

**A Call to Revolutionize
Chronic Pain Care in America:
An Opportunity in Health Care
Reform**

November 4, 2009

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The Mayday Fund, a family foundation dedicated to reducing human suffering caused by pain, convened a special committee to explore issues related to pain and the practice of medicine. The panel of adult and pediatric pain experts, which included anesthesiologists, neurologists, primary care doctors, emergency physicians, nurses, pharmacists, psychologists, and patient advocates, deliberated at a one-day meeting held in Washington, D.C in June, 2009. This report is the outcome of that meeting.

• • • The Background

Chronic pain—commonly defined as pain persisting longer than six months—affects an estimated 70 million Americansⁱ and is a tragically overlooked public health problem. The burden of chronic pain is greater than that of diabetes, heart disease and cancer combined.^{ii, iii} Ongoing pain can also undermine overall physical, psychological, and social well-being, and is a major cause of disability and costly health care utilization.

Poorly assessed, unrelieved chronic pain can rob individuals and family members of a high-quality life, and it profoundly burdens society as a whole. A 1998 National Institutes of Health (NIH) report concluded that just the economic toll of chronic pain may be estimated at \$100 billion a year in the United States.^{iv} It has increased significantly since then.

Most people in pain, including those with chronic symptoms, go to primary care providers to get relief. But current systems of care do not adequately train or support internists, family physicians and pediatricians, the other health care providers who provide primary care in meeting the challenge of treating pain as a chronic illness. Primary care providers often receive little training in the assessment and treatment of complex chronic pain conditions.^v They tend to work under conditions that permit little time with each patient and few options for specialist referrals. It is an unusual patient who has access to coordinated interdisciplinary therapy for ongoing pain symptoms.

Instead of receiving effective relief, patients with persistent pain often find themselves in an endless cycle, seeing multiple health care providers, including many specialists in areas other than pain, who are not prepared to respond effectively. They often endure repeated tests and inadequate or unproven treatments. This may include unnecessary surgeries, injections or procedures that have no long-term impact on comfort and function. Patients with chronic pain have more hospital admissions, longer hospital stays, and unnecessary trips to the emergency department. Such inefficient and even wasteful treatment for pain is contributing to the rapid rise in health care costs in the United States.^{vi}

Adults aren't the only ones who suffer. An estimated 20 percent of children experience chronic pain and millions do not receive effective pain relief. Children in pain often bounce from doctor to doctor. If they do not get the appropriate treatment they are at risk of developing a pain condition that might remain into adulthood.^{vii}

PERSISTENT PAIN: A CHRONIC ILLNESS

Acute pain usually goes away after an injury or illness resolves. But when pain persists for months or even years, long after whatever started the pain has gone or because the injury continues, it becomes a chronic condition and illness in its own right. This chronic illness of pain, if inadequately treated, can impede the lives of individuals and families and produce a huge burden in health care over-utilization, lost work productivity and rising costs of pain-related disability. Prompt effective treatment of acute pain is critical. If pain becomes persistent, it must be effectively managed as a chronic illness not only to limit long-term human suffering but also to prevent lost productivity within our society.

MILLIONS OF CHILDREN SUFFER FROM CHRONIC PAIN

Chronic pain is a significant problem for children as well as for adults. In fact, studies suggest that chronic pain may affect 20 percent of all children. Common causes of ongoing pain in children include headaches, stomach pain, musculoskeletal pain, arthritis, sickle cell crisis, and cancer. Some barriers to effective pain relief in the pediatric population include the fact that children may not communicate pain in the same way that adults do and thus pain symptoms might be ignored. In some cases, health professionals do not have enough training to prescribe medications or techniques to soothe a child in pain.

There is also research suggesting that untreated pain can put children at risk of developing chronic pain or anxiety later in life. For example, most children receive 24 immunizations before their second birthday, yet much of the time their pain is ignored or discounted. Such pain, although brief, can be very intense and can lead to long-lasting anxiety. Infants who undergo circumcision without an analgesic have been shown to demonstrate more pain during subsequent routine immunizations than children who were not circumcised. Some facts on pediatric pain:

- *Each year 1.5 million children undergo a surgical procedure and many do not receive adequate pain relief.**
- *Some 20 percent of children ages 5 to 17 suffer from ongoing headaches.**
- *Juvenile arthritis, a painful disease of the joints, affects nearly 250,000 children under the age of 16.**
- *By the year 2010, 1 in 1,000 children in the USA will be a cancer survivor and might be dealing with an ongoing pain problem.**

*Source: American Academy of Pediatrics and the *American Pain Foundation*

Ideally, all patients with pain should obtain an appropriate assessment followed by a plan of care that reflects best practices, to prevent the adverse effects of that pain—both in the short term and over time. Patients with chronic pain should receive a model of care that matches their need, is safe, appropriate, cost-effective, and guided by scientific evidence. They should also have access to a comprehensive approach, with a referral to pain specialists, when necessary.

Acute pain that is not adequately managed can become chronic pain,^{viii} leading to long-term disability, complications and costs. For example, about one-third of people in pain report that their pain is disabling and has a high impact on their ability to function in daily life.^{ix} Research suggests that the high cost of under-treated pain includes lost productivity. Pain is the second-leading cause of medically-related work absenteeism, resulting in more than 50 million lost workdays each year.^x

To address this public health problem, the Mayday Fund, a family foundation dedicated to reducing human suffering caused by pain, convened a special committee to explore issues related to pain and the practice of medicine. The panel of adult and pediatric pain experts, which included anesthesiologists, neurologists, primary care doctors, emergency physicians, nurses, pharmacists, psychologists, and patient advocates, deliberated at a one-day meeting held in Washington, D.C. in June, 2009. This report is the outcome of that meeting and subsequent deliberations over the course of several months.

• • • The Pain Committee's Findings

Chronic pain treatment needs major reforms to enhance assessment, increase access to the right care, improve quality and equitable care, and cut costs. Initiatives to address the huge public health problem of unrelieved chronic pain should be part of any discussion on reforming the health care system to enhance access and reduce costs.

The Secretary of the Department of Health and Human Services (HHS), Kathleen Sebelius, has said that the current health care system both under-treats and fails to prevent chronic conditions, a flaw that has contributed to spiraling medical costs. She said that better prevention and treatment of such conditions would save the nation money by preventing costly complications.^{xi}

Historically, the health care system has failed to recognize chronic pain as a legitimate condition. However, it is clear that persistent pain is a complex illness that has many causes and affects every part of life, and in the process, exacts enormous social costs. And unfortunately, like many other chronic illnesses, chronic pain is associated with disparities based upon race, ethnicity, age, gender, and class.

This 'pain as chronic illness' paradigm must inform the health care dialogue. Providers must recognize that acute pain needs prompt treatment as a measure to prevent the chronic illness.^{xii} And chronic pain, if it occurs, must be assessed and managed according to best practice, with the goal of providing comfort, improved functioning, equitable care, and a better quality of life—for all people with chronic pain.

Chronic pain must be addressed similarly to other chronic conditions. When the symptoms and their impact are not severe, the best practice should involve a primary care provider with the skills to evaluate the cause and the nature of the pain, and to implement a plan of care. But in severe cases, the best practice may involve a group of interdisciplinary professionals, whose care is coordinated in a way that addresses all facets of the illness and prevents complications. To manage chronic pain successfully, patients need a comprehensive assessment and, when appropriate, access to a pain specialist. Chronic pain patients might also need a team approach, one that includes physicians, nurses, mental health professionals, physical and occupational therapists, pharmacists, and other health care providers.

Individuals with chronic pain often need a combination of multiple daily medications, and sometimes opioids (strong pain medications), psychological, behavioral and social interventions, rehabilitation therapy, and complementary treatments.^{xiii} Because of the level of pain, some patients should also be offered more interventions, such as injection therapies, nerve blocks, or trials of implanted therapies.

The Cost of Uncoordinated and Unequal Care

Most treatment of chronic pain can and should be centered in the primary care environment, and within a health care system that allows for time and resources to coordinate care. A well informed primary care provider, who is familiar with the causes of and contributing factors that influence pain, can provide helpful medicines and prescribe other appropriate treatments. He or she can also coordinate pain care and help the patient avoid duplicative and often costly evaluations and treatments. Primary provider pain care can also improve the lives of a majority of chronic pain sufferers and reduce the economic burden to society.

NO ACCESS, NO RELIEF

Don Dillard's pelvis was crushed on April 5, 1991 when a truck ran over him at a Detroit recycling plant where he worked at the time. With multiple fractures, the accident changed his life. He was flown to the nearest trauma center, spent 40 days in the hospital and was released in a wheelchair—and in agony.

He spent 10 years undergoing operations, including extensive orthopedic and plastic surgery, and grueling physical therapy that enabled him to walk again. But he was in pain and couldn't sleep. Doctors never prescribed anything more than non-steroidal anti-inflammatory medicines, even though these drugs provided little or no relief. Dillard, who had always been an extremely active person, could no longer work. He struggled with clinical depression and fought to get reimbursements from his insurance company for thousands of dollars in medical expenses.

"Everything about my life had been decimated," he says.

His family and his faith pulled him through that dark period. He finally received a referral to a pain medicine specialist, and a decade after his accident, Dillard got a prescription for a medicine strong enough to handle his severe pain.

It is impossible to know whether the inadequate care received by Dillard—who is African American—was influenced by race. However, extensive studies show that minorities are less likely than whites to receive adequate assessment and treatment for their pain, a disparity that puts minorities at risk for untreated pain, says Carmen R. Green, MD, at the University of Michigan in Ann Arbor where Dillard was treated.

Some physicians aren't trained to handle strong pain medications. And in some cases, physicians fear that patients will misuse the drugs and that fear can override all other judgments, Green says.

Even after Dillard was given an opportunity to try a strong opioid, and it worked, he faced another barrier, one that disproportionately affects minorities. He had trouble filling prescriptions because pharmacies in his area didn't stock medications that are often the target of break-ins. He traveled two hours by car in order to fill his prescriptions in a nearby city.

"I was in excruciating pain during those trips," he says about the ordeal.

But, the stronger medicine eases the pain, allows him to sleep at night, and makes it possible for him to do more around his home, like helping to care for his two-year old grandson and getting yard work done. "It might take me all day, but I can do it," he says.

He is just happy to have his life back.

The lack of effective pain treatment weighs on society in more ways. Disparities related to race, ethnicity, gender, age and class have affected access to competent pain care, including specialty pain care. This has added to the burdens for individuals and has increased costs to the healthcare system.^{xiv, xv} For example, multiple studies show that blacks are less likely to receive pain medication than whites to manage comparable disorders.^{xvi, xvii} Hispanics are also at risk of pain under-treatment,^{xviii} and women in pain are often treated less aggressively than are men.^{xix} The most vulnerable members of society, young children and the elderly, often receive far less treatment for pain than others.^{xx, xxi} Lower income individuals also may have decreased access and receive lesser quality pain care.^{xxii}

Efforts to improve the management of chronic pain and diminish disparities in pain care will improve quality of life, reduce disability and decrease health care costs for millions of Americans.^{xxiii} Some of these efforts are learned only through research.

NEAR DEATH EXPERIENCE

As far back as she can remember, Deana Luchs remembers the pain.

In elementary school her frequent stomach aches and muscle pain were dismissed as imaginary. “I was called a hypochondriac by the doctors and even by family members.”

It wasn’t until she was 33 that she got a diagnosis of fibromyalgia, a chronic pain disorder that affects some 10 million Americans.

Like others with fibromyalgia, Luchs suffers from migraine headaches, irritable bowel syndrome and widespread muscular pain. But the diagnosis was just a first step in a long journey, one characterized by numerous trips to doctors, fragmented care, surgeries that didn’t assuage her pain, wasteful medical treatment and finally an event that changed her life.

In June 2008, Luchs had an attack of stomach pain she attributed to irritable bowel syndrome. What she didn’t realize was this: She’d been taking pain medications and as a side effect had developed severe constipation. The pain got worse and finally Luchs had to be rushed to the hospital when her bowel ruptured and she developed a potentially lethal infection.

This episode was life changing for her and it was the first time she knew she needed coordinated life-long treatment. She also lost almost a year of work.

She started to see an internist who coordinates her care, which now includes pain medications, acupuncture, massage therapy and counseling.

At age 61, Luchs still practices as a speech pathologist and has no intention of retiring anytime soon. “I am now leading an active, productive life with a successful career,” she says, adding that pain still interrupts her day but it is manageable. “I have no intention of letting pain take over my life.”

A Problem without Adequate Research

Best practices in pain care remain largely determined by clinical experience. Research is needed to identify new therapies, improve the evidence base in support of established approaches, and provide clinical guidance through comparative effectiveness data.

Remarkably, less than one percent of the NIH budget was devoted to pain research in 2008.^{xxiv} In comparison, research on diabetes, another chronic disease, comprised almost 4% of the 2008 NIH budget.^{xxv} The share of the NIH budget that is invested in pain research has declined sharply, more than 9 percent between 2004 and 2007 (adjusted for inflation).^{xxvi} Given the scope of the problem, the decreasing investment in pain research is a short-sighted policy, and does not reflect the severity and scope of this public health crisis.

The Institute of Medicine's June 2009 report, *"Initial National Priorities for Comparative Effectiveness Research,"* suggests that several areas within pain treatment are ripe for comparative studies on effectiveness, such as treatments for back and neck pain and comparisons of powerful pain medications.^{xxvii}

The Economic Impact of Poor Pain Care

Underfunded pain research and lack of comparative effectiveness data, both of which can lead to the delayed development of new treatments, impede efforts to address the huge cost of persistent pain. Primary care systems that do not routinely support coordinated chronic pain care and have limited access to specialist care can make it difficult to deliver effective pain care.

Data from the 1998 "NIH Guide: New Directions in Pain Research" says that the annual economic impact of pain experienced by the U.S. workforce, in terms of pain management and pain-related productivity, was more than \$100 billion annually. A 2008 study found that care for lower back pain alone, not including other pain conditions and not just limited to workers, amounted to nearly \$86 billion per year.^{xxviii}

There are no current estimates of the total cost of poorly controlled pain in today's dollars. Viewed from the perspective of health care inflation (more than 40% during the past decade^{xxix}), the NIH statistics (\$100 billion annually in health care utilization and lost productivity for those in the workforce,^{xxx} and \$86 billion annually for just one diagnosis^{xxxi}) make it likely that the total U.S. spending on pain is at least comparable to the costs associated with other chronic illnesses. The annual costs associated with pain are probably at least as high as the estimated annual cost of \$174 billion that is attributed to diabetes.^{xxxii}

More needs to be known about the economic impact of chronic pain. But even in the absence of adequate data, it is clear that these enormous pain-related costs represent both a great challenge and an opportunity in terms of improving the quality and cost-effectiveness of care.

If efforts to strive for effective pain care continue to fail, the nation will pay a huge toll. An estimated 75 million baby boomers are in or nearing retirement age and will start—or already have developed—a range of chronic ailments associated with chronic pain. The aging population means that the contribution of pain-related costs to overall U.S. health care expenses are likely to rise sharply in the near future. As this occurs, the economic impact is certain, as are the physical, emotional, social and spiritual impact for millions of people.

TWENTY YEARS OF DEBILITATING PAIN

Gina Libby, age 40, has suffered from lower back pain for 20 years.

She traces the pain back to corrective surgery she had in 1990 for a condition called scoliosis, a curving of the spine. Surgeons fused the bones in her spine together and held them in place with metal rods.

At first, the pain was mild. But by the time Libby turned 30 the pain was severe. The doctors checked the fusion with an x-ray and then sent her home.

“The pain wasn’t really addressed,” she says.

During the 10-year period from age 30 to 40, Libby went from doctor to doctor but either received episodic treatment or no care at all. She never got a solid diagnosis. Some doctors attributed the pain to the fusion surgery and others chalked the pain up to arthritis, an inflammation of the joints.

Meanwhile, the pain got worse and it began to interfere with her performance at work as a food and drug investigator for California. By age 34, the pain was so constant and so severe that she had to resign. “I could no longer function,” she says now about the debilitating pain.

Then Libby got hit with anxiety and depression. “I had always been such a high achiever,” she says. The constant pain interfered with her ability to carry out a daily routine.

After decades of failed treatment, Libby connected with a doctor trained to deal with chronic pain who prescribed long-acting pain medications, acupuncture, talk therapy, steroid injections and a nerve block.

She’s nearly pain free now.

Looking back, Libby wishes that she’d gotten relief for her pain long ago, and thinks that such prompt treatment might have prevented some of the pain she still deals with on some days.

In fact, research suggests that when pain goes on for a long time, there is a greater risk that it will turn into a chronic syndrome, an illness that can be managed but can’t be cured. “My life isn’t perfect,” Libby says. “But now that I have the appropriate pain care I can do the things that I love to do.” And that makes a huge difference in her life.

• • • The Recommendations

The Mayday Fund Special Committee on Pain and the Practice of Medicine was co-chaired by Russell K. Portenoy, MD, chair of the Department of Pain Medicine and Palliative Care at Beth Israel Medical Center in New York City and Professor of Neurology and Anesthesiology at the Albert Einstein College of Medicine; and Lonnie Zeltzer, MD, Director of the Pediatric Pain Program at Mattel Children's Hospital, University of California, Los Angeles (UCLA), and Professor of Pediatrics, Anesthesiology, Psychiatry and Biobehavioral Sciences at the David Geffen School of Medicine at UCLA. After reviewing data and discussing the current status of pain management in the United States, the Special Committee recommends that:

Every American who suffers from chronic pain should have **24/7 access to a well-trained primary care provider** who can offer—and coordinate—pain care that is high-quality, equitable, and cost-effective.

Every American with chronic pain who needs sophisticated or high-tech treatment, or whose pain has not responded to best practices in the primary care setting, should have **access to evaluation and treatment by a pain medicine specialist**.

Every patient should expect to have pain managed in a manner that translates the best evidence into appropriate treatments, and then coordinates these treatments into a plan that is likely to be effective in controlling symptoms and promoting function, while minimizing the risks associated with treatment. At the same time, such a plan should reduce the costs associated with duplicative and ineffective treatments.

In order to improve access to appropriate, high-quality, and cost-effective pain care in the United States, the following action steps should be taken:

- 1 Government, health care payors, and health care providers should develop and utilize coordinated health information technology (IT) systems to track pain disorders, treatments, and outcomes as a mechanism to improve pain care. Quality indicators and performance measures should be developed and applied, and the public should gain access to information on the performance of hospitals, doctors and other health care providers.
- 2 State medical and osteopathic boards, deans of medical and other health professional schools, directors of residency training programs in specialties and subspecialties that provide primary care, professional societies and other stakeholders should make sure that every trainee and health practitioner in the health professions has the skills to assess and treat pain effectively, including chronic pain. Licensing examinations should include assessment of clinical knowledge related to appropriate pain care.

- 3 The Health Resources and Services Administration (HRSA) should expand funding for pain training programs that address competencies in pain assessment and management aimed at pediatric and adult primary care physicians, as well as other health professionals who manage pain, such as nurses, pharmacists, psychologists, physical therapists, social workers and other providers.
- 4 The Department of Health and Human Services (HHS) should establish an independent commission to reform the reimbursement practices for chronic pain. At present, Medicare and Medicaid maintain fee for service systems that incentivize procedures and inadequately compensate professionals for the time required to assess, counsel and educate, and coordinate the care of chronic illnesses like persistent pain. This commission should explore outcome-based payments for a team approach for selected cases, revision of the disparity between non-procedural and procedural pain treatments, and parity for mental health services. Ongoing complex chronic pain management should be treated, when possible, with an interdisciplinary, rehabilitation-oriented, team approach with reimbursement for the team, rather than fee-for-service for specific individuals within the team.
- 5 The National Institutes of Health (NIH) should increase funding for pain research to a level that is commensurate with the size of a public health problem that affects millions of people. The research should put an emphasis on emerging therapies and translational research, comparative effectiveness trials, bio-behavioral treatments, and health services research, as well as basic science. More research should focus on ways to prevent acute pain from developing into a chronic illness and to prevent childhood chronic pain from becoming a lifelong condition.
- 6 The Agency for Healthcare Research and Quality (AHRQ) should expand funding for studies aimed at finding a set of best practices that could be used to treat specific types of chronic pain. Providers and policymakers could use such information to develop and promote high quality pain management models.
- 7 The U.S. Surgeon General should make public education about pain, especially chronic pain, a high priority. Such a campaign could educate the public about the risks of untreated and undertreated pain in children and adults as well as promote preventive strategies that can enhance wellness and reduce the risk for the development of chronic pain.
- 8 Health care providers, insurers and government should work to eliminate disparities in access to pain care related to race, ethnicity, gender, age (e.g. children and the elderly), and socioeconomic status so that chronic pain for all individuals in need is recognized and treated without delay.
- 9 Federal, state and local agencies should publicly adopt a balanced approach to the regulation of controlled prescription drugs, particularly opioids. The clinical decisions of prescribers should not be inappropriately influenced by fear of regulatory scrutiny. Research has shown that state laws continue to harbor requirements that are outdated or reflect poor medical practice. A balance must be achieved between the legitimate need to protect public safety and public health through efforts to reduce drug abuse and diversion, and the imperative to

address the public health problem of unrelieved pain. Policies and actions intended to reduce abuse or diversion must also include a comprehensive public analysis of these actions on access to quality and equitable pain care, including access to medications required for legitimate pain management.

• • • Conclusion

Reducing the burden of uncontrolled chronic pain is a societal necessity, a medical challenge and an economic requirement. Chronic pain, if not recognized and treated as a chronic illness, takes an enormous personal toll on millions of patients and their families, and leads to increased health care costs. Chronic pain can also compromise the productivity of the U.S. workforce. Although the impact of pain on patients and on society is among the most serious of public health concerns, chronic pain has been largely left out of the current national debate on health reform. The nation must take the necessary steps to re-define chronic pain as a unique chronic illness and must immediately address this public health crisis.

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**For a full list of organizations and individuals who have endorsed this report,
please visit www.MaydayPainReport.org.**

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