Toolkit for Managing Persistent Pain

ACT CENTER
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Acknowledgements

This work was conducted by the Center for Accelerating Care Transformation (ACT Center) as part of our learning health system work within Kaiser Permanente Washington. The ACT Center brings together Kaiser Permanente Washington researchers, health system leaders, care teams, and patients to partner on projects that support continuous learning and improvement. Funding for this work was provided by Kaiser Foundation Health Plan of Washington.

For more information about the ACT Center or our learning health system projects, please contact us at act-center@kp.org.

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How this toolkit was designed

This toolkit is written from our perspective as a group of people living with persistent pain, called Patient Partners. As Patient Partners, we collaborated with the Center for Accelerating Care Transformation (ACT Center) at Kaiser Permanente Washington Health Research Institute to design and write this toolkit.

We are experts on living with ongoing pain, and this toolkit is guided by our personal experiences. Our goal is to help other people living with pain. Working with the ACT Center, we have also designed other resources for people like us – including patient education materials, and tools for health care teams caring for patients with pain. The ACT Center works with health care teams to put these resources to use and improve care in a patient-centered way.

This toolkit offers support and resources for people with persistent pain. Many people using this toolkit are working with their health care teams to manage opioid treatment. Some are using other medicines or types of treatment to manage their day-to-day pain symptoms. This toolkit talks about both and is intended as a useful resource for everyone experiencing persistent pain, no matter what treatment methods they are using. We have designed it to:

- **Describe and define persistent pain, self-management, and the roles of patients and care teams in managing pain**
- **Provide information on self-management resources and other tools**
- **Discuss treatment options for ongoing pain**
- **Guide patients in preparing for a pain appointment**
- **Provide guidance on talking with your health care provider during and between visits**
- **Outline key things to know about navigating the health care system**

There is a lot of information here, so don't feel like you have to read everything all at once! We hope you will focus on what's most useful for you right now, and then come back to the toolkit later as your needs change. You might use the questions on the next page to choose a section of the toolkit to start with.

TIP

Throughout the toolkit you'll also see boxes like this that highlight suggestions and information that we've learned through our own experiences as people with persistent pain.

Questions You Might Have on Your Self-Management Journey

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- How does my body understand pain? How does pain 'work'? (page 6)
- What are the goals and responsibilities of a self-manager? (page 7)
- How do I get started? (page 10)

Section 2: Self-Management with Tracking Journals and Goal Setting

- What information should I track for my pain care? (page 13)
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- What should I do if I feel like my provider isn't listening to me? (page 35)
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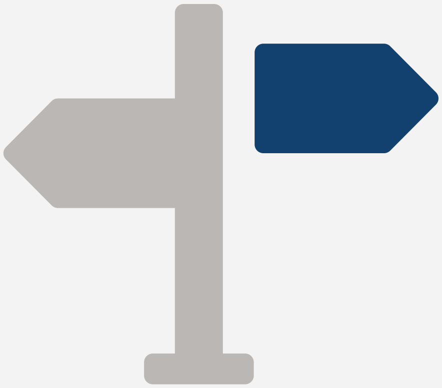
Introduction:
Using this Toolkit to Manage Pain



Introduction:
Using this Toolkit to Manage Pain

What is persistent pain?

When pain lasts longer than 3 months, it's called "persistent" or "ongoing" pain. We will use both of these terms throughout the toolkit, and they mean the same thing. You might also see this kind of pain called "chronic pain," but that can make it sound like the pain will never go away. Many people with long-term pain can manage and reduce it, so in this toolkit we're using the terms persistent pain or ongoing pain.

More than 1 in 5 of U.S. adults – or 50 million people – live with persistent pain. Persistent pain is the leading cause of long-term disability in the United States. We know that pain impacts all parts of your health: physical, mental, and social.

Along with getting care from your health care team, the best way to take charge of your pain is to learn strategies for coping with pain that is persistent. Treating and managing this type of pain may happen with your primary care provider or a pain specialist. This toolkit can support you as you work with your primary care or other health care provider to manage your pain. It will help you prepare for your visit, talk with your provider during your appointment, and take action in-between visits.

Stigma:

a tendency to label, stereotype, or discriminate against people with certain characteristics or group identities, including people living with ongoing pain.

The impact of stigma

We want to talk about stigma first because it can be one of the most challenging aspects of pain care. Although we know that persistent pain is **very real**, as patients we might experience stigma from health care doctors and others in the medical system as we seek care. Stigma shows up in a variety of ways, like having our pain dismissed as being imagined or exaggerated or driven by a desire for opioid prescriptions.

Experiencing stigma is harmful. It can cause people to avoid seeking treatment for their persistent pain or new injuries because they worry their health care provider will treat them with suspicion. It can also contribute to mental health issues, such as anxiety and depression, which can in turn make persistent pain worse.

We know from research that Black people, Indigenous people, and other people of color are more likely to face stigma and a lack of empathy from providers. People of color are also less likely to have their pain taken seriously or receive adequate pain treatment when compared to white people. The different parts of our identity – like race, gender, sexuality, ability, age, and culture – are an important part of understanding how stigma can influence the care you receive. Stigma, bias, and racism within the health care system can cause inequities in treatment and negatively impact a person's overall health.

Everyone deserves access to high-quality care – which means addressing inequities, structural racism, and injustice. It is the responsibility of health care professionals to address stigma, bias, and racism in health care.

If you feel that you have experienced bias or stigma in your care experiences, consider sharing your concerns with the provider, a nurse, or other clinic staff. If you believe you've expereinced discrimination based on race, gender, age, sexual orientation, or religion, there are other civil actions you can take, such as reporting to the Office for Civil Rights at the U.S. Department of Health and Human Services.

How to respond to stigma in the health care system

Experiencing stigma hurts, which can make it hard to respond to it in the moment. The responsibility to respond to stigma does not just rest with us as patients. It's everyone's responsibility in the health care system to recognize and address stigmatizing interactions when they happen. If you experience stigma in the health care system and feel comfortable addressing it, we've included some ideas below. However, we encourage you to first take care of your mental and emotional health in these situations.

- **Ask questions:** If a health care provider or staff member makes a stigmatizing comment, ask a clarifying question such as "What do you mean by that?" This can help to draw the other person's attention to the impact of their language.
- **Share more about yourself:** If you're comfortable, share a little more about you. Clinic staff members only see you during appointments, so helping them know who you are outside of that setting can allow them to better understand you as a person rather than a patient. For example, you could say, "In this appointment I'm someone with persistent pain, but outside of this room I love cooking for my family and walking my dog in my neighborhood. My pain can make it hard to do the things I love, so I'm hoping we can work together to find ways to manage it."

Philip's story: Stigma

"I have been taking opioids for many years to manage my chronic pain. I've worked with my primary care provider to try a bunch of other treatments to manage it and have reduced my dose over time, but I'm still on a small amount. Taking my pain medicine makes the difference between me being able to work and do the things I enjoy vs. having to struggle to get through the day. When I see doctors for other health problems, though, they ask me why I've been on opioids for so long, and it feels like they don't trust or believe me when I explain. It can be depressing to be treated like a well-mannered drug addict."

- **Direct communication:** You can express yourself in a respectful and blame-free way by focusing on how you feel. The phrase "You made me mad," suggests that the speaker's emotions are the fault of the person they are talking to, creating blame. It's much easier to find understanding with others by focusing on what happened and how you felt as two different things, "When you interrupted me, I felt mad."

Try this process[1] to communicate directly:

- Make an observation ("When I see/hear…")
- Describe your feelings ("I feel…")
- Name what you need ("Because I need value…")
- Make a request ("Would you be willing to…?")

For those of us with ongoing pain, this approach could sound like, "When I hear you say there's nothing physically wrong with me, I feel frustrated because it's important to me that others know my pain is real. Would you be willing to listen while I tell you more about how it affects my daily life and goals?"

- **Know when to step back:** There may be situations where the other person isn't willing to acknowledge that they are perpetuating stigma related to persistent pain and/or the conversation becomes heated or emotional. If this happens, it may be best to step back by saying, "This is not a productive conversation. I need to take some time away to reset." It is not our job to educate or convince others that our experiences with pain are real at the expense of our own mental and emotional health.

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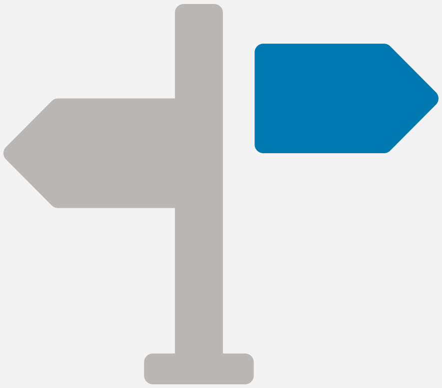
[1] Rosenberg MB. "How you can use the NVC process." The Center for Nonviolent Communication.

Section 1: Persistent Pain, Self-Management, and Support

Pages



Section 1:
Persistent Pain, Self-Management, and Support

Understanding "pain signals"

When our bodies sense extreme temperatures, pressure, or friction that could cause us harm, our nervous system quickly sends a message to our brain saying, “DANGER!” For example, when we touch a hot pan, a “HOT!” signal is sent to the brain. We take action to stop the signal by pulling our hand away, and our bodies begin the process of healing. A “pain signal,” like a “HOT!” signal, forces us to react to what we think is a possible danger.

With persistent pain, which is pain that lasts more than 3 months, there might not be an obvious, immediate cause of pain. Instead, the nervous system keeps reading some signals as dangerous even though they may not be. This can cause our bodies to experience pain without an active threat of harm. When we suffer from persistent pain, we can find ways to cope, even when our nervous system might misread the cause of the pain.

The good news is there’s a lot we can do to help manage our pain. Research has shown that we can retrain our brains to respond to pain in a different way. Pain is communicated in our bodies through billions of nerve cells in the brain and spinal cord. The central nervous system and brain are “plastic,” which means that nerve cells change and adapt to new ways of communicating information all the time. Because of this, you can influence your nervous system with certain thoughts and actions that help cope with pain.

Each day, we have an opportunity to empower ourselves by choosing how we manage ongoing pain. How one chooses to address pain will vary from person to person. But what we know from research and personal experience is that taking no action is unlikely to reduce pain. Developing coping skills as an active self-manager of your pain has several potential benefits, like pain relief and feeling empowered rather than discouraged. Being an active self-manager means working at the physical, emotional, and mental challenges that happen with persistent pain.

In this section, we share strategies and tools for self-managers – people who are making the choice to plan and take action to manage their persistent pain.

★ **TIP**

Understanding pain can decrease pain. Your thoughts and actions affect your experience of pain. By changing your thoughts and actions, you can slowly turn down the volume on your pain.

Stress and pain are closely related. If you can reduce your stress and change your response to it, this will likely help reduce your pain.

Self-manager:

a person who actively learns, uses tools, and creates strategies to cope with ongoing pain and feel empowered.

Roles and responsibilities for self-managers

As a self-manager, you will work closely with your health care team to manage your persistent pain. Your care team may include your health care provider, nurse, medical assistant, and others. Think of your care team as consultants in managing your health. You are the expert and active manager. Your care team is there to help you make informed decisions, evaluate your condition, and offer resources – but they are not doing the work of day-to-day management.

As you work together with your care team, it can be helpful to know what your responsibilities are as a self-manager and what you can expect from your team. This information is outlined in the table below.

TIP

You can change your pain, but it is a process. Be patient and kind to yourself!

SELF-MANAGER	PROVIDER AND CARE TEAM
Communicate clearly and directly about how you feel, how pain impacts your life, and your preferences for treatment	Examine your health and collect information on your pain
Understand your pain to the best of your abilities	Review your medical history
Problem solve and respond to changes in your condition every day	Diagnose your condition: It may be difficult for your doctor to provide a clear diagnosis or answers because persistent pain is complicated.
Make decisions about your care (such as what you want to accomplish and the activities that are important to you)	Provide and recommend treatments
Make an action plan, carry out actions, check in on progress, and adjust your plan, if needed	Give information and advice
Commit to a healthy lifestyle by making healthy food choices and staying physically active	Work with you to make decisions
Use medications safely and as directed by your care team	Treat you, and all patients, with respect and compassion
Reward your successes and celebrate accomplishments	

* Your care team may include your primary care provider, nurse, medical assistant, and others.

Support from family and friends

For those of us living with persistent or ongoing pain, we make thousands of choices and adjustments to manage our symptoms every day.

- *Sit like this, not like that.*
- *Take the other route to get into the store.*
- *Don't forget to bring a pillow for the waiting room chair*

In an online chat group, one person with ongoing pain shared:

> ***"It's hard to keep up the happy face some days. It's even harder to help people understand that when you're dealing with the pain, it's hard to think about anything else."***

As an active self-manager, you can develop communication skills to express your feelings, say "no" when needed, and ask for help. Practicing effective communication helps your loved ones, friends, and care team understand your experiences with pain and learn how to best support you.

Think about a time when your pain impacted a regular activity with friends or family, such as grocery shopping, housework, or preparing a meal. How did the pain affect you? What did you do? How did you feel? It can be helpful for you and the people you care about to talk through what will make regular activities more enjoyable.

One way to approach talking with others is with these four steps: Observation, Feelings, Needs, and Requests.[2]

Hannah's story: Support

"It's my birthday and I had plans to go to my dad's house for dinner tonight, but I had really bad pain starting around 9:00 p.m. last night. I couldn't sleep, didn't rest at all. I had to call my dad and cancel. I feel like I'm letting people down, I feel guilty for not being there, and I want them to understand that my pain is real. Fortunately, I asked my dad if we could reschedule my birthday dinner and he immediately agreed. He even suggested having it a few days from now so I can hopefully get some rest. He sees what my life is like and how I'm feeling on a daily basis, so at least there's that."

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[2] The Center for Nonviolent Communication. 2020 "The NVC Model."

1 **OBSERVE**

Observe how your pain is impacting your participation in the activity.

FEELINGS 2

Acknowledge how you feel about those impacts. Do you feel sad, frustrated, annoyed, tired, alone?

3 **NEEDS**

Name what you need to support you feeling better.

REQUEST 4

If others can help you get what you need to feel better, make a request for their help.

TIP

Don't let setbacks discourage you. It's okay to take a break. It's okay not to be perfect. This is difficult work!

Here's an example scenario:

My partner and I are planning to work in the garden this afternoon.

1. **Observe:** Recently when we've been gardening together, my back pain has made it uncomfortable to get up and down or kneel. After about 20 minutes of gardening, I'm in so much pain I need to go lay down.
2. **Feelings:** I feel bad about needing to rest right away, so I keep working despite the pain. I feel irritated because I want to keep gardening, but my pain makes it unbearable. I feel embarrassed that I can't help with the garden more, and I don't want my partner to be stuck with all the work.
3. **Needs:** I need to work in the garden in a way that doesn't make my back pain worse. I need to take more breaks to rest. I need to hear from my partner that it's okay if I take breaks or work at a different pace.
4. **Request (to my partner):** "When we're working in the garden together this afternoon, I would like to do things that are more comfortable for me – like raking the leaves or watering the flowers. It's painful for me to work on my hands and knees. I've been feeling embarrassed that I can't help with the garden more. I even feel irritated sometimes because I want to keep gardening, but the pain makes it unbearable. Are you okay with me doing different tasks and taking more breaks?"

Here are some ideas for ways others might support you:

- Ask your loved ones about what they notice about how your ongoing pain and treatments might be impacting your physical and mental health. They can tell you what they've observed to help you track your symptoms and successes. They might notice things you don't notice yourself.
- Talk with your loved ones about your experience with pain and treatments. This is good practice for talking with your care team.
- Ask a friend or family member to come to medical visits with you. They can help you advocate for yourself and listen on your behalf. They can also help you ask questions during the visit and remember the answers.
- Ask other people you know who are living with persistent pain for suggestions or resources.

5 ways to get started as a self-manager today

1. Explore movement and activity. You might worry that physical activity will make your pain worse, but movement is likely to lessen your pain. Physical activity helps ease muscle stiffness and improves your mobility. Being active can also help lift your mood and help you sleep better.

If you feel pain or discomfort when beginning physical activity, remember that you are sore but safe. This means that feeling pain does not mean you are causing harm to your body. When you start to do physical activities again, it is normal to have some pain or discomfort. Here are some tips to help you get started:

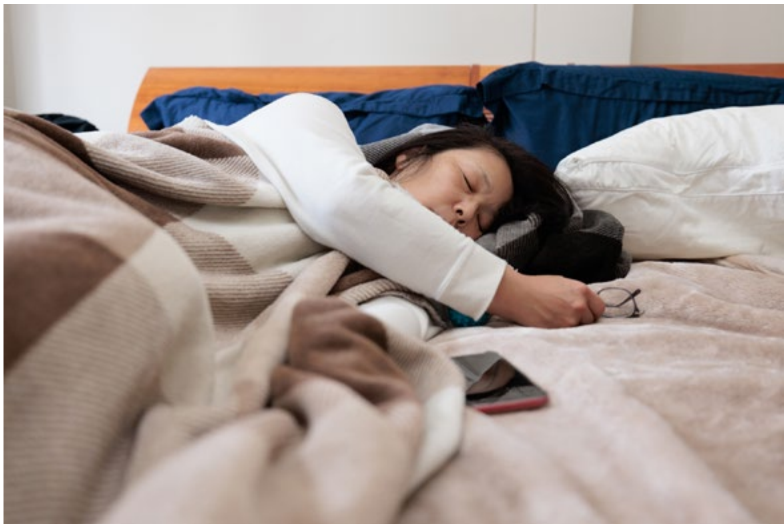
- Start low and slow. If you slowly increase your activity over the next few months, your pain should decrease, and you'll be able to get back to things you enjoy. If you are worried that you might be pushing yourself too quickly, consider seeing a physical therapist. They can help you develop a movement plan unique to you and your needs.
- Joining a fitness class can help you increase physical activity slowly and safely. Gentle yoga, stretching, and tai chi are also good options for low-impact activities.
- If pain is severe, sharp, or constant with physical activity, stop and talk to your health care provider or physical therapist.

2. Boost your mood. Pain and mood are closely connected. Lifting your mood can actually help your pain. Here are some things that you can try to help improve your mood right away:

- Take part in activities you enjoy: Play your favorite song, look at pictures that bring you joy, call a friend, or set aside time for a hobby.
- Spend time with friends, family, or social groups.
- Learn a new technique to relax and reduce stress like deep breathing, meditation, or mindful thinking.
- Join a support group with people who are also managing persistent pain. Support groups are also available online through social media sites like Facebook and Reddit.

3. Attend a workshop. The Centers for Disease Control and Prevention (CDC) recommends self-management education programs to learn strategies for coping with pain. Additionally, the Self-Management Resource Center hosts a directory of resources for people living with chronic conditions of many types. Consider searching for a virtual or in-person program to learn more and connect with others living with ongoign pain.

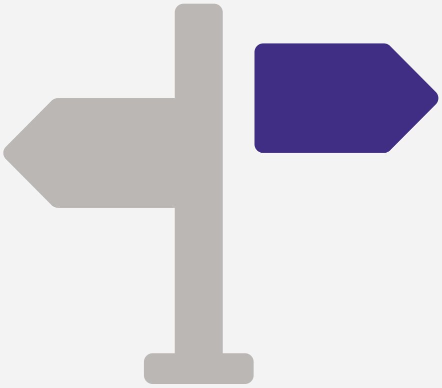
4. Get good quality sleep. Getting restful sleep energizes you to be more active, helps you feel more alert, reduces your cravings for unhealthy foods and can help improve pain and boost mental wellness. Poor sleep can cause increased pain and inflammation. If you wake up feeling groggy or not well-rested most of the time, talk with your health care team. You might need to adjust your medicines or have a sleep study to see if there's a problem that's affecting your sleep.



5. Decrease your use of pain medicine. Sometimes pain medicine does more harm than good. It might be helpful to slowly cut down on the amount you're taking. Cutting down on pain medicine over time is sometimes called a "taper." People often worry that they will not be able to manage their pain with less medicine. You might be surprised to find that your pain medicine may work more effectively at a lower dose. Most people feel better after they taper their medicine and work with their health care team to find new and better ways to treat their pain. Learn more about tapering opioid medicines on page 20.

Toolkit Contents

Section 2: Self-Management with Tracking Journals and Goal Setting



Section 2:
Self-Management with Tracking Journals and Goal Setting

As self-managers of our persistent pain, we have many tools in our toolbox.

We want to highlight two important strategies in particular: setting and tracking SMART goals. In this section you'll find:

- Tips and tools for **tracking pain**, medicines, and treatments.
- A guide to **setting goals** that are **S**pecific, **M**easurable, **A**chievable, **R**elevant, and **T**ime-Bound (SMART).

Tracking journals

An important part of being a self-manager is being aware of how different treatments and aspects of your lifestyle affect how you feel. You may find it helpful to track how things like sleep, exercise, medicines, and other treatments influence your pain. Keeping a tracking journal can help you to see patterns that you may not otherwise notice. A tracking journal can also help you:

- Stay on track with your treatment plan and check-in on progress
- Measure your successes and celebrate accomplishments
- Make informed decisions for daily pain management
- Make sure you're using your medicines safely
- Share what you learn with your health care team to help them understand your experience with persistent pain

One the following pages are examples of tracking journals you can use to take notes about your pain, medicines, and treatments.

TIP

You don't have to track things every day (and sometimes it's better not to). Even having 3 to 4 days of tracking can be helpful to notice patterns or changes, track progress, and collect information to share with your health care team.

You can find a blank version of these tracking journals for you to use on pages 48-51.[3]

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[3] Resources adapted from: MacMillan Cancer Support, "MacMillan Pain Diary."

PAIN TRACKER

Date & Time	Location of pain	Words to describe it	Severity (1-10 scale)	With this pain, I couldn't ...	I tried ... (treatments and meds)	What makes it better?	What makes it worse?
June 5	*Low back*	*Sharp, radiating*	*5 or 6*	*Walk for more than 10 mins at a time*	*Ibuprofen, ice, acupuncture*	*Ice, ibuprofen, walking (with lower severity)*	*Lifting heavy objects, moving quickly*

A scale of 0 to 10 is often used to describe pain. 0 means "no pain," 1 to 3 means "mild pain," 4 to 6 means "moderate pain," and 7 to 10 means "severe pain," with 10 being the worst possible pain.

MEDICINE TRACKER

I take this ...	I take this dose ...	I take it ... (check all that apply)				I was told to take it by ...	Date I started taking it ...	Date I stopped taking it ...	Reason I take it ...	Notes.
		AM	PM	With food	As needed					
Ibuprofen	*200 mg, 1 pill*	*X*	*X*			*Dr. Smith*	*October 8, 2021*		*Mild pain*	*Don't exceed 1,200 mg daily*

TREATMENT TRACKER

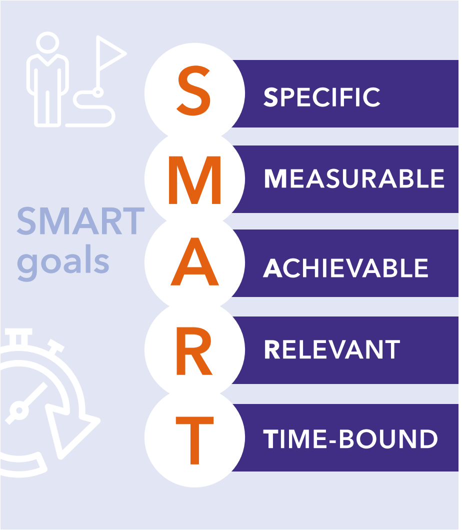
I'm trying ...	How often I do it ...	It was recommended by ...	Date I started ...	Date I stopped ...	Reason I do it ...	Notes.
Yoga	*Online using YouTube videos, 1-2x per week*	*Dr. Smith*	*October 8, 2021*		*Back pain and strengthening*	*After most yoga classes, I feel relaxed*

Setting Goals

Coping with persistent pain day to day can make it hard to see beyond right now. Setting a goal is motivating and helps to create a longer-term plan for managing your pain. After you have a plan in place, you can test and adjust it as you go.

Setting goals also helps you make decisions about your medical care. Sharing your goals during an appointment can help your health care team understand what's important to you in your daily life. One study found that when people with ongoing low back pain worked together with their health care provider on treatment goals and actions, they felt better than those who received standard advice.[4]

One of the best ways to describe goals is to use the "SMART" method. SMART goals are **S**pecific, **M**easurable, **A**chievable, **R**elevant, and **T**ime-Bound.[5]



To set a SMART goal, think about the following questions and example responses. You can also find a worksheet to help you think about and keep track of your SMART goals on page 51 of this toolkit.

1. What is your main issue or concern?

   I feel tired from lack of sleep. My pain related to fibromyalgia is the worst at night when I am trying to fall asleep.

2. What have you tried so far? What are your current options for meeting the goal?

   I have a good mattress that's supportive and comfortable. I have stopped using my phone, computer, or TV the hour before I go to bed.

3. What would you like to do? Be specific and realistic.

   I would like to get 7-8 hours of sleep a night at least 5 nights per week. I would like to meet this goal in the next two months.

4. Is your goal SMART?

   *Yes! I am being **specific** about getting more sleep and I can **measure** the amount of sleep that I'm getting. I think that 7-8 hours of sleep a night is **achievable** if I can learn and practice better sleep habits. Sleep is **relevant** because it's an essential part of health, like drinking water. I would like to get this much sleep at least 5 nights per week. I'll ask my health care team for tips to improve my sleep and whether 2 months is a realistic **timeframe** for this goal.*

Keep a list of goals as you think of them. It's helpful to focus on one goal at a time to start. As you gain confidence, you can choose to focus on a few at the same time. You can also decide if you want to add or change your goals over time.

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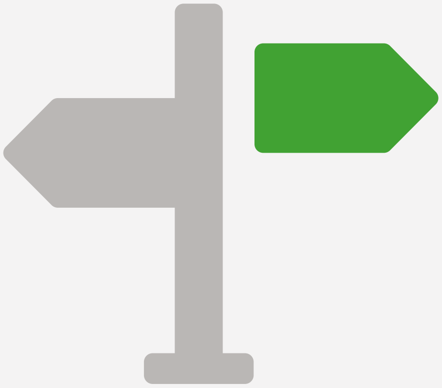
[4] Gardner T, Refshauge K, McAuley J, et al. "Combined education and patient-led goal setting intervention reduced chronic low back pain disability and intensity at 12 months: a randomised controlled trial." *British Journal of Sports Medicine,* 2019.

[5] Kaiser Permanente. "What are your goals? Make them SMART!." Thrive Blog, 2015.

Section 3:
Treating Persistent Pain

Pages



Section 3:
Treating Persistent Pain

Many different treatment options are available for people with persistent pain. These include complementary treatments like acupuncture, massage therapy, and chiropractic care, as well as prescription opioid medicines. In this section we'll talk about these treatment options and how they might help you.

Complementary treatments for persistent pain

Treatments like acupuncture, massage therapy, and chiropractic care can help ease persistent pain. These treatments are often called "complementary" because they complement, or work along with, the care you receive from a health care provider. Usually, these treatments are less invasive than surgery and safer than using prescription pain medicines.

Research shows these treatments are helpful for low back pain, neck pain, headaches, and/or ongoing pain caused by osteoarthritis. To learn more, watch this video[6] about pain treatments other than medicine.

Acupuncture	Massage Therapy	Chiropractic Care
Acupuncture is a type of Chinese medicine that has been practiced for centuries. Acupuncture is done by putting very thin needles into your skin at certain points on your body. This stimulates nerves, muscles, and connective tissue to boost the body's natural response to pain.	Massage therapy involves rubbing the soft tissues of the body, especially the muscles. Massage helps ease pain by: • Reducing muscle tension • Improving blood flow • Relieving pressure on nerves • Restoring normal joint movement	Chiropractic treatments usually involve spinal manipulation (or spinal adjustment). This means using pressure to adjust one or more joints in the spine. The goal of chiropractic treatment is to increase joint movement and relax muscles.

Are these treatments safe? Acupuncture, massage, and chiropractic care are safe when done by a licensed provider. Talk with your health care provider if you have more questions about the safety of a complementary treatment, or if you decide to start one of these treatments.

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[6] Healthwise Staff. 2021. "Chronic Pain: Treatments Other Than Medicine."

Opioid medicine for persistent pain: What you should know for your health and safety

As people with persistent pain, we need to understand the risks of taking opioid medicine long term to manage pain to stay safe and healthy. It's also important to know what all our treatment options are and to create a treatment plan that works for each of us as individuals.

Guidelines about opioid medicine have changed to help keep people safe. Opioid medicine, even when used as prescribed by your health care provider, may result in physical dependence. Physical dependence can lead to serious, life-threatening health issues. It can also cause withdrawal symptoms when someone stops taking opioid medicine.

Because of these risks, new guidelines for opioid prescribing are in place nationwide. Here are some things people with persistent pain should know about the dangers of long-term opioid use:

- Prescription opioids can help treat short-term pain, such as pain after surgery. But in most cases experts do not recommend opioids for ongoing pain because the dangers of long-term opioid use are usually greater than the benefits.
- Long-term opioid use can make a person more sensitive to pain, which makes their pain experience worse.
- Side effects of long-term opioid use are common and can be serious.
- Prescription opioids cause about 41 deaths each day in the United States (based on a report by the CDC). Many deaths happen because people accidentally overdose on opioids prescribed for ongoing pain. Anyone taking opioids is at risk of accidental overdose and death.
- Anyone can become dependent on opioids, even if they've never had problems with medicines before.
- Other treatments for ongoing pain are safer and more effective and should be used before opioids.

Many other treatments for persistent pain are safer and may work better than opioids, including:

- **Movement and physical activity**
- **Physical therapy**
- **Cognitive behavioral therapy**
- **Deep breathing and mindfulness**
- **Acupuncture**
- **Massage**
- **Chiropractic treatment**
- **Low-level laser therapy**
- **Pain relievers such as acetaminophen, ibuprofen, and naproxen, as well as topical medicine and lidocaine patches**
- **Using ice to relieve pain on a regular schedule**
- **Online or in-person workshops for self-managing ongoing pain**
- **Joining a support group**

Creating your treatment plan. Understanding your goals for treatment is an important part of creating your treatment plan. Try writing down answers to these questions so you can share them with your health care team at your next visit:

- What are your goals for managing your pain? Consider using the SMART goal format from page 15.
- How does pain affect your quality of life?
- What important things are you not able to do because of pain?
- What treatments do you want to try or learn more about?
- What will happen if your medicine is reduced and pain becomes unbearable?

How to learn more:

- Ask your health care team for more information about the treatment options listed above.
- Visit the CDC website to learn about the risks of opioid abuse and overdose.
- Watch these videos: "Chronic Pain: How Medicines Can Help You Manage It" and Opioids: Know What's Safe".

Common opioid medicines

- **Hydrocodone (Vicodin, Lortab)**
- **Oxycodone (OxyContin, Percocet)**
- **Oxymorphone (Opana)**
- **Morphine (MS-Contin)**
- **Codeine (Tylenol 3 & 4)**

Common side effects

- **Constipation, nausea, vomiting, and dry mouth**
- **Sleepiness and dizziness**
- **Confusion and other cognitive impairment**
- **Low testosterone that can reduce sex drive, energy, and strength**
- **Itching and sweating**

If you're currently taking opioid medicine, never take more than your prescribed dose. Higher doses of opioids can be deadly. Avoid using substances that can interact with opioids and increase the risk of overdose, including:

- Alcohol
- Benzodiazepines (such as Xanax or Valium)
- Skeletal muscle relaxants (such as Soma or Flexeril)
- Hypnotics (such as Ambien or Lunesta)

Help keep other people safe. Never sell or share your opioids. Store them in a secure, locked location. Take your unused opioids to your local pharmacy for safe disposal or [find a collection site.]

Opioid use disorder:

a chronic disease that changes the 'wiring' of the brain, causing physical and psychological reliance on opioids.

What to know about tapering opioid medicine

For some people, it may be safer for their overall pain management if they taper, or reduce, their pain medicines. In most cases, you and your provider will decide together if this might be a good option for you. During a taper, patients work with their health care team to reach a lower, safer dose or stop the medicine completely. Your provider might talk to you about tapering if:

- You are taking a high dose of opioid medicines.
- You are taking other medicines that can be dangerous when taken at the same time as opioids (such as skeletal muscle relaxants or benzodiazepines).

- You are having side effects from taking opioids.
- Your opioid dose is not helping you manage your pain.
- You develop an opioid use disorder.

Tapers can be slow or fast. A slow taper could take as long as a year, while a fast taper could take only a few weeks. You and your provider will decide what speed is best for you, and your provider can help you adjust as you go along. The most important thing is to continue on your lower opioid dose during the taper because as you reduce your dose, your body may become more sensitive to opioids. This means that a higher dose, even one you used to take safely, may put you at risk for an overdose.

It can be scary to think about reducing your opioid medicine, especially if you've been taking it for a long time. You might worry that your pain will get worse, or that you will have other side effects. While some people have side effects during a taper, they are not dangerous and only last for a few days to a few weeks. Possible symptoms include:

- Problems concentrating
- Stomach cramps
- Nausea
- Diarrhea
- Sweating
- Trouble sleeping
- Fast heartbeat
- Muscle twitching
- Runny nose
- Short-term increase in pain

Your care team can help you manage these side effects and give you suggestions for how to reduce them. Some ways to manage symptoms include:

- Staying active
- Getting support from family and friends
- Drinking plenty of water
- Using non-pharmacologic pain management strategies

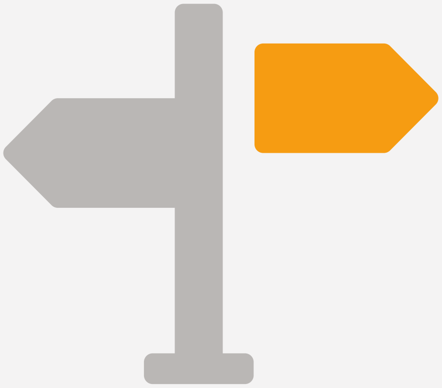
Most patients find that once they have been on their lower dose for a few weeks, their pain is not significantly different than what it was at their higher dose.

Talk to your health care provider about…

- How to safely reduce your opioid use through a taper and what support is available to you.
- Getting naloxone, a life-saving medicine that can reverse an overdose in an emergency.
- Whether you might have opioid dependence. There is help for you!
    - o Tell someone on your health care team
    - o Call the confidential, 24-hour Substance Abuse and Mental Health Services Administration helpline for treatment referral and information (English and Spanish): **1-800-662-HELP (4357)**

Toolkit Contents

Section 4: Preparing for a Visit with Your Health Care Provider



Section 4:
Preparing for a Visit with Your Health Care Provider

Time with our health care providers can be short and we often have many things to talk about. Preparing for a visit can help make the most of that time. After all, one of the most important parts of our medical care is the conversations we have with our health care team.

Appointments are a chance to share information with your health care team and work together on your care plan. Your health care provider's role is to:

- Give information on your condition
- Recommend treatments
- Help you make informed decisions while treating you with respect and care

Your role is to understand your condition the best that you can. It's also important to be clear and direct when you talk about how your pain management plan is working.

During your pain appointment, your health care provider will want to ask you a lot of important questions. They will ask about how your pain feels, what medicines, vitamins, or over-the-counter drugs you're taking, and if you're having any side effects. Your health care provider will also want to know how pain is affecting your quality of life and what you value and prefer in your treatment.

This section offers different tools you can use to gather information that your health care provider will want during an appointment. It also includes suggestions for establishing a relationship with a provider you haven't seen before.

Maria's story: Preparing

"At appointments in the past, it was painful to sit in the waiting room. I didn't feel like I could stretch, so I felt wiggly and uncomfortable. By the time I got to see my health care provider, my pain was so intense that I couldn't remember what I needed to talk to her about. I started keeping notes on my goals for the appointment and what questions I wanted to ask my provider. Even if my pain was intense, I could use my notes to make sure I shared what I needed to. I also brought a pillow with me so that I was more comfortable if I had to wait."

✓ Checklist to prepare for a visit with your health care provider

As you prepare for a visit with your health care provider, gather and review these tools to help you make a list of what you want to talk about and what questions you want to ask. We have described a variety of tools that can be used to prepare. Pick and choose what feels best for you. It is not necessary to complete every item suggested.

- ☐ Self-management tracking journal (from Section 2)
  - ☐ Pain tracker
  - ☐ Medicine tracker
  - ☐ Treatment tracker
- ☐ SMART goals (from Section 2)
  - ☐ Pain profile (this section)
  - ☐ Agenda and questions for your health care provider (this section)

TIP

Telling your health care provider about medicines, doses, and how often you take them can be a lot of information to share. Keep it simple – bring your medicine bottles or a detailed list to your appointment. For video visits, set your medicines nearby so you can grab them if needed. Be sure to include any vitamins, supplements, and over-the-counter medicines that you're taking.

Pain Profile

Answer the questions in the table below to create a "pain profile" that describes the pain you experience. Your answers to these questions can help you talk about your pain and how it affects you. It can also help you notice patterns or trends in your pain.

1. When did the pain start?	
2. Was there a specific cause (for example, an accident) or did the pain develop over time?	
3. Does the pain come in waves and then subside?	
4. Is there a time of day when the pain is worse?	
5. How do you describe the pain? (See below for the list of words that may help describe your pain)	
6. Does the pain wake you from sleep or keep you from being able to sleep?	
7. Have you ever had this type of pain before? When? What was the cause?	

8. What activities or movements increase the pain?	
9. Does the pain move to another part of your body such as your shoulder, back, or legs?	
10. Can you distract yourself from the pain partially or completely?	
11. How does the pain affect your quality of life? How do you feel regularly? Are you able to do things you enjoy, like visit with family or friends?	
12. Does the pain come with other symptoms such as nausea, sweating, or shortness of breath? What do you think may cause the symptoms?	
13. Have you changed your diet, exercise, or medicines in a way that might contribute to symptoms?	
14. What medicines have you taken, if any?	
15. Have any medicines relieved the pain completely or partially? Have any medicines not relieved the pain at all?	

Words for describing pain

The following words[7] can be used in the pain profile you created in the previous section. You might find these words helpful, or you can come up with your own. You can find a printable copy of this list on page 47.

☐ Flickering	☐ Quivering	☐ Pulsing	☐ Throbbing
☐ Beating	☐ Pounding	☐ Pumping	☐ Flashing
☐ Shooting	☐ Prickling	☐ Boring	☐ Drilling
☐ Stabbing	☐ Sharp	☐ Cutting	☐ Lacerating
☐ Pinching	☐ Pressing	☐ Gnawing	☐ Cramping
☐ Crushing	☐ Tugging	☐ Pulling	☐ Wrenching
☐ Hot	☐ Burning	☐ Scalding	☐ Searing
☐ Tingling	☐ Itching	☐ Smarting	☐ Stinging
☐ Dull	☐ Sore	☐ Hurting	☐ Aching
☐ Heavy	☐ Tender	☐ Taut	☐ Rasping
☐ Splitting	☐ Tiring	☐ Exhausting	☐ Sickening
☐ Suffocating	☐ Fearful	☐ Frightful	☐ Terrifying
☐ Punishing	☐ Grueling	☐ Cruel	☐ Vicious
☐ Killing	☐ Wretched	☐ Blinding	☐ Annoying
☐ Troublesome	☐ Miserable	☐ Intense	☐ Unbearable
☐ Spreading	☐ Radiating	☐ Penetrating	☐ Piercing
☐ Tight	☐ Numb	☐ Drawing	☐ Squeezing
☐ Tearing	☐ Cool	☐ Cold	☐ Freezing
☐ Nagging	☐ Nauseating	☐ Agonizing	☐ Dreadful
☐ Torturing			

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[7] Adapted from: Lefort, S. (2015). *Living a Healthy Life with Chronic Pain*, Bull Publishing, adapted from McGill Pain Questionnaire.

Writing an agenda

An agenda is an outline of what topics or issues you want to cover during your visit with your care team. Your SMART[8] goals (described on page 15) are a great starting point to make sure your agenda reflects what's important to you in daily life. Tell your health care provider what you want to achieve so they can tailor their responses to what matters most to you. Keep in mind:

Your agenda may be different depending on the type of appointment.

- When seeing a provider for the first time, the focus of your visit may be on sharing your medical history and experiences with pain. You can find tips for establishing a relationship with a new provider at the end of this section on page 28-29.
- If you're seeing a specialist, they may want to discuss specific topics related to your symptoms or medical condition(s).
- When you're seeing your usual health care provider, you may want to talk about any changes in your pain, how your medicine is working, or treatment that you've recorded in your tracking journal on page 13-14.

Prioritize your agenda, and be sure to talk to your health care provider about:

- New symptoms or problems that are affecting you.
- Any major changes in lifestyle that you're considering – such as planning a pregnancy, changing your diet, or doing more physical activity.

Questions for your health care provider

When you review your pain profile, tracking journals, and goals before your appointments, you may think of questions for your health care provider. Reviewing the visit notes or paperwork from your past appointments can also help you remember what you've discussed before and what you may want to ask about again. As those questions come to mind, add them to a list and organize it by ranking what you would most like to talk about. There are no "bad" questions!

When you are deciding on a treatment plan with your provider, you will likely have many questions. Common questions are about what treatments you can try, the risks of different options, what dose and timing will be best for you, or what the next steps are in your plan.

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[8] Kaiser Permanente. "What are your goals? Make them SMART!" Thrive Blog, 2015.

Here are some examples:

- I've been tracking my pain and noticed it's worse at night, which makes it hard to sleep. One of my goals is getting 7-8 hours of sleep every night. What can I do to better control my pain so I can meet my sleep goal?
- I'm interested in adding some vitamins and supplements to the medicines I take every day. Are these safe to take along with my pain medicines?
- I've heard about acupuncture to manage pain. Would this treatment be right for me? Can you tell me more about what to expect and how to get started?

TIP

If you have questions about information you received at a previous appointment, contact your health care provider via phone or email to save time in your upcoming appointment.

Tips for establishing a relationship with a new or covering provider

Throughout the course of your pain journey, there may be times when you need to start seeing a new health care provider. This might happen if your provider leaves or retires, or if they are out of the office and you need to see another provider. You might also decide you want to change providers.

Establishing a relationship with a new or different provider sometimes takes a little extra preparation to make sure they understand your goals and your life so they can best help you. Here are some things you can do before the appointment to help the visit go smoothly:

- **Goal for the appointment:** Take a few minutes to think about what you'd like to accomplish in the visit. For example, you might want to ask about whether massage or acupuncture would be a good option for you. Write down your goal(s) and any questions you have.

- **Your pain story (background about you):** Having a short "pain story" about your experiences with ongoing pain can help a new or covering provider to understand you better and make recommendations tailored to you. Your pain story might include:
    - Your goal(s) for pain management
    - Where, when, and what types of pain you have
    - Your pain scale, along with details about how your pain affects you: "My pain is usually a 7 out of 10. I can do things while sitting but I can't stand for more than a few minutes."
    - Any recent changes in how long your pain lasts and/or how severe it is
    - Your current and past medicines, including prescriptions, over-the-counter medicines, vitamins, and supplements
    - Other treatments you've tried or are currently using, such as acupuncture, massage, physical therapy, etc.

By taking a few minutes to think about your goals and pain story before your appointment, you can make the most of your time with a new or different provider.

TIP

Your pain story might sound something like this:
"My goal for pain management is to keep working and be able to take daily walks with my kids. Right now, I have low back pain that starts in the middle of my spine and shoots down my left leg. This pain is often at a 7 out of 10. I can sit in front of the computer to do my work with some pain but can't stand or walk for more than a few minutes. In the past few weeks, the pain has started to get worse the longer I sit in one position. I'm taking oxycodone 3 times per day as well as acetaminophen if I need it. I've tried acupuncture in the past and it didn't work, but I'm interested in trying massage therapy."

Section 5: Talking to Your Health Care Provider

Section 5:
Talking to Your Health Care Provider

This section begins with information about what to expect during a pain-related health care appointment if you are prescribed opioid medicine to manage pain. Taking opioid medicine to manage persistent pain is called "chronic opioid therapy." There may be specific requirements during an appointment if you are receiving chronic opioid therapy.

If you live with ongoing pain but are not taking opioids for pain management, you can skip to the "Making the Most of Your Appointment" part of this section on page 34.

What to expect during a chronic opioid therapy visit

People receiving chronic opioid therapy (COT) may need to meet the following requirements as part of pain care. Requirements vary by state and provider, but these are common requirements:

1. Frequent visits with your health care provider may be required for maintaining an opioid prescription.
2. Routine urine drug screening may be required depending on your risk level for complications from opioid use. Risk level is based on things like:
    - Age
    - How much opioid medicine you take per day
    - Other medicines you may be prescribed that can be dangerous when used with opioids (such as muscle relaxers)
    - Other medical conditions like depression, anxiety, sleep apnea, heart disease, or lung disease

There are 3 goals for these requirements:

1. **Make sure your pain management plan is the best one for you.** Even though your pain might be helped by medicines, it's never completely gone, and it still impacts your life. It's human nature to think the treatment plan we are familiar with is the best plan. But it's a good idea to review other treatment options from time to time. You and your provider might find something that works even better for you.

2. **Make sure your plan is safe.** Every medicine has possible side effects. With opioid medicines, the side effects can be serious and unpredictable. There are often safer and more effective ways to manage ongoing pain. Seeing your health care provider on a regular basis helps make sure your treatment plan is as safe and effective as possible.

3. **Make sure care is in line with state and national guidelines.** The Centers for Disease Control and states have created guidelines to keep patients safe when taking opioid medicines. Many clinics and providers have changed their appointment requirements to align with these guidelines.

A chronic opioid therapy visit includes the following:

Assessments

Medical history and screening:	Assessment of pain and function:	Other assessments as needed:
Your health care provider may review your medical history and check for health issues that could affect your risk of problems with opioid medicine. These risks include heart, lung, kidney or liver disease, sleep apnea, or other conditions.	To help understand how your pain is affecting your life, your provider may ask you to fill out a survey that asks you to rate your pain and how it has affected your day-to-day life and your enjoyment of daily activities. Based on your answers, your care team can see a score for the impact pain is having your life. Your provider will use this score to track changes in your pain over time.	Your health care provider might also ask you to complete other surveys, such as the Opioid Risk Tool at your first visit and the Annual Mental Health Questionnaire once a year while you are on COT. These assessments can help your care team support your mental health and understand your risk of problems with opioid medicines.

Other components

Functional goal:

Your provider may ask you to share one or more functional goals for your pain management. A functional goal is something you would like to accomplish in your day-to-day life. Examples might include getting 8 hours of sleep per night or walking for 20 minutes per day. Your goal(s) could be related to sleep, exercise, work, household activities, relationships, self-care, or something else.

Risk/benefit analysis:

Your provider may share the risks and benefits of using opioid medicine. Together, you will talk about whether the risks outweigh the benefits for you.

Urine drug screen:

Your provider may ask you to complete a urine drug screen on a routine basis. Most people on chronic opioid therapy take their medicines as prescribed. But a small number of people take dangerous combinations of substances that could lead to serious harm. Regular urine drug screening helps providers ensure that they are keeping their patients safe. Most providers who require urine drug screens require them from everyone so no one patient is "singled out." If you have concerns about urine drug screening, talk to your provider.

A chronic opioid therapy, or COT, visit may also include the following:

- **Opioid agreement:** Your health care provider may ask you to sign an agreement to handle your opioid medicines safely. The agreement says you will take your opioid medicine exactly as prescribed, that you'll be careful about how you use and store it, and that you won't share it with others.
- **Naloxone:** Your provider may talk to you about a lifesaving medicine called naloxone that can reverse an opioid overdose in an emergency. Naloxone is like a fire extinguisher – you hope to never need to use it, but you keep it around just in case. Naloxone is a standard prescription recomended to all patients who are taking opioid medicines. It is meant to help keep patients and their loved ones safe.

TIP

For some of us, the position we get into for collecting a urine sample for this test might be physically uncomfortable. To reduce the physical discomfort, your clinic may provide a collection container that inserts onto the toilet seat so that you can remain in the most comfortable position possible. If you think this may help you, ask a member of your care team if this container is available.

Making the most of your appointment

We know our bodies best, and we're experts on our own health. While we do the work of day-to-day pain management, talking to our health care provider is a chance to:

- Get help making informed decisions
- Evaluate our health conditions
- Find resources to improve our self-management

Below are 4 common situations that come up during a medical appointment. For each situation, we've offered suggestions to support you in getting the most out of your time with your health care provider. Some of these tips were inspired by a New York Times article, written by a doctor, about how to make the most of a medical appointment.[9] Other tips come from people like you who have ongoing pain.

SITUATION 1	STRATEGY 1
Time is limited, and there is a lot to talk about with your health care provider during the appointment.	Share your agenda with your health care provider at the very start of your appointment

Sharing your agenda

1. Be sure to prepare an agenda for the appointment. For guidance, go to Section 4 on page 27.
2. Tell your health care provider what's on your agenda at the start of the visit.
    - Bring a written or printed agenda to make sure you address your concerns in the appointment.
    - Have detailed notes for yourself – this can reduce the amount of time you spend explaining things to people.
    - Consider making a copy of your agenda, notes, and/or trackers to give to your provider to read and put into your medical record.
3. Listen to what's on your health care provider's agenda.
    - Your provider may need to review requirements from state or federal laws that are related to prescribing opioid medicine. These requirements could include things like additional tests, alternative treatments, and gathering additional information that could help you.

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[9] Danielle Ofri, M.D. "A Doctor's Guide to a Good Appointment," *New York Times*.

SITUATION 2	STRATEGY 2
Your health care provider seems to be multitasking and didn't seem to hear what you've shared.	Be direct, clear, and concise to ensure you and your health care provider have the same understanding.

Being heard by your health care provider

Your health care provider will need to collect some specific information during your visit like how your pain feels, medicines you take and any side effects they cause, and the impacts of pain on your life. Health care providers are required to enter this and other information into the computer's electronic health records during appointments and may type while you talk. However, everyone deserves attention so that we know our concerns and questions can be fully addressed. Here are some pointers for being heard clearly by your provider.

- Summarize information from your Pain Profile on page 24-25 and notes from your self-management tracking journal that describe your experience with pain, medicines you've taken, and treatments you've tried.
- Tell your health care provider if you have preferences for how you would like them to describe your pain. Some options include "persistent," "ongoing," "long-term," or "chronic."
- Summarize things you've learned from personal research so that your health care provider doesn't spend time telling you things you already know.
  - Share your ideas with your provider, including information you've found in articles or books about treatments or changes in lifestyle.
- Be concise and specific when talking about your pain. Consider other ways of describing your experience:
  - Give examples to help explain how numbers on the pain scale affect your life: "When my pain is a 7 out of 10, I can do [example activity] but not [other activity]."
  - Describe how your pain has improved or worsened, rather than just how severe it is. Describe what makes your pain better and worse.
  - Talk about how pain affects your life through things like changes in mood, appetite, sleep, endurance, and concentration.

TIP

If the visit is ending and you haven't talked about your priorities or specific questions, gently remind your health care provider about what you came to discuss. Try saying:

"I noticed that we don't have much time left in our appointment. I want to be sure we get to my priorities, like X and Y, that I mentioned earlier."

As your appointment wraps up, ask questions about information your health care provider shared with you. If you think of questions after your visit, send your health care provider a secure message.

TIP

If you feel like your health care provider is not listening to you, be direct by saying something like:

"I understand that you have to put information into the computer. Let me know when it's a good time so that I can have your full attention for an issue I'd like to talk about."
or

"Do you have a moment so that I can show you something and explain what I've been experiencing?"

Using the word "show" implies that you want the health care provider to look at you and give you their attention.

SITUATION 3	STRATEGY 3
There's a lot happening in the appointment. Information and questions from your provider feel overwhelming.	Make sure you understand information from your health care provider and get clear on your next steps.

Absorbing information

- Repeat back what you hear to make sure you understand correctly. "I heard you say X, am I correct?"
- Take notes. Bring a pen and paper to jot down key points from your visit such as suggestions for treatment, terms you learned, or things you want to learn more about on your own later.
    - Ask to audio-record your visit so that you can review it later if you need to. Depending on the state you live in, both you and your health care provider may need to agree to being recorded.
- Always be sure that you know what you're supposed to do after the appointment and when your health care provider wants you to come back for another visit.
- Afterwards, reflect on what happened at the visit: How are you feeling? What new information did you receive? What are your next steps and what actions do you need to take?
    - Review any paperwork you received for key information from your visit.
    - If you aren't sure about information you received or your next steps, call your health care provider or send them a message.

Asking questions

- Make a list of questions for your health care provider as they pop into your head before the appointment.
    - Prioritize the questions you have and make sure to ask the most important ones early in your visit.
- Suggested questions:
    - Are there other treatments (such as acupuncture, physical therapy, etc.) we haven't tried?
    - What are the pros and cons of each treatment option?
    - How sure can I be that this treatment will help me?

SITUATION 4	STRATEGY 4
You and your health care provider have different ideas about what would be best for your treatment plan.	Bring your treatment goals to your appointment and have a discussion with your provider about both of your ideas for treatments to meet these goals.

Discussing treatment plan priorities

- Bring your goals to the appointment and use them as a basis for talking about your treatment plan. You may want to use the SMART goals template on page 15 to write them down.
- Talk to your health care provider about how your treatment plan is helping you or is keeping you from reaching your goals.
- If your health care provider suggests a treatment you're not sure about, listen openly to their ideas and also share your concerns and questions.
    - For example, you could say, "I'm worried about having side effects if I start a new medicine since that might stop me from reaching my goal of exercising 3 days a week. Can you tell me more about how often side effects happen? Is there anything else I could try instead?"
    - If you need time to think over what your health care provider shares, ask them if you can schedule a follow-up appointment in a few weeks before making any changes.

What to do if you can't agree on your treatment plan

- It's important to feel comfortable with your health care provider and to able to talk openly about your treatment plan. If you and your provider aren't able to agree about what would be best for you, you may want to get a second opinion from another provider.
- You might also decide that you want to change providers. Contact your insurer for more information on seeing a new doctor.
    - If you change providers, be sure to schedule an appointment with your new provider so they can continue managing your chronic opioid therapy plan and prescriptions, if needed.

TIP

Ask a caregiver, friend, or family member to come to your appointment with you to listen and take notes. You may find it helpful to have another person to talk to and compare notes with after the appointment. In between visits with your health care provider, many questions can come up. Keep an ongoing list of concerns and questions that you can use to prepare for your next visit.

Talking with your health care provider between appointments

As people with pain, sometimes we may have questions or things we want to discuss with our health care provider in between visits. Here are a few examples of reasons you may need to connect with your provider:

- New or changing pain symptoms
- New or changing side effects to medicines
- If you have plans to travel out of town and need an early refill of your medicine(s)
- If you're starting a new medicine or treatment for a different health issue and have questions about how it will affect your pain management plan

If these or other situations come up, it can be important to know how to contact your care team. Ask your health care provider how you should contact them if you have questions or concerns between visits.

Making a plan can help you know what to do if something comes up. It can also help you determine what kinds of things need a quick check in instead of a full visit. For example, most providers require a visit before changing a prescription, but many would provide an early refill if a patient sent a message or called to say they were going out of town.

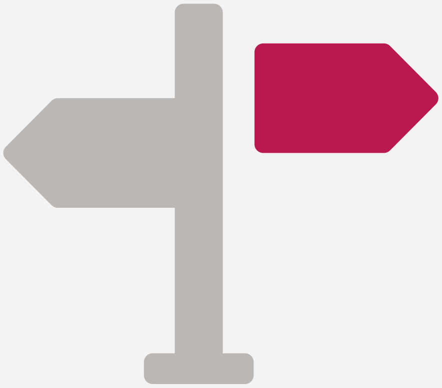
Marco's story: Sharing

"I was nervous during the appointment with my new health care provider. I wanted to make sure that she could understand how pain impacts my life. There was so much to cover in a limited amount of time, I felt myself rushing and missing important details. I paused and took a deep breath, then continued to share my story and goals that I have for managing my pain. I brought a pen and paper to keep track of information she shared with me. Once the appointment was over, I called my partner to talk about the appointment and what I'd learned from the provider."

Toolkit Contents

Section 6:
Navigating the Health Care System

Pages



Section 6:
Navigating the Health Care System

The health care system is complex and sometimes confusing. As patients, knowing some basic information can help us understand what to expect from our health care providers and insurance policies, as well as how to use our benefits. This section provides an overview of key health insurance terms and how to submit an appeal if your insurance claim is denied.

Understanding your health insurance policy

Your health insurance policy determines:

- Which health care services are covered,
- How much you pay,
- How much the insurer pays,
- And any steps you might need to take to have services approved.

Understanding your health insurance policy can help you make the most of your benefits.

Key health insurance terms

Premium: the amount of money you pay every month or every year for your coverage. If you do not pay your premium, your coverage will be cancelled. If you get your health insurance through your job, your premium may be taken out of your paycheck automatically.

Deductible: the amount of money you need to pay before your insurance will cover any services. Deductibles can range from a few hundred dollars to $10,000 or more (for high-deductible plans).

Coinsurance: the amount of money (usually a percentage) you must pay for medical services after you reach your deductible. Coinsurance is often charged for services like lab work or supplies, such as arm braces. For example, your plan may charge 20% coinsurance for x-rays. The rest of the cost is billed to your insurance.

Copay: the amount of money (usually a flat fee) you must pay for medical services after you reach your deductible. Copays are often charged for visits with a health care provider. For example, your plan may charge a $15 copay for a visit with your primary care provider and $35 for a visit with a specialty care provider, such as a neurologist or rheumatologist. The rest of the cost is billed to your insurance.

Explanation of benefits: a statement from your insurer that explains how much of the cost for a visit or service is covered by your benefits and how much of the cost is your responsibility as a patient.

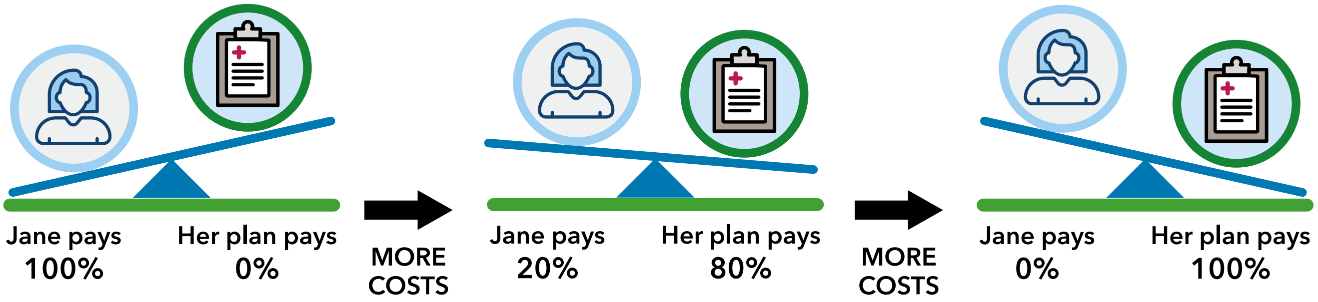
Out-of-pocket maximum: the limit on how much money you will be charged in one year for health services. Your deductible, coinsurance, and copays count towards your out-of-pocket maximum. Any health services not covered by your insurer do not count. If you reach your out-of-pocket maximum, charges above that amount will be paid completely by your insurer at no additional cost to you.

Prior authorization: approval in advance from your insurer for a health service. Your insurer may require prior authorization for:

- Certain medicines
- Procedures such as surgeries
- MRIs or X-rays
- Referrals to certain specialists within or outside of your network of covered providers

Your health care provider will usually handle the paperwork if a prior authorization is required. You can find out if you need prior authorization for a medicine, procedure, or specialist appointment by asking your provider or calling your insurer.

Here is an example of how some of these terms fit together into your overall health insurance coverage[10]:



Jane hasn't reached her $1,500 deductible yet
Her plan doesn't pay any of the costs.

Office visit costs: $100

Jane pays: $100

Her plan pays: $0

Jane reaches her $1,500 deductible; co-insurance begins
Jane has seen a doctor several times and paid $1,500 in total. Her plan pays 80% of costs until she pays $5,000 in total.
Office visit costs: $100

Jane pays: 20% of $100 = $20

Her plan pays: 80% of $100 = $80

Jane reaches her $5,000 out-of-pocket limit
Jane has seen the doctor often and paid $5,000 in total. Her plan pays the full cost of her covered health care services for the the rest of the year.

Office visit costs: $100
Jane pays: $0
Her plan pays: $100

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[10] Kaiser Permanente. "Glossary of Health Coverage and Medical Terms."

Denials and appeals

It’s possible that your insurance provider may deny coverage for a visit, service, or prescription. Some common reasons this might happen include:

- The procedure, service, or medicine is not covered under your health insurance policy.
- The health care provider you saw isn’t covered under your policy.
- The procedure, service, or medicine isn’t considered to be “medically necessary” by your insurance provider.
- You didn’t receive prior authorization before receiving the procedure, service, or medicine.

If your insurance provider denies coverage for a visit, service, or prescription, you have the right to appeal that decision.

Your right to appeal

There are two ways to appeal a health plan decision:

- Internal appeal: If your claim is denied or your health insurance coverage canceled, you have the right to an internal appeal. You may ask your insurance company to conduct a full and fair review of its decision. If the case is urgent, your insurance company must speed up the process.
- External review: You have the right to take your appeal to an independent third party for review. This is called an external review. External review means that the insurance company no longer gets the final say over wheter to pay a claim.

Visit HealthCare.gov's page on appealing a health plan decision to learn more.

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Appendix:
Self-Management Resources

Key terms

Appeal: Request from a patient to their insurer to review a decision to deny insurance coverage for a visit, service, or prescription.

Benzodiazepines: Benzodiazepines, sometimes called “benzos,” are a type of prescription sedative to help with anxiety or insomnia. Common benzodiazepines include Xanax, Valium, Ativan, and Klonopin. Benzodiazepines can interact with opioids and increase the risk of overdose, so they should not be used together.

Care plan: Plan for medical care. A care plan is a strategy that patients and providers create, agree to, and follow together to manage a health condition.

Care team: Everyone involved in patient care (health care providers, nurses, physical therapists, pharmacists, social workers, etc.).

Claim: Request from a patient or health care provider that a visit, service, or prescription be paid for by the insurer.

Cognitive behavioral therapy (CBT): A proven way to help people cope with a health problem by changing how they think, since changing how you think can affect how you feel. CBT can be helpful for ongoing pain by changing the way you think about pain and helping you build skills for managing it.

Complementary treatments for pain: Non-medicine treatments such as acupuncture, massage therapy, and chiropractic care used to treat pain. These treatments are called “complementary” because they complement care from a health care provider. They might also be called complementary and alternative medicine (CAM) or complementary and integrative health (CIH).

Coinsurance: Amount of money (usually a percentage) you must pay for medical services after you reach your deductible. Coinsurance is often charged for services, like blood work, supplies, and arm braces. For example, your plan may charge 20% coinsurance for X-rays. The rest of the cost is billed to your insurance.

Copay: Amount of money (usually a flat fee) you must pay for medical services, after you reach your deductible. Copays are often charged for visits with a health care provider. For example, your plan may charge a $15 copay for a visit with your primary care provider and $35 for a visit with a specialist. The rest of the cost is billed to your insurance.

Co-prescription: When you take more than one prescription medicine.

Deductible: Amount of money you must pay before your insurance will cover any services. Deductibles can range from a few hundred dollars to $10,000 or more (for high-deductible plans).

Dosage: Amount of medicine you take and how often you take it (for example, a dosage of 90 milligrams, taken once per day).

Evidence-based: Based on scientific research

Explanation of benefits: Statement from your insurer that explains what portion of the cost for a visit or service is covered by insurance and what portion of expenses you must pay as a patient.

Morphine equivalent dose (MED): Way to compare the strength of different opioid medicines.

Non-pharmacologic treatments/therapies: Pain management strategies that do not involve medicines (cognitive behavioral therapy, physical therapy, massage, etc.).

Naloxone: Medicine that rapidly reverses opioid overdose. It works by restoring normal breathing to a person who has slowed or stopped breathing after taking too much opioid medicine.

Opioid use disorder: A chronic disease that changes the 'wiring' of the brain, causing physical and psychological reliance on opioids.

Out-of-pocket maximum: Maximum amount of money you will be charged in one year for health services. Your deductible, coinsurance, and copays count towards your out-of-pocket maximum. Any health services not covered by your insurer do not count. If you reach your out-of-pocket maximum, charges above that amount will be paid completely by your insurer at no additional cost to you.

Patient-centered: Care and treatments that are respectful of and responsive to what a person needs, prefers, and values.

Pharmacological/pharmacologic therapies: Medicines used to manage pain.

Premium: Amount of money you pay every month or year for your health insurance coverage. If you do not pay your premium, your coverage will be cancelled. If you get your health insurance through your job, your premium might be automatically taken out of your paycheck.

Prior authorization: Approval in advance from your insurer for a health service. Your insurer could require prior authorization for:

- Certain medicines
- Procedures such as surgeries, MRIs, or X-rays
- Referrals to specialists within or outside of your network of covered providers.

Your health care provider usually handles the paperwork if a prior authorization is needed. You can find out if prior authorization for a medicine, procedure, or specialist appointment is required by asking your provider or by calling your insurer.

Sedatives: Medicines that slow down brain activity and have a calming or sleep-inducing effect. When taken in combination with opioids, sedatives can significantly increase a person's risk of accidental overdose.

Self-management support: Strategies which help people take control of their own pain and pain treatment.

Skeletal muscle relaxant (SMRs): Prescription medicines that relax and reduce tension in muscles. Common skeletal muscle relaxants include Soma, Flexeril, Zanaflex, and Robaxin. Skeletal muscle relaxants can interact with opioids and increase the risk of overdose, so they should not be used together.

Stigma: Tendency to label, stereotype, or discriminate against people with a certain characteristic or group identity, such as living with ongoing pain.

Taper: When the dose of a medicine, such as an opioid, is reduced over time. Patients work with their health care team to reach a lower, safer dose or stop the medicine completely.

Urine drug screen: A test performed on your urine to make sure you are not taking dangerous combinations of substances that could lead to serious harm. Your health care provider may require all people taking chronic opioids for pain to complete a urine drug screen. Your health care provider will tell you how often you need to complete the test.

Whole-person care: A model of health care that considers everything patients need to thrive, including things like mental health and community health. Whole-person care often involves the coordination of health care, social services, and community resources.

Resources to continue learning

RESOURCE	DESCRIPTION
Communication tools from the American Chronic Pain Association	These communication tools can help you talk with your care team, identify patterns related to pain in your daily life, and more. The American Chronic Pain Association's website has lots of information and resources.
American Chronic Pain Association – Stanford Resource Guide to Chronic Pain Management	This guide includes lots of information on types of pain, non-medicine treatments, prescription treatments, and more. It was created by the American Chronic Pain Association and the Stanford Division of Pain Medicine.
Living a Healthy Life with Chronic Pain by Sandra LeFort et. al.	This book provides a variety of strategies and skills to help people manage their ongoing pain. It discusses how to be an active self-manager. Key topics include managing symptoms, communicating with loved ones and health care providers, incorporating exercise, managing medicines, and more.
Taking Charge: Making Your Health Care Appointments Work for You by Ricky White	This book, written by someone who lives with a painful long-term condition, provides recommendations and tips for how to make the most of appointments with your care team.
Less Pain, Fewer Pills by Beth Darnell, PhD	This book about ongoing pain offers real-word examples and tips on how to lessen the use of opioids to manage pain by using cognitive behavioral strategies. It is written by a clinical professor of pain medicine at Stanford University.
U.S. Pain Foundation	The U.S. Pain Foundation has a range of programs and resources, including patient education webinars, support groups, infographics/handouts, and more.

Words for describing pain

Adapted from “Living a Healthy Life with Chronic Pain” by LeFort et al[11]. You may find it helpful to print this list and keep it in your wallet!

- ☐ Flickering
- ☐ Quivering
- ☐ Pulsing
- ☐ Throbbing
- ☐ Beating
- ☐ Pounding
- ☐ Pumping
- ☐ Flashing
- ☐ Shooting
- ☐ Prickling
- ☐ Boring
- ☐ Drilling
- ☐ Stabbing
- ☐ Sharp
- ☐ Cutting
- ☐ Lacerating
- ☐ Pinching
- ☐ Pressing
- ☐ Gnawing
- ☐ Cramping
- ☐ Crushing
- ☐ Tugging
- ☐ Pulling
- ☐ Wrenching
- ☐ Hot
- ☐ Burning
- ☐ Scalding
- ☐ Searing
- ☐ Tingling
- ☐ Itching
- ☐ Smarting
- ☐ Stinging
- ☐ Dull
- ☐ Sore
- ☐ Hurting
- ☐ Aching
- ☐ Heavy
- ☐ Tender
- ☐ Taut
- ☐ Rasping
- ☐ Splitting
- ☐ Tiring
- ☐ Exhausting
- ☐ Sickening
- ☐ Suffocating
- ☐ Fearful
- ☐ Frightful
- ☐ Terrifying
- ☐ Punishing
- ☐ Grueling
- ☐ Cruel
- ☐ Vicious
- ☐ Killing
- ☐ Wretched
- ☐ Blinding
- ☐ Annoying
- ☐ Troublesome
- ☐ Miserable
- ☐ Intense
- ☐ Unbearable
- ☐ Spreading
- ☐ Radiating
- ☐ Penetrating
- ☐ Piercing
- ☐ Tight
- ☐ Numb
- ☐ Drawing
- ☐ Squeezing
- ☐ Tearing
- ☐ Cool
- ☐ Cold
- ☐ Freezing
- ☐ Nagging
- ☐ Nauseating
- ☐ Agonizing
- ☐ Dreadful
- ☐ Torturing

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[11] Lefort, S. (2015). Living a Healthy Life with Chronic Pain. Bull Publishing. Adapted from McGill Pain Questionnaire.

PAIN TRACKER

Date & Time	Location of pain	Words to describe it	Severity (1-10 scale)	With this pain, I couldn't …	I tried … (treatments and meds)	What makes it better?	What makes it worse?

A scale of 0 to 10 is often used to describe pain. 0 means "no pain," 1 to 3 means "mild pain," 4 to 6 means "moderate pain," and 7 to10 means "severe pain," with 10 being the worst possible pain.

MEDICINE TRACKER

		I take it … (check all that apply)								
I take this …	I take this dose …	AM	PM	With food	As needed	I was told to take it by …	Date I started taking it …	Date I stopped taking it …	Reason I take it …	Notes

TREATMENT TRACKER

I’m trying …	How often I do it …	It was recommended by …	Date I started …	Date I stopped …	Reason I do it …	Notes

SMART goal worksheet

Stating your goals as part of preparing for an appointment can help your health care provider understand what's important to you in your daily life. One of the best ways to describe goals is to use the "SMART" method. SMART goals are:

Specific, **M**easurable, **A**chievable, **Re**levant, and **T**ime-Bound.

Use the chart below to create several SMART goals to take to your appointment. Consider marking your goals that are highest priority.

Primary issue or concern	**What would I like to do to address it? Be specific and realistic.**	**How will I measure my progress?**	**How long will I do this?**	**When will I stop and why?**	**My full SMART goal.**