Your Guide to Pain Management

A Road Map for painACTION.com, 2nd edition

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When you are in pain, nothing else seems to matter. All of your attention is focused with a laser-like intensity on the sensations within your body. Whether your pain comes from an aching back, throbbing in your head, the total body discomfort of cancer and its treatment, or any other pain condition, you feel as though your world revolves around your pain. Because of your pain, you may not be able to go to work or participate in the relationships and activities you enjoy. As a result, you may find yourself feeling depressed or hopeless because you see no end to your suffering.

Do not despair! Help is at hand. Your Guide to Pain Management along with the painACTION website, on which it is based, will give you the information and unique tools you need to understand your pain, choose the best treatments, adopt effective lifestyle changes, and find a supportive, informed community to help you.

Your Road Map to Pain Management

At times, you might feel as though you are the helpless victim of your pain. We at painACTION want to help you change that perspective. With the information and tools available to you in this Guide and on the website you can take control of your chronic pain. Think of yourself as an explorer in search of the best ways to manage your pain and live a full, satisfying life. This journey may lead you to new places that are unfamiliar to you, but you can use this book as your “road map” and travel guide. It will direct you to resources and information you need on your journey, while helping you avoid pitfalls.

In particular, this Guide will give you detailed information about building a productive partnership with your healthcare provider, and help you develop effective skills for self-management, communication, and coping. You will also learn about the safe use of pain medications. While there are many kinds of pain, our focus here is specifically on back pain, migraine pain, cancer-related pain, neuropathic pain,
arthritis pain, and the pain experienced by returning military service members. You may also find that the information is useful if you are dealing with other kinds of pain.

Are you ready to set off on your journey to effective pain management? If so, read on to learn more about the painACTION website and this companion book, Your Guide to Pain Management.

**painACTION: Helping You Take Control**

The painACTION website is a useful online resource that helps people with chronic pain take control of their pain and live fulfilling, satisfying lives. Together with this companion Guide, painACTION will provide you with the tools and resources you need to help manage back pain, migraine pain, cancer-related pain, neuropathic pain, arthritis pain, and pain experienced by returning military service members. The website and this Guide provide:

- The latest, scientifically **proven pain treatment strategies**, including complementary/alternative methods
- **Expert advice** tailored to **your** personal needs
- **Informative articles**, comprehensive lessons, interactive self-assessment, and self-help tools, to use in your journey toward effective pain management
- **Inspiring stories** of people who are successfully managing their chronic pain
- A supportive community of fellow “travelers” and renowned pain experts to call upon whenever you need them

Turn the page to learn more about chronic pain and the effective techniques that will help you take control of your pain!
Not all pain is bad. In fact, in some situations, pain can actually be helpful. It can warn you that a stove is too hot or be an early warning sign of a potentially serious illness or a tumor. Chronic pain however, usually serves no useful purpose. The International Association for the Study of Pain defines pain as, “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage... Pain is subjective.” What does this mean? It means that your pain is real, and you have the right to treatment, even if your healthcare provider can’t find a physical cause for your discomfort. In the year 2000, pain was categorized as “the fifth vital sign,” meaning that during every medical encounter, health care professionals should ask if you are in pain, in addition to checking your pulse, temperature, blood pressure, and respiratory rate.

Chronic pain—pain that persists for three months or longer, even after the original cause has healed—can itself become a major focus of disability or dysfunction. Chronic pain can evoke emotions like fear, depression, and hopelessness (because we can see no end in sight), despair, and isolation. These emotions may be coupled with the feeling of being out of control and the victim of your body. Because of this complex interplay of emotions, the effective treatment of chronic pain requires a holistic, multi-dimensional approach—focusing not only on the physical cause, but also on your feelings, beliefs, and life-coping skills. This approach is precisely what the painACTION website and this Guide offer you. Before we begin, however, let’s take a closer look at chronic pain.¹

¹ Acute pain, which generally has a specific cause, such as injury, disease, or surgery, and lasts for less than 3 months, is not the focus of this book or painACTION.com.
All About Chronic Pain

You are probably reading this book because you are experiencing some form of chronic pain. If so, you are not alone. An *Institute of Medicine* report from 2011 states that chronic pain affects at least 100 million American adults; more than the total affected by heart disease, cancer, and diabetes combined. The report describes that chronic pain represents a national challenge. About one-third of people who report pain indicate that their pain is “disabling,” defined as both severe and having a high impact on functions of daily life.

There are many causes of chronic pain. If you are experiencing back pain or migraine pain, you have plenty of company. These are the two most common forms of pain. In addition, based on 2003-2005 data from the National Health Interview survey, 46 million American adults reported doctor-diagnosed arthritis, which represents a considerable cause of chronic pain as well. Among people undergoing active treatments for cancer, an estimated 30 to 50 percent of them experience significant levels of pain. This rises to 70 percent for those with advanced stages of the disease, according to the National Cancer Institute. Because neuropathic pain may be sometimes harder to diagnose and categorize, how often it occurs is unknown.

This is why the *painACTION* website focuses on these five main causes of pain (back, migraine, cancer, arthritic, and neuropathic pain). In addition, the number of military service members coping with chronic pain continues to rise. The annual cost of all kinds of pain in the United States, including healthcare expenses, lost income, and lost productivity is estimated to be $635 billion. Of course, this does not include the additional toll that pain may be taking on family life, social relationships, self-esteem, and happiness. In fact, the psychological component of chronic pain is so important that it is featured in an article on the *painACTION* website, titled “Pain and the brain” by psychologist Robert N. Jamison, Ph.D. We are including a summary below, but recommend reading the entire article, when you have the time.
You will find many articles that are equally informative on the website, so be sure to take time to explore painACTION as you read this book.

**Pain and the Brain**

“Pain is complicated. It is a result of much more than the initial disease or injury that sets it off,” writes Dr. Jamison. In the past, explains Jamison, people believed that pain signals traveled only one way—from a nerve injury up to the brain. Scientists have now learned that the brain has the ability to act like a “gate,” controlling the pain messages that are received and sent out from it. They call this the “Gate Control Theory” of pain. An important part of this theory is that in addition to receiving pain signals from the body, the brain can also send messages that block painful sensations to different parts of the body.

The power of the brain to block painful sensations is one of the reasons why pain is such a deeply personal experience, so the more you understand about your pain and its particular “triggers,” the more you can play a role in blocking them. And the more active a role you can take in managing your pain, the better your chance of success. Research, for example, tells us that people who feel a sense of control—of ownership—of their health actually do better clinically than those who feel that they are helpless victims of their illness.

One way to take control of your pain, Dr. Jamison says, is to use physical, mental, and emotional gatekeepers to “close the gate,” thus reducing pain sensations. Read the painACTION article, “Pain and the brain” to see several examples of these pain “gatekeepers;” and the rest of this Guide as well as the website will tell you how to use them.
Physical gatekeepers include:

- Medications
- Surgery
- Stimulation by heat, massage, or acupuncture
- Techniques to reduce muscle tension

Emotional gatekeepers include:

- Your optimistic feeling that things will get better
- Social support from family, friends, co-workers, and healthcare providers
- A healthy mental attitude
- A lowered level of anxiety
- Management of depression

Mental gatekeepers include:

- Distraction (taking your mind off the pain)
- Humor
- Actively taking charge, rather than passively waiting to see what happens
- Having feelings of control over the pain

An important goal of the painACTION program is to help you break the vicious cycle of chronic pain. The pain makes you feel anxious or depressed, which then contributes to more pain, which then causes more anxiety and depression...

Dr. Jamison’s article shows how you can break the cycle. The article provides you with information on how to take control of your pain. And by using the painACTION program, you can gain a better understanding of your pain and control of how you perceive pain. You will also identify how your personality, family history, and level of emotional distress contribute to your pain. Pain experts have discovered that people who are not too anxious, worried, or depressed; have strong social support; and a generally optimistic outlook; are better able to be distracted from their pain, keep a more objective, realistic outlook, and find good ways to actively cope with their pain.
Part I
Your Pain Management Journey: Starting Off
Your Pain Management Journey: Starting Off

No matter what your chronic pain experience is, the chapters in this section will help with several aspects of your journey to pain management. The skills and ideas in this section apply to all forms of chronic pain. Topics include working with your healthcare team, finding reliable information, taking responsibility for your pain, dealing with your emotions, and understanding your medications.

Part II of this book gets more specific, with chapters that focus specifically on back pain, migraine pain, cancer-related pain, neuropathic pain, arthritis pain, and the pain experienced by military service members. Before you go into the chapters most relevant to you, however, it is a good idea to read the Introduction to that section. It will help you understand what the various kinds of pain have in common and how they are different, and will give you a better understanding of your own personal journey to pain management.
Chapter 1
Productive Partnerships: Working With Your Healthcare Providers

When it comes to pain, you don’t have to go it alone. It may not take a village, but it certainly does take a team to manage pain—and you are a very important member of this team! This chapter is about working as a partner with your doctors, nurses, and other healthcare providers, to control and manage your pain. Along your journey to managing your pain these people will be your “tour guides.” But, in order to guide you properly they need to know: Where do you want to go and what is pain stopping you from doing? Perhaps you want to go and:

- Have more fun with your children
- Sleep more comfortably
- Play golf or tennis with your friends
- Travel
- Spend more time at work
- Walk with less pain
- Perform daily tasks easily

Whatever your goals are, it is important that you talk with your healthcare providers about them, along with the best ways to achieve them. Some of your goals may not be realistic, at least for now. For example, if you have severe pain, you may not be able to train for a five-mile run. However, you may be able to use a guided weight-training program and exercises to build up to a couple of miles of brisk walking. After that, who knows what your limits will be?

To begin, make two lists on a sheet of paper about who is on your healthcare team. In one column, write down the names of your healthcare providers. This might include:
• Your primary care doctor
• Nurse or nurse practitioner
• Pain specialist
• Physical therapist
• Bodywork or massage therapist
• Physician assistant
• Alternative practitioners, such as an acupuncturist
• Psychologist or social worker

The second column should include your own name, as well as any family members or friends who are helping you. These columns form the two sides of your “partnership team.” This chapter will describe the roles and responsibilities for individuals on each side of this team to help you create the kinds of healthcare partnerships that will help you manage and control your pain.

Ideally, each side of the team should have equal responsibility – split 50–50 between you and your family or friends on one side and all of your healthcare providers on the other. This means that you should have a say in every decision that is made about your pain, such as:

• Medications
• Exercise plan
• Special procedures and other treatments
• Surgery

One way to think about your partnership with your provider is to imagine that you are working together to fight a forest fire. Even if you can’t completely put out the fire, you can stop it from burning out of control, or at least you can slow it down so that it only flares up once in a while. In working with your provider to control your pain, you will always be balancing two goals:
1. What you would like to do for work, family life, and recreation
2. What you need to do for your pain, including medication, exercise, diet, and activities (for example, you may need to cut down on some of them).

The trick is to find the best balance for you at any given time.

Creating a Medical Home

Once you’ve completed your list of providers, choose either your primary care physician or nurse practitioner as the one who will oversee the “big picture” of your care to address all of your healthcare needs. This person and his or her team will become your “Medical Home.” This term refers to a team-based approach to healthcare, the team being you and your healthcare provider. As a partner, your healthcare provider can guide you throughout your pain control journey by helping you navigate through all of your medical care (visits, prescription medications, and referrals to specialty care, like a rheumatologist if you have arthritis). They can also help to coordinate ongoing services that you may need like physical therapy, home health care, complementary and alternative medicine treatments, exercise programs, and family and support services. For more information, read the article, “Your primary care provider: The center of your treatment” on the painACTION website.

Your primary care provider will always be there to give you trusted medical advice, since he or she knows you best and understands your needs and concerns as well as the details of your home and work life. For your treatment to proceed safely, be sure to share all information about your diet and any over-the-counter medications you may be taking, including herbal supplements. Your medical home is also a source you can rely on to help you sort through all the information you may be hearing on television or reading in the news or on the Internet. For details on how to find trustworthy medical information, please see Chapter 3 on knowledge-based skills.
What to Expect From Your Medical Home

The provider you choose to coordinate your care has several responsibilities. Here are some ideas of what you can expect. You should feel free to discuss with this provider how you would like to work together to:

✔️ **Figure out what is causing your pain**

When you have unexplained chronic pain, it is a good idea to make your *first visit* to the person you have chosen as your medical home provider, such as your primary care doctor or nurse practitioner. By listening and talking with you, this provider will have the best chance of determining the source of your pain and in helping you choose the best combination of ways you can help yourself, along with medicine or treatments. For more information about taking control of your pain, see Chapter 2. Whenever you talk to your medical home provider, it is very important that you *freely ask every question that occurs to you, as well as share details about your life, your diet—including supplements and over-the-counter medicines—and your regular activities.* This is the kind of information that will help your provider make an accurate diagnosis about the cause of your pain.

✔️ **Help you decide on realistic treatment goals**

As mentioned earlier in this book, it may be difficult to eliminate your pain completely. However, it is the responsibility of your provider, always in consultation with you, to recommend the best ways to *at least reduce* the pain and improve your ability to live a satisfying life. In order to do this, your provider needs to know what your goals are and the ways in which the pain is preventing you from reaching those goals. The “destination” of your pain management journey may change over time, so it is important for you and your provider to keep talking and listening to each other. There are several articles and lessons on the painACTION website that can help you communicate with your provider. Examples are the lesson, “How to set reachable goals” and the article, “Your pain goals: Fantasy or reality?”
Create a Treatment Plan

Your medical home provider will also assist you in creating a customized treatment plan. Your plan will consider the source of your pain and available treatments, your physical abilities, and the lifestyle and behavior modification skills that are right for you. Your treatment plan should also include all the team members involved in your care in addition to your medical home (for example, social workers, physical therapists, and any other specialists), so that your treatment plan reflects a smooth course of care among all the members of your team.

The goal of your treatment plan is to reduce and manage your pain, improve your physical activity, restore and maintain daily functioning, and identify other issues that also need treatment, such as depression, anxiety, insomnia, and fatigue. So, it’s important to stick to the plan. You can read the articles, “Why it’s important to follow your treatment plan” and “How to stick to your medical plan” on painACTION.

Personal Perspective: Your Half of the Partnership

You, as the patient, have as much responsibility as your healthcare team for managing your pain. No one else is inside of your body, and no one else knows exactly how you are feeling. Even if you share this responsibility with a family member, friend, spouse, or other non-medical person, you should have the “big picture” view, just like your medical home provider. This is especially important in the treatment of pain, since pain is the only medical condition in which the patient has the final say in how successful the treatment is. Here are some ways you can take charge of your pain treatment:

✓ Coordinate your team

You may decide, in the course of your treatment, that you wish to add another provider to your “team,” such as a chiropractor, a massage therapist, an acupuncturist, psychologist or other mental health professional. This is fine, as long as you keep your medical home provider informed of what you are doing and whom you are seeing and make those decisions together.
Keep it going

No matter who you bring onto your team, the key to successful pain management is a long-term relationship with your medical home provider. Ideally, this person has known you for some time and understands your life goals, treatment preferences, stresses, relationships, and medical/personal history. You trust and respect each other and feel comfortable challenging and raising questions in an open discussion of treatment options.

An Expert Opinion

Some examples of productive partnerships

Here are examples of some questions you might ask your healthcare provider as part of a “productive partnership” discussion about your pain:

Q  Why can’t my healthcare providers relieve my pain completely when there are so many “miracles” that medicine can provide?

A  This is an excellent question, and a source of distress for many patients, who see medical advances on TV every day, yet can hardly walk because they cannot find adequate relief for their aching backs. The simple truth is contained in your question: the fact is that despite all available medical technologies we are often able to control chronic pain, but we are almost never able to completely get rid of a chronic pain problem, unless the reason behind it is easily correctable. In fact, the patients who succeed most in benefiting from pain management techniques are the ones who accept that they will not be able to get rid of their pain problem, and seek help to reduce their level of pain and improve their level of functioning. Why have we not done better? This is a matter for speculation, and people will have different opinions. One important reason is that very little funding has gone into improving the understanding and
A Road Map for painACTION.com

Q I’ve been told to exercise, but every time I do, my pain increases. Doesn’t my healthcare provider understand I can’t exercise?

A Talk with your healthcare provider about your difficulty exercising, if you haven’t done so already. Pain experts tend to encourage their patients to exercise because exercise can help patients with chronic pain in many ways. Exercise can increase your ability to function in your day-to-day life, can help reduce pain, can improve mood, and improve sleep. Of course, if you can’t exercise because it increases your pain, you will not be able to reap these benefits. The good news is that there are a variety of things you can do to get around this problem. First thing is to “take baby steps” and begin with exercises that you can do before moving onto the more difficult ones. Next, use ice or heat before, during, or after the exercise; take a pain medication an hour before you plan to exercise. A good physical therapist, and an attentive healthcare provider, should be able to guide you through this problem.

In Summary...

- Identify your “destination” – with regard to your goals and what you want to achieve when managing your pain
- Construct a list of your healthcare providers, and their role in managing your pain
- Find a “Medical Home” that can coordinate all of your care and understand all of the pieces of the puzzle
- Understand your responsibility in managing your pain
- Become a partner in your pain management, not a “passenger”
When you are in pain, do you sometimes feel like a helpless victim, just waiting for it to go away? Many people have this experience. It is easy to become overwhelmed and hopeless when it seems like pain has taken over your body.

This chapter is about a new way to deal with your pain, by taking control and directing your own journey to pain management. While you may not be able to eliminate your pain entirely, you can, with the self-management skills you will learn in this chapter, manage it and feel less helpless.

**What Are Self-Management Skills and How Will They Help Me?**

The painACTION lesson “How to take control: self-management and pain” explains it this way: “Self-management means taking care of yourself and your needs, in a healthy way. A person with self-management skills understands how to keep track of his/her symptoms and treatments. He/she also knows that his/her thoughts and actions can change how his/her illness behaves on any given day.”

Self-management skills can be learned. They are not based on who you are, but on what you are able to do for yourself. Self-management does not mean taking over from your healthcare providers. It means working as an equal partner with them to manage your pain. After all, you only see your healthcare provider for about fifteen minutes or half an hour at a time. What about the hours, days, and weeks between your appointments? During these times, you need to be able to take care of yourself, just as a “savvy traveler” may head off to a destination without a tour guide for parts of the trip. Yes, you need to take the prescribed medication and follow the advice you are given, but there is much more you can do as well. Here are some examples:
Notice How You Are Thinking About Your Pain

What you believe really does make a difference in how you feel. For example, do you believe the following facts about pain? (Hint: they are all true.)

☑ Successful pain management usually takes several different approaches, rather than one “magic bullet.”

☑ Studies show that passive methods–using only rest, hot/cold packs, and medications to treat pain – are less effective and are linked to more chronic pain and disability than active treatments (exercise, for example).

☑ Confident people usually have better results with pain management.

☑ Getting more control over your stress and feelings like depression and anxiety can help to manage your pain.

If you would like help with changing the way you think about your pain, talk to your healthcare provider or ask for a consultation with a social worker or a psychologist.

Keep Track Of Your Pain

In order to help you, your providers must learn how, when, and where you’re hurting, and you are the only one who can tell them. The “Daily Tracker” tool, which can be found on the painACTION My Page, will help you prepare the information you need to bring up during your medical appointments. This includes:

☑ The intensity of the pain

☑ How well your medications work

☑ Your ability to manage the pain

☑ How the pain interferes with your daily routines, sleep, mood, and relationships.
The *Daily Tracker* will also teach you accurate ways to describe your pain, because some days it may be worse than others. You can think of this as your “travel journal.”

**Take an Active Role**

There are many ways to be active in your pain management program. Here are just three of them:

- **Become physically active by exercising**
  
  Exercise is truly the most active part of self-management, although it works best when it’s started gradually and properly paced. Exercise builds strength and flexibility and causes a natural “antidepressant” effect—which is important as many people with chronic pain become depressed. Need more motivation? If you *don’t* exercise, you can experience stiffer joints, weak muscles, less stamina or “staying power,” and lower pain tolerance.

- **Become an active learner**
  
  Find out everything you can from your providers and the sources they recommend about your diagnosis and your medications (including side effects and the dangers of missed doses).

- **Become a problem solver**
  
  Problems are inevitable. These might include pain flare-ups, medication that no longer works, or difficult life events. How are you going to deal with them? First, take a deep breath, and then consider the following steps:
  
  - **Clearly identify the problem.** This may take some time, as the actual problem may not be immediately obvious.
  - **Decide on your goals.** What do you want to accomplish in this situation?
  - **Figure out your options.** What are the possible solutions?
  - **Pick the most likely solution.**
  - **Take action.**
Be Your Own Advocate

Advocates are those who fight for the rights of others. You, as the person who knows your pain best, are your own best advocate. So don’t be shy! Ask questions. State your preferences and let your voice be heard. If, for example, you prefer not to take pain medications ask if there are alternatives. Sometimes exercise programs, such as “back pain boot camp,” or changes in your diet to control migraines, can help avoid or limit the need for pain medications. Other options, described on painACTION, include biofeedback and alternative treatments, such as massage and acupuncture.

Another important way in which you can be your own advocate is to participate fully in your visit to your healthcare provider. An article from painACTION, “Medical appointments: Making the most of your visit” lists ways you can do this, including: transferring your records, collecting and bringing important information, making a list of questions, bringing someone with you to take notes and remember what was said, scheduling enough time, repeating back what you hear in summary at the end of the visit, and requesting a copy of any important materials. The article also discusses ways to make important decisions about your treatment and management, keeping a pain diary, and making follow-up plans.

Even as you advocate for yourself, there is always a community of others to support you. This can be your personal relationships including, family, friends, or clergy, or it can be pain organizations and support groups, such as those listed on painACTION. If you join the website, you will also find a ready-made community of professionals and other patients who are always available for questions, guidance, and support.

Taking Control of Pain

Here are examples of questions from patients who are taking control of their pain. These questions show patients how to follow some of the advice in this chapter by acting as advocates for themselves, becoming active learners, and making their preferences known.
An Expert Opinion

Q My pain keeps me from sleeping. What can I do to help me get at least one good night of sleep?

A Difficulty sleeping is one of the main problems experienced by patients with chronic pain. Sleeplessness in turn seems to make pain worse, causes anxiety, irritability, depression, and daytime fatigue, and makes it much more difficult to cope with the pain. Therefore, getting a decent night’s sleep every night is a critical necessity for patients with chronic pain. There are many ways to approach this problem, and your healthcare provider should be able to provide you with advice about how to get proper sleep.

The basic approaches, called “sleep hygiene,” are those followed by any person with insomnia. Such approaches include avoiding napping during the day, avoiding caffeine, exercising during the day (but not close to bedtime), avoiding stimulating activities (such as TV) in bed, and reserving the bed for sleeping. A nighttime snack or glass of milk or tea may also help.

For patients with chronic pain, other techniques may be needed. First, it is worthwhile to remember that many medications and some medical problems may cause insomnia as a side effect. When it is the pain itself keeping you awake, changing your sleep surface (e.g. a different mattress) may help. Finally, a number of medications may help with this problem. Taking an extra dose of a pain medication at bedtime (with your healthcare provider’s approval) may help, although it’s worth remembering that short-acting medications may wear off in the middle of the night, and some may even cause a “rebound effect,” leaving you with more insomnia when they wear off. For that reason, long-acting pain medications are better for maintaining sleep than short-acting ones.
Finally, there are a number of “sleeping pills” that can be used to help with this problem. It is important to remember that none of these strategies are intended for you to try on your own. These are issues you need to discuss with your healthcare provider and decide to try together.

**Q** Ever since my pain began I have been steadily gaining weight. What can I do to lose weight? Is there a special diet I can follow?

**A** First remember that there are many reasons a person with chronic pain may gain weight, and it is important to figure out the correct reason. Weight gain can be caused by a variety of medical problems, such as hypothyroidism or edema (swelling), so you need a thorough medical evaluation, including blood tests, if you are starting to have unexplained weight gain.

Second, some medications can cause weight gain as a side effect. People who develop mood disturbances, such as anxiety or depression, can have changes in their weight. Finally, the most common reason for weight gain in a patient with chronic pain is that they are eating more, exercising less, or both. This can be caused by a change in daily routine, such as not working any more, or not sleeping as well, which creates more opportunities to eat. There are many ways to deal with this that your healthcare provider can direct you to. Finding a good nutritionist to help on the eating side, and a physical therapist to help on the exercise side, may be useful.

**Q** Physical therapy only makes my pain worse, but doctors often prescribe physical therapy. Why do they keep prescribing treatments that don’t work?

**A** You may have a legitimate complaint, in that healthcare providers who are not as aware of all the options for pain management may continue to prescribe, in vain, the only treatments
they know about, including physical therapy. But there may be another explanation: healthcare providers know that exercise is critical for the recovery of most patients with chronic pain. A good physical therapist will try to help you gradually increase the amount and type of exercise that you do, and will give you specific advice on tricks you can use to tolerate increasing your level of exercise (such as ice, heat, massage, exercising in water, and pacing yourself).

Many patients fear exercise because they are concerned about harming themselves; it is critical to get a clear statement from your healthcare provider that even though you may feel increased pain while you exercise, that does not mean you will harm yourself. Finally, your healthcare provider may be able to work with your physical therapist to find medical strategies (such as taking your pain medication an hour before exercise) that allow you to tolerate your increasing level of exercise.

**In Summary...**

- Notice how you are thinking about your pain
- Keep track of your pain
- Take an active role in managing your pain
- Be your own advocate
- Take control of the situation; don’t let it control you
With pain, as with travel, what you don’t know can hurt you. It is important to know where the pitfalls are and what to trust. This chapter tells you why it is important to seek out reliable information about your pain and its treatment. It also tells you how to find out what you need to know as you begin your pain management journey, and how to figure out the sources of information that you can safely rely on.

When you are in pain, it is important to learn about your condition and the various possible treatments. Why? Then you will be able to work in partnership with your healthcare provider to make the best choices. As you embark on your “search and discover” fact-finding mission, there are two main ways to find out what you need to know:

- From your healthcare provider
- On your own

This chapter tells you how to make the best use of both sources.

**Your Medical Home: The First Stop On Your Journey**

In Chapter 1, you learned about the idea of a “medical home.” This is the provider and clinical team overseeing your care, where you can feel as if you are “at home.” Your medical home is also your best source for trustworthy advice and information. Often, the person you have the most contact with in your medical home is your primary care doctor, but it can also be a nurse or other healthcare provider. The key is that the medical home has all of the information about you, your pain condition, your other health conditions, your activities, your life situation, your family, any treatments you are having—including “alternative” therapies, and all medications you are taking, including herbal remedies and all over-the-counter medicine or supplements.

Your medical home provider is an excellent first stop on your fact-finding journey, since this provider knows enough about you to be
able to direct you to information that is relevant to your pain, your preferences, and your treatment. It is important to realize, however, that this is not a one-way flow of knowledge—from provider to you. It is also important for knowledge to flow in the other direction—from you to your provider, especially about any treatments you are having (such as chiropractic, massage, or acupuncture), and any over-the-counter supplements or medications you are taking. You can also ask for clarification about information you received from another source, for example, “my massage therapist thinks that I would benefit from a yoga class. What do you think?”

Questions to Ask

Now that you know where to begin your fact-finding journey, what other kinds of questions should you ask? Here are a few examples. The answers may be spoken during a conversation, or your provider may give you written materials or direct you to a reputable website for more information:

- What is my exact diagnosis?
- What are the likely causes of my pain?
- What can I do on my own, including diet, exercise, and stress reduction? (See Chapter 5, “Coping with Your Feelings”)
- What tests do you recommend (e.g. MRI, CT scan)? Can you explain how they are done?
- What procedures do you recommend? Can you explain them?
- What medications do you recommend? What are the side effects?
- Would surgery be indicated, and what kind? (You would also want to talk to a surgeon in this situation.)
- What can I expect, realistically, in terms of feeling better?
- What websites do you recommend?
Second Opinions

If you are not satisfied with the answers to these questions—or even if you are—you might want to hear from another healthcare provider. This is a good idea because it gives you different perspectives on the same problem. You don’t have to worry about hurting someone’s feelings by asking for a second opinion. Any reputable healthcare provider would welcome your right to talk to another provider, and would not be threatened or insulted in any way. After all, you are the “boss” of your own body and you need to be completely comfortable about any treatments.

A few guidelines about second opinions however:

☑️ Do make sure that any second opinion that you seek is from another provider of the same type as your first one.

☑️ Don’t, for example, seek a second opinion from a chiropractor and try to compare that to the opinion you received from a primary care doctor. These people have different types of training, so it would be like trying to compare apples and oranges. If you are comparing opinions from specialists, make sure they are of the same kind: For example, two neurologists, two pain specialists, or two surgeons.

Your Internet Guide

In addition to talking with your provider and reading any written materials you are given, you might join the millions of people who turn to the Internet every day for medical advice and information. While the Internet is a wonderful resource, it can also be difficult to sort out fact from fiction and to find information you can trust and rely on. Here are a few guidelines. For more Internet advice, see the painACTION article, “Caught in the Net? Online health information you can trust.”
Check the URL

After you type your question or topic into a search engine, you will see a list of relevant Internet sites. Instead of just clicking, begin by doing some screening. First, look at the URL, the web address after the name of the website. Generally the most reliable sites end with “.gov” (for government agencies), and “.edu” (for academic centers). You can also look for national organizations that provide information on the condition you are interested in, which will end with “.org.” Just make sure these are nonprofit organizations, such as The American Cancer Society, www.cancer.org.

Other reliable sites

Even if the suffixes “gov,” “edu,” and “org” don’t appear in a URL, the site still might be useful and safe, as painACTION.com is, for example. Here is a way to evaluate other sites: Is the site easy to navigate? Is the organization reputable? You can often determine this by doing a search on the organization itself to see if there are complaints or lawsuits. Is the site trying to sell you a product to improve your health? If so, warning bells should go off! View with suspicion any site that is trying to sell you something, whether it is a medicine, a food, or a health-related device. At a minimum, ask your health care provider for advice.

Evaluating Internet information

Once you are satisfied with the site itself, look closely at the information on it:

✔️ Is it current? Always check the date that the information was posted. This usually appears at the bottom of each screen. If there is no date, beware! This might indicate that there is disproved or outdated information, or a sloppy, untrustworthy website.

✔️ Is the information factual (rather than opinion or ranting) and backed up with references to primary sources, such as research studies?
Are experts cited? Even if there are no research studies to back up the advice, there should be some other reliable source, such as a reputable expert who is associated with a major academic medical center, or a reliable research organization.

The guidelines in this article should help you become a smart information-gatherer and a savvy consumer, all of which will increase your chances of dealing successfully with your pain.

Want to learn more? Read the painACTION article, “Online support groups: Getting connected.”

Other suggestions:

- MEDLINEplus is a consumer-oriented website licensed by the National Library of Medicine. It includes an online illustrated medical encyclopedia and dictionary. http://medlineplus.gov
- For evidence-based information about complementary and alternative therapies, visit the website of the National Center for Complementary and Alternative Medicine, part of the National Institutes of Health, which is an excellent consumer health information website. http://nccam.nih.gov

In Summary...

- Your medical home should be the first stop on your journey
- It’s important to know what questions to ask your healthcare provider
- Second opinions can be helpful
- Choose your Internet resources carefully
In your journey to pain management, the healthcare providers you meet along the way can serve as helpful “tour guides.” In order to help you, however, they need to know where you are going—your destination: What are the goals of your pain management and what would you like to be able to accomplish? This chapter is about how to help your healthcare provider help you during this important life journey. You might think, as many people do, that your doctor, nurse, physician assistant, or other medical professional knows everything about your pain. But this is only partly true. Your healthcare providers may know a great deal about pain in general, and how to treat it. But they probably don’t know the details about your pain and its effect on your life. So it is important for you to tell them, to communicate with them about what your pain is doing to you in your own life. After all, you are the only person in your body, so you are the expert about your own pain! For example, is your pain:

- Making it harder for you to do your job?
- Preventing you from enjoying your favorite activities?
- Interfering with your sleep or your relationships?
- Affecting your ability to take care of your children or other family members?
- Causing you to become depressed or anxious?

No two people will answer these questions in exactly the same way, so that is why it is a good idea to share this information with your healthcare provider. Why is this so important? Because, as discussed earlier in this book, one key to successful pain management is shared decision-making between you and your healthcare provider about the course of treatment. Part of shared decision-making is setting realistic goals and expectations. If your provider does not know how your pain is preventing you from reaching your goals, how can he or she
give you a good idea of what the treatment should be and what kind of relief you can expect? And later on, how can you together decide if the treatment is working? If you want to take a journey, you need to know where you would like to end up. For tips about starting that conversation, you might want to look at the painACTION lesson, “How to set realistic goals when you have chronic pain.”

Pain is Not a Score; It is an Experience

As they evaluate your pain, many providers will ask you to rate it on a scale of 0 to 10, “0” being no pain, and “10” being the worst pain imaginable. This is important information, but it is not enough, because pain is not a score; it is an experience. For example, if you have back pain, it is not enough for your provider to know that the treatment brought it down from a “9” to a “6.” Your provider also has to know if your goal was to be able to play 18 holes of golf (or repair a transmission, sit at a desk for 8 hours, or pick up your grandchildren). Have you reached your goals? If not, the treatment has not been successful and you and your provider need to re-evaluate and come up with a different plan.

There is an old saying that if a healthcare provider simply listens and gives the patient enough time to talk about his or her problem, the diagnosis will become clear, even without a lot of expensive tests. But what if your provider is not a good listener, or doesn’t give you enough time to talk? Here are some things you can say:

- “I know you are in a rush, but I would really like to tell you how this pain is making it hard for me in my life right now. Do you have a few minutes to listen?”
- “Thank you for this pill prescription, but what else can I do to help this pain go away?”
- “How long before I can realistically expect to feel better?”
- “I really don’t like taking pain pills if I don’t have to, is there some kind of exercise program, like ‘back pain boot camp,’ that I can do to see if it helps instead? Any other non-pill treatments like acupuncture or biofeedback?” These are all described in painACTION.
• “Here is what I’d like to be able to do in a few weeks; is this realistic? How about in a few months [insert your goals here]?” For example: take a dance or yoga class, do weight training at the gym, start jogging, go hiking, and take a car trip.

• “It has been two months, and my pain is really not going away. I am getting discouraged and frustrated. Can we talk about a new plan?”

Communicating With Family and Friends

In addition to communicating with your healthcare provider, there are other people in your life: family, co-workers, and friends. Often, these people might not realize how pain is affecting your life. Perhaps you even feel that pain is in control of your life, but people don’t see this. They also may not understand that you are on a personal journey to control and manage your pain. It can be very difficult for many people suffering from chronic pain to communicate with others about their experiences. People in acute pain, such as from a sprain or fracture, often show visible signs of their distress. You might look upset or moan and groan, or always be trying to find a comfortable position. Healthcare providers might measure a fast pulse or heart rate, high blood pressure, or other obvious physical signs of discomfort and discuss these findings with family members so that they understand the pain more clearly.

People with chronic pain don’t usually show such obvious signs, however, which may lead an inexperienced observer, such as a friend or family member, to think that the problem “really isn’t that bad.” It is helpful to explain to your friends and family members that people with chronic pain—even if it is severe—may not show it. But you don’t want to overdo these explanations either, or some people might say that you are “always complaining.” You may want to read the painACTION article, “Are they listening: Talking about your pain.” That is why it may be a good idea to ask your healthcare provider, or a psychologist, to help you communicate in a positive way with your loved ones, so that they understand your pain and the ways in which they can be supportive to you in your “journey.”
Sometimes the most common causes of frustration, anxiety, or depression are what you don’t know, rather than what you do know. That is why communication is so important. If, for example, you thought your sprained ankle would get better in a week, but the pain is dragging on for a month, wouldn’t it have been helpful to know from your healthcare provider that ankles can take three months to heal? The only way to know this kind of information is to ask outright, since many providers might not want to give you discouraging news. But once you do have the facts, you can take steps to cope with them, and that is what the next chapter is about.

An Expert Opinion

Communicating with your healthcare provider

Here is an example of a question you might want to ask your provider, and a possible answer. Try this question and see what answer you get!

Q My healthcare provider just prescribed an antidepressant for me. Why? I’m not depressed, I have pain!

A Many medicines have benefits for more than one condition. Antidepressants have effects on depression, of course, but may also have effects on certain types of chronic pain. For example, many antidepressants are effective for neuropathic pain (i.e. pain resulting from nerve injuries); antidepressants can be effective for other types of pain as well.

On the other hand, patients with chronic pain do in fact frequently suffer from depression as well. So a person with pain who does have depression also may be prescribed an antidepressant. The bottom line is that there are many good reasons for a patient with chronic pain to be prescribed an antidepressant, and it certainly does not mean your healthcare provider thinks you are crazy, or your pain is all “in your head.”
In Summary...

- Pain is not a score, it is an experience
- Try to think about what you want to say to your healthcare provider
- Communication is key
  - With your healthcare provider
  - With your family and friends
Before you set off on a car trip, you might consult a travel agent or seek advice from friends and family about where to go and what to see. But, in the end, only you can take the wheel. This is your journey, and you are in charge of both your final destination and your route. The same is true of pain management. You can and should seek help from a number of sources, but you have to direct your own path. So trust your instincts when something doesn’t feel right. From time to time, you may have to redesign your itinerary or travel plans—feeling a sense of control will actually help you emotionally cope with the difficult moments. This chapter will give you the tools you need to plan a successful emotional journey as you manage your pain. You will learn about stress, anxiety, and depression, and discover tips on how to develop more positive feelings, even when you are coping with pain.

First, here’s a little background about the connection between emotions and pain. Does your body know what is going on in your mind? Surprising as this may sound, the answer is “yes.” When you are feeling stressed or anxious, for example, your brain triggers the release of chemicals called stress hormones in your body. These include adrenalin and cortisol, and they can have powerful effects on your pain. You may be feeling stressed or anxious as the result of the pain itself, because of the reactions of those around you to your pain, or because of things—such as work or family troubles—that have nothing to do with your pain. But whatever the cause, the result is the same: it can make it harder for you to cope with your pain. Feeling sad and depressed can also make your pain worse.

What is Stress and How Can it Make Pain Worse?

Stress is the response we have to situations that demand that we focus our minds and bodies in some way. Some stress can be thrilling, such as the exhilaration of skiing a steep mountain or holding on during a
roller coaster ride. Other stress can be unpleasant, such as the anxiety of being late for a presentation at work, or the frustrations of a family disagreement. No matter where it comes from, stress generally creates a “fight, flight, or freeze” response as stress hormones flood our bodies to help us meet the challenge. In response to these hormones our muscles tighten, we breathe faster, we take smaller, shallower breaths, and our hearts speed up. If the stress is “acute,” meaning it does not last long, these effects soon disappear. But if you are feeling stress every day, for weeks or months at a time, this is called “chronic.” The painACTION Tool, “Stages of Stress: Fight or Flight” may help you understand how stress can affect your body.

Chronic stress or anxiety can make pain worse. It can cause your body to continue to hold muscles tighter than they need to be. At the same time, your shallow breaths bring less fresh oxygen to those overworked muscles. As you know if you clench your fist or hunch your shoulders for any length of time, tight muscles contribute to pain. Not only can stress and anxiety make back pain worse, it can also contribute to migraine pain, as the painACTION article “The link between stress and migraine” describes.

**Coping With Stress and Anxiety**

If you’ve ever experienced significant stress while on vacation, you know that it can make it much harder to enjoy a trip. Chronic stress or anxiety will have a similar negative effect on your journey of pain management, so it’s important to learn how to control these feelings. There are several ways to manage stress and anxiety. Identify the causes, talk about it, take ownership of your situation, and use proven stress reduction techniques. The tips in the rest of this chapter will help you reduce your stress, allowing you to continue your journey more comfortably. Your healthcare providers can give you a great deal of helpful guidance, but always remember that you are in charge of mapping out your voyage.
Identify the Causes

The first step in lowering your stress and anxiety levels is to figure out the source. You can think about this on your own or ask your healthcare provider to help you. You would not simply head to an unfamiliar country without learning something about your destination (talk about stressful!), so take the same proactive steps when it comes to this journey. If you have some realistic information about your path to pain management, you may be less stressed or anxious about it. If your stress is coming from feeling that your pain is lasting too long, for example, ask some frank questions of your healthcare provider: “How long can I expect this to go on?” “Will my pain ever completely go away?”

Talk About It

If your stress is coming from your family relationships, it might be a good idea to figure out what your family can do to help you, and then brainstorm with them about ideas that might help. For example, you could share the following: “At the end of the day, my back is really sore and it would be really nice if someone else would do the dishes. I can finish cleaning up after I sit down for a few minutes.” Even if you don’t come up with practical solutions, just talking about your pain with a trusted person helps to ease the burden. Some people have found support groups or advocacy organizations helpful as well. You can find links to such resources on the painACTION website.

Take Ownership

Evidence shows a direct link between your mood and your ability to cope with pain. If you are feeling down in the dumps, and like a helpless victim of your pain, you might actually find your pain levels increasing. If, on the other hand, you can feel good about yourself as someone who is taking control of your life and your situation, you will very likely find that you are feeling less pain. Easier said than done? Here’s how you can take control of your pain:
全额\textbf{Be creative about changing the sources of your stress}

If you are feeling overscheduled, see what can be eliminated. Create a one-night “oasis of calm” each week, when you stay home and relax. Since sleep has been shown to be important in coping with pain, pick one night a week to go to bed by 10:00 p.m.

\textbf{Get the “fight” out}

If you feel that anger is bursting out of you, tame it by doing some regular, vigorous exercise every day, such as brisk walking, jogging, or a spinning or aerobics class.

\textbf{Keep a “travel” journal}

Many people find that keeping a journal while traveling enhances their enjoyment of the trip and allows them to sort through their feelings and experiences. The same is true of emotional coping; writing your worries down has been shown to reduce stress and alleviate some pain.

\textbf{Calm your body down}

There are a number of techniques that you can learn to do for yourself to help reduce the pain, which will make you less anxious, such as relaxation exercises, biofeedback, and self-hypnosis. Do whatever feels most comfortable to you. Sign up for classes in meditation, yoga, or tai chi (also called “moving meditation”), or find a trained biofeedback therapist. Practice deep, slow breathing, or go for a long walk or bike ride. Learn more about these techniques from the \textit{painACTION} Tool, “\textit{Complementary and Alternative Medicine (CAM)}.”

The \textit{painACTION} website also has several tools you can use to feel calmer, less stressed, and more relaxed -- feelings which have been shown to make pain more bearable. The \textit{painACTION “Relaxation Response Tool”} for example, teaches a proven meditation method called the \textit{relaxation response} that is used in medical centers throughout the country to help people cope with pain and discomfort. You can also use \textit{painACTION’s “Guided Imagery Tool”} to take your body on a “mini vacation.”
What About Depression?

It’s common for people with chronic pain to have depression. Depression can worsen and prolong the pain. Pain and depression can take over a person’s thoughts and feelings with more pain leading to more depression, creating a cycle that is difficult to break. In the painACTION article, “Depression and pain: Break the cycle” you can learn more details about this. The lesson “How to deal with depression” gives more tips.

These are just some suggestions for ways that others have successfully reduced their stress, anxiety, and depression on their journeys to better pain management. You are a unique individual, however, so it is important to find what works best for you. One way to do this is by looking back at your life to find out how you have successfully coped with emotional problems in the past. A mental health provider can also be helpful in figuring out the best ways for you to feel better. In the meantime, the following lessons on the painACTION website will be helpful:

- “How to develop a positive frame of mind”
- “How to handle stress in your life”
- “How to face the challenges of living with pain”
- “Taking things one day at a time”

An Expert Opinion

Coping with emotions

Q My pain specialist says I have to see a psychologist before he will take me on as a patient. I am not crazy. Do you think I should have to do this?

A Chronic pain causes major problems for many patients, in addition to pain itself, which is bad enough. Patients with pain that lasts for a long time may get depressed, develop anxiety, have
trouble sleeping, or may have trouble in relationships with spouses, friends, and employers. Recognizing this, many healthcare providers suggest that patients see a psychologist to help with any emotional problems while the pain itself is being worked on. So being referred to a psychologist doesn’t mean that anyone thinks you are crazy – it usually means that your healthcare provider is trying to find every possible way to help you.

**Q** I’m told that I need to reduce the stress in my life to help with my pain management. How can that help?

**A** Stress is a part of life, and cannot be completely escaped. This is even more the case when you have chronic pain. As you have seen in this chapter, stress and the anxiety and irritability it may lead to, may make pain more intense, and may also make it harder to cope with your pain. There are many different ways to cope with stress, and learning healthy ways to manage stress can decrease the impact that stress has on managing your pain. Throughout this chapter, there are links to the painACTION tools and lessons that give you useful stress management techniques.

**In Summary...**

- Chronic stress or anxiety can worsen the experience of pain
- Managing stress is important to successful pain management
- Take ownership of your mood and ability to cope with pain
- Depression may occur with chronic pain
  > Talking about depression with a mental healthcare provider can help
When you are traveling in unfamiliar territory, you take a number of precautions to ensure your safety and the safety of the people with you. When you drive a car, you follow the rules of the road. It is important to bring that same caution and respect for safety rules when you use medicine that helps you on your pain management journey.

Using medicine safely applies to all of the medicines you take. This includes those over-the-counter pain relievers or cough syrups you get at the local drug store, as well as the vitamins and herbal supplements you may pick up at a health food store. Sometimes the safety concern is not one specific medicine, but the combination of medicines you take. The best way to know you are using a medicine safely is to be sure that your healthcare provider and your pharmacist know about everything you take. The painACTION website has several articles with good information about this subject, including:

- “Your pain medication: Don’t mix and match”
- “Over-the-counter pain relief: Part of your plan?”
- “What you should know about acetaminophen”

**Prescription Medications Safety Guidelines**

The prescription pain pills in that little bottle may look innocent, but they can be as dangerous as a car accident if used improperly. In this section, you will learn some important—and possibly surprising—facts about pain medication, particularly opioids, facts that will help to ensure your safety. There are a few important “rules of the road” about prescription pain medicine:

**✔ Follow the dosage and frequency instructions EXACTLY**

Never change your medication schedule or dosage (even if you think it is not working) without consulting with your healthcare provider.
✔ Contact your healthcare provider if you experience troubling medication side effects
Use the painACTION “Medication Side Effects Tool” to find out the possible side effects of different medications, and read the lesson “How to manage opioid side effects.”

✔ NEVER give your medication to anyone else
Under any circumstances, it is never safe to share your prescription pain medication with someone else.

✔ Always keep medicine locked up and concealed in a safe place where casual visitors are unlikely to see it or have access to it
You can’t always predict who will be coming to your home; better safe than sorry.

✔ NEVER keep the medication after you no longer need to take it
Discard it safely. The painACTION article, “Getting rid of unneeded medications: Out of sight is not out of mind” will give you specific suggestions.

What are Opioids?
If you have pain that is not responding to other medicine, your healthcare provider may prescribe opioids for you. Opioids—among the oldest medicines in the world—belong to a group of medications called analgesics, which give relief from pain. Opioid is a medical term that describes what are commonly referred to as “narcotics.” The natural opioid, morphine, which comes from the opium poppy plant, has been used as a pain reliever for centuries. Other opioids, such as codeine, fentanyl and oxycodone, are manufactured synthetically.

Opioids are prescribed by healthcare providers to treat pain, control coughs, and treat diarrhea. Some are taken by mouth in pill form, while others are given transdermally (skin patches), intranasally (nose spray), or by injection. In the thousands of years that opioids
have been used to treat pain, no other pain medication has been found that is as effective. This is because our bodies have natural “receptors” in our cells that respond to them. It is as if the opioid medicine is the “key” that fits perfectly in the “lock” of our cells, to open the door to pain management. So far, so good. But there are some problems with opioids if they are used in ways that are not prescribed. As we’ve talked about in previous chapters, good information is a key to travel safety. Here are some definitions to help understand the potential problems with opioids.

**Tolerance**
This can happen naturally when your body gets used to a particular medication. As a result, the medication does not work as well as it used to and you might feel that you need to take more of it to get the same relief. *You should never make your own decision about this.* Always discuss the situation with your healthcare provider (*tolerance* is very different from addiction, which is discussed below). Sometimes the solution is simply to change medications or add a new medication.

**Dependence**
This is another naturally occurring state that happens when your mind and body get used to a medication, but in a different way than tolerance. When you become physically *dependent* on a medication, your body actually needs this medication in order to continue working properly. This means that *you should never suddenly stop taking any medication* without first talking to your healthcare provider.

**Misuse**
This refers to taking a medication in a way that it was not prescribed, or for a condition other than the one for which it was prescribed. If you have medication for your back pain but decide to take it to help you sleep, for example, that is *misusing* it. *This is something you should never do because it is unsafe.*
Abuse
If you use a prescription pain medicine to get a result that has nothing to do with the pain it was intended to treat, this is abuse. You are abusing your pain medicine, for example, if you take it to feel better, or get “high.” Like medication misuse, abuse is very dangerous. You are not trained to understand the ways in which medications interact with anything else you are taking or with your physical condition. Abusing your medication is just as dangerous as driving recklessly or ignoring safety warnings while traveling. Respect the rules laid out by your healthcare provider, and protect the safety and health of your body.

Addiction
People who become addicted to a prescription pain medication are abusing the drug uncontrollably, to the point where it is causing physical harm. Unlike tolerance and dependence, addiction is an unnatural state. If you feel you are becoming addicted to your medication, meaning that you feel the need to take more and more of it and cannot control yourself, seek immediate medical help.

Diversion
You wouldn’t hand your car keys to an unlicensed driver, and you wouldn’t send a friend into a dangerous or unfamiliar city alone. Use these instincts about safety when it comes to your prescription pain medication. Your medication is meant only for you. You should never give it anyone else, either for money or because you think it might help him or her. You are not a trained pharmacist, so you can’t possibly know which medications work safely for each person.

There is much more information about medication safety on the painACTION website, including articles, tools, and lessons. Here are some suggestions:
• “Opioid medication basics”
• “How to start an opioid safely”
• “How to discuss opioids with your healthcare provider”
• “How to travel with opioids”
• “Caution: More websites selling drugs”

Safe Storage and Disposal

When you are behind the wheel, you are not only responsible for your own safety, but also for the safety of the other people in your car. If you took your friends or family on a trip, you would do your best to keep them as safe as possible. Accidents happen, but taking the right safety precautions reduces the risk. When it comes to pain medication, these precautions are not just limited to proper usage. Not only is it important to use your prescription pain medication safely, you must also know what to do when you are not using it. These are powerful drugs and if they fall into the wrong hands they can cause severe consequences, and even death.

Abuse of prescription pain medications is reaching epidemic levels in this country, especially among people between ages 18 and 33. Most of these young people get the medications from their friends or family. In 2007, of the 467 drug-related overdoses leading to death in the state of Utah, 317 were attributed to legal drugs and 261 of them involved prescription pain medications. So if you have these powerful prescription pain medicines in your possession, you have a responsibility to prevent anyone else from finding and using them. You can do this by locking and storing them in a hiding place that only you know about, and disposing of any leftover medications in a way that makes sure no one will get them. The painACTION lesson “How to take, store, and dispose of opioids,” has some useful suggestions.

An Expert Opinion

Medication Safety

Q If I take an opioid pain medication you are prescribing for me, will I become addicted?
There is a chance you may become addicted. The risk of addiction may not be high, although some experts state that it can range from 3-20%. You might, however, become dependent on the medication, which means you should never stop taking it suddenly; you also might become tolerant, which means your healthcare provider might need to increase the dosage of your prescription. It is important to use the medicine ONLY as it is prescribed, without misusing or abusing it. If you feel you are becoming addicted, tell your healthcare provider so you can get the help you need. And certainly remember never to divert this medication to anyone else because you would be giving them a very powerful substance that could do harm.

The last time I took an opioid, I was constipated for a month. Is there anything I can take or do after my upcoming surgery to prevent that?

All opioids may cause constipation. In fact, it is the most common side effect of these medicines. This side effect is more of a problem for some people than others. Uncontrolled constipation is a leading reason that patients don’t take their pain medicines as instructed. The first thing to do is to tell your healthcare provider that opioid-related constipation is a big problem for you, and ask that a stimulant and/or laxative be prescribed along with the pain medicine. Most laxatives are taken by mouth and some can be taken as a suppository.

The usual advice about preventing constipation—increasing fluids and fiber in the diet—are probably not helpful for opioid-related constipation. Some laxatives, known as stool softeners, may be helpful, but are not enough. Opioid-related constipation requires a stimulant laxative that encourages the bowel to move the stool along and makes it easier to have a normal bowel movement. Most laxatives are available without a prescription—ask your doctor and pharmacist for specific recommendations. It is very important to prevent and treat
constipation. If it becomes a problem for you, let your healthcare provider know so the treatment plan can be changed.

Q

I’ve been on the same pain medicine now for a year, and it seems that my pain is worsening. Is it possible that the medicine is no longer working for me?

A

There are many things that can affect how well a medication is working to control the pain. If you have been on the same medicine and dose for a long time and notice a change that lasts more than a few days, here are some things to discuss with your healthcare provider.

- Have you changed your diet or changed other medicines recently—including herbals and natural products?
- Has the brand of pain medicine changed?
- Have you had unusual stress?
- Have you been sick?
- If there is a known cause for your pain, when was the last time you had a checkup? It is possible that the underlying condition that caused the pain has worsened. See also the definition of “tolerance” above, since this could be a factor as well.

Another possibility is that there has been a buildup of “metabolites,” which can actually increase pain, called hyperalgesia. Almost all drugs are processed in the body and changed in some way as they move through the liver. Sometimes this processing creates by-products or metabolites. For most patients this is not a problem, because the by-products are removed by the kidneys and leave the body in the urine. If the kidneys do not remove enough of the metabolites, they can build up and make the nerves more sensitive to things that wouldn’t normally cause pain. Sometimes, changing to a different pain medication takes care of the problem, and your pain will be under better control again.
In Summary...

- Tolerance, dependence, misuse, abuse, addiction, and diversion have different meanings
- Medications can be a very effective way to treat some types of pain, but it is important for them to be taken exactly as directed
- Contact your healthcare provider if you have medication side effects
- NEVER give prescription pain medicine to anyone else
- ALWAYS store your medicine in a concealed, secure, safe place
- Discard unused medicine safely (you may get information about this from your pharmacy)
Part II
Your Personal Pain Profile
Your Personal Pain Profile

In this part of the book our “travel guide” gets more specific. If you are dealing with back pain, migraine, cancer-related pain, neuropathic pain, arthritis pain, or experiencing post-deployment pain as a returning military service member, refer to the appropriate chapter or chapters in this part. First, however, please take a moment to read this overview, since it will help you take better advantage of the information in the upcoming chapters.

The six types of chronic pain discussed in this section are, of course, quite different from each other, but they also have several common features. Each of them can be with you for many years. However, like any long journey, the more you travel, the easier it gets. Each of these types of pain requires “baggage,” but the type of load you are carrying may be different. If you have back pain, for example, you probably feel as if you are carrying some sort of burden every day, because your back never gets a day off! It must work all day long, even when you lie down, to support your body. With back pain, the only difference from day-to-day is, “how much pain will I be in today? Will I be able to do the things I want and need to do?” So, in the back pain chapter we discuss how to modify your
life to minimize and manage the pain you might be dealing with every day.

By contrast, migraine pain may leave you free of baggage for days or weeks at a time. The question here is “Will I get a migraine today?” The uncertainty is of course a difficult burden to carry, but you can be sure that if you do not get a migraine, you will be able to have a normal day. So, the challenge here is what can be done to prevent the headache from beginning, and how to minimize the pain if you do get one. These are the questions we focus on in the chapter about migraine pain.

Cancer-related pain is quite different from other types of chronic pain. Because of advances in cancer treatment, people are living longer and many achieve remission from the disease. Rather than worrying about survival, many cancer patients now are shifting their attention to the pain that results from either the treatment or the long-term effects of the disease itself. In the cancer chapter, therefore, we focus on the causes and types of cancer-related pain and the most effective ways to manage them.

Neuropathic pain can develop suddenly or over time, and your baggage may be “what is going to happen next” since its course and response to treatment can sometimes be
unpredictable. At the same time, by speaking up about your pain, by continuing to search for better treatment and a better quality of life, you are helping healthcare professionals become better at identifying neuropathic pain, and encouraging them to work to develop better treatments.

While there are many kinds of arthritis, osteoarthritis, which is primarily a result of the long-term “wear and tear” on your joints, is the most common. Since everyone is on the journey through life, and the expectation for longevity in the United States continues to increase, managing the pain and potential disability of osteoarthritis has become a national priority.

Returning military service members with chronic pain may find that their “baggage” results from the increased likelihood of surviving an injury that may have been physical, emotional, or both, and may have resulted in continued chronic pain. Unfortunately, feeling alone and uncared for is often a common experience for service members, and great efforts are being made to right that wrong.

To sum up the chapters in this section, there are different ways you might wake up in the morning: If you have
back pain, arthritis pain, or neuropathic pain (Chapter 7, 10, 11), you might be thinking, “How bad is today going to be?” If you have migraines (Chapter 8), your question might be, “Is today going to be a good day or a bad day?” If you have cancer-related pain (Chapter 9), your feelings might be mixed: “I’m happy to be alive and cancer-free today, but how do I cope with the long-term pain that remains?” And as a returning military service member (Chapter 12) you may be thinking, “Does anybody care about my pain?”
If you are on a journey to manage your back pain, you have plenty of traveling companions. Government surveys report that back pain is the second most common neurological ailment in the United States (headache is the most common). At some point, nearly everyone has back pain that interferes with work, routine daily activities, or recreation. Low back pain is the most common cause of job-related disability and is a leading contributor to missed work. Other research has found that one quarter of Americans report that they suffer from back pain, particularly low back pain that lasted a whole day, and almost 14% of Americans report neck pain. Back pain is also very expensive. It is estimated that Americans spend about $50 billion each year on low back pain treatment.

So now that you know you are not alone, what is this problem all about? This chapter talks about some of the main causes of back pain, and will direct you to more information about prevention and treatment on the painACTION website.

Your back extends from the top of your neck down to your tailbone, and you can have pain anywhere along that long stretch of spine. Sometimes, the pain might even radiate to your arms and legs. The spine is a collection of bony rings called vertebrae. Their major function is to provide support for the body and protect the spinal cord—a kind of “scaffolding” for your body. The vertebrae are stacked on one another, and are separated by firm, pliable “cushions” called discs. The stack of bones and discs is held together by ligaments and moved by muscles. The vertebrae form a kind of “tunnel” that houses the spinal cord -- a collection of nerves that form a “communications center”, sending and receiving messages from your brain, and branching off to the rest of your body. The “Anatomy of the Back” tool from painACTION has helpful diagrams and explanations.
The back never gets a moment off, even when you are sleeping! The muscles attached to the spine must always be working to keep it in alignment. So if you have back pain, you probably feel as if you are always carrying some form of “baggage” on your journey to pain management. Some days your burden might be lighter, and some days it will be heavier – but you are probably always aware of the potential for pain. In this chapter, you will learn the most common causes and types of back pain, as well as suggestions for how to manage it. For more details, please consult the Back Pain section on painACTION.

**Categories of Back Pain**

The most common types of back pain originate in one or more of three places in the back:

- The bones of the spine, the vertebrae
- The muscles, tendons, and ligaments attached to these bones
- The nerves that come from the spinal cord that weave in and out of the spine

Structural changes in bones or soft tissue can press on nerves, which results in pain. In some conditions, the nerves themselves become inflamed, and this causes pain. The conditions and symptoms described below fall into one or more of these three categories.

**Muscle Strain or Sprain**

This is the most common cause of back pain, since no matter what your position, your muscles are always working to hold your spine in alignment. The muscles of your neck work especially hard since they hold up your head, which weighs between 8 and 12 pounds. Muscle injury causes inflammation and swelling of the soft tissue, which may press on nearby nerves, resulting in pain. With commonsense treatments including rest, mild stretching, ice, and/or heat, most muscle strains and sprains resolve on their own.

**Wear and Tear**

As we get older, the bones, muscles, and ligaments of the spine are exposed to wear and tear, especially if you participate (or have par-
Anticipated in younger years) in contact sports or other activities that subject the spine to impact. By contrast, moderate exercise, such as walking, jogging, or stretching, is actually beneficial because it promotes blood flow to the spine.

Wear and tear cause symptoms in the bones and nerves of the spine. These include arthritis of the spine, which is called *spondylosis* [*pronounced ‘spondi – lo-sis’*]. *Spinal stenosis* is one form of arthritis where there is narrowing of the space within the spinal canal. Both of these conditions can cause pain by compressing or “pinching” spinal nerves.

**Osteoporosis**
As the body ages, bones often become thinner and more brittle, especially in post-menopausal women. Osteoporosis can be treated by diet, weight-bearing exercise, and medications, but it still has the potential to cause pain. Thinner vertebrae can also fracture, either due to physical activity or simply because of the effects of gravity on the spine.

**Herniated (slipped) Disc**
Discogenic back pain occurs when the cushioning, shock-absorbing discs between the vertebrae malfunction or break, slipping out of position and pinching spinal nerves.

**Spondylolisthesis**
*Spondylolisthesis* [*pronounced ‘spondi –lo-lis –thesis’*] occurs when one vertebra in the spinal column slips forward over another. This disrupts the whole integrity of the spine, destabilizing it. When the spine is destabilized, the vertebrae pull on muscles, ligaments, and other discs, compressing nerves and causing pain.

**Sciatica**
The sciatic nerve is actually a collection of spinal nerves joined together at the lower part of the spine. At the end of the spine, the sciatic nerve splits in two, sending branches through the buttocks and down the back of each leg all the way to the feet. When any one nerve in this group gets irritated or compressed, it sends pain signals to all of the other nerves, and this pain can extend all the way down the leg.
Back Pain Management

The conditions above can cause pain that can be described as aching, stiffness, burning, “crackling”, shooting, stabbing, or throbbing. The different experiences of pain mean that it is very important to describe the pain accurately to your healthcare provider, including its location. Back pain is not only felt in the back, but may radiate outward to arms and legs, and appropriate treatment depends on a correct diagnosis.

Now that you understand the common sources of back pain, you can take advantage of the pain management skills described in Part 1 of this book. You may also find the tools, lessons, and articles on painACTION useful. Here are a few suggestions to get you started:

- “Back pain treatment: Myths and realities” (Article)
- “Back spasms: What they are, what to do” (Article)
- “Back Pain Circle of Care” (Tool)
- “How to save your back doing everyday tasks” (Lesson)

In Summary...

- If you suffer from back pain, you’re not alone. Back pain is the most common cause of job-related disability
- The back never gets a moment off; it’s working even when you’re sleeping
- Any part of the back and spine can cause pain
- Back pain is not only felt in the back – sometimes it may radiate outward to arms and legs, and appropriate treatment depends on a correct diagnosis
Your interest in this chapter probably means that you don’t need to be told what a migraine headache feels like. The throbbing or pulsating pain in your head, accompanied by nausea or vomiting, and a sensitivity to light and noise, are all too familiar. What you may not know however, is that while nearly half of the 30 million Americans with migraines could benefit from preventive therapies, only 1 in 5 currently take advantage of them, according to the National Headache Foundation. Preventive therapies can decrease the occurrence of migraine by 50 to 80 percent, as well as reduce the severity and duration of migraines that do occur. Yet many migraine sufferers are not incorporating these into their treatments.

Migraines are sometimes set off by a combination of causes, also called “triggers”, and these may be different for each person. They may include some combinations of eating and sleeping habits, certain foods, muscle tension, stress, medications, hormone changes, and even the weather. While you can stay away from some migraine triggers, such as certain foods, and reduce others, such as stress or muscle tension, it is impossible to avoid all stress, changes in your hormone levels, and of course, the weather. So it is important as you begin your pain management journey to have a complete diagnosis and assessment of what is causing your migraines, so that you can arrive at an effective treatment plan. In order to do this, you’ll need to be in partnership with a knowledgeable healthcare provider – a travel guide on your journey to migraine prevention and treatment. If you and your provider can identify and then reduce or eliminate your migraine triggers, your journey will be that much smoother and the burden of “pain baggage” that you carry will be lightened!

Did you know that half of the people with migraine headaches choose to “travel alone” by treating themselves and not seeking medical help? Traveling alone on the journey to migraine management is never a
good idea. The problem with trying to treat your migraines by yourself is that you may not have the correct diagnosis, and you will also be missing out on a professional, personalized, and systematic approach to pain relief.

While medications can be successful in preventing migraines (and you should discuss these with your healthcare provider), a big focus of this book is the self-management of pain. What can you change about your lifestyle, coping mechanisms, and diet that can reduce your migraine triggers? Read the painACTION lesson “How to recognize headache triggers” for more information.

As is true for most types of chronic pain, there is usually not one single solution: Your migraine relief will depend on putting together a “package” of treatments, including medication, that responds to your own migraine triggers. And for this, you need a healthcare provider who will become your long-term partner in finding the right collection of treatments for you. (Refer back to the chapters in Part I about communication and creating partnerships with your healthcare provider.) The painACTION lesson “How to understand migraine treatments” summarizes and explains various migraine treatment options.

Preventing Migraine: You in the Driver’s Seat

While there is much about migraine causes that is not understood, we do know that lifestyle, food, and other measures that you can take, can prevent the headache, or at least reduce its power. Rather than feeling like a helpless victim of your headaches, you can be in the driver’s seat and take some control. Here are several suggestions to discuss with your healthcare provider. You can find many more, in the articles, lessons, and tools in the Migraine section of painACTION.

Traveling Food

As you travel toward your destination of migraine management, consider the food that you take along on your journey. Many foods and beverages, including cheese, chocolate, and caffeine, have been
shown to trigger migraines in certain people – although in some cases, caffeine is also used to control migraines. These painACTION articles discuss the relationship between what you eat and drink and migraine headache:

- “Understanding migraine triggers”
- “Caffeine and migraine”
- “Can drinking alcohol cause migraines?”
- “Hypoglycemia and migraine”

**Lower the Stress**

Your levels of stress, anxiety, and depression, can also trigger migraines, so experts recommend that you incorporate stress-reduction techniques into your life. You can find stress-management information on the painACTION website:

- “How to cope with emotional distress” (Lesson)
- “Depression and pain: Breaking the cycle” (Article)
- “How to use relaxing images to reduce pain” (Lesson)
- “Six ways to reduce anxiety” (Article)

**Broaden Your Options**

If you’re frustrated because your migraine headaches have not responded to treatment, you are not alone. Half of all people with migraines stop seeking care for their headaches partly because they are dissatisfied with their treatment. Before you go that route and decide to simply live with pain, consider broadening your options. Research shows that combining treatments from several different medical specialties—called a “multidisciplinary” approach—can be helpful in the treatment of migraine. The painACTION article “Holistic migraine treatment” describes a holistic, multidisciplinary approach to migraine treatment, including biofeedback, relaxation training, herbs and botanicals, craniosacral therapy, yoga, and Tai chi.
Other painACTION resources to review include:

- “Positive Frame of Mind” (Tool)
- “Relaxation Response” (Tool)
- “Using biofeedback to manage migraines” (Article)

In Summary...

- Migraines are sometimes set off by a combination of causes – also called “triggers”; and these may be different for each person
- It’s important to have a complete diagnosis and assessment of what’s causing your migraines so you can arrive at an effective treatment plan
- As is true for most types of chronic pain, when it comes to migraines, there is usually not one single solution, but a group of strategies. Don’t give up!
If you are a cancer survivor, your pain management journey is unique: You most likely began your travels with the goal of simply surviving the disease. Pain was probably not uppermost in your mind when you first received your cancer diagnosis. Now that treatments are better at battling your disease, or maybe have put it into remission, you may find yourself revising your travel destination: You would now like to live more comfortably, with less pain. In this chapter we will talk about the major sources and types of pain for people with cancer as well as treatment options for each. The painACTION section on cancer has additional information about coping with cancer pain, and also has expert advice about the effects of cancer on your family.

Cancer isn’t always painful. But if you do have pain, it is important to tell your healthcare providers and to expect to work in partnership with them to manage it. You have the right to pain treatment, so do not be shy about expressing your need for help. At the same time, you must do your part by sharing the details of your pain experiences with your providers. Everyone’s pain is different, so no one but you knows when there’s pain and exactly how it feels. Also, everyone responds differently to pain and pain treatment, so what works for one person may not work for another. Both Chapter 1, on partnerships with your providers, and Chapter 4, on communication, are particularly relevant if you are dealing with cancer-related pain.

**Where Does Cancer Pain Come From?**

Cancer-related pain usually comes from one or both of these sources:

- Pain due to the cancer itself, such as a tumor pressing on a nerve or organ
- Pain due to cancer treatments:  
  - *Chemotherapy* side effects may include mouth sores, pain and tingling in the fingertips and or toes, pains in your bones or joints when you walk or move.
- **Radiation** side effects can include skin reactions and localized pain. For example, radiation to the head or neck may cause a sore throat.

- **Surgery and/or procedures** can cause pain to incisions and during recovery. In addition to being painful, cancer surgery can be scary: You might worry about what will happen during the operation. You may wonder what the surgeon will find, and whether you’ll be in pain afterwards. It’s common to feel alone at this time, and to be anxious about the future. The *painACTION* article, “Coping with pain after cancer surgery” describes the physical and emotional effects of surgery, and its after-effects, including pain.

**Two Kinds of Pain**

No matter where your cancer-related pain is coming from, it usually falls into one or both of these two categories:

- **Nociceptive pain** is pain caused by stretching, pressure, or injury to tissues, muscles, or organs anywhere in the body and includes aches or pains deep within the body.

- **Neuropathic pain** is caused by pressure, injury, or irritation of nerves. People usually describe it as burning, stabbing, shooting, or electric-shock like pain. Neuropathic pain can come on without warning and persist, on and off, for weeks, months, or longer.

While there are specific things to do for pain associated with radiation, chemotherapy, and surgery described in several articles in the *painACTION* cancer section, treatment depends on the **type** of pain you are having, and whether it is mild, moderate, or severe. As described in earlier chapters, it is the **quality** of the pain—and your own experience of it, including how it is affecting your life—that is most important. This is why **it is critical to communicate and work in partnership with your healthcare providers** – your travel guides in your journey to manage cancer-related pain. Common cancer-related pain problems, discussed in more detail in the articles, include skin reactions to radiation, mouth sores due to chemotherapy, as well as swelling and pain (lymphedema) after cancer surgery.
As with other types of chronic pain, it is very important that you seek professional help in managing cancer-related pain. Be sure to tell your healthcare provider everything you are doing or taking—including herbs, dietary supplements, and over-the-counter medicines—for your pain, since there can be dangerous interactions.

**Emotional Pain**

When coping with cancer, the physical pain you might have is only part of the experience. You are also dealing with a serious, frightening, unpredictable disease. It is only natural for you to have some emotional discomfort as well, especially when it comes to your children and other family members. The painACTION cancer section has several articles, lessons, and tools to help you cope with the physical and emotional pain that cancer brings. Here are just a few examples of the advice you will find there:

- **Realize that you are more than your body**
  You are still “you,” even if your body has changed, or parts of your body don’t work like they did before

- **Ask for help**
  Reach out to get help from your caregiver, partner, friend, or another family member

- **Recognize the healing power of time**
  As you recover from surgery and/or cancer treatments, you will be able to move on with your life, even if it doesn’t feel that way right away

- **Share your wide range of feelings**
  Communicate with a professional, a cancer support group, or by writing in a journal. Even if your cancer has been found and treated, you may still feel grief, anger, shock, or resentment that this illness happened to you in the first place. All of these feelings are normal.
Seek spiritual support

Spiritual and religious practices and beliefs may help you to cope with the pain of cancer and with the uncertainty and fear of a cancer diagnosis. Many people rely on faith to make sense of their lives and to feel connected to others—but you may also be looking for a connection to something larger: This could be some form of higher power or “god;” or maybe the worlds of nature, music or art; or even a deep attachment to the people you love. For some people, spirituality comes in the form of organized religion, but this certainly is not necessary. Spirituality is found in all cultures and, for many people, it also includes a search for the meaning of life. If you are interested in reading more, go to the painACTION article “Coping with cancer through spirituality.”

In Summary...

• You have the right to pain treatment, so do not be shy about expressing your need for help
• Cancer pain may be related to the cancer itself, or as a result of its treatment
• It is critical to communicate and work in partnership with your healthcare providers to manage cancer pain
• When coping with cancer, the physical pain you might have may only be part of the experience. There could be emotional aspects of your pain that need to be addressed.
Imagine that you wake up to the sound of a smoke detector going off in your house. You remember that you burned something while cooking the other day, but the smoke has cleared out since then – so why is the smoke detector still setting off the alarm? Neuropathic pain is very similar to a malfunctioning smoke detector because what set it off may be a mystery.

**What is neuropathic pain?**

Neuropathic pain affects nearly 20 million people in the U.S. It can be hard to diagnose, difficult to understand, extremely painful, and for some people, very disabling. People with neuropathic pain may have one or more of a variety of different symptoms. For example, they may feel sensations of sharp pain, dull pain, tingling pain, and even burning pain. Neuropathic pain may change the route of your life’s journey. But with appropriate management techniques, understanding, and knowledgeable “tour guides,” you can find your way to your destination, although it may be different than your original plan.

Because neuropathic pain can be hard to understand, hard to diagnose, and sometimes is invisible, it is very important to learn as much as you can about it to understand the “territory.” Sometimes this can be a lot of work.

To better understand neuropathic pain, it’s helpful to know how your nerves work. Nerves act as messengers between your body and your brain. When you injure yourself, your nerves send a message to your brain, causing you to feel pain. This is actually protective as it is a warning, not unlike the red light on your car’s dashboard that tells you something is wrong and needs attention. Usually, after you’ve injured yourself and feel pain, the injury heals and the pain goes away, just like when you fix the car problem. This is called *nociceptive* pain.
With neuropathic (nerve) pain, the source or site of the pain isn’t always clear. In neuropathic pain, the nervous system can malfunction and fire off pain messages to your brain repeatedly, creating an endless cycle. The pain signals continue to travel back and forth between your brain and body. As a result, you may feel pain for what seems to be no obvious reason. The “faulty smoke detector” might sound the alarm for months, or even years, making it hard to work, sleep, or even perform daily tasks. To better understand this cycle, see the “Neuropathic Pain Cycle Tool” on painACTION.

What causes neuropathic pain?
The cause of neuropathic pain may not always be completely clear, even to your healthcare provider. Sometimes it’s the result of an injury or chronic disease, and sometimes it’s the result of the treatment for certain diseases.

Examples of different causes of neuropathic pain include:
• Diabetes
• Post-herpetic neuralgia resulting from a shingles attack
• Phantom limb pain after a limb amputation
• Cancer surgery
• Chemotherapy or radiation treatment for cancer
• Complex Regional Pain Syndrome

Diabetic neuropathy is a common disorder that affects people with long-standing or poorly controlled diabetes. Symptoms typically include tingling, burning, and/or numbness in the lower legs and feet, but pain may radiate to other body parts as well. The National Institutes of Health estimate that between 60% and 70% of people with diabetes also have neuropathy.

Shingles is the acute outbreak of a blistering and extremely painful rash along neural pathways in certain areas of your body, often your back or the side of your chest. The pain is caused by an inflamma-
tion of nerves affected from the chickenpox virus, which healthcare providers call the “varicella-zoster” virus. It only occurs in people who have had chickenpox in the past. If you’ve had chickenpox, the virus stays “sleeping” in your body and may reappear as shingles in adulthood, for no apparent reason. Shingles-related pain can last for an indefinite amount of time even after the rash has healed. When this happens it is called post-herpetic neuralgia (PHN). PHN is one of the more common types of neuropathic pain, usually occurring in older people.

Phantom limb pain is a type of neuropathic pain that may often occur when a person has a limb amputated. Although the limb is no longer there, the nerves from the remaining part of the limb still send pain signals to the brain that appear to be coming from the limb. This is because the “wiring” in the nervous system is not working properly, sending messages that can feel like itching, burning, shooting, or throbbing, from the “missing limb.” This can have a devastating effect on a person’s quality of life.

Pain after cancer surgery is a growing concern, especially after breast cancer surgery, as the number of people surviving cancer grows. Researchers are paying attention to this problem and are developing recommendations for surgical techniques that will lower the risk of this happening.

Chemotherapy or radiation for cancer can also lead to neuropathic pain because they may have caused a nerve injury or inflammation of nerves. These are sometimes known to be possible side effects of these treatments, so understanding this in advance may help the patient and healthcare provider plan ways to lessen the likelihood that this will happen. Sometimes treatment is adjusted, depending on the severity of the pain.

Complex regional pain syndrome (CRPS), formerly known as reflex sympathetic dystrophy (RSD), is characterized by severe pain that lasts long after an injury has happened and appears to have healed,
usually affecting the area where the injury occurred. The injury may have been as minor as a sprained ankle, or as severe as a fracture. Symptoms include excruciating pain that can also feel like burning, sensitivity to even the lightest touch, such as clothing or a sheet, and swelling and redness in the affected area. It is important to seek medical attention to try to diagnose CRPS early. Because it may be hard to recognize and should be treated aggressively once it is identified, finding a knowledgeable health care provider is very important.

There are many articles on painACTION that provide more information about different types of neuropathic pain.

- “Diabetic neuropathy: Prevention and treatment”
- “Postherpetic neuralgia: Shingles pain that doesn’t stop”
- “Cancer and neuropathic pain: Tingling, numbness, and sensitive nerves”
- “Pain that continues after breast cancer surgery”
- “Understanding phantom limb pain”
- “Trigeminal neuralgia: When your face is on fire”

Managing Neuropathic Pain

Because neuropathic pain is seemingly “invisible” it may be difficult to talk about it and to find ways to manage it. It can be very discouraging to feel like you’ve steered off course during your journey, but there are roads that may be manageable. Below, you’ll find some information to help you with this type of pain. You can find more articles, lessons, and tools about living with neuropathic pain on painACTION.

✔ Learn the language of neuropathic pain

It might be hard to describe your pain. Both words and actions can help your healthcare providers better understand the source of your pain and try to figure out the diagnosis. Point out the exact areas where the pain strikes, and don’t be afraid to use descriptions such as “on fire” “excruciating” or “throb-bing.” The more specific you are the better. When it comes to your pain, especially neuropathic pain, every detail matters!
✔ Understand that pain management is not the same thing as a cure
Unfortunately, there isn’t often a one-size-fits-all treatment that works over the long-term for people with neuropathic pain. A lot of patience is going to be required for the diagnosis to be determined, and even more patience for treatment approaches to have an effect. It can take months. Most people who have neuropathic pain will tell you that the path from identification to effective treatment is a long and winding, and sometimes quite a “rough road.”

It’s important that you don’t confuse a long-standing treatment plan with a “cure.” For most people, there may be no permanent or complete solution to neuropathic pain. It may come down to a matter of coping and getting support from others. Support from others is often a critical piece of the road map when it comes to neuropathic pain. Certainly realistic goals and expectations are going to be important.

✔ Realize that research is ongoing – and that you can be a part of it
Research about neuropathic pain management continues to grow. There are many reasons to be optimistic about the increased ability to diagnose it sooner and treat it more effectively. In the year 2011 there were 170 research studies in the works relating to neuropathic pain treatment. Many studies often actively look for participants with neuropathic pain. If you are interested in learning more about up-and-coming research and/or clinical trials, you can read the painACTION article, “Thinking of joining a clinical trial” and search for a trial on the National Institutes of Health website www.clinicaltrials.gov.
Neuropathic pain will define the course of your journey, possibly more than any other type of pain. The painACTION website has much more information about neuropathic pain management, including:

- “The Neuropathic Pain Cycle” (Tool)
- “The language of neuropathic pain” (Lesson)
- “What makes neuropathic pain different from other pain” (Article)
- “Why aren’t there better treatments for neuropathic pain?” (Article)

In Summary...

- Neuropathic pain reveals itself in different ways and affects people differently
- The cause of neuropathic pain may not always be clear; although this type of pain is often associated with certain situations or health conditions, such as an injury or diabetes
- To ensure appropriate diagnosis and treatment, it is important to use your own words to explain your symptoms to your healthcare provider
- There is no standard treatment for neuropathic pain, so it will require you to be patient
- Research about new management techniques for neuropathic is ongoing, so don’t lose hope
If you have arthritis, pain may be a part of your journey from time to time. But you’re not making the trip alone since arthritis is one of the most common health problems in the U.S. In a recent government survey, nearly 50 million people reported that they had been diagnosed with some form of arthritis. In addition, 21 million people can’t perform some daily activities because of their arthritis condition.

Pain is one of the hallmark symptoms of arthritis. Arthritis-related pain occurs because the supporting structures of your body – your bones and joints – become damaged or swollen. And unlike other kinds of pain, it may feel worse after periods of rest rather than after activity.

Contrary to popular belief, arthritis doesn’t just affect the elderly (usually defined as age 65 or older) as many Americans younger than age 65 have some form of arthritis, too. Since many “baby boomers” are now reaching the age of 65 that may not seem very old. “Baby boomers” have been more actively involved with sports and exercise than previous generations, and may actually be even more at risk of developing degenerative osteoarthritis because of the increased wear and tear to their joints. As the population continues to age, the number of people living with arthritis will continue to rise as well. With an annual healthcare cost of more than $80 billion, arthritis is also one of the most expensive health conditions and is likely to become even more expensive.

To better understand how to manage arthritis-related pain, it’s helpful to know a little bit about the condition. First of all, “arthritis” isn’t just one disease. There are more than 100 different types of arthritis conditions, all of which may include joint inflammation, which is the basic definition of arthritis. A joint can be thought of as a “meeting point” between two bones. Without joints, you wouldn’t be able to
move or bend. Inflamed joints often cause pain, swelling, and stiffness, and can seriously limit the ability to get around and do everyday activities. Different types of arthritis affect different numbers of joints, so your symptoms may vary depending on what type of arthritis you have. Osteoarthritis, rheumatoid arthritis, and gout, are among the most common types of arthritis.

**Osteoarthritis**

Osteoarthritis (OA) is the most widespread type of arthritis in the U.S. It is referred to as a *degenerative joint disease* because this type of arthritis typically results from “wear and tear.” The most common cause of OA is aging. Over time, the smooth surfaces of a joint may wear away or become irregular and roughened. Along with the roughness often comes irritation (inflammation) of the joint surfaces, which can be painful. Just like the brake pads on your car, joints can wear out. A joint may also be more likely to become “arthritic” if there was a past injury, such as a fracture or torn cartilage, when you were younger. OA pain may be accompanied by stiffness, “cracking,” or creaking in the affected joint. OA usually worsens over time.

**Rheumatoid Arthritis**

Rheumatoid arthritis (RA) is the most common arthritis-related *autoimmune disease*. With an autoimmune disease, the body’s immune system attacks healthy tissue as though it was a foreign invader, like a bacteria or a virus. RA can affect many joints in the body at the same time, while OA is usually limited to one or two joints. Unlike OA, RA typically affects people at an earlier age, and may even occur in children; it is usually a progressive disease. Much like OA, RA usually causes some limitation of physical activity and pain. People with RA often have other symptoms besides pain and joint involvement. The table below summarizes the differences between OA and RA.
<table>
<thead>
<tr>
<th></th>
<th>Osteoarthritis</th>
<th>Rheumatoid Arthritis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age of onset</strong></td>
<td>Usually affects people over age 60</td>
<td>Can strike at any age, but generally affects 20 to 50 year olds</td>
</tr>
<tr>
<td><strong>Cause</strong></td>
<td>“Wear and tear” of the joints over time, previous injury</td>
<td>Autoimmune disease</td>
</tr>
<tr>
<td><strong>Joint involvement</strong></td>
<td>Can affect one joint</td>
<td>Usually affects many joints throughout the body</td>
</tr>
<tr>
<td><strong>Stiffness</strong></td>
<td>Stiffness usually occurs for a short period of time in the morning</td>
<td>Stiffness can last for hours or for a whole day</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Common in men and women</td>
<td>Affects more women than men</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td>X-rays are helpful</td>
<td>Lab tests can identify the problem along with x-rays</td>
</tr>
<tr>
<td><strong>Other symptoms</strong></td>
<td>Pain and swelling in the affected joint(s)</td>
<td>Pain, chronic fatigue, fever, weight loss, along with swelling of the joints</td>
</tr>
<tr>
<td><strong>Treatment options</strong></td>
<td>Pain relievers (over-the-counter or prescription), physical therapy, mobility aids, surgery when necessary</td>
<td>Pain-relieving medications along with “disease-modifying” medications to halt the progression of disease, mobility aids, surgery when necessary</td>
</tr>
</tbody>
</table>
Gout

Gout is another common form of arthritis that can cause excruciating pain, tenderness, and swelling of certain joints. It is triggered by a buildup of uric acid in the body, which deposits as crystals within the joint(s). Gout pain can occur suddenly and usually affects a single joint when it strikes. Although it often starts at the base of the big toe, it can affect other joints in the body, such as ankles, knees, wrists, and hands. A “gouty attack” can come on suddenly, and be so painful that it might wake you from sleep. The condition is more common in men, but women are increasingly prone to gout after menopause. Other risk factors include being overweight or having a history of eating rich foods and drinking alcohol. Gout may also run in families.

Arthritis Pain Management

There are many possible treatments for arthritis-related pain. While the specific type of arthritis usually plays an important role in choosing a treatment plan, some forms of treatment are commonly used for all types of arthritis. Many people will use a combination of ways to deal with their pain on their journey to pain management.

✔️ Medications to reduce pain

There are many medicines available to treat the pain of arthritis. Some can be purchased at a drug store without a prescription, and some require a healthcare provider to prescribe them. Medicines can come in a variety of forms, including creams, pills, and injections into the joint itself. Since many of these medicines can be purchased without a prescription it is important to keep your healthcare provider informed about everything you use to treat your arthritis pain, to avoid problems than can result from taking more than one medicine at a time.

✔️ Medications to treat the cause of the arthritis condition

Both rheumatoid arthritis and gout are examples of medical conditions that may be treated with prescription medicines meant to change the underlying disease that is causing the pain. Making the decision about which medicines to use, and
when, can be complicated; your healthcare provider will weigh the benefits and risks of each option available to you. Treatment with medicines may need to be repeated over time, as the disease may occasionally “flare-up” and become more active.

**Non-medication ways to reduce pain**
There are many ways to reduce arthritis pain without using medicine, including the use of heat or cold, physical therapy, massage, and acupuncture. Because osteoarthritis is such a common health problem, it is important to be aware of the “too good to be true” miracle cures that are frequently advertised, and may be just a waste of money. It’s always a good idea to discuss all treatments you are considering with your healthcare provider to make sure that you don’t do more harm than good.

**Life-style changes**
Life-style changes are often recommended to reduce pain from arthritis conditions, especially osteoarthritis. Common recommendations include a weight loss program (when excess weight is an issue) to lessen the “wear and tear” on weight-bearing joints; learning proper body mechanics, such as the right way to lift, or sit, or get up from a chair; and exercises to strengthen muscles that can help support the joints. With low risk and low cost, life-style changes may be the most cost-effective way to treat arthritis pain, and you play a major role in these solutions.

**Adaptive equipment**
Adaptive equipment, such as braces, canes, or walkers can help reduce pain by reducing the amount of stress on the joints by helping to bear some of the weight. In addition, they can help keep people active and mobile.

**Surgery**
Joint replacement is an option for some arthritic joints, most often the weight-bearing joints, the hips, and the knees. While this kind of surgery is becoming more common, there is a lot to
be learned about joint replacement surgery if you think it may be in your future. The painACTION article “What to consider when making decisions about joint replacement surgery” may help.

These painACTION lessons and articles may be useful on your arthritis pain management journey:

• “Arthritis tips and tools for easier living” (Lesson)
• “Staying socially connected when living with chronic pain” (Lesson)
• “Arthritis and nutrition” (Article)
• “Bolstering your resiliency” (Article)
• “Fun ways to be physically active when you have arthritis” (Article)
• “Chair yoga” (Lesson)

In Summary...

• Arthritis is one of the most common health problems in the U.S. and stands to increase as the population gets older
• There are over 100 types of arthritis, but osteoarthritis, rheumatoid arthritis, and gout are among the most common
• Your healthcare provider or medical home can help you develop a pain management plan that fits best with your condition and lifestyle
• There are many strategies to help relieve arthritis pain. Keep an open mind!
As a current or former military service member, you have probably experienced a lot during your tour of duty, including deployment to a war zone. If your service in the military was recent, you were likely deployed to a war zone multiple times. Your pain may have come from a combat injury, an accident while on duty, or from overuse of your joints and muscles in a physically demanding job. Regardless of how your pain began, coming home to begin a pain management journey was probably the last thing you envisioned when you joined the Armed Forces.

You should know that you are not alone in this journey. Due to better body armor and improved delivery of medical care down range, soldiers are living through wounds that would have killed them in the past, so the number of Wounded Warriors coming home has increased. Although these numbers constantly change, the U.S. Casualty Report for April 13, 2012 listed 47,818 individuals wounded in action while serving in Operation Iraqi Freedom (OIF), Operation Enduring Freedom (OEF), and Operation New Dawn (OND). And thousands more are treated in the Veteran’s Health Administration (VHA) system for injuries sustained in military duty prior to these operations. Many of these injuries result in chronic pain, medical discharge from the military, and changes in the quality of daily and family life.

Your treatment is a matter of concern for the United States Department of Defense (DOD) and the VHA. A taskforce organized by the Office of the Army Surgeon General has published a guide to pain management that focuses on comprehensive and standardized care for all military members (See the Additional Resources page at the back of the book). This care is to focus on using multiple treatments and specialists, including complementary and alternative treatments like acupuncture, to improve your functioning and your life.
**Warriors’ Pain**

The type of pain you have depends on your experiences and injury. Back pain is the most common pain symptom for deployed service members. Some other common types of pain from military experience are listed below:

**Acute pain**
This is the type of pain that occurs immediately after an injury or tissue damage such as a surgical procedure, and is usually sharp and sudden.

**Neuropathic pain**
This type of pain comes from pressure, injury, or irritation to nerves, and is often described as ‘burning’ or ‘shooting’.

**Phantom pain**
Phantom pain is the pain felt in an absent limb following an amputation.

**Nociceptive pain**
This kind of pain is caused by stretching, pressure, or injury to tissue, muscles, or organs anywhere in the body, and includes deep aching.

**Central Pain**
Central pain is caused by damage to or dysfunction of the brain, brainstem, or spinal cord, which are parts of the central nervous system.

**Headache pain**
Headaches can result from many types of injuries, including injuries to the neck, head, and brain.

**Burn pain**
BURNS can result in different types of pain, depending on the kind of burn (e.g., chemical, electrical, fire), and the depth of the tissue damage.

**Otalgia**
This is ear pain that can result from exposure to blasts or loud noises.

You may have experienced polytrauma, or multiple combat blast injuries and traumas, including post-concussive syndrome (also called shell shock, in which symptoms of a mild head injury like headache,
confusion, or irritability continue over days or weeks). This may make your pain problem more complex. Added to your pain may be traumatic brain injury (TBI), post-traumatic stress disorder (PTSD) or mild TBI along with substance abuse.

**Pain Management for Warriors**

Here’s the good news: Military service has prepared you well to steer a course through the obstacles presented by chronic pain. Below are some suggestions.

** ✓ Don’t delay your treatment**
Warriors are used to a tough, no-nonsense, “no pain, no gain” way of living. *You must do the opposite for pain treatment to work.* The longer you tough it out with no treatment, the harder your pain will be to treat.

** ✓ Build a supportive team**
As a member of the military, *you know the value of a team.* *And you know what qualities you need to make a team work.* So use these skills to build a pain management treatment team that can give you good directions and guide your path. *Include former service members in your support team as well,* since they will share your experiences.

** ✓ Be willing to try new things**
Relaxation, meditation, medical massage, or acupuncture can be helpful if suggested by your healthcare provider.

** ✓ Conquer the emotional obstacles**
Combat-related stress, difficult memories, loss of friends, and the family costs of multiple deployments, may affect your thoughts and emotions and make your pain experience worse. It takes courage to steer around these emotional obstacles, but *it can be done and there are people willing to help you.* Although the memories of what happened in those difficult times may not go away completely, the emotional intensity of re-experiencing them will diminish with treatment and can stop interrupting your life.
✔️ Develop a new mission

*Embarking on a pain management journey means selecting an initial destination.* That may mean a new mission for your life. Use your resilience and strength to redefine your mission. You are still able to live a life of service by finding a way to contribute to the lives of others. *Find a cause bigger than yourself and make a first step, even if it’s a small one.*

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**In Summary...**

- There are many types of pain, including pain associated with head trauma, that may be part of a Warrior’s pain management journey
- The most courageous thing you can do is to get help for physical and emotional wounds
- You are still resilient and strong and can use these qualities for good, no matter how your body is affected by pain
- You can live a life of selfless service as a Warrior or civilian
You are now at the end of your journey through this book, but that does not mean your travels have stopped. Managing pain, whatever its origin, for some, can be a lifelong journey. The message of this book is that you can be in control of this journey, accompanied by healthcare professionals as your “travel guides,” as well as resources like this book (your “road map”), and the painACTION website.

While you would like to be completely free of pain (who wouldn’t?), your key to successful pain management is to recognize that the most realistic goal is to improve the quality of your life and be able to achieve your goals in work, relationships, and the activities you enjoy.

There is a Buddhist saying: “Pain is inevitable; suffering is optional.” We all have pain, to one degree or another; what makes the difference in life is how we choose to understand and manage it. With this attitude, you will be able to have the quality of life that you want with the type of pain that you have.
Additional Resources

**Afterdeployment.org:**
A website providing wellness resources for the military community. 
[afterdeployment.org](http://afterdeployment.org)

**Arthritis Foundation:**
A national nonprofit organization. [arthritisis.org](http://arthritisis.org)

**National Center for Alternative and Complementary Medicine:**
A part of the National Institutes of Health. [nccam.nih.gov](http://nccam.nih.gov)

**National Headache Foundation:**
A national nonprofit organization. [headaches.org](http://headaches.org)

**National Institute of Arthritis and Musculoskeletal and Skin Diseases:**
A part of the U.S. National Institutes of Health. [niams.nih.gov](http://niams.nih.gov)

**National Institute of Neurological Disorders and Stroke:**
A part of the National Institutes of Health [ninds.nih.gov](http://ninds.nih.gov)

**National Cancer Institute:**
A part of the National Institutes of Health. [cancer.gov](http://cancer.gov)

**Pain Management Task Force, Final Report, May 2010, Office of the Army Surgeon General:**
Available at [amedd.army.mil/reports/Pain_Management_Task_Force](http://amedd.army.mil/reports/Pain_Management_Task_Force)

**The Neuropathy Association:**
A national nonprofit organization: [neuropathy.org](http://neuropathy.org)

**U.S. National Library of Medicine, National Institutes of Health:**
A free resource provided by the National Institutes of Health. [nlm.nih.gov](http://nlm.nih.gov)