

Managing Your Pain



A GUIDE FOR PATIENTS WITH
CHRONIC OR SERIOUS PAIN

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Introduction

Being in constant pain can change a person's quality of life. Living with pain may make it hard to eat, sleep, and do daily tasks. Pain can also be hard to control because everyone feels pain in different ways.

Some patients may downplay their pain because they don't want to be a burden or may see pain as a weakness. However, it is important for patients who are able to communicate to clearly tell their care teams how they feel.

Good communication leads to better pain management.

This booklet has tools to help patients talk about pain with the care team. You do not need to suffer alone if you or someone you're caring for is in serious pain. We're here for you.

"Time is not a cure for chronic pain, but it can be crucial for improvement. It takes time to change...and to make progress."

— Mel Pohl, MD, FASAM, *A Day Without Pain*

PATIENT'S NAME & DATE

 Constant

-**10**
↑
WORST PAIN
(It is unbearable.)

- Do any of these things make the pain better or worse? If any do not affect your pain, leave those blank.

	BETTER	WORSE		BETTER	WORSE
Lying down	<input type="checkbox"/>	<input type="checkbox"/>	Vibration	<input type="checkbox"/>	<input type="checkbox"/>
Sitting	<input type="checkbox"/>	<input type="checkbox"/>	Deep breaths	<input type="checkbox"/>	<input type="checkbox"/>
Walking	<input type="checkbox"/>	<input type="checkbox"/>	Urinating	<input type="checkbox"/>	<input type="checkbox"/>
Stretching	<input type="checkbox"/>	<input type="checkbox"/>	Bowel movement	<input type="checkbox"/>	<input type="checkbox"/>
Heat	<input type="checkbox"/>	<input type="checkbox"/>	Other: _____	<input type="checkbox"/>	<input type="checkbox"/>
Cold	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>
Pressure	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>

- When does the pain feel the worst? Check all that apply.

<input type="checkbox"/> Morning	<input type="checkbox"/> Afternoon	<input type="checkbox"/> Night
<input type="checkbox"/> Before eating	<input type="checkbox"/> After eating	Other: _____
<input type="checkbox"/> Before sleeping	<input type="checkbox"/> After sleeping	_____
<input type="checkbox"/> Before toileting	<input type="checkbox"/> After toileting	_____

- Are there things you can't do because of your pain?

<input type="checkbox"/> Sleep	<input type="checkbox"/> Get dressed	Other: _____
<input type="checkbox"/> Sit	<input type="checkbox"/> Grooming	_____
<input type="checkbox"/> Stand	<input type="checkbox"/> Eat	_____
<input type="checkbox"/> Walk	<input type="checkbox"/> Drive	_____
<input type="checkbox"/> Lift things	<input type="checkbox"/> Urinate	_____
<input type="checkbox"/> Bathe	<input type="checkbox"/> Move bowels	_____

- How much does your pain keep you from enjoying life or doing things you normally enjoy?

☐ Not at all
 ☐ A little
 ☐ Some
 ☐ A lot
 ☐ Completely

- Have you felt any of these emotions lately? Check all that apply.

<input type="checkbox"/> Nervous	<input type="checkbox"/> Worried	<input type="checkbox"/> Angry	<input type="checkbox"/> Panicky
<input type="checkbox"/> Restless	<input type="checkbox"/> Afraid	<input type="checkbox"/> Hopeless	<input type="checkbox"/> Sad
<input type="checkbox"/> Depressed	<input type="checkbox"/> Guilty	<input type="checkbox"/> Easily annoyed	
Other: _____			

- Past trauma can also affect your pain. Have you ever been through or witnessed a serious accident, natural disaster, war, assault, or other very scary or terrible event? ☐ Yes ☐ No

- Do you have a history of drug or alcohol misuse? ☐ Yes ☐ No

Pain Treatment Options

We can help you find the right combination of treatments to manage your pain. Treatment options may include medication, nerve blockers, electrical stimulation, and more. Surgery may also be an option for some—but not all—seriously ill patients.

Severe, chronic pain is often treated with prescription medicine. Prescriptions vary by the delivery method, the dose, and the schedule.

- **Delivery.** Pain medicine can be given by pill, liquid, injection, IV, suppository, or skin patch. We will choose the type based on the kind of pain, the level of pain, and how it affects your daily life. If one delivery method does not work well for you, we can try another.
- **Dose.** Since each person reacts differently to pain medicine, the amount of medicine used will be unique in each case. The first dose is based on the patient's weight, height, age, pain level, and medicines already in use. Then the dose can be adjusted until the right one is found.
- **Schedule.** Long-acting drugs can be taken on a schedule to treat pain over time. Fast-acting drugs for “breakthrough pain” (when pain is stronger than normal) can be taken as needed.

Emotions can make pain better or worse, so treatment may also include meditation, yoga, music therapy, aromatherapy, pet therapy, counseling, or spiritual care.

Other non-drug-related therapies (such as physical therapy, heat, cold, massage, stretches, exercise, acupuncture, hypnosis, good sleep hygiene, etc.) may be suggested to reduce the need for medication, if possible.

What you can do:

- **Always take pain medicine as prescribed.** Do not skip a dose, even if you feel better. The goal of pain management is to stay *ahead* of pain. Waiting for it to get worse may make it harder to manage.
 - Contact us before taking other medicines or supplements, including medical cannabis, over-the-counter drugs, and vitamins.
 - Do not drink alcohol when taking pain medicine.
 - Keep children, pets, and others safe. Store pain medicine in a locked drawer. Never throw away drugs where children or pets can get to them. Please contact us for guidance on what should be done with unused medicine.
 - Avoid tasks that make the pain worse, or ask us if an extra dose can be taken before or after doing those tasks.
 - Keep notes to track the progress of treatment. You may be given forms to fill out. If there are no forms, write notes with details such as:
 - Date/time for each entry
 - Medicine and dose taken
 - Type of pain felt*
 - Rate pain before medicine*
 - Rate pain one hour after*
 - Side effects felt
- * Use pain descriptions and ratings on page 2 as a guide
- Let us know if anything in your pain assessment (pages 2 and 3) has improved, gotten worse, or changed.

Opioids and Pain Management

Opioids (**oh-pee-oyds**) are strong drugs that block pain signals to the brain. They are often the best way to relieve severe pain when other treatments have failed. Some opioids are natural and others are man-made. There are mild forms, such as codeine. Major opioids, like morphine, can be used for very serious pain.

Opioids are not right for everyone. They must be used carefully, and always as directed by a doctor. Common questions about opioids are below. Call us if you have more questions.

- Will I become addicted to the drugs?

“Addiction” is often confused with “dependence.”

Dependence is the physical change to the body that comes with long-term medication use. Many patients develop dependence over time, which is completely normal.

Addiction is when someone misuses drugs or loses control over their drug use. Some patients could become addicted. Talk to us if you are worried about or have a history of addiction. We can watch for signs of addiction and adjust treatment if needed.

Fear, shame, or denial can make it hard to reach out for support. **Please know that we are here to help *all* patients with compassion and without judgment.**

Addiction is less of a concern for end-stage patients (see page 9). End-of-life patients should NOT skip doses for fear of addiction. The focus in this case is to manage pain.

- Do opioids cause withdrawal symptoms?

Once the body is used to pain medicine it will feel signs of withdrawal if the drug is reduced or stopped. Common symptoms are anxiety, aches, sweating, or vomiting.

Any changes to treatment are made slowly and safely to lessen withdrawal symptoms. If any symptoms are felt, we can help manage them.

- Are withdrawal symptoms a sign of addiction?

Remember there is a difference between addiction and dependence. Withdrawal symptoms are a sign of physical dependence, and are common when there are changes to pain medications.

- Will I have to take higher doses of opioids later?

The right dose should relieve pain for a while. For many, higher doses are only given for breakthrough pain or if the pain gets worse. Some patients may “build a tolerance” over time and have to take more opioids to get the same relief. This is also a normal response to long-term medication use. Call us if you have concerns.

Opioid Side Effects

Most side effects of opioids go away once the body adjusts to the medication—and they all can be managed. If you are taking opioids, what side effects are you feeling? Check all that apply.

☐ Constipation

☐ Vomiting

☐ Can't focus

☐ Dizziness

☐ Drowsiness

☐ Itching

☐ Nausea

☐ Confusion

☐ Dry mouth

Other side effects may include muscle stiffness, seizures, low blood pressure or heart rate, slowed breathing, sexual dysfunction, inability to urinate, or extreme restlessness. Do you have these or any other symptoms you want us to know about? Write them here:

Common side effects of opioids include:

- Constipation **from opioid use will not get better on its own and must be treated.** Tell us right away if your bowel movements are harder to pass or if you have not passed stool in 3 days. There is no need to be embarrassed—this is *very* common. We will prescribe laxatives or stool softeners. Tips that may help:
 - Take laxatives/softeners as directed; do not skip doses.
 - Stay as active as possible. Light exercise or stretching may help some patients.
 - Drink plenty of water and limit caffeine.
- Dizziness, nausea, and vomiting can be treated with medicine. Tips that may help:
 - Eat 6 small meals a day; sit up to rest after each meal.
 - Avoid caffeine and food that is fatty, acidic, or spicy.
 - Ask us if herbs (like mint or ginger) can be taken to help soothe the stomach.
- Drowsiness and confusion. Opioids may cause sleepiness or disorientation for the first few days. This should go away as the body adjusts. Tell us if it does not. If you feel sleepy or confused, avoid tasks that need focus, like driving or cooking.
- Itching and dry mouth. We may treat dry mouth and itching with medication. Ice chips and good oral care can also help dry mouth.

Signs of opioid allergy include swelling, rash, throat tightness, or trouble breathing—let us know if you have these symptoms right away. Other drugs can be used in the rare case of an allergy. **Call 911 in case of severe allergic reaction.**

Opioids at the End of Life

Patients at the end of life are often in need of major pain relief. Opioids are sometimes used for “palliative sedation” to help dying patients who have very severe, uncontrolled pain. This allows the patient to be free from pain in their final weeks and days and helps promote a more peaceful and dignified death.

The dose for dying patients is based on pain levels. Doses are higher when pain levels are higher. Some people think that opioid use in these cases hastens death by stopping breathing. Studies have found this is not true. Opioids can slow breathing, but for many patients, that side effect goes away once the body adjusts. In some cases, opioids can actually help patients breathe easier.

At the end of life, it is important to remember that the *disease* is causing death, not the pain medicine. Breathing slows down as a normal part of the dying process.

Hospice care is recommended for all patients expected to live 6 months or less. The hospice care team works with the patient’s existing care teams, makes care plans, treats pain, orders medicine, and provides important spiritual and emotional support to the patient and the family. Please contact us if you have questions about hospice care.


"Some people think that to be strong is to never feel pain. In reality, the strongest people are the ones who feel it, understand it, and accept it."

— Unknown

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