

Advocacy Guide & Resources for Patients



When communicating with your Health Care Team, YOU are your best Advocate. Please educate yourself by using the resources provided in this Guide.

When your Doctor hears how well versed and up to date you are on the most current news, laws, and regulations he/she will most definitely be much more receptive to addressing your concerns about your individual needs in order to develop a specific treatment plan designed to adequately manage & address your Pain moving forward.

Please use the information provided to your advantage and share the pages or reports which are included herein to present to your physician or prescriber to review at their own leisure.

If you have any questions or need assistance please feel free to reach out to our advocacy team at team@painwarriorsunite.com or Call (202) 792-5600

What should you discuss with your Physician or Prescriber?

Agreements & Pain Management Contracts:

- [Pain Treatment with Opioid Medications: Patient Agreement](#)

Guidelines For Prescribing Opioids For Chronic Pain:

What Patients Should Ask:

- [Physicians Before Taking Opioids](#)
- [Advanced Practice Nurses, Dentists and/or Optometrists Before Taking Opioids Before Taking Opioids](#)
- [What Practitioners Should Discuss with Their Patients](#)

State Laws & Regulations For Prescribing Opioids



- [State Prescribing Laws Here](#)
- [Opioid Regulations by State Here](#)
- [State Database of Prescribing Rules and Statutes](#)
- [State Prescribing Profiles - USA Map](#)
- [State Pain Care Related Laws & Policies – Interactive Map](#)

[This map identifies and displays key features of more than 700 laws and other regulatory policies across all 50 states.](#)

Click [HERE](#) to find Your State's Prescribing Laws & Regulations.

This new **LEGAL MAP** covers important features of **state pain care-related laws and other regulatory policies**.

It includes **laws and policies** that address **prescribing of controlled substances** (Schedule II opioid analgesics), and Definitions creating parameters for health care practice.

- **[Morphine Equivalent Daily Dose \(MEDD/MME\) Policies by State](#)**

Previous research indicates that patients who receive **higher doses** of prescription opioids have an **increased risk of overdose** and mortality, leading several states to **establish** Morphine Equivalent Daily Dose (MEDD) or Morphine Milligram Equivalent (MME) **thresholds**.

MEDD or MME is a measurement that **converts opioid prescriptions to their equivalent dose in morphine** and divides the total prescription by the number of days the prescription is intended to last, allowing for **comparison among different opioid formulations and strengths**. MEDD/MME policies **set thresholds for prescribers**, which may **only be exceeded in limited circumstances**, such as when being prescribed to **certain patient groups** or as short-courses.

Click [HERE](#) to Check Your State Policy's MME Threshold

Click [HERE](#) to Calculate Your Current MME Conversion Rate

- **[Pain Related Regulations by State](#)**

- **[Abuse Deterrent Formulations](#)**
- **[Access / Reimbursement for Integrative Pain Care](#)**
- **[Awareness](#)**
- **[Clinician Pain Education](#)**
- **[Insurance / Pharmacy Benefit Management](#)**
 - **[Medication Synchronization](#)**
 - *[Non-Medical Switching / Continuity of Care](#)*
 - **[Prior Authorization](#)**
 - **[Specialty Tier](#)**
 - **[Step Therapy](#)**
 - **[Transparency](#)**
- **[Medical Marijuana](#)**
- **[Miscellaneous](#)**
- **[Naloxone Access](#)**
- **[Pain Clinic Regulation](#)**
- **[Pain Medication Prescribing and Dispensing](#)**
 - **[Biologics and Biosimilars](#)**
 - *[Forced Off-Label Prescribing](#)*
 - **[Partial Fills](#)**
- **[Pain-Related Commissions, Studies, Task Forces](#)**
- **[Prescription Monitoring Programs \(PMP\)](#)**

<http://www.painpolicy.wisc.edu/database-statutes-regulations-other-policies-pain-management>

INFORMATION & FACTS ABOUT OPIOIDS

[CDC - Center for Disease Control - Opioids](#)

[CDC OPIOID PRESCRIBING GUIDELINES HERE](#)

[FDA - Drug Safety Information](#)

[HHS - Department of Health and Human Services - Opioids](#)

[NIH - National Institute of Health - Opioid Summary by State](#)

[MME CALCULATOR HERE:](#)

[\(Morphine Milligram Equivalent\)](#)

Self Advocacy:

Is defined as individuals speaking out for themselves. Individuals can be defined as the person with pain and/or family, personal caregivers or health care professional speaking on the behalf of their patient with pain.

Make a commitment to **learn how to become your best advocate**. Get the **quality pain care you deserve** by starting to build healthy and positive relationships with your friends, family, caregivers, and health care providers. Build a network of support at home, in your local community and online.

- The skills of advocacy by the individual include open, honest communication with pain care team (family, friends, caregivers and clinicians), tracking impact of pain on daily living, work and relationships with others, reporting pain treatment successes and challenges and keeping open to adopting new pain treatments, techniques and lifestyle changes.
- The skills of advocacy by another working on the behalf of the person with pain include mediating, coordinating, clarifying, resolving conflict, and assisting them to acquire, interpret, and utilize health care information.
- Advocacy in pain management requires that the individual, clinician and caregiver must:
 - Take an active role in the education and care of one's self or the person with pain.
 - [Person with pain] Report when pain is not managed effectively or access to pain care is denied. Work with others who are attempting to intervene and problem solve
 - [Clinician/Caregiver] Represent the cause or interest the person affected by pain, even if that cause or interest does not necessarily coincide with one's personal beliefs, opinions, conclusions, or recommendations.
 - Teach and support others as they learn skills to self-advocate and advocate for others (patient, peer or group).
 - Speak out on issues of concern that affect pain care and impact on the person affected by pain and those around them. This can be seen in a variety of ways:
 - In the clinical setting (office visit, hospital bedside, long-term care settings) or hospital/college outreach programs.
 - Informal settings at home or in your community such as talking with a neighbor, family member or workplace colleague.
 - In your community such as churches, synagogues, rotary clubs and chamber of commerce
 - Formal settings such as sitting down and talking to a legislator or a media interview;
 - Intensive activities such as engaging in efforts to change a change in laws or policies to improve access to pain treatment, public or professional pain education or pain research.

Having your pain assessed well is one of the most important steps in achieving quality pain care. Documenting critical information allows your health care provider(s) to better understand YOUR pain experience and build a pain care plan with YOU that works for YOU.

Research shows that health care providers – even pain experts – do not accurately interpret the degree of pain that patients are experiencing. To better understand pain, the person with pain and the health care provider must have a thoughtful and targeted conversation. TOGETHER, providers and individuals must be willing and able to work as a team – your pain care team.

Assessment Tools: Providers use many different clinical tools used that have been well researched and have proven value over time. Some form of a pain assessment should be used in every practice setting. Whichever pain assessment tool your health care provider uses, it should contain come key elements.

- **The self-report that pain exists.** A simple question like: Are you in pain? (Yes or No)

- If yes, the assessment continues.

- **Location:** Commonly an outline of a human figure, back and front is provided where you can indicate where you feel your pain. You may be asked to place a simple mark, arrows, or shade areas on one or more locations. Some may recommend that you prioritize the area(s) that cause you the most concern (#1 is my worse or more challenging area, for example).

- **Description:** What does the pain sensation feel like? There may be words to circle or an area where you can use your own words. The description helps your health care provider to select what may be the underlying cause of the pain. Examples are:

- Sharp; Dull

- Stabbing; Throbbing

- Squeezing; Colicky

- Burning; Shooting

- Heavy; Pressure

There may be a section where you are asked to describe your pain in your own words.

- “It feels like 2 dogs are fighting inside my belly”

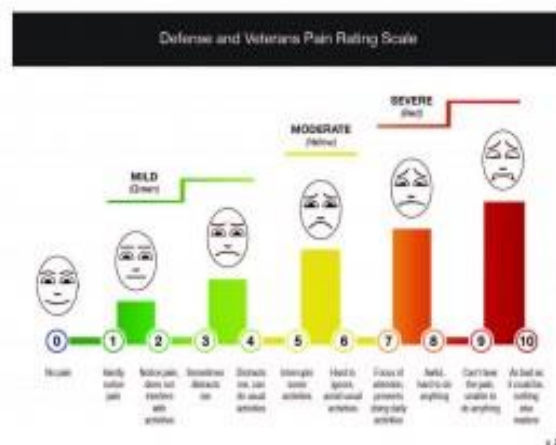
- “My feet are numb and they feel like they are on fire at the same time”

- “An elephant is sitting on my chest”

- “My head has a vice around it from the back of my neck to over my forehead”

- “An ice pick is stabbing my left eye”

- **Intensity:** This is where the pain scoring is used – the zero (no pain) to 10 (worse imaginable pain) pain scale is most commonly used. New tools have been developed and tested that help explain the effect of that pain on your ability to function. Colors and faces have been included. The newest tool modified for the military and veteran population has undergone rigorous testing.



Pain intensity should be measured during several times – for example, when you are at rest, when you are moving, what you are experiencing now and perhaps the worst pain you had over the past few days. Pain intensity scores can be used to measure effectiveness of comfort measures, as well. For example, when you get up in the morning and are stiff, rate your pain; then stretch, take a warm shower and rate it again.

Some people with pain have voiced their concerns about how pain scales are used during office visits and hospital stays. Many blame the use of the pain score, but digging deeper, the primary complaint seems to focus on how someone is approached with the question “what is your pain score?” An abrupt tone of voice and the failure to ask follow-up questions to seek understanding are far too common. Health care providers must be mindful that pain intensity scores are just one small piece to the pain puzzle and should never be considered the full pain assessment.

Behavior	w/movement score	at rest score
Nonverbal Vocalization: sighs, gasps, moans, groans, cries		
Facial Expression: furrowed brow, narrowed eyes, clenched teeth, tightened lips, jaw drop, distorted expressions		
Bracing: clutching or holding onto furniture, equipment or area of the body		
Restlessness: constant or intermittent shifting of position, rocking, intermittent or constant hand motions, unable to keep still		
Rubbing: repeated massaging of body in same area(s)		
Verbal Complaints: words expressing discomfort or pain [e.g., "ouch," "that hurts"]; cursing during movement; exclamations of protest [e.g., "stop," "that's enough"]		
Subtotal		
Scoring: 0=not present; 1=present		
Total		

Source: Modified from Feldt, KS, Herr, K, 2000

There are a variety of pain rating tools that can be used depending on the needs of the person being evaluated:

- Infant and children
- Elders
- Various languages
- Multi-dimensional tools that also measure mood, sleep, appetite, self-care, etc.
- Those who have difficulty thinking or understanding
- Those who are unable to self-report; one example is the Checklist for Non-verbal Pain Indicators (CNPI)
- **Timing:** When does the pain occur? Does it come and go? If so, are their activities or events that cause it? Is it always there? If so, does it stay the same? Does the time of day or change in the weather affect it? Keeping a pain diary, journal or notebook will help you answer these questions. There are [smartphone apps](#) now available.
- **Effect of pain treatment measures:** What makes the pain ease or flare up? What have you tried to lessen the pain or help you continue through your day? List any comfort measures such as ice, heat, exercise, stretching, rest breaks, braces, dietary changes or supplements, over the counter medications, prescription medications, special injections, surgery, acupuncture, chiropractic manipulations, etc. What worked and what did not? Did you experience any side effects from the pain treatment measures? If so, what were they

Your Office Visit:

Office Visit Checklist:

- Be prepared and do your homework; be ready to cover your top 3 priorities. *Remember that the average visit lasts 8 minutes. If you have a long list of issues or spend your time telling the long version or your story, you will lose ground quickly.*

- Bring your list. *Have on hand and offer your list of key questions, a list of your current medications with how many you have left or bring them with you, a brief summary of your medical condition(s) and your current pain treatment plan.*
- Have on hand a copy of important documents (especially for the first visit). *Share your copy of your medical records (be sure to get them back before you leave), any medical tests done within the past year (blood tests, X-rays, CT scans, MRI's, etc.)*
- Ask for your provider's email address. *Promise to use it respectfully and not excessively—reserve its use for problems or need for clarification. If given to you—keep your promise. If this is denied, you may consider this a deal breaker and decide to find a new provider who is willing to be more accessible.*
- Take your “pain buddy” or an advocate with you. *This person can help take notes of the answers to your questions, prompt you to stay focused on your top priorities and serve as your memory by reviewing what was explained once the visit is over. He/she can be a valued, trusted member of your team by helping you work on your pain care plan in between office visits.*

Preventing Medication Withdrawal

What can cause withdrawal from Pain Medications?

Withdrawal symptoms from opioids can occur when:

- the medication is abruptly discontinued or rapidly reduced, or
- another medication is given to reverse the effect of the opioid (called an antagonist, like Narcan).

All medications have side effects, contraindications and risks along with benefits.

Your healthcare provider along with your pharmacist should speak with you about these before prescribed or dispensed, and each time they are renewed or refilled. Some medication used for pain relief causes your body to adapt to them.

Physical dependence is the body's way of accepting the medication as familiar or natural, which results in withdrawal symptoms when the medication is abruptly discontinued or rapidly reduced.

Physical dependence is not the same as **addiction** (or substance use disorder), where cravings or obsession for the “high” or “escape” is present along with other features of substance abuse.

What medications are considered opioids?

A: Opioids include morphine, oxycodone, oxymorphone, hydrocodone, hydromorphone, methadone, codeine and fentanyl.

Anyone who takes opioid pain relievers on a regular basis (for more than 1-2 weeks) will develop physical dependence. If you suddenly stop taking them, you can experience serious side effects, including withdrawal, which can be unpleasant. A plan to decrease and stop them needs to be discussed with your healthcare provider.

A Healthy Doctor/Patient Relationship

1. Does the pain care provider have current training in the treatment of pain?
If not, are they willing to research and/or reach out to other providers for advice?
2. Does the provider listen to your pain report, ask questions and listen carefully to your response and concerns?

3. Do you report accurately and truthfully about your pain and the effect of the treatment plan? Do you use a pain journal or diary to illustrate how your pain affects your daily living?
4. Does the provider encourage you to ask questions and answer them in a thoughtful manner?
5. Do you ask questions and answer in a thoughtful manner?
6. Does the provider help you set realistic goals to reach with your pain treatment?
7. Are you working hard to reach those goals?
8. Does the provider take the time to explain each treatment to you? Are both the risks as well as the benefits explained?
9. Are you and the provider willing to accept that you may not be in full agreement in the treatment plan and work towards a reasonable compromise?
10. Is the provider willing to speak with and listen to your advocate/family or friend, if you are experiencing great pain and unable to express yourself? Is that person allowed to be part of the medical visit?
11. Are you and the provider willing to work together to build an effective and workable pain management plan and expect/respect you as a key member of your pain care team?
12. Are you and the provider willing to admit when one of you does not understand an issue that affects your pain care?
13. Are you willing to research different treatments and medications that are available and comfortable sharing those results with the provider? Is the provider open to receiving and discussing those findings?

Basic Human Rights

The United Nations Charter recognizes the inherent dignity and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world.

- **All human beings are born free and equal in dignity and rights.** They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.
- Everyone is entitled to all the **rights and freedoms set forth in this Declaration**, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.
- Furthermore, no distinction shall be made on the basis of the **political, jurisdictional or international status** of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.
- **Everyone has the right to life, liberty and security of person.**

- **No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.**
- Everyone has the right to **recognition** everywhere as a person before the law.
- **All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.**
- Everyone has the right to an effective remedy by the competent national tribunals for **acts violating the fundamental rights granted him by the constitution or by law.**
- No one shall be subjected to **arbitrary arrest, detention or exile.**
- Everyone is entitled in **full equality to a fair and public hearing by an independent and impartial tribunal**, in the determination of his rights and obligations and of any criminal charge against him.
- **No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honor and reputation.** Everyone has the right to the protection of the law against such interference or attacks.
- **Everyone has the right to freedom of opinion and expression;** this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.
- **Everyone has the right to freedom of peaceful assembly and association.**
- **Everyone has the right to take part in the government of his country, directly or through freely chosen representatives**
- Everyone has the right of equal access to public service in his country.
- Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.
- **Everyone has the right to work, to free choice of employment, to just and favorable conditions of work and to protection against unemployment**
- Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.
- Everyone has the right to a standard of living adequate for the health and **well-being of himself and of his family**, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control
- Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

Tools & Resources for Patients:

[Check the \(CMS\) Centers for Medicare & Medicaid Services database](#) to see if your doctor received money from a pharmaceutical or medical device company for consulting, travel expenses, meals, research and speaker fees.

[Dollars for Docs](#) is a website created by ProPublica that tracks payments to doctors by pharmaceutical and medical device companies.

[Consumer and Patient Health Information Section \(CAPHIS\)](#) has compiled a list 100 health websites it considers trustworthy.

[PubMed](#) allows you to search for published research studies involving treatments and medications.

[Physician Compare](#) helps patients find and compare doctors and other providers enrolled in Medicare.

[Healthfinder](#) is a U.S. government website where you can **apply for Medicare** and patient **assistance programs** that offer free or discounted medications.

[Patient Advocate Foundation Co-Pay Relief Program](#)

The Patient Advocate Foundation Co-Pay Relief program **assists** insured patients who are financially and medically qualified and are being treated for specific conditions. **Call 866-512-3861 or apply online.**

[The National Association of Free & Charitable Clinics](#) provides a range of medical, dental, pharmacy, vision and behavioral health services to economically disadvantaged Americans. Their website can also help find a free or charitable clinic near you that provides meals, companionship and safety checks to seniors and others with mobility issues.

[Dental Lifeline Network](#) provides **donated** dental services. They will connect you with a dentist who will make up a treatment plan for you. [Click Here](#) to see if you qualify for donated Dental Services in your State. **Phone: 303-534-5360**

[Partnership for Prescription Assistance \(PPA\)](#) helps match patients with **assistance programs** that may lower medication costs. The organization also locates nearby clinics.

▶ **888-477-2669**

[WellRx](#) also has a free **discount program**. Registered users get a **savings card** that they can use at pharmacies to get an average of **45% off the cost** of brand and generic prescription drugs.

▶ **800-407-8156**

[GoodRx](#)

Available via website or an app, it searches for and **compares** prescription medications to find the **lowest price** available.

▶ **855-268-2822**

[Filing for Social Security Disability \(SSDI\)](#)

If you meet state requirements and file the necessary paperwork, you will receive benefit payments, generally every two weeks.

▶ **800-772-1213**

[Caring Voice Coalition](#)

Caring Voice Coalition aims to improve the lives of people with chronic illnesses with **outreach programs** ranging from health insurance counseling to disability assistance.

▶ **888-267-1440**

[National Alliance on Mental Illness](#)

NAMI advocates for those affected and helps navigate work issues, from requesting leaves of absence to requesting work accommodations. Ambassadors include actors Utkarsh Ambudkar, Mayim Bialik, Carly Chaikin, Clark Gregg and Corinne Foxx.

► **800-950-NAMI**

[Partnership for Safe Medicines](#)

[FENTANYL 101 INFOGRAPHIC](#)

[DEA CHRONICALS](#)

[Pain Crisis in America](#)

Below are selected resources relating to federal and state policies governing pain management and the appropriate use of opioid analgesics, including methods to reduce medication diversion and non-medical use:

- [Database of Statutes, Regulations, & Other Policies for Pain Management](#)

- Federation of State Medical Board's [Model Policy on the Use of Opioid Analgesics in the Treatment of Chronic Pain](#)

[PDMP's:](#)

- [Prescription Monitoring Programs](#)

[Palliative Care:](#)

- State Policies Governing [Continuing Medical Education for Pain and Palliative Care](#)

[Drug Enforcement Agency:](#)

- DEA Code of Federal Regulations: [Part 1306 Prescriptions](#)
- DEA Rules re: ["Issuance of Multiple Prescription"](#)

- [Timeline of DEA Policy Statement and Proposed Rule re: Multiple Prescriptions](#)
- [Diversion on prescription opioids](#)

Commentary by Aaron Gilson & David Joranson:

- ["Is the DEA's New 'Prescription Series' Regulation Balanced?"](#)

Electronic Prescribing:

- [DEA Rules re: E-Prescribing of Controlled Substances](#)

[Comments on DEA Proposed Rule: E-Prescribing of Controlled Substances \(comments.pdf\)](#)

Congressional Statute (REMS):

- [FDA Authority to Require Risk Evaluation and Mitigation Strategies \(REMS\)](#)
- [List of Medications Requiring a REMS](#)
- [REMS for Extended-Release and Long-Acting Opioid Products](#)
- [REMS for TIRF \(transmucosal immediate-release fentanyl\) products](#)
- [Comments on FDA REMS re: Extended-Release and Long-Acting Opioid Products](#)

- [Office of National Drug Control Policy's \(ONDCP's\) Prescription Drug Abuse Prevention Plan](#)

Federal Government Websites

[Centers for Disease Control and Prevention](#)

[Code of Federal Regulations](#)

[National Institute on Drug Abuse](#)

[Office of National Drug Control Policy](#)

[Substance Abuse Mental Health Services Administration \(SAMHSA\)](#)

[U.S. Congress - Congressional Record](#)

[U.S. Federal Register](#)

[U.S. Food and Drug Administration](#)

[U.S. Drug Enforcement Administration, Office of Diversion Control](#)

[U.S. Drug Enforcement Administration, Office of Diversion Control Organization Chart](#)

[U.S. Government Printing Office \(Federal Register\)](#)

[U.S. House of Representatives](#)

[U.S. Legislation \(Legislative information from the Library of Congress\)](#)

[U.S. Senate](#)

Pain Care & Medical Associations:

[Alliance for Safe Online Pharmacies](#)

[U.S. American Academy of Pain Management](#)

[American Academy of Pain Medicine](#)

[American Association for the Treatment of Opioid Dependence](#)

[American Chronic Pain Association](#)

[American Dental Association](#)

[American Hospital Association \(AHA\)](#)

[American Medical Association \(AMA\)](#)

[American Osteopathic Association \(AOA\)](#)

[American Pain Society](#)

[American Pharmacists Association \(APHA\)](#)

[American Psychological Association \(APA\)](#)

[American Society of Addiction Medicine \(ASAM\)](#)

[Federation of State Medical Boards](#)

[National Alliance for Model State Drug Laws](#)

[National Association of Boards of Pharmacy](#)

[National Council for Prescription Drug Programs \(NCPDP\)](#)

[National Fibromyalgia & Chronic Pain Association \(NFMCPA\)](#)

[National Association of Drug Diversion Investigators](#)

[Pain and Policy Studies Group](#)

[Pharmaceutical Research and Manufacturers of America \(PhRMA\)](#)

[State Pain Policy Advocacy Network](#)