Navigating Pain Challenges
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One of Many
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Innovative Therapies

Kathy Sapp, CEO (Cover)
American Chronic Pain Association

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www.theACPA.org

#TogetherWeHeal
Our Mission

The ACPA Chronicle is our voice to help facilitate peer support, education, and hope for individuals living with pain conditions. We strive to raise awareness among the health care community, policymakers, and the public at large about issues of living with physical and emotional pain. Our vision is to motivate those with pain conditions to seek quality care, to optimize healthcare office visits, and to prevent chronic disease. Our goal is to provide those with pain conditions the resources needed to make educated and shared decisions with their healthcare provider. Opinions in the Chronicle are those of the Authors and do not necessarily reflect the opinions or viewpoints of the ACPA. Although some topics may seem controversial, it is important for the Chronicle to cover a variety of topics regarding pain. And as always, consult a healthcare professional on all healthcare decisions.
Navigating the Challenges of Finding Healthcare Providers
By Kathy Sapp

At ACPA, we frequently receive requests from individuals living with chronic pain who need primary care services or a pain specialist. Often, these individuals are urgently seeking a primary care provider, as this is the first step toward getting necessary referrals or prescription refills. The shortage of primary care providers is a well-known issue. According to the Health Resources and Services Administration (HRSA), the "State of the Primary Care Workforce 2023" the report predicts a shortage of 68,020 full-time physicians by 2036, with a significant impact on non-metro areas.

Living in a large metropolitan area, I have access to many primary care clinics and hospitals. However, I recently experienced the difficulty of finding a new primary care provider firsthand. Despite the abundance of healthcare resources, I faced numerous rejections when trying to schedule a simple yearly checkup. Many providers were not accepting new patients, were nearing retirement, or had met their Medicare quotas. It took ten phone calls before I found a Physician Assistant who could see me. This experience gave me a deeper understanding of the struggles faced by individuals with chronic pain who are often turned away. It’s no wonder emergency rooms are frequently overwhelmed.

The Impact of Healthcare Provider Shortages
Everyone will likely face a disappointing experience with the healthcare system at some point. Healthcare providers across various specialties are also deeply concerned about their patients due to the widespread shortage of physicians.

Navigating Health Information on Social Media, TV, and the Internet
With the shortage of providers, many people turn to social media, TV commercials, and the internet for information. While this is common, it’s important to verify the information before discussing new treatments with your doctor. A reliable resource is the ACPA - Stanford Resource Guide to Chronic Pain Management. Continuously updated by Dr. Sean Mackey, Dr. Steven Feinberg, and their team, the guide provides accurate and relevant information about chronic pain treatments and is available on the ACPA website.

You can click here to visit the ACPA website.
The Journey of Pain – Understanding, Managing, and Thriving

By Scott Farmer, MBA

Living with chronic pain is an enduring journey, one marked by daily challenges and profound resilience. As we step into the summer of 2024, the ACPA continues its commitment to support, educate, and inspire individuals grappling with chronic pain. This edition of our Summer Chronicle delves into the multifaceted nature of chronic pain, offering insights, strategies, and stories that illuminate the path toward a fulfilling life despite pain.

Understanding Chronic Pain

Chronic pain, defined as pain persisting for more than three months, affects millions of people worldwide. It often stems from conditions such as arthritis, fibromyalgia, migraines, and neuropathy, but can also be a result of injuries or surgeries. Unlike acute pain, which signals an immediate injury and diminishes as the body heals, chronic pain persists, often with no clear cause. This persistence can lead to a cascade of physical, emotional, and psychological challenges.

The Science Behind Pain

Advancements in pain research have unveiled complex mechanisms behind chronic pain. Neuropasticity, the brain’s ability to reorganize itself, plays a significant role. In chronic pain conditions, the nervous system undergoes changes that can amplify pain signals. Understanding these mechanisms is crucial for developing effective treatments. Researchers are exploring innovative therapies, from neuromodulation and regenerative medicine to advancements in pharmacology, aiming to provide relief and improve quality of life.

Managing Pain: A Holistic Approach

Effective pain management often requires a multifaceted approach:

• **Medical Interventions**: Medications, physical therapy, and interventional procedures are common medical treatments. Tailoring these to individual needs is essential for optimizing outcomes.
• **Mind-Body Techniques**: Techniques such as mindfulness, meditation, and cognitive-behavioral therapy (CBT) have shown promise in reducing pain perception and improving emotional well-being.
• **Lifestyle Modifications**: Regular exercise, a balanced diet, and adequate sleep are fundamental. Gentle activities like yoga and tai chi can enhance flexibility and reduce stress.
• **Support Systems**: Connecting with others who understand the experience of chronic pain can provide emotional support and practical advice. Support groups, both in-person and online, can be invaluable.

Personal Stories: Triumphs and Trials

In this issue, we feature inspiring stories from individuals who have found ways to thrive despite their chronic pain. From a caregiver who discusses true love, to a mother who manages fibromyalgia while raising her children, these narratives offer hope and practical insights.
Continued: Challenges of Finding Healthcare Providers
By Kathy Sapp

If you have questions about the information in the guide, use the ACPA Communication Guide to jot them down and discuss them with your provider during your next visit. Your provider will appreciate your proactive approach when the information comes from a credible source.

Embracing Healthcare Advancements: Be Curious
As we continue to advocate for quality healthcare, it's important to remain open-minded, curious, and hopeful. Technological advances, including AI, could potentially address issues like opioid tapering and physician shortages by improving efficiencies and speeding up the development of new treatments.

Reflecting on my time in the pharmaceutical industry, I recall when the first disease-modifying treatment for Multiple Sclerosis (MS) was approved. Now, there are around 19 different therapies for MS. Similarly, when I was diagnosed with Migraines as an adolescent, treatment options were limited. Today, there are numerous effective treatments for Migraines, offering hope and relief to many.

Pain specialists now have more tools at their disposal than ever before and are increasingly setting up comprehensive practices with diverse expertise. Education for both patients and providers is crucial as these new treatments become available. ACPA remains committed to providing resources and education for managing pain. Check the ACPA website frequently for updates:

You can click here to visit the ACPA website

How Can I Help?
Living with chronic pain requires courage to navigate the healthcare system. If you encounter obstacles, ask how you can help address the problem. Make it clear that you are an engaged, informed patient who wants to be part of the solution. Keeping the conversation going is vital.

Take care of yourself and each other. Have a safe and enjoyable summer!

Moving Forward Together
The ACPA remains steadfast in its mission to empower individuals with chronic pain through education, support, and advocacy. This summer, we encourage you to embrace your strength and continue navigating your pain journey with courage and resilience. Together, we can create a community where everyone has the tools and the support they need to manage their pain and lead fulfilling lives.

As you read through this edition, remember that you are not alone. The journey with chronic pain is challenging, but with knowledge, support, and perseverance, it is possible to live a rich, meaningful life.
Surprises That Come with Caregiving
By John Garrett

Life can be a funny thing. For all its day-to-day mundanity, all its ho-hum, been-there-done-that snoozery, it can throw you a screw ball. Sometimes it can surprise the heck out of you.

And so, it is with taking care of someone with high-impact chronic pain (the type that includes life-upending function restrictions and mental health challenges.) Even though I’ve been caregiving for 43+ years now, I don’t pretend to know it all. But when you get a front row seat to something for that long, you pick up a thing or two... about a thing or two, along with some strong intuitive knowledge.

It doesn’t mean caregiving can’t still spin your head on occasion. And with that, here are three big surprises early in my caregiving journey – things that to this day still fill me with awe.

Muscle That You Never Thought You Had
I never planned on caregiving being a part of my life, but then most of us don’t, especially when I was an early twenty-something focusing on an acting career. It’s a new reality that comes out of left field, without an instruction manual or tutorial.

But there I was. Staying up night after night, saying whatever I could to soothe and comfort someone with full blown Complex Regional Pain Syndrome (aka, The Suicide Disease.) And when I wasn’t pulling out every inch of whatever to keep hope alive, I was running errands, making meals and changing bed pans (being bedridden isn’t for the faint of heart.) I was quickly burning out, emotionally and physically exhausted beyond anything I’d known before.

During the darkest times, I’d lie awake and think about how much gas was in my banged-up Honda Civic. How far could it get me? 200, 300 miles. That’s far enough to get away from all of this.

Then the epiphany hit. I love this woman. And when you love someone, you don’t run, you don’t surrender. I never knew I had this fortitude – but once I did, I never looked back.

Sometimes you’re surprised by your own strength, and what you can muster when the chips are down and out.
Surprises That Come with Caregiving

By John Garrett

And along the way, if you have the strength to embrace this awesome challenge, this exquisite journey makes you a better person – with a deeper wisdom and appreciation for what’s truly important and authentic.

Gradually, Then Suddenly

When Ernest Hemingway in his classic, The Sun Also Rises, wrote about bankruptcy coming on “gradually, then suddenly”, he could have been writing about the “a-ha” moment of caregiving.

Once I made a commitment to stay by my one-and-only with CRPS, I went about the business of day-to-day doing for another. Days turned into weeks, weeks into months without a break. But what do you call this? What was this steady act of service to another… another who needs you in this fundamental, yet most vulnerable, way?

I distinctly remember leafing through a Good Housekeeping magazine, eyes half closed from another sleepless night. I came upon an article that spoke of something called caregiving, and then and there I instinctively knew the article was talking about me. I’d at last found an identity and, in a surprising way, a home, a connected community of people by circumstance and fate who made it their priority to care for someone they hold dear.

The Love of Caregiving

In the 1996 film, Marvin’s Room, starring Diane Keaton and Meryl Streep, we’re gifted a rare examination of some essential truths about caregiving by Hollywood.

In the film’s final act, Keaton’s character Bessie, a long-time caregiver of her father tells her estranged sister, Lee, who’s only now coming to the reality of taking on the role of caregiver, that she’s been blessed. She explains that she’s been lucky to be loved for so long – and that she’s been lucky to provide love for all of those years.

That scene always chokes me up as I understand Bessie so very well.

After deciding to stay and discovering I’m part of a web of essential family caregivers (54+ million in the US alone), I surprised myself once more by how much I appreciate having the honor of devoting myself to the person I love. Despite the all-consuming crazy-making, hair-pulling upset and never-enough-sleep exhaustion that often comes with caregiving, there are few things better one can do with their life.

That’s the core truth about caregiving; to provide love and caring, and, in turn, graciously receive love and appreciation for that impossible work. Really, there’s nothing surprising about that at all.
Samantha Lee was a loving mother of two young children when she was diagnosed with fibromyalgia. The constant, widespread pain and fatigue associated with the condition made everyday tasks feel like monumental challenges. Simple activities like playing with her kids, doing household chores, and even getting out of bed some days seemed almost impossible.

Determined not to let fibromyalgia define her life, Samantha sought ways to manage her condition while still being the active, caring mother she wanted to be. She started by educating herself about fibromyalgia, learning about the importance of a comprehensive approach to managing the symptoms. She worked closely with her healthcare team to develop a personalized treatment plan that included medication to help manage pain and improve sleep.

In addition to medical treatment, Samantha embraced lifestyle changes. She began a gentle exercise routine, incorporating low-impact activities like swimming and walking, which helped reduce her pain and improve her overall energy levels. Recognizing the importance of mental health, she started practicing mindfulness and meditation to cope with the emotional toll of chronic pain.

Samantha also became an advocate for self-care. She established a daily routine that included periods of rest, ensuring she didn’t overexert herself. She learned to ask for help, relying on her family and community for support with her children and household tasks when needed. This not only eased her physical burden but also strengthened her relationships.

Despite the challenges, Samantha found joy and fulfillment in motherhood. She discovered creative ways to engage with her children that didn’t exacerbate her pain, like storytelling, arts and crafts, and movie nights. These activities allowed her to maintain a strong bond with her kids while respecting her physical limitations.

Samantha's journey with fibromyalgia taught her the importance of balance and resilience. By prioritizing her well-being and embracing support, she managed to thrive as a mother and individual. Her story inspires others with chronic pain, showing that with perseverance and a supportive network, it’s possible to lead a fulfilling life despite the challenges of chronic illness.
Ever felt completely overwhelmed by the challenges life tosses your way? During one such episode, the word “choice” popped into my head. What could it mean? Why now? Quickly dismissing it in favor of addressing demands of the day, I gave the word no more thought right then. But over the course of the next few days, it made appearances in conversations, articles, podcasts, and videos. Might be worth exploring, I thought.

So began a journey into the powerful role that choice could play in my life. While I had never really taken it for granted, I was not truly appreciating the opportunities that choice could offer. Here are a few things that I discovered.

**Interpreting Life’s Events**

Amid rapidly changing circumstances when there seems no time or inclination to do so, and the mind is creating noise, just STOP! Is there more than one way to understand what is happening? How would another person perceive the situation or event? More importantly, which of the available interpretations would be most beneficial? A change in perspective based on a calm and objective review of the facts can be a very powerful choice.

**Pesky Thoughts**

Negative thinking is a path toward exhaustion, frustration, discouragement, anxiousness, or even a sense of defeat. While we can’t prevent them from arising in the first place, with a bit of practice, we can learn to release unhelpful thoughts and shift our focus. Mindfulness meditation has proven effective for many wanting to cultivate this skill. Simply slowing down and recalling an enjoyable experience for a minute or two or remembering some act of kindness we observed or received from another, can interrupt unproductive, troubling, or catastrophic thoughts. Learning to influence our mental landscape is a worthy investment and a health enhancing choice.

**Presenting Ourselves**

Each of us likely has some mental image of how we would like others to see us, whether in specific situations or just in our day-to-day lives. These may have developed over many years or even decades without much conscious reflection or periodic examination. The way we have been presenting ourselves through language, facial expressions, and other behaviors may have served us well in the past. But are they communicating what we need and want to express now? Would we feel more authentic and comfortable with ourselves and others if we made a change? We always have that choice.

**What’s New?**

How many of us stick with a hobby or interest that no longer energizes us? Do we continue because we are a part of a community we might miss if we move on? Is a significant portion of our identity built around it? Why not consider trying out something new? Only we can decide how best to use the time we are given in life. Let’s don’t let apprehension cause us to bypass a potentially rewarding and adventurous choice.

**Right or Wrong – Really?**

Just because we’ve always done something a certain way doesn’t necessarily mean it’s right or best. Maybe what worked well before no longer does. Exploring alternatives does not suggest that what we’ve done in the past was wrong. Course correcting with no blame or regret is a smart choice.

When the pace of life seems too hectic and the path ahead appears barely visible, I now recognize that choice is indeed a gift, present in every moment to be exercised with great care and gratitude.
Do you use opioids for pain? Do you have plans to use medical cannabis for pain but haven't started yet?

We want to learn how medical cannabis can affect pain and opioid use. This study looks to understand if medical cannabis might help people reduce their dose of opioid medications, while health teams give support to manage pain.

We are looking for people who are:

- 18 - 75 years old
- Use opioids for chronic pain
- Do not regularly use cannabis

8 study visits
Visits are completed over 6 months, and can be done from home. You can do your visits in the day or evening. You will also take a short daily survey to keep track of your health.

Weekly pain management support group

- Work with a health team to learn pain management skills and create an opioid reduction plan to match your goals.
- Groups meet once a week for 6 months on Zoom.

Earn up to $1,150

Interested? Want to learn more?
Scan the QR code or contact Bryn at 617-643-4537 or potsandmm@mgh.harvard.edu
The Role of Community in Chronic Pain Management

By Scott Farmer, MBA

Chronic pain can be an isolating experience, affecting every aspect of a person’s life. However, the power of community can play a pivotal role in transforming this experience from one of solitude to one of shared strength and resilience.

The Power of Shared Experiences

One of the most significant benefits of being part of a community is the opportunity to connect with others who truly understand the struggles of living with chronic pain. Shared experiences can provide validation and comfort, helping individuals feel less alone in their journey. Support groups, both in-person and virtual, offer a safe space to share stories, exchange advice, and offer mutual encouragement.

Building a Support Network

Creating a robust support network is essential for managing chronic pain effectively. This network can include family, friends, healthcare providers, and fellow pain sufferers. Each member of the network plays a crucial role:

• **Family and Friends:** Their understanding and empathy can provide emotional support and practical assistance.

• **Healthcare Providers:** Clinicians, physical therapists, and mental health professionals offer medical expertise and treatments.

• **Fellow Pain Sufferers:** They provide unique insights and tips based on their own experiences, fostering a sense of camaraderie.

Digital Communities and Resources

The rise of digital technology has revolutionized how people with chronic pain connect and find support. Online forums, social media groups, and virtual support meetings allow individuals to share their experiences and advice from the comfort of their homes. Websites and apps dedicated to chronic pain management offer resources such as guided meditation sessions, exercise routines, and dietary tips tailored to those living with pain.

Advocacy and Awareness

Communities can also be powerful advocates for change. By coming together, individuals can raise awareness about chronic pain conditions, push for better treatment options, and influence healthcare policies. Organizations like the American Chronic Pain Association (ACPA) play a vital role in these advocacy efforts, providing a collective voice to those who might otherwise feel unheard.

Personal Stories: Finding Strength in Community

Stories of individuals who have found strength and solace in their communities benefit others when they tell their stories. Don’t be scared to share your story, and for those who don’t want to listen, then they are not the support you are looking for.

Moving Forward Together

As we navigate the complexities of chronic pain, it is crucial to remember the importance of community. Whether through support groups, advocacy efforts, or online connections, finding a community can provide the strength and resilience needed to manage chronic pain more effectively.

The ACPA celebrates the power of coming together, emphasizing that no one has to face chronic pain alone. Together, we can foster a supportive environment where everyone feels valued and understood, paving the way for a more compassionate and informed approach to chronic pain management.
The One of Many Documentary

697 Self-Recorded Videos of Mike
Brittany Tells the Story of...
• A Blue-Collar Hard-Working Man that Suddenly is Faced With Chronic Pain
• The Bureaucracy of Pain Management
• Becoming the Caregiver for Mike
• A Single Parent, that is facing intimate questions of meaning and self
• What Happens When Access to Quality Care is Not Found
People with pain can play an important role in the development of new therapies by taking part in clinical trials. Find a listing of IRB-approved clinical trials that might be of interest to you at www.ACPANow.com/research/. New trials are posted often, so check back regularly.

Current Research Studies
- Knee Osteoarthritis
- Cannabinoids
- Fibromyalgia
- Rheumatoid Arthritis
- Dermatomyositis
- Anxiety and Pain
- Opioids and Alcohol

FDA Study on the Use of Digital Health Technologies for Opioid Use Disorder
FDA is funding a study to learn about how digital health technologies (e.g., apps, programs, or devices that are used for monitoring, tracking, or providing education about health topics) can be used to help people with opioid use disorder (OUD) manage their condition. As part of this study, a researcher from RTI International (www.rti.org) will conduct a focus group with people who have been diagnosed with OUD and are either currently or have recently been in treatment for OUD. The discussion will take place over Zoom, an online video platform and will last 90-minutes. In appreciation of your time, you will receive a $75 gift card after the discussion.

To see if you qualify, please click the link below to complete a short survey.
https://redcapdec.rti.org/ccs/surveys/?s=NEMDXDWL79MTYW3A

If you have any questions, please contact the study team at 877-212-7218 or FDADigitalHealthTechnologies@rti.org.
Innovative Therapies for Chronic Pain Relief

By Scott Farmer, MBA

As the understanding of chronic pain evolves, so do the approaches to its treatment. These emerging treatments aim to provide more effective relief and improve the quality of life for those with chronic pain.

Neuromodulation Techniques

Neuromodulation is at the forefront of innovative pain management therapies. It involves the use of electrical stimulation to alter nerve activity and reduce pain. Two common forms of neuromodulation are:

- **Spinal Cord Stimulation (SCS):** This technique involves implanting a device that sends electrical impulses to the spinal cord, blocking pain signals before they reach the brain. SCS has been effective in treating conditions like failed back surgery syndrome and complex regional pain syndrome.

- **Transcutaneous Electrical Nerve Stimulation (TENS):** A non-invasive method where electrodes placed on the skin deliver electrical pulses to stimulate nerves and reduce pain. TENS units are portable and can be used at home, providing a convenient option for pain management.

Regenerative Medicine

Regenerative medicine focuses on healing damaged tissues and restoring function through innovative biological therapies. Two promising treatments in this field include:

- **Stem Cell Therapy:** Stem cells have the potential to differentiate into various cell types, aiding in tissue repair and regeneration. For chronic pain, particularly in joint and spine conditions, stem cell injections can promote healing and reduce inflammation.

Pharmacological Advancements

Recent advancements in pharmacology are also providing new options for chronic pain relief:

- **Non-Opioid Medications:** Researchers are developing new medications that target pain pathways without the risks associated with opioids. These include drugs that target specific pain receptors and neurotransmitters involved in pain signaling.

- **Cannabinoids:** Derived from the cannabis plant, cannabinoids like CBD and THC have shown promise in managing chronic pain. These compounds interact with the body’s endocannabinoid system to reduce pain and inflammation.

Integrative and Complementary Therapies

Integrative medicine combines conventional treatments with complementary therapies to address the whole person—mind, body, and spirit.

The Future of Chronic Pain Management

As research continues to advance, the future of chronic pain management looks promising. These innovative therapies are not only expanding the options available to patients but also offering new hope for those who have struggled to find relief through traditional treatments.

At the American Chronic Pain Association, we are dedicated to keeping you informed about the latest developments in pain management.
Dear ACPA Members,

Since 1980, The American Chronic Pain Association has advocated for people living with pain and provided them with resources. Our efforts have reassured people with pain that they are not alone, as we offer the support and the hope they deserve. The ACPA has shown millions of people in pain how to achieve reduced suffering and a better quality of life.

The ACPA understands the daily battles people in pain fight. Therefore, we continue to advocate for your rights and provide pain management strategies and tools for you, your caregiver, and your healthcare team to better understand your condition. We believe more resources are needed to provide empowerment and shared decision-making in pain management.

We are grateful for your partnership. When you support the ACPA, you help fight for people living with pain to be heard, respected, and treated equally. Your support makes the important work of the ACPA (like this Chronicle) possible, so please consider support today.

Sincerely,

Kathy Sapp, CEO
American Chronic Pain Association

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- Corporate Membership. Email us for pricing: acpa@theacpa.org
- Consider the ACPA in your Estate Planning: acpa@theacpa.org

IMPORTANT NOTE: STANDARD MEMBERSHIP IS FREE. EVERYONE GETS ACCESS TO ALL RESOURCES!
We Have Big Plans for 2024... and We Want You Involved. Corporate Memberships and Chronicle Advertising opportunities are available.

APPLY HERE
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By Scott Farmer, MBA

Thank You for Reading!

Have a Wonderful Summer —ACPA Team—

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