Today We Grow... Together We Heal
Finding Power From Our Pain and Letting The World Know It

Strength in Our Scars
Together We Heal
Time Reimagined
Pain in Primary Care
Skills Training
Hurt Feelings
Losing Weight
Pain Misconceptions
Peer Support
One of Many
Research Opportunities
Caregiver Importance

Also...
Chronic Pain in Congress
Dermatomyositis
Biosimilars & Rheumatic Disease
Osteoarthritis

Stefanie Boyer (Cover)
Encove Health
Nominated for her support of women in pain

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**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.*
Strength in Our Scars
By Stefanie Boyer (Encove Health)

It was a normal spring day in 2011. The spring breeze was coming in the kitchen window, and I’d come back from a training run for my first half marathon. I finished up the dishes quickly. I bent down to close the dishwasher, like I had done dozens of times before. I froze. I was unable to stand back up. That moment echoed throughout the next year of my life as I descended into an ordeal of debilitating pain, unanswered questions, medical appointments, fear, immobility, and ultimately, isolation and depression. During that time, I experienced what I’ve affectionately named the Boomerang Spaghetti Effect. Sound like an absurd name? That’s precisely the point. How else do you describe the journey of a person in persistent pain? Our journey typically consists of a circuit of visits to multiple providers. Maybe you get a diagnosis and treatment; maybe you don’t. Either way, it feels like you’ve tried everything, visited a million providers and arrived back at square one, where the only option left feels like throwing spaghetti on the wall to see what sticks.

If you found yourself in my story, I want you to know, you aren’t alone.

Ultimately, I ended up finding a manual therapist who helped me look beyond the myopic lens of where the pain was in my body. This changed everything for me. For the first time, someone was taking the time to help connect all the dots. I would later learn that this is a foundational part of effective pain care—addressing the whole person.

When I reflect on that horrendous year and how miserable it felt to make a short trip to the grocery store or achieve a decent night’s sleep, I’m struck by the fact that no one was talking to me about my habits, my sleep, my relationships, what I could be doing at home to support myself, and the emotional toll this journey was taking. Even worse, I felt deeply unseen and dismissed by provider after provider.

This formative experience sent me deep into the world of integrative care and pain science, where I’ve been passionately committed to helping women in their pain journey like I wasn’t. We can no longer separate physical pain from emotional pain. Have you ever met someone in the throes of pain, living their best life? Likely not.
Today We Grow, Together We Heal: Finding Power From Our Pain

By Scott Farmer, MBA

In my life, pain is an unfortunate reality that continues to weave its way through daily experiences. It’s our universal language however, spoken in the silent echoes of our struggles, the whispered cries of our hearts, and the unspoken stories etched into the fabric of our existence. Yet, within the depths of our pain lies a remarkable power – the power to heal, to grow, and to transform.

Today, as we navigate the labyrinth of life’s challenges, let us embrace the profound truth that our pain is not a burden to bear alone, but a beacon guiding us towards our own inner strength and resilience. In the darkness of despair, we discover the flickering flames of hope. In the throes of adversity, we unearth the seeds of resilience waiting to sprout. And in the midst of our deepest wounds, we find the raw material for our greatest healing.

It is often said that pain is inevitable, but suffering is optional. While we cannot always control the circumstances that cause us pain, we can choose how we respond to it. We can allow ourselves to be consumed by bitterness and despair, or we can harness the transformative power of our pain to propel us towards growth and healing.

Every setback, every heartache, every moment of anguish carries within it the seeds of opportunity – the opportunity to learn, to evolve, and to emerge stronger than we were before. Like a spark rising from the ashes, we have the power to transcend our pain and emerge reborn, resilient, and ready to face whatever challenges lie ahead.

But healing is not a solitary journey; it is a collective endeavor that requires the support and solidarity of those around us. Together, we can create a safe space where vulnerability is welcomed, and authenticity is celebrated. Together, we can share our stories, our struggles, and our triumphs, knowing that in our shared humanity, we find strength.

Today, let us stand together as guardians of the heart, united in our commitment to healing ourselves and healing each other. Let us be beacons of hope in a world shrouded in darkness, illuminating the path towards healing with the light of our resilience and the power of our collective courage.

As we journey forward, may we always remember that our pain does not define us; it empowers us. It is not a sign of weakness, but a testament to our strength. And it is not the end of our story, but the beginning of a new chapter filled with promise, possibility, and the infinite potential of the human spirit.

Today we grow, together we heal, and with each step forward, we let the world know that no matter how dark the night may seem, the dawn of healing and transformation is always within reach.
Strength in Our Scars Continued
By Stefanie Boyer (Encove Health)

Imagine if in that first appointment instead of being dismissed or sent out with a long list of referrals or stretches, you were actually heard. You learned about the complex nature of pain as well as some recovery methods for coping at home. Let’s be real - we place so much hope on that appointment that we have waited so long for, but what about all the life we live between appointments? How do we cope, how do we live, how do we enjoy the life we have?

This is where we really need support, teaching and learning.

Friend, regardless of where you are at in your journey, I hope you feel empowered to find providers out there that are knowledgeable and care. Keep going. Don’t lose hope. There is always something you can do to regain control and increase the quality of your life - even if it’s small.

I’ll leave you with this.

Pain care of the future must:

• Be trauma-informed
• Be grounded in pain science
• Be compassionate and supportive
• Address the whole person
• Support empowered self management strategies

Stay tuned for part 2!

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Time Reimagined
By Jennifer J. Weisbrod, MS

There is nothing quite like a health challenge to focus our attention on time. How much do I have left on this planet? How should I spend it? Have I been wasting it or using it wisely? Those managing chronic pain and other medical conditions on a daily basis are no strangers to these questions. Facing a procedure or a new diagnosis, though not the easiest of experiences, does afford us an opportunity to reassess our relationship with time and mine some nuggets of positivity from a difficult circumstance. But any moment at any age is an appropriate occasion for shifting our awareness of, and perspective on, time.

Never Enough
While we can never know exactly how much time remains in our own life, it is certain that there will never be enough to do everything we would want. Acceptance of that fact is a first step in making peace with time rather than fighting it. This allows us to take the next step toward effectively using what time we do have.

What Matters
If our time is finite, why spend it on things that don’t matter to us? Are we succumbing to the “tyranny of the shoulds?” Where did the “ought to” items on the to-do list of life come from in the first place? Examining what gives our lives meaning, purpose, and joy now is a good investment of time. If we offload less personally relevant activities, perhaps we won’t be in a constant battle against the clock.

Always Someday
How often have we heard of people who work hard all their lives, postponing that vacation or pursuit of a hobby, only to run out of time?

Dreams for the future motivate and help carry us through the tough times. Postponing special events, enjoyable experiences, and shared memory-making episodes indefinitely, however, doesn’t generate any more time and robs us of a life fully lived.

Regret
Few individuals go through life without ever having regrets about what they did or didn’t do on a particular occasion or during some period in their history. The past can be a springboard for personal improvement, impetus for reconciliation, and a chance to celebrate accomplishments. When reflection results in rumination over what cannot be undone, it steals time better used for living fully in the present and pursuing what matters most.

Generosity
If we think back on the person who has had the greatest positive influence on us, chances are the individual gave generously of their time to be with us. Wouldn’t we want to do the same for someone else? Fretting over the scarcity of time in our day can easily distract us from making a difference.

Time for Self
Self-care can be an uncomfortable message but building in “me” time becomes possible when we reprioritize and remove tasks that do not contribute to what matters in our lives.

Spring is a perfect season for fresh perspectives. Why not plant an intention to focus on what matters? Fully savoring each of our days, leaving behind regret about the past and preoccupation with the future, surely leads us on a path toward a healthier relationship with time.
Nerveli Application Review
By Scott Farmer, MBA

Nerveli is a mobile application that provides users with an empathetic and interactive pain recovery guide. Their mission is to take the stress and uncertainty out of dealing with chronic pain through evidence-based and personalized recommendations. Their CEO had to see twenty-three physicians during his frustrating and anxiety-filled journey to find answers for his debilitating pains. He knew there had to be a better solution...That's how Nerveli was born.

Nerveli was founded by a team of expert Physicians, Neurologists, Pain Psychologists, and Neurosurgeons. So how does it work? It first determines the type of pain you have through proprietary and scientific sensory tests, which will then provide users with more context around their pain. From there, the journey to living more pain free begins! It seems the app is here to support you and enable you to take control back over your pain.

Nerveli offers the following features:
• Tracks pain levels over time.
• Prepares users for appointments with their healthcare provider.
• Offers evidence-based advice on mood, sleep, exercise, and stress levels.
• Provides tailored feedback on coping with pain via cognitive behavioral therapy.
• Recommends alternative ways to manage specific types of pain.
• Builds a network of community support.
• Gives users a platform for interactive journaling.
• Shares advice from expert clinicians and psychologists.

Nerveli is currently signing up beta testers to provide feedback on the user experience of their mobile application. Beta testing will begin at the end of March, and the first 1,000 people who sign up will receive lifetime free access to their mobile and web applications. Sign up by filling out the form here. You can find out more information about Nerveli at www.getnerveli.com.
Treating Chronic Pain in Primary Care

By Scott Farmer, MBA

Treating patients with chronic pain requires a comprehensive approach that addresses both the physical and psychological aspects of pain management. Here are some strategies that primary care clinicians can implement to better treat patients with chronic pain:

Conduct a thorough assessment of the patient's pain history, including onset, duration, aggravating and alleviating factors, and impact on daily functioning. This assessment should also include an evaluation of the patient's mental health, social support system, and any co-existing medical conditions.

Collaborate with other healthcare professionals (HCPs), such as pain specialists, nurses, physical therapists, dieticians, psychologists, and occupational therapists, to develop a holistic treatment plan tailored to the patient's needs.

Provide education about chronic pain, including its potential causes, mechanisms, and treatment options. Help patients understand the importance of self-management strategies and lifestyle modifications in managing their pain.

Prescribe appropriate medications, considering the potential risks and benefits for each patient. Utilize medications as part of the treatment plan and follow evidence-based guidelines for prescribing.

Incorporate non-pharmacological interventions such as physical therapy, exercise, acupuncture, massage therapy, cognitive-behavioral therapy (CBT), diet, mindfulness-based stress reduction (MBSR), and relaxation techniques into the treatment plan.

Offer behavioral interventions to help patients develop coping skills, improve self-efficacy, and manage psychological distress associated with chronic pain. This may include CBT, acceptance and commitment therapy (ACT), or other psychotherapeutic approaches.

Encourage regular physical activity and exercise tailored to the patient's abilities and preferences. Exercise can help improve physical function, reduce pain severity, and enhance overall well-being.

Integrate mind-body interventions such as yoga, tai chi, and meditation into the treatment plan to promote relaxation, reduce stress, and improve coping with pain.

Schedule regular follow-up appointments to assess the patient's progress, adjust treatment strategies as needed, and provide ongoing support and encouragement.

Involve patients in shared decision-making processes regarding their treatment options, goals, and preferences. Empower patients to take an active role in managing their pain and making informed choices.

Recognize and address social determinants of health that may impact the patient's experience of pain, such as socioeconomic status, access to healthcare, housing stability, and social support.

Coordinate care with other HCPs involved in the patient's treatment to ensure continuity of care and optimize outcomes.

By implementing these strategies, primary care clinicians can better support patients with chronic pain and improve their overall quality of life.
Chronic Pain Management Skills Training

Volunteer for the Research Study

Researchers at Washington State University Spokane are looking for people with chronic pain to participate in one 2-hour pain education and skills training program.

Empowered Relief® is a scientifically tested pain program that may help individuals learn effective pain management skills while also learning to better understand pain. The purpose of this research is to demonstrate that Empowered Relief classes taught by nurses can help individuals better understand and manage their chronic pain.

**Those eligible to participate will be:**
- Adults 18 years of age or older with chronic pain for more than 3 months
- Able to speak and read English
- Able to attend one 2-hour class online
- Able to complete online questionnaires before and after the class
- Participants can earn up to $30 in gift cards for completing three surveys

For additional information scan the QR code below, click on the link or call or email the research team:
- Link: [https://redcap.spo.aws.wsu.edu/surveys/?s=9NHNF9NHMF7NDW3E](https://redcap.spo.aws.wsu.edu/surveys/?s=9NHNF9NHMF7NDW3E)
- Phone: 509-324-7443 or Email: Spokane.painstudy@wsu.edu

This study IRB # 20013-001 has been certified as Exempt by the Washington State University Human Research Protection Program. Principal investigator Marian Wilson WSU College of Nursing 509-324-7443 marian.wilson@wsu.edu

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**Your Voice Matters!**

Are you passionate about advocating for the chronic pain community? Do you want to play an important role in driving digital health innovation? Share your pain experience and earn a $40 gift card for your feedback.

We believe in the power of digital tools to empower individuals to find relief from pain. As we develop these tools, your lived experience with chronic pain is invaluable in shaping our efforts.

If you’re interested in participating in a 30-minute interview with one of our team members, please contact us at ACPA@theacpa.org for more information. Please note, participants will need access to a computer, table, or smartphone to participate in the interviews which will be conducted via Zoom.

Join us in our mission to create a resilient world, liberated from fear and pain.
Imagining a Future in Pain is Scary
By Randall H. Duckett

Late at night, after watching Stephen Colbert, I lie in bed trying to fall asleep while my mind drifts to disturbing thoughts. Despite trying to fend them off by mentally singing the chorus to “Let it Go,” the hit song from Frozen, terrifying notions float through my brain. The worst isn’t the Big D, though. It is the reverse: worry about living with my severe chronic pain (mostly from degenerative osteoarthritis due to a rare genetic disease). What, I ask myself, will life be like the next day, the day after, and so on throughout the years as my body continues to decay? There, in the dark, my fear of future pain is overwhelming. It turns out there is a name for what I feel: algophobia. According to the Cleveland Clinic, it is “an extreme fear of physical pain.” While nobody wants to experience pain, people with this phobia have intense feelings of worry, panic, or depression at the thought of pain. ... It’s most common in people with chronic pain syndromes. Other names for this condition include ‘pain-related fear’ and ‘pain anxiety’. ... One study suggests that half of people with low back pain have an elevated sense of fear about their pain.

That makes sense. When pain is a constant in your life, you’re on alert all the time against it. Worry builds as you anticipate the next ache, stab, or burn. In the worst cases, the phobia can bring out-of-control panic attacks. (I am fortunate not to have experienced that yet.)

Fear is part of the fight, flight, freeze mechanism we all have. Our bodily sensors—touch, sight, sound, taste, and smell—are constantly arrayed against harm.

Our sensors gather data about what’s going on inside and outside our bodies, ready to react if pain comes. We are sensing machines—feeling, yes, but more so thinking, analyzing, imagining, anticipating, fearing.

Normally, sudden pain is a screeching alarm that something is wrong. It zaps you, activating the instinct to do something to stop it: clench your muscles against it, scream to blow off the feeling, or break out in sweat. If you’re lucky, eventually whatever caused the pain heals and the problem goes away.

With chronic pain, however, the hurt endures. It persists and resists treatment, leaving those of us who have it in a constant state of dread. The mind girds itself against further hurt. Imagination anticipates the pain to come. Fear distorts thinking. And, also according to the Cleveland Clinic, “Unfortunately, exaggerating the threat of pain can actually make the pain worse. ... The same chemicals in your brain that regulate fear and anxiety also regulate how you perceive pain. So chemical imbalances can trigger both problems.”

So, fear of pain begets more pain. Catch 22: Trying to avoid pain causes more of it.

Randall H. Ducket
ACPA Contributing Member
Author of Seven Cs: The Elements of Effective Writing
randallhduckett.com
Losing weight can be difficult to accomplish in general, however trying to do so when dealing with chronic pain and fatigue can seem impossible. This struggle, I know all too well, enduring symptoms for decades and being officially diagnosed with fibromyalgia and CFS in 2015.

As a teenager I devoured every fitness magazine I could get my hands on, tried every extreme diet, and jumped on the bandwagon of every fad workout. Despite years of grueling workouts and strict dieting, I just couldn’t achieve the results I should have. What I didn’t realize was the type of exercising I committed myself to was the very thing sabotaging my progress.

In 2010 I became a certified trainer and helped many others achieve their fitness goals, however I was still personally plagued with chronic pain, often crashed after workouts, and experienced bouts of fatigue. I knew I had to do something different.

Popular exercise methods often are designed to push our bodies to extremes, even the so-called beginner workouts. I had to learn that one size, definitely does not fit all. Today I live by the motto, “Listen to your body,” and that little tip has helped me to look at exercising in a completely different way, especially when dealing with chronic pain and fatigue.

For me, almost every workout I tried, even pilates, consistently resulted in higher pain and fatigue. So, I created my own unique method of exercising that got results without making me crash.

These routines incorporate specific exercises and sequencing that prevents excess pain and fatigue via low to moderate intensity moves that are always low-impact.

Even as I got better, if I veered away from this method my pain and fatigue would return. But if I stuck with it consistently, (even just five minutes per day) the results were very encouraging.
Hurt Feelings-Fear Itself: Imagining a Future in Pain is Scary Continued

By Randall H. Duckett

In my body, fear and pain have a weird relationship. I’ve noticed that my mind doesn’t remember pain well. Once hurt is eased, the memory fades. My wife tells me that’s why women choose to have more children after their first; the agony recedes with time. I think that’s what it’s like for everybody, but though the specific memory of pain may be hard to dredge up, the trauma of it remains. The body keeps score. The problem isn’t so much the pain itself; it’s the anticipation that hurts the most.

My dread of more pain is both short term and long term.

In the short term, each moment may bring another hurt. It’s like a scary movie: The buildup, accompanied by spooky music, is more stressful than the actual monster, no matter how gross, gooey, or gory. Fear of painful shocks makes me consider my movements carefully. I stress at the thought of getting up from my La-Z-Boy and doing something as simple as walking into the kitchen for a handful of Wheat Thins and a Propel. Every move is a wary calculation about whether the result is worth the pain I’ll feel. Mostly, I prefer to sit still.

Over the long term, fear grabs me on an even deeper level. Because of my anxiety about more pain, I feel an existential dread of the future. I envision how my life will be at age 70, 75, or 80, if I live that long. I imagine myself decayed and suffering. At worst, I wonder whether I can survive all the pain to come. The battle is to not let panic, either short term or long term, ruin my life.

Yes, objectively I’ll have pain as long as I live. Dealing with the emotional fear of pain, though, is often as much hard work as physically coping with it. It’s tough to keep fear—something so basic to being human, something so instinctive, something so irrational—from getting the better of me.

Remember the momentous words of President Franklin Roosevelt: “The only thing we have to fear is fear itself.” He meant that anxiety is often worse than the problem at hand—in his case, the 1941 bombing of Pearl Harbor pulling us into World War II. It was a pretty bold thing to say after the “day that will live in infamy” when about 2,400 people had been killed. But I take his point.

When one has chronic pain, particularly my kind that becomes worse with time, fear can be all-consuming. More than pain itself, I fear... fear.

Randall H. Duckett is the author of Seven Cs: The Elements of Effective Writing (randallhduckett.com).

Attention chronic pain sufferers: Sharing is healing. Chronicle columnist Randall H. Duckett is writing a book in which he explores the fierce emotions of living with chronic pain, such as grief, compassion, fear, courage, and love. It will be published in partnership with the American Chronic Pain Association later this year. He invites you to share your pain story and the feelings you’ve experienced, so that your fellow pain sufferers understand they are not alone. Offer information, insights, and inspiration that help you feel seen, like you matter, and healed. To have your story considered for the book, please send your name, email address, and up to 100 words summarizing your chronic pain journey to randall@hurtfeelings.life

-Thank you for sharing-
Here are three tips that I would like to share to help you on your fitness journey when dealing with chronic pain:

1. Don’t underestimate stretching! I used to think stretching was a waste of time. However, it can provide an immediate release to some pain and fatigue, and it prepares the body to exercise with better form. The ability to exercise with proper form will make every routine you do more effective and cause less pain. It’s a foundational step many skip, but then pay the consequences.

2. Perform moderate resistance training. You don’t need to lift heavy weights to get results. Even when you keep the resistance very light, it helps amp your metabolism and burn more calories while you are at rest. It will take a little trial and error to find the right amount, so don’t give up.

3. Light cardio will help you long term. Getting completely out of breath is not necessary. Aerobic exercise improves the lymphatic system resulting in a variety of benefits. It can be difficult to resist the urge to push yourself to do what others are doing. Even if you keep it light you will experience incredible benefits.

After discovering what really worked for our special community of chronic pain and fatigue sufferers, I realized there was no place to go to find these kinds of exercises, so I created Cocolime Fitness. Here I publish my entire collection of stretches, exercise routines, and programs so we can exercise safely, lose weight and improve our conditions.

It’s my privilege to help people like us to look and feel their best using this method and I’m excited to have you join us.

Suzanne Wickremasinghe
Personal Trainer, CEO Cocolime Fitness
https://cocolimefitness.com
POLICY SPOTLIGHT
Employee Autoimmune Disorder Protection Act
By Emmanuel Sessegnon

There is a new bill being introduced in Maryland called the Employee Autoimmune Disorder Protection Act (HB1084). This law would explicitly make working from home a legal right for those with autoimmune diseases and the immunocompromised.

It also expands certain ADA protections to small businesses and creates a brand-new enforcement system separate from the EEOC. It is the first law of its kind in the nation, and with COVID-19 once again intensifying while crackdowns on remote work are occurring, this law is important to the immunocompromised. This is especially important because autoimmune diseases are becoming more common in the United States – around 23-50 million Americans suffer from these illnesses.

Most of these illnesses cause chronic pain. Some examples include MS, Fibromyalgia, Rheumatoid Arthritis, and many others.

More info can be found here:

And here:
https://doubleutriplea.org/eadpa-maryland-apa

The hearing is on March 6th at 1:00 pm.

HHS/SAMHSA Releases New Opioid Treatment Program (OTP) Regulations

AATOD commends HHS/SAMHSA in releasing their final regulations, which provide guidance to OTPs. These enlightened and thoughtful regulations:
• will increase access to treatment admission to OTPs by eliminating the one-year requirement of opioid use disorder history prior to patient admission;
• make take home medication flexibilities permanent and based on the clinical judgment of OTP personnel;
• allow for methadone induction through audio-visual telehealth through the OTP;
• eliminate stigmatizing language in referring to patients in treatment. MORE INFORMATION
Misconceptions of Chronic Pain Management

By Faith Munsell

Chronic pain is a prevalent issue leading many to seek medical attention. It affects not just the physical body but also has profound impacts on social interactions, mental health, and work life.

But despite its commonality, there are many misconceptions about chronic pain. Understanding these misconceptions and the truths about pain is the first step in learning how to safely manage it.

Clarifying Common Misconceptions

Exercise makes chronic pain worse
Many believe that exercise worsens chronic pain, but this is often not the case. Inactivity can exacerbate pain. While it’s advisable to limit physical activity during severe pain episodes, regular movement and mild to moderate exercise can be beneficial and may speed up recovery.

Pain will stop after the injury is healed
A common belief is that pain should cease once an injury heals. However, chronic pain can linger long after an injury has recovered, especially if there’s nerve damage involved. Pain lasting more than three months is typically classified as chronic.

Medication is the only way to heal
Contrary to popular belief, managing chronic pain doesn’t only involve medications. Complimentary treatments like physical therapy, aromatherapy, music therapy, biofeedback, and relaxation techniques such as meditation and massages can greatly help.

Chronic pain is an age-related symptom
Another common misconception is that chronic pain is an inevitable part of aging. While some pain is natural with age, chronic pain is abnormal and can affect individuals of all ages. It often originates from injuries, health conditions, or nerve damage.

What works for someone else should work for me
Pain relief is subjective and varies from person to person. Treatment plans should be tailored based on the type of pain, its cause, and the patient’s overall health. These plans may include medications, lifestyle adjustments, and various therapies.

Remember, progress in pain management is gradual, and the aim is to manage pain to improve daily functioning.

Regardless of the nature of your pain – be it a manifestation of a more intricate health issue, stemming from a back injury or disc herniation, or persisting with minimal improvement... we all are seeking to heal.

For personalized assistance in managing your chronic pain, contact a pain specialist today.
FEATURED RESEARCH

HAVE YOU LOST SOMEONE WITH PAIN TO SUICIDE, OR DO YOU KNOW SOMEONE WHO HAS?
A new research study seeks to interview people who have lost a friend or family member to suicide after a taper or stoppage of opioid pain medication. To date, no other team has sought to understand these losses in depth.

The study team is led by Dr. Stefan Kertesz at University of Alabama at Birmingham. Dr. Kertesz has a history of federally funded research and also of speaking out on behalf of people with both disability and pain. Click Here

Pain News Network published Dr. Kertesz’s description of the this study late last year "Why We Need to Study Suicides After Opioid Tapering" Click Here

People interested in this study can check out the online screening survey at https://go.uab.edu/csiopioids or they can call 1-866-283-7223.

People who qualify under the screening survey will be asked to consider whether they would like to do a longer interview. All information is kept entirely confidential. General information about the study is at www.csiopioids.org.

This study is approved by the Institutional Review Boards at the University of Alabama at Birmingham and the US Department of Veterans Affairs.

For anyone thinking about suicide, please contact the 988 Suicide & Crisis Lifeline [link: 988 Suicide & Crisis Lifeline], available online, via chat, or by dialing “988.”

PSYCHOSOCIAL TREATMENTS OF CHRONIC PAIN

- Conducted by: Rush University Medical Center, Wayne State University
- Location: Home-based/Remote
- Several universities, funded by the National Institutes of Health (NIH), are studying different psychological interventions for adults with chronic back or neck pain in a randomized trial. All assessments and interventions are conducted remotely (by Zoom), and the interventions are provided for free. Participation will last about 9 months, and participants will be paid up to $325 for completing evaluations of their health.
- If you would like to learn more, please complete this survey to see if you qualify: https://redcap.link/pain-study
- Email our team at paintreatmentstudy@gmail.com with any questions.
- This study has been approved by RUMC IRB (Protocol number 22010705)
- Registered clinicaltrials.gov ID: NCT06044649

Letter to the Editor

Good day! I am a physical therapist in a nursing home. I have been downloading the ACPA Chronicle to give to my patients with Chronic Pain. One patient was very grateful since it helped her a lot. It greatly helps all my patients at my facility. Appreciate it. –Chrislyn-
Peer Support: Encouraging Personal Growth
By Scott Farmer, MBA

Start With Small Goals
• When starting an ACPA Peer Support Group, we encourage the setting of small, achievable goals. These goals can provide a sense of purpose and accomplishment, contributing to a gradual sense of renewal.
• An example of a goal would be to find one or two others with pain to discuss how to live more fully while living with pain.

Dreaming of Possibilities
• Allow space for individuals to dream of possibilities beyond their current circumstances. While pain is present, it does not define the entirety of one's future. Encourage them to envision a path forward, even if it starts with small steps.

Supporting Each Other Through the Journey
• Remind individuals that they are not alone in their journey. Emphasize the importance of reaching out for support and connecting with others who may share similar experiences.
• In times of pain, the journey toward wonder and renewal may require patience and self-compassion. By incorporating these suggestions, individuals may find moments of peace, strength, and the resilience needed to navigate their unique paths.

Peer Support
Peer support plays a crucial role in personal development, mental health, and overall well-being. Here are several reasons why peer support is so important:

Find Support Groups: TheACPA.org

Understanding and Empathy
Peers who have experienced similar challenges can offer a unique level of understanding and empathy. They've walked similar paths and can relate to the emotions, struggles, and triumphs that others may be going through.

Reducing Isolation
Dealing with challenges, especially mental health issues, can often make individuals feel isolated. Peer support creates a sense of community and belonging, breaking the isolation and fostering connections with others who share similar experiences.

Validation and Normalization
I DID NOT WANT TO JOIN A GROUP! But peer support provided validation by acknowledging the reality of my experiences. Knowing that others have faced similar challenges helps normalize feelings and reduces the stigma associated with certain issues.

Sharing Practical Strategies
Peers can offer practical insights and coping strategies that have worked for them. This exchange of practical advice can be invaluable, providing individuals with a variety of tools to navigate their own challenges.

Building Confidence and Self-Esteem
Interacting with peers who have overcome similar pain obstacles can boost confidence and self-esteem. Seeing others succeed can inspire hope and motivate individuals to take positive steps in their own lives. Peer support creates a safe and non-judgmental space where individuals can openly discuss their experiences. This safe space encourages honesty and vulnerability, fostering a sense of trust and openness.
How to Start An ACPA Peer Support in Your Community

By Scott Farmer, MBA

Peers can serve as role models for personal growth, healthy coping skills, and/or recovery. Witnessing others overcome challenges can inspire individuals to set and achieve their own goals, promoting a sense of empowerment.

Promoting Mental Health and Well-Being
Peer support is a key component in promoting mental health and well-being. It contributes to the development of a supportive network that helps individuals cope with stress, manage emotions, and maintain a positive outlook on life.

Enhancing Social Skills:
Interacting with peers provides an opportunity to practice and enhance social skills. This can be particularly beneficial for individuals who may be struggling with social anxiety or have difficulty connecting with others.

Long-Term Recovery and Maintenance:
Peer support is not only beneficial during times of crisis but is also important for long-term recovery and maintenance of well-being. Continued connection with a supportive community can provide ongoing encouragement and reinforcement.

Empowerment and Shared Decision-Making
Peer support empowers individuals to actively participate in their own decision-making processes. It encourages autonomy and allows individuals to make informed choices based on shared experiences and insights. It is a powerful tool in promoting mental health, personal growth, and resilience. The shared understanding, empathy, and practical assistance that peers provide create a foundation for individuals to navigate challenges and build a fulfilling life.

See the Big Picture of the ACPA
ACPA Facilitators strive to See the Forest Through the Trees. We use this phrase to describe the challenges of pain management that we the people with pain and the clinicians that treat pain face everyday... yearning to navigate our way to a better future. For ACPA facilitators, there comes a time where the big picture becomes clear, and we work to help our communities strive in spite of pain. If every tree in the forest represents one pressing issue in pain management, it becomes overwhelming and seemingly impossible to find solutions. However, when we work together, we can divide and conquer the forest as a whole. Knowing that you are not alone in this battle is the mission of ACPA peer support groups.

ACPA facilitators are self-starting leaders that help conduct peer support groups for others in pain. Facilitators are people so close to the pain situation, that they can see the big picture objectively and can help others discuss healthy coping strategies.

If you are ready to step back and look at the situation as a whole, and lead others to find ways to live more fully while dealing with pain conditions, then by all means join the ACPA mission... the ACPA welcomes your leadership.

Follow these 6 steps to become a facilitator:
1. Review and follow the ACPA Facilitator Guidelines [Click Here]
2. Learn and practice the Ten Steps from Patient to Person [Click Here]
3. Review and follow the ACPA Fundraising Policy [Click Here]
4. Review and follow the ACPA Nondiscrimination/Anti-Harassment Policy [Click Here]
5. Review and follow the Drug and Procedure Discussion Policy [Click Here]
6. Take the ACPA Prospective Facilitator Screening [Click Here]
The One of Many Documentary

Brittany Wagner
Director | ONE OF MANY

Mike

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

One of Many (acpanow.com)
JOIN US!
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://redcapedc.rti.org/ccs/surveys/?s=NEMDXDL79MTYW3A
If you have any questions, please contact the study team at 877-212-7218 or FDADigitalHealthTechnologies@rti.org.
The Importance of Caregivers
By Scott Farmer, MBA

Caregivers play a crucial role in supporting individuals who may be dealing with health challenges and pain conditions. Whether caring for someone with chronic pain, recovering from surgery, or managing a condition like diabetic neuropathy, there are several important things caregivers can do to provide effective and compassionate care:

**Educate Yourself:** Learn as much as you can about the person's condition, treatment plan, and any medications they may be taking. This knowledge will help you better understand their needs and communicate effectively with healthcare professionals.

**Communicate Openly:** Foster open and honest communication with the person you are caring for. Encourage them to express their feelings, concerns, and preferences. Listen actively and be supportive.

**Create a Supportive Environment:** Make the living space safe, comfortable, and conducive to the person's well-being. Ensure that any necessary medical equipment is readily accessible.

**Assist with Daily Activities:** Help with daily tasks that may be challenging for the individual, such as bathing, dressing, and grooming. Be attentive to their needs and provide assistance as required.

**Administer Medications:** If applicable, ensure that medications are taken as prescribed. Keep track of medication schedules and any potential side effects. Communicate with healthcare professionals if there are concerns.

**Encourage Independence:** Support the person's independence as much as possible. Encourage them to participate in activities they enjoy and can safely manage.

**Coordinate Healthcare:** Assist in scheduling and attending medical appointments. Keep track of important health information, such as test results and upcoming treatments.

**Provide Emotional Support:** Offer a listening ear and emotional support. Managing a health condition can be challenging, and having someone to talk to can make a significant difference.

**Promote Healthy Lifestyle Choices:** Encourage a balanced diet, regular exercise, and other healthy habits that align with the person's medical needs.

**Take Care of Yourself:** Caregiving can be demanding, so it's essential to prioritize your own well-being. Ensure you get enough rest, seek support when needed, and consider taking breaks to recharge.

**Coordinate and Communicate with Others:** If there are multiple caregivers or family members involved, coordinate responsibilities and share information often to ensure continuity of care.

Remember that each caregiving situation is unique, and the specific needs of the individual you are caring for may vary. Regular communication with healthcare professionals and a supportive network can help caregivers navigate challenges and provide the best possible care. Additionally, seeking support from caregiver resources and support groups can be beneficial.

Download a Caregiver Brochure
For anyone in our community interested in participating in research, a new clinical trial for Dermatomyositis is enrolling across the US. The investigational treatment is an oral pill, and researchers are inviting patients between ages 18-75 who are currently on stable treatment to explore their eligibility:

https://lpcu.re/VALORStudy

Participant Qualifications:
• Age 18 to 75 years old
• No history of cancer in the past 5 years
• No current severe liver disease
• No thrombotic events in the past year
• On a stable dermatomyositis treatment for the last 3 months

It’s not always easy to know where to start with exploring clinical trial options, and the study team aims to make the process as comfortable as possible by guiding you each step of the way. If you think you might be interested, fill out a short questionnaire here:

https://lpcu.re/VALORStudy

You’ll be connected with someone on the team to determine whether it might be a good fit for you.

Note: Any personal information you fill out is secure and confidential.

NEW! cMigraine

cMigraine is a coloring book that enables a parent to explain and learn about Migraine, along with a child! As you color, you will learn important migraine management techniques.

www.theacpa.org

Profits go to the ACPA!

Order Here: www.acpanow.com/cb

With biosimilars increasingly in the news, many patients have been wondering what these medications are, how they might vary from medications they’re already on, and if they are effective at treating rheumatic disease. The ACR’s whiteboard video, infographic, and fact sheet, linked here, are meant to help patients answer these questions and guide discussion with their healthcare providers.

- Click here to watch our whiteboard video to learn more.
- For a quick overview of biosimilars, check out our five fast facts on biosimilars infographic here.
- And if you want to take a deep dive into all things biosimilars, read our fact sheet here.

Thanks for taking the time to check out these new educational tools.
**Osteoarthritis Research Program**

This Research Program aims to solve treatment challenges in osteoarthritis by developing new ways to help the human body regenerate its own joints.

The program, called Novel Innovations for Tissue Regeneration in Osteoarthritis (NITRO), is the first of several programs.

OA is a common and often very painful condition where bones and cartilage break down. The condition currently affects more than 32 million Americans, with numbers predicted to rise as the population ages. There is currently no therapy available to reverse the damage caused by the disease. To get a better solution to everyone with OA, NITRO will explore technologies focused in three areas - injectable bone regeneration, injectable cartilage regeneration, and replacement joints built from human cells.

Through a Broad Agency Announcement (BAA), ARPA-H’s NITRO program will solicit proposals to develop and leverage innovative forms of regenerative medicine to create minimally invasive therapeutics that fully regenerate damaged joints. For more on NITRO, visit the ARPA-H website at [https://arpa-h.gov/engage/programs/nitro/](https://arpa-h.gov/engage/programs/nitro/)

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**The Great Now What** is a feature length documentary film executive produced and co-written by ACPA member Maggie Whittum. The film is about resilience in the aftermath of a major health crisis. The documentary follows Maggie’s life after surviving a massive brainstem stroke at age 33, and learning to live with intense nerve pain. It also features several other women with disabilities and chronic illnesses who are performing artists and visual artists. The film explores how art is an invaluable part of the healing process.
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

If preferred, send donations by mail
Mailing Address
American Chronic Pain Association
11937 W. 119th Street, Suite 216,
Overland Park, KS 66213

HOW TO SUPPORT THE ACPA

• Recognize someone to be featured in the Chronicle Click Here
• Make a One-Time Donation Click Here
• Schedule a Monthly Donation! Click Here
• Advertise in the Chronicle. Email us for pricing: acpa@theacpa.org
• 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.
THE ACPA MISSION
By Scott Farmer, MBA

The American Chronic Pain Association (ACPA) is a non-profit, 501(c) (3) organization. Our Mission is to 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.

Have a Wonderful Spring
-ACPA Team-

Thank You for Reading!

VISIT OUR WEBSITE!
www.theACPA.org