

Chronic Pain: The Neglected Malady

**For Grace Change Agent Pain Summit: Part Two
November 2, 2018**

Full Report



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“Doctors look at me as if I’m crazy because my blood work always comes back normal. My symptoms don’t make sense to doctors, but they are very real.” This is the voice of just one of the estimated 50 to 100 million U.S. adults (not including special populations such as children, nursing home residents, military personnel, etc.) who suffer from chronic pain. These people’s voices have for too long been ignored or even silenced by poorly informed clinicians, legislators, and insurance providers, and by a systemic lack of understanding of the gravity of this public health epidemic.

For Grace Calls for Change

In 2017, For Grace, a California-based nonprofit, began an urgently needed, multi-year process to improve pain care in California. This report, a product of the second For Grace pain summit in 2018, focuses a bright light on the barriers to adequate care confronted by people with chronic pain and gives an overview of recent federal efforts to address this growing crisis. It also outlines recommendations submitted to the California legislature by the For Grace Policy Committee on how California can implement a forward-thinking statewide strategy modeled on the groundbreaking National Pain Strategy (NPS).

For Grace is a nonprofit organization founded in 2002 with the goals of increasing public awareness of chronic pain through the media and public education and enlightening public policy makers about chronic pain as a major public health issue. In September 2017, inspired by the 2011 report by the Institute of Medicine (IOM), *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*,¹ and the 2016 *National Pain Strategy: A Comprehensive Population Health-Level Strategy for Pain (NPS)*,² For Grace hosted “Change Agent Pain Summit: Part One.” The goal of this one-day event was to hear directly from chronic pain sufferers and their caregivers about the barriers they face to getting optimal care and to explore ways to accelerate solutions for better pain control. Attendees also learned about the NPS and the benefits of integrative pain care, where patients and clinicians are partners in the healing process, as a best practice model for pain management. The overwhelming feedback from patients was that they had difficulty accessing appropriate pain care and that health insurance insufficiently covered comprehensive integrative pain therapies.

On November 2, 2018, For Grace’s “Change Agent Pain Summit: Part Two” convened leaders in health care and public policy to share ideas and make specific recommendations on how best to implement the major goals of the NPS in California, and thereby instigate a

statewide, and hopefully a nationwide, movement toward more enlightened health care for people in chronic pain.

Chronic Pain: A Disease in Itself

Acute pain is a normal, evolutionarily valuable sensation that alerts us to possible injury. Chronic pain, on the other hand, may persist for months or years, long after it has served its purpose of warning of possible physical danger. It may arise from an initial injury or have no discernable cause. Persistent headaches, pelvic pain, arthritis, fibromyalgia, complex regional pain syndrome, chronic low back pain, and peripheral neuropathy are among the numerous types of chronic pain that can restrict a person's movements, strength, and flexibility. Decades of scientific evidence demonstrate that chronic pain is a complex multisystem disorder, affecting the neurologic, immunologic, and endocrine systems. It is common for people to suffer from multiple pain conditions simultaneously, along with a number of other chronic non-pain conditions, such as sleep and mood disorders, fatigue, and cognitive impairment. High-impact chronic pain is pain that has persisted for three months or longer and has restricted at least one major activity, such as being able to work outside the home, go to school, or do household chores. The inability to participate in important and enjoyable activities can lead to depression and despair, compounding the deleterious effects of chronic pain on sufferers and caregivers alike.

It is estimated that in the U.S., 50 to 100 million people suffer from some form of chronic pain, one of the most prevalent, costly, and disabling health conditions in the country—and its prevalence may be rising. A 2018 analysis used data from the Medical Expenditure Panel Survey to evaluate trends over 18 years in overall rates of pain not associated with cancer. In that time period, the number of American adults who reported at least one painful health condition increased from 120 million to 178 million.³ In the U.S., pain conditions comprise 4 of the top 10 causes of long-term disability, including low back pain, the leading cause of such disability.⁴

Latest figures from the U.S. Census Bureau⁵ indicate that the population of California comprises about 12% of the U.S. population. Thus, a fair estimate of the number of Californians experiencing chronic pain would be 6 to 12 million. How such a huge subpopulation could go virtually unnoticed and tragically undertreated for so long, and how to sensibly rectify this situation without causing further harm to society, is the subject of this report.

Prevention Is Primary

Chronic pain usually cannot be cured, but with better data, better public education, appropriate training of health care providers, and adequate access to an integrative strategy, it can be managed. The focus of any treatment, of course, must be to reduce pain, improve function, and restore wellness. But in the case of chronic pain, prevention must be a priority.

Millions of chronic pain sufferers represent billions of dollars in lost productivity and increased health care costs for interventions that often are of no long-term benefit. Health economists from The Johns Hopkins University reported that in the U.S. in 2012 the annual cost of health care and lost productivity due to chronic pain was \$560 to \$635 billion, more than the annual costs for cancer, heart disease, and diabetes.⁶ One solution to this economic drain on society lies in preventing chronic pain in the first place, as well as preventing those with chronic pain from becoming more disabled and developing multiple pain conditions and comorbidities, including psychological disorders. A comprehensive strategy for preventing chronic pain must include better research and education and deploying an integrative approach to patient care.

Proper Pain Management Reduces Opioid Use

Chronic pain is one of the most poorly understood public health challenges. Millions suffer off the radar of clinicians, researchers, and policy makers, and the recent intense focus from the media, politicians, and the medical community on the opioid crisis has driven chronic pain even deeper into the shadows. According to the Centers for Disease Control and Prevention, since 1999 deaths involving prescription opioids (OxyContin®, Vicodin®, etc.) and nonprescription opioids (heroin, fentanyl, etc.) have increased four-fold.⁷ The National Institute on Drug Abuse reported that in 2017, 2,199 people in California died from opioid overdose. This rate (5.3 deaths/100,000 persons) was significantly lower than the national rate during the same period,⁸ but nevertheless represents a crisis that must be addressed rationally.

This crisis of increasing deaths due to opioid overdose emerged in part due to widespread deficiencies in the management of chronic pain, which were driven by failures of policy and practice and further fueled by inadequate support for research addressing chronic pain. Indeed, there is growing awareness that an inadequate and misguided response to chronic pain by health care and insurance providers may have contributed to the current unprecedented rise in the use of opioids. Moreover, some of the over-dependence on opioids may stem from sufferers' attempts to self-medicate chronic pain in parts of the nation where effective, integrative treatments are unavailable or unaffordable. When adequate pain relief resulting from clinician-prescribed opioid drugs is withheld from those who need it most, while offering no alternative treatments, desperate people may turn to illegal sources of pain relief. As Dr. Wayne Jonas, Executive Director of Samueli Integrative Health Programs, points out, we urgently need a new perspective on the issue of opioid use—one that does not unnecessarily deprive chronic pain sufferers of a vital element of their treatment arsenal. "What we have," Dr. Jonas stresses, "is not an opioid crisis but a chronic pain mismanagement crisis." An important factor in this current situation is the historical lack of federal funding for pain research, which has resulted in inadequate evidence for the efficacy of non-opioid treatments and has slowed development of new therapies. Also, insurance coverage is inadequate for the full range of potentially effective pain therapies (i.e., complementary therapies).⁹ Simply stated,

for most chronic pain conditions, we don't know what works for whom and at what cost or risk. The result is that individuals spend months to years undergoing a trial-and-error process to find a combination of treatments that is safe and effective, without producing intolerable side effects.

In addition to better research, providing high-quality pain care for every person with chronic pain will also require addressing deficits in medical education, health care delivery systems, and payer policies. For instance:

- A 2018 systematic review of medical school curricula¹⁰ found that 96% of U.S. medical schools had no compulsory courses in pain medicine. In fact, on average, in the entire curriculum only 11 hours were dedicated to pain and related issues. This is not adequate coverage, given the prevalence and public health impact of inadequately managed pain.
- The current health care system in the U.S. and the system of insurance reimbursements undercut clinicians' motivation to spend adequate time with patients whose problems are not simple and straightforward. Nor do most insurance providers cover integrative therapies such as acupuncture, massage, biofeedback, and psychotherapy, which are often the best approaches to managing chronic pain.⁹
- Finally, laws and enforcement practices concerning the use of opioids can have a chilling effect on physicians' willingness to undertake the long-term treatment of patients with chronic pain. Many states have codified the CDC's non-mandatory guideline on prescription opioids,¹¹ and many physicians and insurers have misinterpreted the guideline to the detriment of patient care.¹² Limitations on clinicians' ability to prescribe adequate doses for their patients, along with state medical board disciplinary actions and DEA enforcement practices, have created a climate of fear in the medical community. Many clinicians are refusing to take on chronic pain patients or have taken patients off of prescription opioids. As a consequence, patients harmed by this one-size-fits-all approach are increasingly turning to street drugs or suicide.^{13,14}

The Institute of Medicine: *Relieving Pain in America*

The 2010 Patient Protection and Affordable Care Act mandated that the Department of Health and Human Services (HHS) enlist the Institute of Medicine (IOM) to examine pain as a public health problem. The IOM (now known as the National Academy of Medicine) is an independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision makers and the public. In 2011, in recognition that the millions of Americans suffering from underdiagnosed and undertreated pain constitute a public health problem of immense proportions, the IOM released a report called *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. The report called for a coordinated national effort of public and private organizations to transform how the

nation understands and approaches pain management and prevention. Among the underlying principles of the IOM report are that:

- Pain management is a moral imperative.
- Chronic pain can be a disease in itself.
- Comprehensive treatment must be the ultimate goal.
- Interdisciplinary approaches provide the best way to meet that goal.
- Prevention must be the first step in pain management.
- We must make better use of, and more effectively disseminate, existing knowledge about chronic pain.
- We must confront issues surrounding the use and misuse of opioids.
- Patients and clinicians must work collaboratively.
- A public health issue of this magnitude requires a community-based approach.

National Pain Strategy

After the 2011 release of the IOM's report, HHS tasked an interagency group, spearheaded by the National Institutes of Health, with developing a National Pain Strategy (NPS) that recognizes access to safe and effective care for people suffering from chronic pain as a public health priority. The completed strategy, published in March 2016, makes recommendations for improving overall pain care in America in six key areas:

1. Population research.
2. Prevention and care.
3. Disparities in prevalence and treatment of chronic pain.
4. Service delivery and payment practices.
5. Professional education and training.
6. Public education and communication.

As the precursor to the NPS, the IOM report provided a clear blueprint for action to address chronic pain nationwide. The NPS, on the other hand, is a strategic, tactical document with very specific goals and deliverables. Developed by 80 nominated volunteers with expertise from the medical, scientific, public, private, insurance, and patient advocacy communities, as well as representatives from six federal health agencies, the NPS provides first steps in a long-term strategy to transform how our nation perceives, assesses, and treats pain.

In announcing the release of the NPS,¹⁵ HHS outlined the strategy's more specific goals:

- "Developing methods and metrics to monitor and improve the prevention and management of pain.
- Supporting the development of a system of patient-centered, integrated pain management practices based on a biopsychosocial model of care that enables providers and patients to access the full spectrum of pain treatment options.

- Taking steps to reduce barriers to pain care and improve the quality of pain care for vulnerable, stigmatized, and underserved populations.
- Increasing public awareness of pain, increasing patient knowledge of treatment options and risks, and helping to develop a better-informed health care workforce with regard to pain management.”

Implementing a Statewide Pain Strategy Begins with Better Research

Panelists at For Grace’s “Change Agent Pain Summit: Part Two” emphasized that addressing chronic pain in America will first of all require new and better research. In the last few decades, we’ve made significant advances in our understanding of the basic mechanisms of pain, but there is still much to learn, especially about chronic pain disorders. Gaps in our knowledge prevent advances from being translated into safe and effective therapies. However, addressing these gaps will require more than further studies. It will require a cultural shift in the way pain research is conducted. The IOM and NPS have recommended that:

- Academia and industry improve the way new pain-control agents are developed.
- With support from the National Institutes of Health, academic institutions should encourage research on fundamental causes and methods to treat, cure, manage, and prevent chronic pain.
- Federal and private funders of pain research should increase support for interdisciplinary and longitudinal research in pain.

Better research will produce better data that can be passed on to clinicians, who can use it to address disparities in the prevalence of chronic pain in the national population. For instance, the National Health Interview Survey (2016–2017) found that chronic pain and high-impact chronic pain are more prevalent among women, older adults, the poor and unemployed, people relying on public health insurance, rural residents, and those whose education did not go beyond high school.¹⁶

The NPS recommends that the best way to make progress toward improving prevention and management of chronic pain in America is to use this kind of population research to estimate the prevalence of chronic pain overall and of defined pain conditions, the various population groups chronic pain affects, and to track changes in these areas over time. To do this effectively, we will need to employ standardized methods of obtaining and sharing electronic health care data to determine the best use of treatments and the cost of care.¹⁶

Effective care for patients with chronic pain requires a team approach, where the patient is an essential member of the team. This applies, as well, to gaining better data and research. To answer the questions, “How do we know if we’re really helping people get better?” and “What does ‘better’ mean?” clinicians must translate every patient encounter and every clinic visit into meaningful data. We must turn clinics into research labs that collect data to help people suffering from chronic pain. Ideally, these data could then be entered into an

electronic database accessible to everyone, including pain patients. These are necessary steps to achieving personalized pain care.

Personalized Pain Management: An Integrative Approach

Primary care is where pain management usually begins. We have a strong consensus as to which models work, but we don't know how to make them work in our current system of health care delivery due to the fact that insurance typically only covers traditional therapies. According to Dr. Jonas, in medical schools, pain education stops at diagnosis and pharmacology, when we know that what works for chronic pain patients is a coordinated, interdisciplinary approach to integrative health care that tailors treatment to each individual. To summarize the NPS, we need a strategy that is holistic, evidence-based, and integrated, with patient-centered teams that actually work together to relieve pain and suffering.

Promoting Comprehensive Integrative Health

The question before us is not who should pay for health care, but what kind of health care we should be paying for. Our current system of health care delivery and reimbursement for services is broken. To truly reduce costs and improve outcomes we need a system that doesn't merely treat symptoms with drugs and procedures, but that promotes—and reimburses the costs of—treatments and lifestyle changes that lead to overall health and well-being.

Comprehensive integrative medicine takes into account a patient's unique conditions and circumstances and uses the most appropriate interventions from an array of disciplines to heal illness and help people maintain optimum health. It is grounded in a definition of health that is not merely the absence of disease, but a state of complete physical, mental, and social well-being. It personalizes care by going beyond merely treating symptoms to addressing all the causes of a patient's illness or pain. The patient and clinician are partners in this process, working together to deduce the underlying causes of painful conditions, find approaches to healing that fit the patient's social and economic circumstances, and move the patient toward personally meaningful goals. Beyond this, comprehensive integrative medicine focuses on prevention and fosters healthy behaviors and skills for effective self-care throughout the patient's life.

Comprehensive integrative medicine sits at the intersection of conventional medicine, complementary therapies, and self-care. In fact, only 15% to 20% of health is the product of medical treatment.¹⁷ Importantly, this integrative approach addresses behavioral and lifestyle factors and social, economic, and environmental factors. Many patients with chronic pain are deducing this for themselves, spending thousands of unreimbursed dollars on natural foods and supplements, yoga, chiropractic, acupuncture, psychotherapy, and mind/body modalities. For some, a combination of these approaches gives significant relief from some chronic pain

conditions. A true cultural shift in pain management would restructure our reimbursement system to reward and promote these efforts at self-care and prevention. It would also incentivize clinicians to spend more than the usual 15 to 20 minutes per office visit with patients suffering from chronic pain. The potential savings in medical reimbursement costs could be significant.

In sum, an individualized, integrative approach is essential to treating chronic pain effectively. A patient-centered, biopsychosocial, team-based approach to identifying and addressing all the conditions that patients suffer from, as well as other factors contributing to the perpetuation of their pain, is the best model for effective management. Health care providers and patients must work as a team to develop and implement individualized, multimodal, goal-based care plans.

To help implement these changes in California's health care system, the For Grace Policy Committee has drafted a recommendation for consideration by the California state legislature and the California Health and Human Services Agency. Implementation of this recommendation would make California a national leader in efforts to transform the health care system and improve the lives of chronic pain sufferers.

For Grace Policy Committee Recommendation

We urge the California legislature to direct the Secretary of the California Health and Human Services Agency to establish a Center for the Improvement of Chronic Pain Research, Management, and Prevention within the Agency. The Center shall be tasked to:

- 1) Establish a network of Comprehensive Integrative Pain Treatment and Research Centers of Excellence across the state. These Centers shall reside at academic medical centers that can demonstrate sufficient resources, expertise, and institutional support to implement ongoing research into the causes of chronic pain and diverse treatment and management modalities, and to provide comprehensive chronic pain treatment and management services for California residents. Comprehensive integrative chronic pain treatment and management services shall include biomedical, psychosocial, and complementary (i.e., non-pharmacologic) therapies. A model for such a Center is the Stanford Pain Management Center. See <https://stanfordhealthcare.org/health-care-professionals/medical-staff/medstaff-update/2013-april/201304-changing-how-pain-is-assessed.html>
- 2) Improve and expand education and training about the diagnosis, treatment, management, and prevention of pain for all clinicians who have patients with acute and chronic pain. Such improvements shall include minimum hours of training, with a focus on awareness of acute and chronic pain; skillful clinical appraisal; understanding of the causes of chronic pain; awareness of different treatment modalities; and promotion of compassionate practices. See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6069634/>
- 3) Work with state agencies responsible for state employee health insurance, Medi-Cal, and Workers Compensation coverage to revise coverage and reimbursement policies for chronic pain to include non-pharmacologic therapies, where evidence of effectiveness exists, and to urge commercial payers to make the same or similar changes in their policies. See <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2705853>
- 4) Develop and implement a statewide public health campaign to educate (i) all California residents about the causes of chronic pain and ways to prevent it; and (ii) chronic pain patients about the risks and benefits of various treatment/management options, including self-care, and about available resources for finding appropriate treatment. See <http://www.ahdbonline.com/articles/2028-advocacy-collaboration-and-education-solutions-to-public-health-issues-in-chronic-pain>

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Presenters and Panelists

Roger B. Fillingim, Ph.D.

- Distinguished Professor, University of Florida College of Dentistry
- Director, University of Florida Pain Research and Intervention Center of Excellence (PRICE)
- Past President, American Pain Society

Dr. Fillingim's research program endeavors to identify the mechanisms and clinical implications of individual differences in pain and analgesic responses, particularly the influences of sex/gender, race/ethnic group, age, and genetic factors. He is also investigating pain sensitivity, psychosocial variables, and genetics as potential risk factors for development of chronic pain conditions.

At the For Grace Change Agent Pain Summit: Part Two, Dr. Fillingim was a panel member, addressing issues of disparity in the health care system.

Diane E. Hoffmann, J.D., M.S.

- Director, Law and Health Care Program, University of Maryland Francis King Carey School of Law
- Jacob A. France Professor of Health Care Law, University of Maryland Francis King Carey School of Law

Ms. Hoffmann has taught courses on Law and Medicine, Health Care Law, Legal Problems of the Elderly, Critical Issues in Health Care, Research with Human Subjects, and Health Care for the Poor. Her research interests include issues at the intersection of law, health care, ethics, and public policy. She has authored numerous articles on legal obstacles to the treatment of chronic pain.

At the For Grace Change Agent Pain Summit: Part Two, Ms. Hoffmann was a panel member, addressing issues in health law and policies as they relate to chronic pain.

Wayne Jonas, M.D.

- Executive Director, Samueli Integrative Health Programs
- Clinical Professor of Family Medicine, Georgetown University
- Former Director, Office of Alternative Medicine, National Institutes of Health

Dr. Jonas is a practicing family physician, an expert in integrative health and health care delivery, and a widely published scientific investigator. He is currently Executive Director of Samueli Integrative Health Programs, an effort supported by Henry and Susan Samueli to empower patients and clinicians by providing solutions that enhance health, prevent disease, and relieve chronic pain.

At the For Grace Change Agent Pain Summit: Part Two, Dr. Jonas was a panel member, addressing the health care system and reimbursement. He was also the Lunch Speaker on the topic of "How Healing Works."

Sean Mackey, M.D., Ph.D.

- Chief, Division of Pain Medicine, Stanford University
- Director, Systems Neuroscience and Pain Laboratory, Stanford University
- Redlich Professor of Anesthesiology, Perioperative and Pain Medicine, Neurosciences and Neurology, Stanford University
- Co-Chair, National Pain Strategy

Under Dr. Mackey's leadership, researchers at Stanford have made major advances in the understanding of chronic pain as a disease in its own right, one that fundamentally alters the nervous system. His efforts have led to the development of a multidisciplinary treatment model that translates basic research into innovative therapies and personalized treatments for patients with chronic pain.

At the For Grace Change Agent Pain Summit: Part Two, Dr. Mackey was the Keynote Speaker on the topic of the National Pain Strategy and, as a panel member, addressed prevention and treatment of chronic pain.

Steven Richeimer, M.D.

- Chief, Division of Pain Medicine, Keck School of Medicine, University of Southern California
- Professor of Clinical Anesthesiology and Psychiatry & Behavioral Sciences, Keck School of Medicine, University of Southern California
- Director, Online Master's Degree in Pain Medicine, Keck School of Medicine, University of Southern California
- Director, Norris Comprehensive Cancer Center Pain Management, University of Southern California

Dr. Richeimer is the former Director of Pain Management at the University of California Davis Medical Center, where he established a national reputation for his comprehensive, multidisciplinary approach. He is dedicated to using the full scope of medical science to provide personalized, effective care for patients with chronic pain. He is board certified in anesthesiology, psychiatry, and pain medicine.

At the For Grace Change Agent Pain Summit: Part Two, Dr. Richeimer was a panel member, addressing deficiencies in education on pain treatment in medical schools.

Christin Veasley

- Cofounder and Director, Chronic Pain Research Alliance
- Oversight Panel Member, National Pain Strategy

Ms. Veasley's experience of living with life-altering chronic pain led her to obtain a science degree, conduct neuroscience research at The Johns Hopkins University School of Medicine, and advocate for pain research. The Chronic Pain Research Alliance is the country's only collaborative advocacy program focused on advancing a strategic research, translational, and industry effort toward improving and accelerating multidisciplinary pain research.

At the For Grace Change Agent Pain Summit: Part Two, Ms. Veasley was a Co-Keynote Speaker with Dr. Mackey, presenting an update on the National Pain Strategy with a focus on the prevention of chronic pain.

Executive Support

John Garrett

Director, For Grace

Cynthia Toussaint

Founder & Spokesperson, For Grace

Mindy Meyer

Lead Mediator, Center for Collaborative Policy, California State University, Sacramento