly www.SafeguardMyMeds.org.

I have learned to advocate for myself. Just saying, “I’m in pain,” is not enough. To fully communicate clearly has helped me to fill our management tools with treatment options and coping techniques, including exercise, sleep hygiene, nutrition, massage, meditation, distraction, acupressure 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, how the pain feels, and what makes it feel better. Your second tool is communication. You will be asked to identify which combination of treatments on your journey makes it feel better.

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As an athlete, you that people learn to take concussions seriously. This is so important for players to take concussions seriously for the long-term impacts on your body. The more you know about concussions, the better your life will be in the long run.
Pain knows no boundaries

For Certified Registered Nurse Anesthetist Jackie Rolles, developing a comprehensive treatment program for pain management is crucial, no matter the patient. "I care for trauma, students, executives, farmers, construction workers, professional athletes, mothers, fathers, retirees, nursing home patients, and disabled patients. Pain knows no boundaries," Rolles explains.

"When 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," Rolles says.

"CRNAs 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 1890’s. CRNA John Kane runs a pain office in Wolfeboro, New Hampshire and has the authority to do more pain management than doctors are able to do.

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 spent nearly a year recovering, and was fitted with prosthetic arms. He eventually found work in the security field, with smoke coming out of the tent poles. "The pole hit the line and I lost ten miles to get to Brian is like night and day. Within ten minutes of the first shot, I had no pain at all. Plus, I can go ten miles, time when I use cervical epidurals with good success," Bradley explains. "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 1890’s. CRNA John Kane runs a pain office in Wolfeboro, New Hampshire and has the authority to do more pain management than doctors are able to do."

Flachmeyer, an avid fisherman and hunter says, “The difference going to Brian is like night and day.” Bradley explains, “Dan wears a prosthesis that replaces his neck. The pressure on his neck broke his spinal cord, and he was left without any feeling from his shoulders down to his hips, resulting in considerable pain. We’ve been treating him with cervical epidurals with good success.” Bradley, who works at a practice specializing in 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."
DOCTORS SAY NEW GENETIC TEST COULD REVOLUTIONIZE PAIN MANAGEMENT

PCT testing
Millennium is one of the nation’s largest urine drug screening companies, but PCT is a saliva-based test — designed to detect genetic variations in enzymes that influence how a patient’s metabolism processes opioid. 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 PCT to a select group of physicians in June and is now expanding its use to other healthcare professionals who want to incorporate the genetics into their practices.

“By identifying patient-specific drug metabolisms, pharmacogenetic testing can potentially pave the way for personalized medicine in the field of pain management. Three years ago following a stroke, Rick Forrest and I became aware of pharmacogenetic testing and its potential to help patients,” Tentmann says.

In June, Millennium announced the start of a large monitoring tool that will help physicians tailor their opioid prescriptions. The line has to be found between those who need the medications and those abusing them, added Bogema. “That is where monitoring comes in. But this screening and testing must be done with expertise 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 Leider, MD, chief medical officer of Ameritox. “There aren’t many studies done on these patients, but our protocol is for 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 metabolism could impact the efficacy of pain medications since those who are uniquely qualified to treat issues ranging from meeting with psychologists, physical therapists, and acupuncturists. The team puts together a pain management plan that also involves strict monitoring of pain medications since many of those — specifically opioids — can be addictive.”

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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 surgery. In fact, a great amount 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, chiropractors, neurologists, etc.) who should determine whether the cause of the low back pain is curable with surgery. These include such as: obesity, smoking, alcohol misuse (a lifestyle of the vertebral), severe bone erosion of the spine (typically prior surgery), severe scoliosis, and some spinal anomalies (new root pain). Patients with these diagnoses could become candidates for surgery but only after failing 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 patient will need to be evaluated by an experienced physician.

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.

I heard everything. I don’t need to be evaluated by an experienced physician.

In January 1974 when playing Washington State, Bill was “breeze-ted” an injury that flipped him upside down on his back, and went his back fast to the floor. “I heard two bones in my spine that night, and those were never the same for me ever again,” he recalled. But he had no fear of surgery because his back still not his best. “It was always there,” he said. “That pain. That discomfort. That limitation. That restriction.”

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.

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

Q: What are some of the advantages of minimally invasive spinal 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, shorter hospital stays, improvements in function, and smaller surgical incisions.

Q: What is the role of physiatrist, neurologists, and spine surgeons in the treatment of back pain?

A: Physiatrists, neurologists, and spine surgeons play a critical role in the evaluation and treatment of back pain. They work together to determine the cause of the pain and develop a treatment plan that is tailored to the individual’s needs.

Q: What are some minimally invasive techniques that can be used to treat spinal stenosis?

A: Minimally invasive techniques such as vertebroplasty and kyphoplasty can be used to treat spinal stenosis. These procedures involve injecting cement or air into the vertebrae to relieve pressure on the spinal cord and nerves.

Q: What are some of the challenges you face as a spine surgeon?

A: As a spine surgeon, you face the challenge of ensuring that each patient receives the best possible care. This requires a thorough understanding of the patient’s condition, as well as the ability to communicate effectively with the patient and their family.

Q: What are some of the benefits of minimally invasive spine surgery compared to traditional surgery?

A: Minimally invasive spine surgery offers several benefits over traditional surgery, including less pain, shorter hospital stays, and faster recovery times.

Q: What are some reasons why patients should consider minimally invasive spine surgery?

A: Patients should consider minimally invasive spine surgery if they are looking for an alternative to traditional surgery, or if they are looking for a less invasive procedure with shorter recovery times.

Q: What are some of the factors that determine whether a patient is a candidate for minimally invasive spine surgery?

A: Factors that determine whether a patient is a candidate for minimally invasive spine surgery include the patient’s age, health status, and underlying medical conditions.

Q: What are some of the potential complications of minimally invasive spine surgery?

A: Potential complications of minimally invasive spine surgery include infection, bleeding, and nerve damage.

Q: What are some of the long-term outcomes of minimally invasive spine surgery?

A: Long-term outcomes of minimally invasive spine surgery vary depending on the individual patient and the specific procedure performed. Some patients experience significant improvement in pain and function, while others may see limited improvement.

Q: What are some of the limitations of minimally invasive spine surgery?

A: Limitations of minimally invasive spine surgery include the need for specialized equipment and trained surgeons, and the potential for more postoperative pain compared to traditional surgery.

Q: How do you evaluate a patient for minimally invasive spine surgery?

A: A thorough evaluation is conducted to determine if the patient is a candidate for minimally invasive spine surgery. This includes a physical examination, imaging studies, and consultation with the patient and their healthcare team.

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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 have 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 as often as needed. When going to a concert meant standing by the doorway so that I could use the restroom as often as needed, I was shocked to hear that I was in pain every single day. This disease was negatively impacting every aspect of my life.

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 once-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.

“Cystitis (IC) began in 1995. I woke up every single 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 retraining, physical therapy and trig-ger point injections, she is now dramatically better. She was eventually promoted and is sexually active.” According to physical therapist Bernadette Kamin, “Most IC sufferers are in pain 24/7. They 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.

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Finding hope:
Living with Interstitial Cystitis (IC)
Paula Abdul talks pain, support, and hanging in there.

**BEETTER 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 hang 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 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 hung in there really are better days ahead, and to hang in there.

**RSD FACTS**

- Burning pain is the hallmark symptom of RSD. Feeling as if you are on fire and can’t put it out.
- Anyone can get RSD (all ages, races, and both men and women). It affects females 3 to 1 over males.
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- One limb will be a few degrees different than the other.
- There are approximately 10 million Americans with RSD.
- RSD was first diagnosed over 150 years ago by Dr. Walter L. McGee, a military surgeon in the civil war.
- There have been over 20 names for this condition including RSD, CRPS, Causalgia, Polyneuropathy. It is most commonly known as RSD, Reflex Sympathetic Dystrophy.

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- Brachial Plexus Neuropathy
- Phantom Limb Syndrome
- Pudendal Pain
- Postherpetic Neuropathic Pain (PHN)
- Post-surgical Neuropathic Pain
- Reflex Sympathetic Dystrophy (RSD) or CRPS
- Chronic Neuropathic Pain
- Visceral Pain

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Managing chronic migraines

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

Migraine is divided into episodic or chronic based on frequency of attacks. Chronic migraines (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 are inadvertently worsening their pattern of migraines, a condition called medication overuse headache. While many clinicians find it understandable that someone experiencing 15 to 30 days of headache a month have medications to treat migraines, they also know that successful management of CM is difficult unless the medication causing the problem is discontinued. Medications implicated as causing medication overuse headache are pain medications such as opioids, benzodiazepines, tramadol, and ergotamines when used more than 10 days per month and many over-the-counter (OTC) products when used more than five 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 double 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.

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.

Roger K. Cady, MD
editor@headaches.org

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