

# Chronic Overlapping Pain Conditions

*Patient Guide*

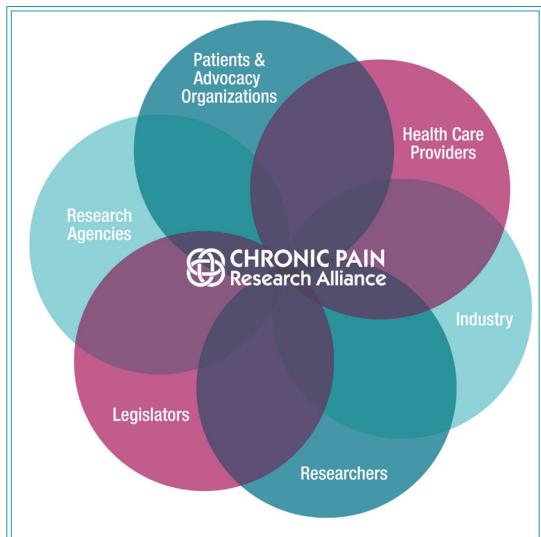


[ChronicPainResearch.org](http://ChronicPainResearch.org)

## About the Chronic Pain Research Alliance

The Chronic Pain Research Alliance (CPRA)—the country's first and only collaborative initiative with a specific focus on Chronic Overlapping Pain Conditions—exists to provide a voice for millions of people suffering with COPCs. CPRA works to promote high-quality scientific research on COPCs, translate new research findings into educational programs for health care providers and patients, and drive the development of safe and effective treatments.

The CPRA accomplishes its goal by working with all invested stakeholders, including patients, lawmakers, medical-scientific professionals, industry, advocacy groups, and federal health research agencies. The CPRA envisions a future where those with Chronic Overlapping Pain Conditions will receive a timely diagnosis, followed by the highest quality and most comprehensive medical care that is informed by the latest and best scientific evidence.



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# CHAPTER 1: Overview of Chronic Overlapping Pain Conditions

Chronic pain conditions that often occur together in the same person and share similar disease mechanisms have been termed by the National Institutes of Health as Chronic Overlapping Pain Conditions (COPCs, see Figure 1).

Not everyone who develops one of these conditions will go on to develop more, however many do, particularly women. The complexity of overlap is shown in the figure - any combination and number of conditions is possible. Some people develop multiple conditions around the same time, while others develop them in succession over many years.

A brief summary of each COPC follows.

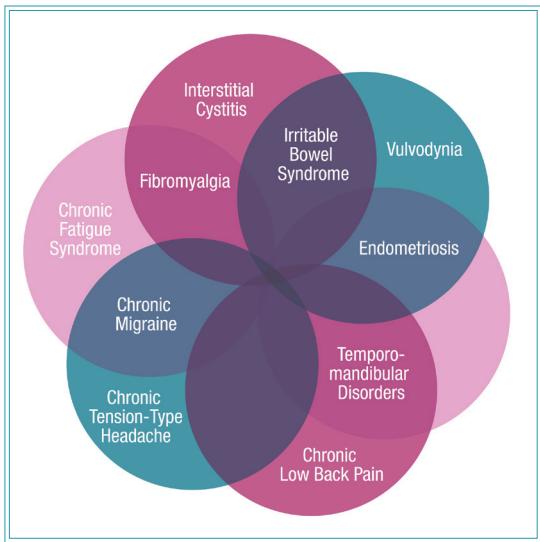


Figure 1



**Vulvodynia** is chronic pain in the vulva—the area surrounding the vaginal opening—without an identifiable cause. The most common symptom is burning, however, some women describe the pain as stabbing, raw, stinging and knife-like. Some women with vulvodynia have pain all or most of the time, while others only experience pain with touch or pressure to the vaginal opening, such as with tampon insertion, gynecological examination or intercourse. One in four women of all ages and ethnicities will develop vulvodynia at some point in their lives, and one study suggests it may be quite prevalent in adolescents as well.<sup>1,2</sup> A study of adult women found that symptoms frequently begin between the ages of 18 and 25.<sup>3</sup>

**Temporomandibular Disorders (TMD)** are characterized by pain in the jaw joint and surrounding muscle and tissues, along with limitations in jaw movement. One or both joints may be involved, affecting one's ability to speak, chew, swallow, make facial expressions and even breathe. Approximately 35 million Americans suffer from TMD.<sup>4</sup> The prevalence is higher in women than in men, as 90 percent of patients seeking treatment are women of childbearing age. Symptoms typically begin in the teens up to age 50.<sup>5,6</sup>



## **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)**

(ME/CFS) is a complex, debilitating disease characterized by profound fatigue lasting for six or more consecutive months that is not improved by bed rest and that may be worsened by physical or mental activity. The nature and severity of symptoms vary, and include severe muscle and joint pain, cognitive impairment (i.e., difficulty thinking clearly or understanding), unrefreshing sleep and a worsening of symptoms with mental or physical exertion. Between 1 and 4 million people in the U.S. have ME/CFS.<sup>7</sup> ME/CFS affects four times as many women as men.<sup>8</sup> Symptoms begin in two distinct ranges—between the ages of 10-19 and 30-39.<sup>9</sup>

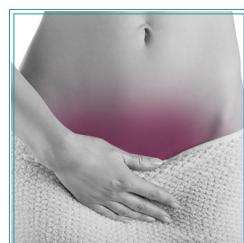


**Irritable Bowel Syndrome (IBS)** is a condition whereby people experience abdominal pain or discomfort, along with a change in bowel movement patterns. There are four subtypes of IBS: with diarrhea (IBS-D), with constipation (IBS-C), with diarrhea and constipation ("mixed," IBS-M), and unknown. The U.S. prevalence of all types of irritable bowel syndrome is estimated to be 12% of the general population.<sup>10</sup> Women are approximately two times as likely to suffer from IBS compared

to men, and adults under the age of 50 years are more likely than older adults to be affected.<sup>11</sup>

## **Interstitial Cystitis/Painful Bladder Syndrome (IC/PBS)**

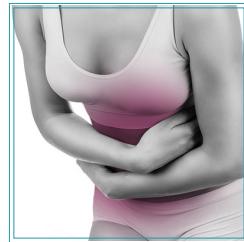
is characterized by pain, pressure or discomfort of the bladder in the absence of infection or other pathology, typically accompanied by urinary frequency (i.e., the need to urinate more frequently than usual) and urinary urgency (i.e., a sudden compelling urge to urinate). Based on the RICE and BACH studies, between 3-8 million women and 1-4 million men in the U.S. suffer from IC.<sup>12 13</sup> On average, symptoms begin at age 40.<sup>14</sup>



**Fibromyalgia** is a chronic condition characterized by widespread body pain, as well as accompanying comorbidities, such as disturbed sleep, fatigue and cognitive difficulties (i.e., difficulty thinking and understanding clearly, often described as "brain fog").<sup>15 16</sup> It is estimated that fibromyalgia occurs in 2% of the general US population, roughly equal to 4 million people.<sup>17</sup> Women are 2-3 times more likely to have fibromyalgia compared to men.<sup>18 19</sup> Diagnosis is most likely to occur between

the ages of 20 and 50.<sup>20</sup>

**Endometriosis** is a chronic neuro-endocrine-immune system disease, in which the endometrial tissue (i.e., the tissue that lines the inside of the uterus) is found out of its place within the abdomen, which causes pain, infertility and other problems. The most common symptoms are pain before/during menstruation; pain during sexual activity; pain with bowel movements and urination; fatigue; infertility; and heavy bleeding. The true prevalence of the condition is unknown because surgical confirmation is necessary to diagnose the condition. It is estimated that 2 to 10 percent of women and girls in the US have endometriosis; the number is most likely at least 6.3 million, or 4 percent.<sup>21</sup> Sixty percent of women develop symptoms prior to age 20.<sup>22</sup>



**Chronic Migraine and Tension-Type Headaches** are defined as primary headache disorders, i.e., those that exist independent of another disorder. Both headache disorders are classified as chronic when they occur 15 days or more a month for three months in the absence of medication use (migraine) or six months (cTTH). Typically, a migraine headache will affect one half of the head, is pulsating in nature, lasts from 2 to 72 hours and is generally made worse with physical activity; associated autonomic symptoms include nausea, vomiting, sensitivity to light, sound or smell. Up to one-third of those with migraine perceive an aura—a transient visual, sensory, language or motor disturbance. Chronic tension-type headaches are characterized by pain (pressure, tightening or feeling like the head is being squeezed with a vice), frequently on both the left and right sides of the head. The pain can radiate from the lower back of the head, neck, eyes or other muscle groups. Individuals also report sensitivity to light and sound and may experience nausea. Chronic migraine affects 1% of American adults, equivalent to 2.5 million people. It is three times more common in women.<sup>23</sup> Symptoms peak in the 40s. Chronic TTH affects 2.2% of American adults, equivalent to 5.5 million people.<sup>24</sup> Chronic TTH typically begins in the teenage years, and is 1-2 times more likely to affect women.<sup>25 26</sup>

**Chronic Low Back Pain (cLBP)** is low back pain that occurs at least half of the days in the past six months. Symptoms include dull aching, sharp pain, tingling or burning sensations and/or weakness in the legs or feet, among others, in the low back (i.e., the lumbar region of the back between the bottom of the rib cage and top of the buttocks). Chronic LBP affects approximately 10% of adults.<sup>27</sup> It is 50% more common in women, and 3-4 times more likely in people age 50 and older, compared to those between the ages of 18-30.<sup>28</sup>



## CHAPTER 2: The Nervous System & How the Body Processes Pain

In order to understand the disease mechanisms responsible for initiating and maintaining COPCs, it's essential to have a basic understanding of the body's nervous system and how it works.

### Parts of the Nervous System & How They Work<sup>29</sup>

The nervous system is made up of all the nerve cells in your body. It takes in information through your senses (i.e., sight, sound, taste, touch, smell), processes that information, and then triggers bodily reactions, such as making your muscles move or causing you to feel pain. For example, when you touch something hot, your nerves send pain signals to your brain and you reflexively pull your hand away to prevent injury.

The nervous system has two parts, called the Central Nervous System (CNS) and Peripheral Nervous System (PNS), due to their location in the body. The CNS includes the nerves in the brain and spinal cord. The Peripheral Nervous System (PNS) includes all the other nerves in your body (see Figure 2).

Both the CNS and PNS have voluntary and involuntary parts.

- The Somatic Nervous System (voluntary) controls parts and processes of the body that we can consciously influence, such as moving our arms and legs.
- The Autonomic Nervous System (ANS, involuntary) regulates processes in the body that we cannot consciously influence, such as our breathing, heart beat and metabolism.

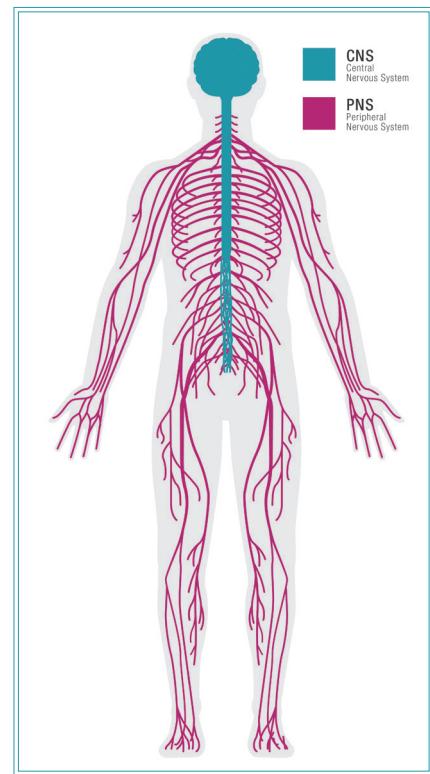


Figure 2

The ANS is further broken up into three parts, which become important in understanding normal and abnormal pain processes. They include:

- Sympathetic Nervous System — prepares your body for physical and mental activity, often referred to as “fight or flight.” In the right condition, i.e., you need to run away quickly, it increases your heart rate, opens your airways to help you breathe easier and shuts down your digestive system.
- Parasympathetic Nervous System — controls your body’s functions at rest. For example, it stimulates digestion, slows down your heart rate and respiration and activates metabolic processes.
- Enteric Nervous System — a separate system for your bowel, which on its own, regulates the contractions that your bowel makes during digestion.

### **Pain & the Nervous System<sup>30</sup>**

To understand how the body senses and processes pain in normal circumstances, it's important to know more about the Peripheral Nervous System (PNS). The PNS has two main types of nerves—sensory and motor. The brain and spinal cord are the hubs, and the sensory and motor nerves span across the body, like information highways (see Figure 1). Sensory nerves send messages, such as when you sense pressure, touch or pain, to the spinal cord, which then get sent to the brain. The brain then processes this information and sends messages back to the spinal cord, and then to the motor nerves, which help us to act. For example, we have certain receptors in our skin that only sense pressure; so when someone grabs your arm, sensory nerves interpret this sensation as pressure and send signals to the spinal cord and brain, and then the brain sends back a message, through the spinal cord, to our motor nerves, causing us to pull away.

The normal process of pain works in a similar way. There are special types of sensory nerve receptors throughout our body called nociceptors, which activate when there is an injury or potential injury. Nociceptors send a message to the brain, via the spinal cord, in a fraction of a second. One part of the spinal cord, called the dorsal horn, is very complex and functions like a switchboard, transmitting all kinds of signals to and from the brain, simultaneously. It can send a message to our motor nerves, called “reflexes” before or at the same time that it sends the pain signal to our brain, causing us to “reflexively” pull our hand away from a hot flame to prevent a burn injury.

When the pain signal reaches the brain, it first goes to a part of the brain called the thalamus. The thalamus then directs the message to several other areas of the brain for interpretation, including one area called the limbic system, which is the part of the brain responsible for emotions. Many factors determine how your brain interprets a pain signal, including your past experiences, expectations and your mood.

When pain becomes chronic, the body's normal pain processing system becomes dysfunctional. These mechanisms are discussed in detail in the next chapter.

# CHAPTER 3: Underlying Mechanisms of Chronic Overlapping Pain Conditions

People suffering from Chronic Overlapping Pain Conditions (COPCs) are more likely to be female, experience similar symptoms and benefit from similar treatments. Studies increasingly support the idea that both within and across COPCs, there are many subgroups with common disease mechanisms, each being responsive to treatments that specifically target those mechanisms.<sup>31</sup> This section summarizes the findings of emerging research on common underlying disease mechanisms of COPCs.

## Genetic and Environmental Factors

Research shows that there are a number of genetic variations that determine how sensitive our nervous systems are to pain and other sensory input (e.g., smell, taste, sound), as well as our risk of developing chronic pain.<sup>32 33 34</sup> Studies have identified a number of genetic variations associated with a higher risk of developing COPCs, most of which involve the regulation of the immune, neurological and endocrine systems, specifically related to sensory/pain processing.<sup>35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50</sup> Likewise, research has shown a strong familial component to developing COPCs.<sup>51 52 53 54 55 56 57</sup> As with most illnesses that may have a genetic underpinning, environmental factors, such as infection, trauma, surgery and injury, may play an important role in triggering the onset of COPCs.<sup>58 59 60 61 62 63 64 65 66 67 68 69</sup> Once COPCs are triggered, the factors and mechanisms responsible for maintaining the conditions are numerous and complex.

## Abnormal Pain and Sensory Processing

Once COPCs develop, the most common abnormality is pain and sensory processing dysfunction. Although rare, some people are born without the ability to feel pain at all. Others fall on the opposite end of the spectrum and are “hypersensitive,” perceiving normal touch and pressure as painful. Studies show that COPCs patients fall into this latter category and experience amplified pain perception—both increased pain intensity and lowered sensory and pain thresholds—with the application of various forms of sensory stimuli, such as pressure, hot/cold and vibration. Not only are these sensitivities found at the body site where a person experiences chronic pain, but at other body sites, such as the thumb, shin and arm.<sup>70 71 72 73 74 75 76 77 78 79 80 81 82 83 84 85 86 87 88 89 90 91 92 93 94 95 96</sup> Recent studies further show that those with COPCs are also sensitive to other sensory input, such as light, sound and odor.<sup>97 98 99 100 101 102</sup>

## Where does Chronic Pain Exist?

Experts used to think that chronic pain had to result from some disease process in the peripheral tissues, i.e., if you have ankle pain, then there must be ongoing inflammation, swelling or infection in the ankle itself that is driving the brain to sense/experience pain; therefore, in order to get rid of the pain, you have to apply some sort of treatment to the ankle.

We now know after decades of research that this is only part of the story. Although a ‘peripheral’ event, such as infection, swelling, inflammation, etc., might have caused the pain to begin, in many people, months or years later, no abnormalities in the peripheral tissue can be found. Rather, significant changes are seen in the central nervous system (CNS), i.e., the brain and spinal cord. Several theories have been proposed regarding the relative contribution of the peripheral nervous system (PNS) and the central nervous system in the development and maintenance of COPCs. One theory is that they both exert influence on a continuum. In individuals with mild to moderate symptoms, there may be a greater contribution from the PNS, which is influenced by environmental factors, such as infection or injury. In those with moderate to severe symptoms, the CNS is proposed to have a greater contribution, resulting in abnormal CNS pain processing, which then leads to abnormalities in the PNS. What is unclear at this time is whether the abnormal processes in the brain and spinal cord can be the sole source of COPCs, as some studies demonstrate in order for CNS abnormalities to persist, persistent input from the PNS is necessary.<sup>103 104 105 106 107</sup>

### Autonomic Nervous System Abnormalities

In the last chapter, we reviewed the parts of the Autonomic Nervous System—the Parasympathetic Nervous System and Sympathetic Nervous System. You’ll recall that the Sympathetic Nervous System is referred to as “fight or flight,” and prepares the body for activity, such as increasing heart rate, opening airways, and slowing the digestive system. The Parasympathetic Nervous System controls the body’s functions at rest, i.e., slows down heart rate and respiration and stimulates digestion (see Figure 3).

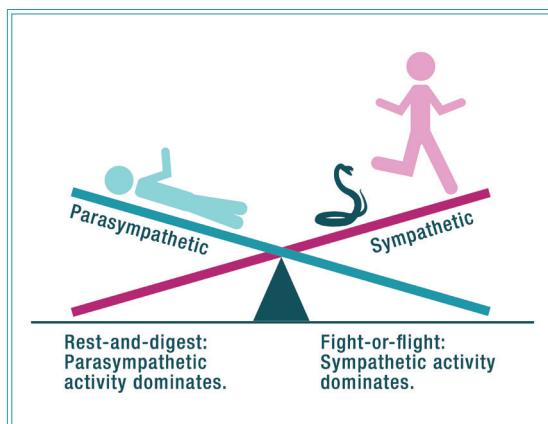


Figure 3

Studies have shown that in some patients with COPCs, the Sympathetic Nervous System is more active than it should be and is out of balance with the Parasympathetic Nervous System. This has led some to propose that dysfunction of the autonomic nervous system, often referred to as “dysautonomia,” could be one of the common underlying disease mechanisms in a subgroup of COPCs patients.<sup>108 109 110 111 112 113 114 115</sup>

## **Brain Imaging Abnormalities**

Brain imaging research shows that people with COPCs, as well as other pain disorders, have changes in their brain structure, referred to as white and grey matter.<sup>116 117 118 119 120 121 122 123 124 125 126 127 128</sup> Further, studies of people with COPCs indicate that in response to painful stimuli, similar brain regions show increased activity or are “activated,” including those that integrate and process sensory information, cognition and emotion.<sup>129 130 131 132 133 134 135 136 137 138 139 140 141 142 143 144</sup>

Other studies have investigated how different areas of the brain communicate or “connect” with one another, either while a person is at rest or performing a specific task.<sup>145</sup> Studies that examine the brain’s activity while people are at rest (i.e., resting state analysis) enables one to determine the brain changes associated with chronic spontaneous pain, as well as examine how chronic pain may disrupt non-pain related functions, such as one’s ability to think and understand clearly. Studies investigating how different parts of the brain communicate with each other (i.e., functional connectivity studies) have shown that people with COPCs have altered connectivity among several regions of the brain.<sup>146 147 148 149 150 151 152 153 154 155 156</sup>

## **Female Predominance and Role of Hormones**

More women than men are affected by COPCs and scientists have suggested multiple reasons for this.<sup>157</sup> Basic science studies show that female, or ovarian, hormones have distinct effects on inflammation, stress response, emotional states, and pain systems that can either increase or decrease pain reactivity.<sup>158 159</sup> Studies show that during different phases of the menstrual cycle, women experience alterations in pain severity, pain threshold and pain tolerance.<sup>160 161 162 163</sup> Further, imaging studies have even shown that men and women have different connectivity between brain regions that process emotion and cognition.<sup>164</sup> Advancing knowledge of the mechanisms by which male and female hormones influence pain is necessary and will aid in understanding why pain tends to be more frequent, severe and disabling in women.<sup>165 166</sup>

## **Neuroendocrine & Neuroimmune Abnormalities**

Chronic pain research shows that there is a complex relationship among immune cells, nerve cells and glia (i.e., connective tissue of the nervous system) that affects immune response and modulates pain pathways and sensitivity in both the peripheral and central nervous systems.<sup>167 168 169</sup> Studies of COPCs patients indicate that a host of immuno-inflammatory mediators, both in the bloodstream and in painful peripheral tissues, are altered and play a role in the development and/or maintenance of these conditions in at least a subgroup of patients.<sup>170 171 172 173 174 175 176 177 178 179 180 181</sup>

The hypothalamic-pituitary-adrenal (HPA) axis consists of a complex set of interactions between two parts of the brain – the hypothalamus and the pituitary gland—and the adrenal or suprarenal glands that are located at the top of the kidneys. These three endocrine glands control stress and regulate a wide array of body functions, such

as immunity, digestion, emotions and energy storage. Although study results are inconsistent, dysregulation of the HPA axis appears to play a role in at least a subset of those with COPCs.<sup>182 183 184 185 186 187 188 189 190 191 192 193 194</sup>

## **Role of Stress, Behavior and Psychological Factors**

The role of adverse childhood experiences, early life (and/or ongoing) stress, and behavioral and psychological factors are known to play a role in the incidence and maintenance of many chronic illnesses, including type 2 diabetes, heart disease and cancer.<sup>195 196 197 198</sup> Studies demonstrate that the relationship between chronic pain and distress is complex, and that distress can either come before or after chronic pain begins.<sup>199 200</sup> In this latter situation, individuals experience difficulty functioning in their various roles after developing COPCs, which can worsen symptoms and lead to difficulties in coping. Studies are beginning to identify distinct subgroups or “clusters” of patients with COPCs, with similar profiles related to symptom severity, pain/sensory sensitivity and psychological and social functioning, identifying some groups that appear to be more “resilient” to pain and its effects than others.<sup>201 202 203</sup>

## CHAPTER 4: Diagnosing Chronic Overlapping Pain Conditions

Most COPCs are ‘diagnoses of exclusion,’ meaning that they are diagnosed after known causes for the pain, such as infection or cancer, are ruled out. Due to a lack of awareness and training, misdiagnosis is common and many clinicians are unaware of the inter-relationship of these conditions. Because our health care system is organized by medical specialties that typically involve a body system/part, i.e., urologists treat bladder and kidney conditions, while gynecologists treat conditions involving the female reproductive tract, many types of specialists conduct diagnostic exams for each of the COPCs. For example, a woman with vulvodynia and irritable bowel syndrome may visit a gynecologist and gastroenterologist. Primary care providers and internists also diagnose and treat many people with these disorders. It’s important for you to discuss all of your medical conditions with each health care provider whom you consult, even if you think that your health conditions are unrelated.

General information on the diagnosis of each COPC follows.

### **Vulvodynia<sup>204</sup>**

After taking a thorough medical history and asking questions about your symptoms, a clinician will examine the vulva, vagina and vaginal secretions to rule out an active infection or skin disorder. A blood test to assess levels of estrogen, progesterone and testosterone, may also be recommended. Clinicians conduct a cotton-swab, or “Q-tip” test, during which gentle pressure is applied to different parts of the vulva and women are asked to rate the severity of pain experienced. If any areas of skin appear suspicious, clinicians may use a magnifying instrument to visualize the skin and/or take a small skin biopsy. Health care providers will also examine the pelvic floor muscles to assess for spasm or weakness. Vulvodynia is diagnosed when a woman has had vulvar pain for at least 3-6 months that is not caused by another condition, such as an infection or skin disorder.

### **Temporomandibular Disorders**

The American Association for Dental Research recommends that a TMD diagnosis be based primarily on information obtained from the patient’s history and a clinical examination of the head and neck.<sup>205</sup> For example, clinicians may assess whether patients experience pain when mild pressure is applied to the joint itself or to the chewing muscles. In addition to obtaining a medical history related the teeth and their arrangement, as well as the head and neck, clinicians should also obtain more comprehensive information about other pain and non-pain medical symptoms and conditions that patients may be experiencing. Blood tests are sometimes recommended to rule out other medical conditions as a cause of the problem. Before undergoing any costly diagnostic test, it is always wise to get an independent opinion from another health care provider of your choice (one who is not associated with your current provider). In addition to a detailed history and careful clinical examination, imaging studies of the

teeth and jaws may sometimes be helpful as a diagnostic tool. This includes dental x-rays and panoramic radiographs, which provide an image of the teeth and bony structures of the temporomandibular joint. If an x-ray of the joint shows bony changes, your provider may recommend a CT scan, which provides greater detail of the bone, or an MRI, which provides images of the disc, as well as the muscles and other soft tissues surrounding the joint.

### **Irritable Bowel Syndrome (IBS)<sup>206</sup>**

Clinicians will conduct a thorough medical history that includes questions about any family history of digestive diseases, such as celiac, inflammatory bowel disease or colon cancer, as well as medications you take, recent infections, stressful life events that correlate with the start of your symptoms, your diet and history of other health problems that are common in people with IBS. During the examination, your health care provider will assess abdominal bloating, bowel sounds and abdominal tenderness. If you have other symptoms (e.g., anemia, infection, weight loss, rectal bleeding, bloody, black or tarry stools), certain tests that examine your blood, stool and/or gastrointestinal tract may be ordered to rule out other conditions.

You may be diagnosed with IBS if you have two or more of the following symptoms (at least once a week for the last 3 months or if your symptoms started more than 6 months ago):

- Pain related to bowel movements (either worsening or improvement)
- Change in how often you have a bowel movement
- Change in the way your stools look

### **Interstitial Cystitis / Painful Bladder Syndrome (IC/PBS)<sup>207</sup>**

Diagnostic evaluations for IC/PBS take into account a patient's medical history, physical exam and lab tests. After conducting a careful medical history, health care providers will typically conduct a pelvic examination in women to determine if symptoms may relate to spasm in the pelvic floor muscles. Men may be given a digital rectal exam to check for prostate problems, as well as pelvic floor muscle dysfunction. Depending on a patient's symptoms, a urinalysis, urine culture and/or a cystoscopy may be ordered. Cystoscopy involves the placement of a small tube in the urethra and bladder to look for bladder ulcers, cancer, swelling, redness and signs of infection.

You may be diagnosed with IC/PBS if you have pain in or near the bladder, usually with urinary frequency (i.e., the need to urinate more frequently than usual) and urinary urgency (i.e., the sudden urge to urinate), in the absence of other conditions that could cause similar symptoms, like urinary tract infections or endometriosis, in women, or infection or inflammation of the prostate, in men.

## **Endometriosis<sup>208</sup>**

Right now, surgery is the only way to confirm an endometriosis diagnosis. Laparoscopy is the most common procedure to do so. During a laparoscopy, surgeons inflate the abdomen with gas, make a small cut in the abdomen and insert an instrument with a light, called a laparoscope, to examine the reproductive organs, intestines and other organs for endometrial tissue. In some cases, the surgeon will take a biopsy to confirm the diagnosis by looking at the tissue under a microscope. To detect larger areas of endometriosis, such as nodules or cysts, clinicians may order an ultrasound or MRI.

Your health care provider will perform a laparoscopy only after taking a medical history and performing a complete physical and pelvic exam. Researchers are investigating non-surgical ways to diagnose endometriosis and to determine how severe the disease is, including a “diagnostic classifier” for endometriosis based on the presence of certain genes.<sup>209</sup>

## **Fibromyalgia**

As with other COPCs, fibromyalgia is a diagnosis of exclusion, so the first step involves taking a thorough medical history. As such, your provider may order certain lab (and other) tests to rule out conditions with similar symptoms, however, there is currently no diagnostic test for fibromyalgia. In 1990, the American College of Rheumatology (ACR) developed general guidelines for diagnosing fibromyalgia, which included two criteria: 1) widespread body pain, and 2) tenderness at 11 or more of the 18 tender points.<sup>210</sup> In 2010, the ACR revised their criteria, eliminating the tender point examination and replacing it with two scales: The Widespread Pain Index and the Symptom Severity Scale. These questionnaires are given during an appointment and measure the severity of pain, fatigue, unrefreshed sleep, cognitive dysfunction (i.e., problems with thinking and understanding clearly) and other symptoms.<sup>211</sup> If a patient has had widespread body pain, as well as other symptoms, including fatigue, cognitive difficulties and unrefreshed sleep, that are not attributable to another medical condition for three or more months, fibromyalgia may be diagnosed. Although no longer part of the ACR guidelines, some health care providers may still perform a physical examination to detect tenderness and exclude other potential causes of muscle pain.<sup>212</sup>

## **Chronic Migraine and Tension-Type Headaches<sup>213 214 215</sup>**

As with other COPCs, clinicians begin with a comprehensive medical history. Clinicians will conduct a physical and neurological exam to rule out other causes of headache, such as head trauma, high blood pressure, or systemic illnesses like lupus or cancer. Depending on your symptoms and medical history, your clinician may order an imaging test, however, clinicians typically rely on a detailed history and medical exam to make a diagnosis. A headache diary can be very helpful to capture headache frequency and duration, as well as other important factors, such as headache triggers and medication response. Many headache diaries are available online at no cost.

Migraine and tension-type headaches are classified as “episodic” when patients experience attacks less than 15 days per month, and “chronic” when patients experience them on 15 or more days per month for at least 3 months.

To be diagnosed with chronic migraine headache, at least two of the following characteristics must be met:

1. pain on one side of the head (called unilateral pain);
2. head pain that is pulsating;
3. head pain intensity that is moderate to severe; or
4. head pain that is aggravated by, or causing avoidance of, routine physical activity, such as walking or climbing stairs.

In addition, during headache attacks, at least one of the following occurs:

1. nausea and/or vomiting; and/or
2. light sensitivity (called photophobia) and sound sensitivity (called phonophobia).

To be diagnosed with chronic tension-type headache, at least two of the following characteristics must be met:

1. pain that is on both sides of the head (called bilateral pain)
2. head pain that is pressing or tightening (non-pulsating)
3. head pain intensity that is mild to moderate; and
4. head pain that is not aggravated by routine physical activity, such as walking or climbing stairs.

In addition, during headache attacks, patients need to meet both of the following criteria:

1. can experience only one of the following symptoms: light sensitivity (called photophobia), noise sensitivity (called phonophobia) or mild nausea; and
2. neither moderate or severe nausea or vomiting.

### **Myalgic Encephalomyelitis/Chronic Fatigue Syndrome<sup>216</sup>**

Clinicians will take a full medical history, conduct a thorough physical and mental status examination and possibly order certain blood, urine or other tests to assess a patient for ME/CFS and to rule out other conditions that can cause similar symptoms. Patients may also be referred to specialists, such as a neurologist, rheumatologist or sleep specialist to check for other conditions that can cause similar symptoms.

Three “core” symptoms are required for diagnosis of ME/CFS. They include:

1. Greatly lowered ability to do activities you were able to do before, that occurs along with fatigue. The fatigue associated with ME/CFS is much different from just being tired; it can be severe, occurs with only minor (or no) activity, is not relieved by rest, and has not been a problem in the past.
2. Worsening of ME/CFS symptoms after physical or mental activity that would not have caused a problem before, called “post-exertional malaise.” Many people with ME/CFS describe this as a “crash,” that may take days, weeks or longer from which to recover.
3. Problems with falling asleep, staying asleep or not feeling better or less tired after a full night of sleep.

In addition to these core symptoms, one of the following is required for diagnosis:

1. Problems with thinking and memory. Patients describe this as not being able to think clearly, like having a “brain fog.”
2. Worsening of symptoms while standing or sitting upright, called “orthostatic intolerance.” Symptoms include light-headedness, dizziness, weakness, or feeling faint. Vision changes like blurring or seeing spots can also occur.

Although not required for diagnosis, many people with ME/CFS experience various types and severities of pain. This includes muscle pain/aches, joint pain, headaches, tender lymph nodes in the neck or armpits, frequent sore throat, gastrointestinal pain, and chills and night sweats.

### **Chronic Low Back Pain<sup>217</sup>**

You may be diagnosed with chronic low back pain if you've experienced low back pain on at least half of the days over the last six months. A complete medical history, as well as back and neurological exam are used to determine other possible causes for the pain, however, the causes of chronic lower back pain are often difficult to determine even after a thorough examination. As with other COPCs, a diagnosis is typically made based on symptoms, so health care providers will ask detailed questions about the onset, location, and severity of the pain; duration of symptoms; any limitations in movement; and history of previous episodes or any health conditions that might be related to the pain. Clinicians may order certain tests (e.g., x-ray, CT scan, nerve conduction studies, blood work) to rule out conditions that may be causing the pain, such as fractures, tumors, herniated discs, nerve compression or infection.

## CHAPTER 5: Impact of Sleep, Mood and Other Factors on Chronic Pain

It's common for COPCs patients to suffer from other chronic conditions, such as sleep or mood disorders. Also, chronic pain has a far-reaching impact, causing fatigue, difficulty with thinking and understanding, and varying degrees of physical, social and sexual dysfunction (see Figure 4). These conditions can develop before chronic pain starts, at the same time, or afterwards. In addition, certain medications and treatments for chronic pain or other health conditions that you may have can contribute to the development of these conditions, i.e., sleep disturbance, fatigue, etc. The interplay among these conditions and other factors is complex and highly unique to each person.

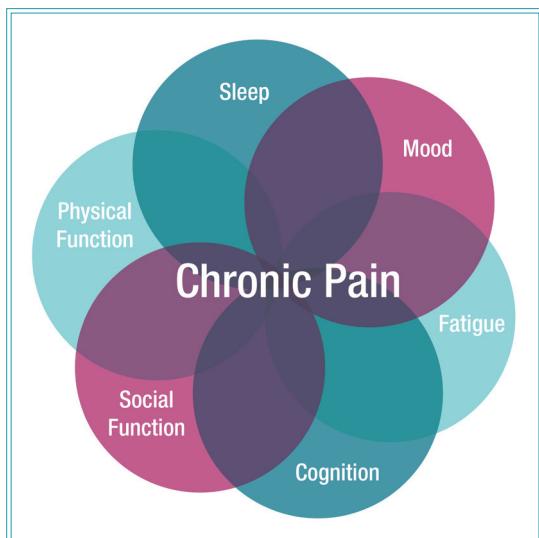


Figure 4

To develop an effective treatment plan, it's essential to first identify all co-existing health conditions and factors that play a role in your individual health situation. For example, a person with COPCs, who also has a sleep disorder and depression, will need a different treatment strategy than another COPCs patient who has anxiety, cognitive difficulties and fatigue.

The remainder of this section will focus on sleep and mood disorders, as they are the most common co-existing conditions in patients with COPCs.

### Chronic Pain and Sleep Disturbance<sup>218 219</sup>

People with chronic pain commonly experience difficulties with sleep. Research demonstrates that pain can negatively affect your ability to fall and stay asleep and sleep disturbance can increase the severity and impact of your chronic pain (see Figure 5).

There are 10 sleep-wake disorders recognized by the Diagnostic and Statistical Manual of Mental Disorders (DSM).<sup>220</sup> They include:

1. Insomnia — difficulty falling asleep or staying asleep
2. Hypersomnolence — excessive daytime sleepiness or prolonged night-time sleep that is not restorative

3. Narcolepsy — excessive uncontrollable daytime sleepiness
4. Breathing-related — a number of sleep disorders that involve difficulty breathing during sleep, termed “apneas”
5. Circadian rhythm — sleep disorders affecting the timing of sleep, causing an inability to sleep and awaken at the times commonly required for work, school and/or social responsibilities
6. Non-rapid eye movement sleep arousal — episodes of incomplete awakening from sleep that can involve either sleepwalking or night terrors
7. Rapid eye movement (REM) sleep behavior — involves abnormal behavior during REM sleep
8. Nightmare — a type of sleep disorder that involves undesirable experiences that occur during sleep, typically during REM sleep
9. Restless leg syndrome — condition where people have a nearly irresistible urge to move the legs, typically in the evenings
10. Substance/medication-induced sleep disorders — include severe problems with sleep due to alcohol, caffeine, sedatives, stimulants, cocaine, opioids, tobacco, or other medications



Figure 5

Insomnia is the most common sleep disturbance and is generally defined as the inability to acquire adequate sleep to feel rested in the morning. The most common complaints in those with insomnia include difficulty falling asleep, difficulty maintaining sleep (i.e., frequent awakenings or problems falling back asleep) and/or early-morning awakenings with inability to return to sleep.<sup>221</sup> Insomnia is considered chronic if it occurs at least three nights a week for at least three months. Insomnia causes significant distress or impairment in one's ability to function in normal daily activities. Common daytime consequences also include fatigue, reduced mental comprehension and other symptoms.

Generally speaking, sleep apneas and restless leg syndrome are commonly associated with chronic pain.<sup>222</sup> Obstructive sleep apnea hypopnea (OSAH) is a disturbance of breathing during sleep, which includes snoring, gasping and breathing pauses. A diagnosis is based on having five or more episodes of partial or complete upper airway collapse while sleeping.<sup>223</sup> This is measured by a test that monitors your brain, eye movements and heart rhythms during sleep, called a polysomnography. As with insomnia, people with OSAH experience daytime sleepiness, fatigue and unrefreshing sleep. Restless leg syndrome (RLS) is characterized by an urge to move the legs while resting, which is most frequent and severe at night, at least three times a week for three months.<sup>224</sup> This is accompanied by uncomfortable sensations which are partially relieved by movement, and results in significant distress or impairment in functioning.

Despite the evidence for the association between chronic pain and sleep disturbance, as well as the negative effects of sleep deprivation on mood, pain sensitivity and disability, clinicians don't often address sleep disturbance during medical visits. If you are experiencing sleep disturbance, you should talk to your health care provider and/or visit a sleep specialist. There are a variety of questionnaires and medical tests that can be used to diagnosis and monitor sleep disturbances. Health care providers typically begin with a careful medical history, which includes questions about the time required to fall asleep, number and length of awakenings, length of time spent in bed after waking up in the morning, as well as questions about bed type, sleep position and sleep description. Information on caffeine and alcohol intake, as well as physical activity patterns, are important. A sleep diary, where you record your sleep habits daily, can be helpful.

Treatment will differ depending on the type of sleep disorder you have. For example, for people with sleep apnea, a continuous positive airway pressure (CPAP) device may be recommended, whereas those with RLS may be prescribed certain medications. The overall treatment approach to improving sleep in those with chronic pain includes optimizing pain control, identifying and treating other medical conditions that may affect sleep and pain, identifying abnormal sleep patterns and using a range of drug and non-drug treatments to improve sleep quality and duration.

## Tips to Improve Your Sleep

Although sometimes difficult with chronic pain, try to establish healthy sleep hygiene practices, outlined below.<sup>225 226</sup>

- Keep a consistent sleep schedule. Go to sleep and get up at the same time every day, even on weekends or during vacations.
- Limit daytime naps to 20-30 minutes.
- Don't go to bed unless you are sleepy.
- If you don't fall asleep after 20 minutes, get out of bed.
- Establish a relaxing bedtime routine.
- Use your bed only for sleep and sex.
- Make your bedroom quiet, relaxing and a comfortable cool temperature.
- Get adequate exposure to natural light during the day and limit exposure to bright light in the evenings.
- Turn off electronic devices at least 30 minutes before going to bed.
- Don't eat a large meal before bedtime or foods that trigger indigestion. If you're hungry at night, eat a light, healthful snack.
- Exercise regularly and eat a healthy diet.
- Avoid stimulants (e.g., caffeine, nicotine) and alcohol in the afternoon/evening.
- Reduce your fluid intake before bedtime.

## Chronic Pain & Depression<sup>227</sup>

It's common for people with chronic pain to experience mood changes, including depression. It's logical and normal for those with chronic pain to be sad about their condition and its impact on their lives. Depression ranges from mild, temporary episodes of sadness to severe, persistent depression. Clinical depression, also referred to as major depression or Major Depressive Disorder (MDD), is the more severe form. To develop an individualized treatment strategy, it's important to know if you meet the criteria for MDD.

To make a diagnosis of Major Depressive Disorder clinicians use the symptom criteria below from the Diagnostic and Statistical Manual of Mental Disorders.<sup>228</sup> Patients must experience 5 (or more) of the 9 symptoms below nearly every day during the same two-week period; further, at least one of the symptoms must be either 1 or 2 below. Further, these symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

1. Depressed mood during most of the day (e.g., feelings of sadness, emptiness, tearfulness, hopelessness), can include irritable mood
2. Markedly diminished interest or pleasure in all, or almost all, activities during most of the day
3. Significant weight loss or weight gain, or decrease/increase in appetite
4. Sleep disturbances, including inability to fall or stay asleep or sleeping too much

5. Slowed thinking, speaking or body movements
6. Tiredness and lack of energy, so even small tasks take extra effort
7. Feelings of worthlessness or guilt, fixating on past failures or self-blame
8. Trouble thinking, concentrating, making decisions and remembering
9. Frequent or recurrent thoughts of death, suicidal thoughts, suicide attempts or suicide

If you are experiencing any of these symptoms, contact your health care provider to be evaluated and to discuss available treatment options. Common treatments for MDD include a number of antidepressant medications and/or psychotherapy with a psychiatrist, psychologist or other mental health professional.

### **Helpful Tips for Coping with Depression<sup>229</sup>**

In addition to obtaining professional help, you may also benefit from some of these self-help tips for coping with depression.

#### **1. Stay Connected**

People experiencing depression tend to withdraw and isolate, such that connecting with even close family members and friends is difficult. Feeling exhausted to talk, ashamed of your situation or guilty for neglecting relationships is normal. But, staying connected to others and participating in social activities can make a big difference in your mood and outlook. Reaching out is not a sign of weakness and doesn't mean that you're a burden. If you don't have anyone to turn to, seeking out support groups or social clubs are a couple of many options.

#### **2. Do Things That You Enjoy**

Do things that you enjoy (or used to enjoy). Many people find that picking up a former hobby, beginning (or resuming) to express yourself through music, art or writing, getting together with friends, and getting outside, are helpful. You can't force yourself to have fun, but you can push yourself to do things, even if you don't feel like it, with the understanding that this is part of overcoming depression.

#### **3. Exercise / Stay Active**

Exercising or being active may be the last thing that you feel like doing when you're feeling depressed, but studies show that regular exercise can actually help to reduce depression, as well as reduce stress, improve sleep and combat fatigue. Aim for 30 minutes of light physical activity each day if you're able. If your chronic pain worsens with certain types of exercise, avoid them, but still aim for light physical activity. Even a short walk can be of huge benefit, helping to reduce fatigue over time. A good rule of thumb is to 'start low and go slow.' If you haven't been active in a while, start where you can, even if that's just a 1-2 minute walk. Gradually increase the duration, intensity and frequency over time as you can tolerate. Consider making an appointment with a physical therapist, who can

work with you to develop an exercise/activity plan that is specific to your health condition and needs.

#### **4. Healthy Eating and Sleeping**

What you eat and how well you sleep impact how you feel. There is no specific diet that's been proven to relieve depression, but eating a healthy diet is beneficial to your overall health and well-being, and part of any treatment plan for chronic illness. Consider meeting with a nutritionist who can help you to develop a healthy eating plan customized for you. Likewise, as discussed prior, sleep has an enormous impact on your overall health and mood.

#### **5. Sunlight**

Sunlight boosts serotonin levels, which can improve your mood. Aim to get 15 minutes of sunlight a day. On cloudy days you can use light therapy, also called phototherapy, to expose yourself to light that mimics natural outdoor light. This typically includes sitting in front of a light box for 15-30 minutes day.<sup>230</sup>

#### **6. Challenge Negative Thinking**

Negative thought patterns can fuel depression, so it's important to identify and address them. They include:

- All-or-nothing thinking – Looking at things in black-or-white with no middle ground ("If I fall short of perfection, I'm a failure.")
- Overgeneralization – Generalizing from a single negative experience ("I can't do anything right.")
- Mental filter – Ignoring positive events and focusing on the negative, i.e., if 9 out of 10 things went right, you focus on the 1 thing that went wrong
- Diminishing the positive – Coming up with reasons why positive events don't count ("She said she enjoyed our date, but she was just being nice.")
- Jumping to conclusions – Making negative interpretations without evidence ("He must think I'm pathetic.")
- Emotional reasoning – Believing that the way you feel reflects reality ("I feel like a loser. I'm no good.")
- Shoulds & should nots – Holding yourself to a strict list of what you should and shouldn't do, and beating yourself up if you don't measure up
- Labeling – Classifying yourself based on mistakes and perceived shortcomings ("I'm a failure; an idiot; a loser.")

Once you identify destructive thought patterns that contribute to depression, you can start challenging them. Ask yourself:

- What evidence do I have to support this thought?
- What would I tell a friend who had this thought?
- Is there an alternate way of looking at the situation?
- How might I look at this situation if I didn't have depression?

As you cross-examine negative thoughts, you'll find that most of them don't hold up. This process can help you to develop a more balanced perspective and help to relieve some of your depression.

### **Chronic Pain & Anxiety<sup>231</sup>**

Many people with chronic pain also experience anxiety, either by itself or along with depression. Both are believed to stem from the same biological vulnerability, which may explain why they often co-exist. Depression can make anxiety worse and vice versa, so if you're experiencing both, it's important to seek treatment for both.

Similar to depression, there is a difference between feeling anxious from time-to-time and having a diagnosable anxiety disorder. Again, it's important to know the difference in order to be able to develop an individualized treatment plan that addresses all of the symptoms/disorders that are unique to your situation.

Anxiety is a natural response to danger or when facing a stressful situation. But when it becomes constant or overwhelming, interfering with relationships and activities, anxiety can become a disorder. Anxiety disorders are a group of related conditions rather than a single disorder, so they can look very different from person to person. However, all anxiety disorders share one major symptom – persistent or severe fear or worry in situations where most people wouldn't feel threatened. In addition to this primary symptom, other common emotional symptoms of anxiety include: feelings of apprehension or dread; watching for signs of danger; anticipating the worst; trouble concentrating; feeling tense and jumpy; irritability; and feeling like your mind has gone blank. Anxiety also includes a wide range of physical symptoms, including: pounding heart; sweating; headaches; stomach upset; dizziness; frequent urination or diarrhea; shortness of breath; muscle tension or twitching; shaking or trembling; and insomnia.

There are six major types of anxiety disorders:

- Generalized Anxiety Disorder (GAD) — People with GAD chronically worry and feel anxious nearly all of the time, even though they may not know why. Symptoms like insomnia, stomach upset, restlessness and fatigue are common.
- Panic Disorder is characterized by repeated, unexpected panic attacks and fear of experiencing another episode.

- Obsessive Compulsive Disorder is characterized by unwanted thoughts or behaviors that seem impossible to stop or control. Obsessions, such as worrying that you forgot to turn off the oven, and uncontrollable compulsions, such as repeated hand-washing, are common.
- Phobias and Irrational Fears — A phobia is an unrealistic/exaggerated fear of a specific object, activity or situation that, in reality, presents little to no danger, such as fear of animals, flying or heights.
- Social Anxiety Disorder — A debilitating fear of being seen negatively by others or humiliated in public.
- Post-Traumatic Stress Disorder occurs after a traumatic or life-threatening event. Symptoms include flashbacks, nightmares, startling easily, withdrawing from others and avoiding situations that remind you of the event.

The type, components and length of therapy will differ depending on which type(s) of anxiety disorder you suffer from. Traditional anti-anxiety drugs, such as benzodiazepines (e.g., Xanax®, Valium®), as well as newer options of antidepressants, such as Selective Serotonin Reuptake Inhibitors (SSRI), can be used to help manage your anxiety. It's important to understand their potential benefits, as well as common side effects and safety concerns, and then weigh the pros and cons with your health care provider.

Some helpful questions to ask yourself and your clinician about anxiety treatment include:

- Is medication the best option to treat my specific type of anxiety disorder?
- How long will I need to take the medication and what are common side effects?
- Am I willing to deal with unpleasant side effects in exchange for anxiety relief?
- What are my options for non-drug anxiety treatments?
- Do I have time and am I willing to pursue non-drug treatments?
- What self-help strategies might help me to control my anxiety?
- If I decide to use medication, should I pursue other therapies as well?

Therapy can give you the tools to overcome anxiety, as well as teach you how to use them. It can help you uncover the underlying causes of worries and fears, learn how to cope with them, look at situations in a new, less frightening way, and develop better coping and problem-solving skills. Many different types of therapy are used to treat anxiety, but the most common approaches are cognitive behavioral therapy (CBT) and exposure therapy.

- CBT addresses negative thought patterns and distortions in the way we look at the world and ourselves. It involves two components – cognitive therapy, which examines how negative thoughts, or cognitions, contribute to anxiety, and behavior therapy, which examines how you behave and react in situations that trigger anxiety. The goal of CBT for anxiety is to identify and correct negative

thoughts and beliefs. As you change the way you think, you can change the way you feel.

- Exposure therapy exposes you to anxiety-producing situations or objects. The goal with repeated exposures is that you'll feel an increasing sense of control over the situation and your anxiety will diminish. This is usually done in steps, through a desensitization process, which allows you to gradually challenge your fears, build confidence and master skills for controlling anxiety.

Other complementary therapies include exercise, relaxation techniques, biofeedback, hypnosis and others.

### **Helpful Tips for Dealing with Anxiety<sup>232</sup>**

In addition to treatment, these tips on coping with anxiety may be helpful:

1. Accept that you cannot control everything. Achieve perspective by asking: "Is it really as bad as I think?"
2. Do your best. Perfection isn't realistic, so be proud of all you've done, rather than pursue something that isn't achievable.
3. Maintain a positive attitude. Replace negative thoughts with positive ones.
4. Learn what triggers your anxiety. When you feel anxious, journal about the situation and your feelings. Look for a pattern and develop a plan to avoid triggers (if that's possible) or how to deal with them.
5. Replace alcoholic and caffeinated drinks, which can aggravate anxiety, with water.
6. Eat healthy, well-balanced meals and snacks. Don't skip meals.
7. Get a proper amount of sleep and develop a frequent exercise routine, daily if possible.
8. Learn relaxation techniques you can use to cope with anxiety, including deep breathing, meditation, music therapy, etc.
9. Talk to someone. Seek professional help from your health care provider or therapist. Be open with friends and family—share what you're experiencing and let them know how they can help.
10. Volunteering may seem like a strange thing to do, but it can help a great deal. Being active in your community creates a support network and a sense of larger purpose and community.

## CHAPTER 6: Developing an Individualized Treatment Plan

In the last chapter, we discussed some of the conditions and factors that can affect the severity and impact of chronic pain, such as sleep and mood. It's essential to identify all the health disorders and factors that play a role in your medical condition to develop a comprehensive treatment plan. Once you identify these conditions/factors, you can begin the process of working with your health care provider to develop a treatment plan that is best suited for you.

Many treatments are available to manage chronic pain and its related disorders; however, everyone is unique and responds differently to treatments. With most chronic pain conditions, including COPCs, a combination of drug and non-drug treatments are most effective in reducing the severity of pain and improving quality of life. It can take some time and trial-and-error to find treatments that work best for you without producing intolerable side effects.

The U.S. Food and Drug Administration (FDA) has approved treatments for some COPCs, such as fibromyalgia and chronic migraine (see Table 1), while no FDA-approved treatment options exist for other COPCs. However, there are many drug and non-drug options that are used off-label to treat COPCs, in specific, and chronic pain, in general. Similarly, related conditions, such as sleep and mood disorders, can be managed with various treatment options, and many strategies exist to combat other factors at play, such as fatigue and cognitive difficulties.

Essential to long-term improvement is setting small attainable goals that you will begin to work towards with treatment. This helps to measure overall progress and improvement in function, as well as to provide motivation and hope. (See 'Functional Goal Setting' on page 33.)

General types/classes of treatments used to manage chronic pain, including COPCs, are summarized below.<sup>233</sup>

### **Antidepressant Medications<sup>234</sup>**

There are many theories as to why antidepressant medications are also effective in treating chronic pain. The most popular is that antidepressants impact the uptake of the same neurotransmitters implicated in chronic pain (e.g., serotonin, norepinephrine).<sup>235</sup> Several different classes of antidepressant medications are used to manage chronic pain. Those most commonly used include:

- Tricyclic Antidepressants (TCAs) — TCAs are an older class of antidepressants that can be effective in treating chronic pain. Possible side effects include, but are not limited to weight gain, dry mouth, constipation, dizziness, and low blood pressure when standing. (see note\*\*)

**Table 1. FDA-Approved Treatments for COPCs**

COPC	Treatment Name	Manufacturer	Year Approved
Chronic Low Back Pain	INTRACEPT® Intraosseous Nerve Ablation System	Relievant Medsystems	2016
	Senza® Spinal Cord Stimulation System	Nevro Corporation	2015
Chronic Migraine*	Botox®	Allergan	2010
Irritable Bowel Syndrome	Xifaxan®	Salix Pharmaceuticals	2015
	Viberzi®	Allergan	2015
	Linzess®	Forest Labs & Ironwood Pharmaceuticals	2012
	Amitiza®	Sucampo Pharmaceuticals	2006
	Zelnorm®	Novartis	2002
	Lotronex®	GlaxoSmithKline	2000
Interstitial Cystitis	Elmiron®	IVAX	1996
Fibromyalgia	Savella®	Forest Labs	2009
	Cymbalta®	Eli Lilly	2008
	Lyrica®	Pfizer	2007
Endometriosis	Aygestin®	Duramed Pharmaceuticals	2005
	Depo SubQ Provera 104®	Pfizer	2005
	Lupron Depot®	TAP Pharmaceuticals	1999
	Synarel®	Pfizer	1990
	Zoladex®	Zeneca Pharmaceuticals	1989
	Danazol®	Teva Pharmaceuticals	1971

\*Other treatments are approved for episodic migraine; however, Botox® is the only approved treatment for chronic migraine.

- Selective Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs) — SNRIs are a newer type of antidepressant medication that, similar to TCAs, influence the uptake of norepinephrine and serotonin, although in a slightly different way. Two SNRIs are FDA-approved for the treatment of fibromyalgia (see Table 1). Cymbalta® is also FDA-approved to treat chronic muscle or joint pain, such as that experienced by people with low back pain and osteoarthritis.<sup>236</sup> Common side effects include, but are not limited to dizziness, nausea, dry mouth, insomnia, sweating, headache, tiredness, anxiety and sexual dysfunction.<sup>237</sup> (see note\*\*)

\*\* A note about medications discussed in this guide: The dose of these medications is typically increased gradually to allow your body to adjust to them. Similarly, these medications can cause adverse effects if stopped abruptly. Before beginning (or stopping) any medication, talk to your health care providers about the benefits and risks, as well as common side effects and possible interactions with other medications you may be taking. For a searchable database and detailed information on medications, please visit [www.drugs.com](http://www.drugs.com) or [www.rxlist.com](http://www.rxlist.com).

## Anticonvulsant Medications

Medications developed to treat epilepsy have also been found to be effective in the treatment of certain chronic pain disorders. One anticonvulsant—Lyrica®—is approved for the treatment of one COPC—fibromyalgia—and for the treatment of neuropathic pain associated with diabetic neuropathy, postherpetic neuralgia and spinal cord injury. Anticonvulsants are used off-label to treat other pain disorders. The side effects of various anticonvulsant medications differ. As one example, common side effects reported in trials of Lyrica® include dizziness, tiredness, dry mouth, swelling, blurred vision, weight gain and difficulty with concentration/attention.<sup>238</sup> (see note\*\*)

## Muscle Relaxant Medications<sup>239 240</sup>

Medications that act as central nervous system depressants and have sedative and musculoskeletal relaxant properties are called muscle relaxants. One type of muscle relaxants—called antispastics—treat muscle spasticity, which is continuous muscle spasm that causes stiffness and rigidity and interferes with walking or talking; antispastics are used to treat conditions like multiple sclerosis and cerebral palsy. The other type—called antispasmodics—treat muscle spasm, which are involuntary contractions of a muscle or muscle group, common in some COPCs like chronic low back pain and fibromyalgia. Examples of antispasmodics include Flexeril® and Zanaflex®. Common side effects include, but are not limited to drowsiness, dizziness, headache, nervousness and low blood pressure when standing. (see note\*\*)

## A Note About Over the Counter Medications

Over the counter medications, such as acetaminophen and ibuprofen, are generally used for short periods of time to treat temporary pain episodes and are not recommended for long-term use in the treatment of chronic pain conditions. Sometimes people think that

over the counter medications, including acetaminophen and ibuprofen, are generally safe because you do not need a prescription to obtain them. However, when used for extended periods of time and/or at higher doses, these medications do carry risks. For example, the FDA has limited the amount of acetaminophen that can be used in prescription medications, warning of possible severe liver injury and allergic reactions.<sup>241</sup> The FDA also strengthened its warning of non-aspirin nonsteroidal anti-inflammatory drugs, including ibuprofen, stating an increased risk of stroke and heart attacks.<sup>242</sup> (see note\*\*)

## Thermotherapy and Cryotherapy

Applying heat or cold to painful areas of the body may provide immediate, short-term relief. Heat helps to relax muscles that are tense or in spasm and increase local circulation, which can help to reduce pain and stiffness. Cold reduces muscular temperatures and acts to decrease local metabolism, inflammation, and pain.

## Physical and Occupational Therapy

The goal of physical therapy is to maximize and then maintain one's functional ability, without increasing pain severity.

For example, you learn that chronic pain does not necessarily imply that tissue damage is taking place, and that avoiding an active lifestyle can worsen pain severity over time as your body deconditions (see Figure 6).

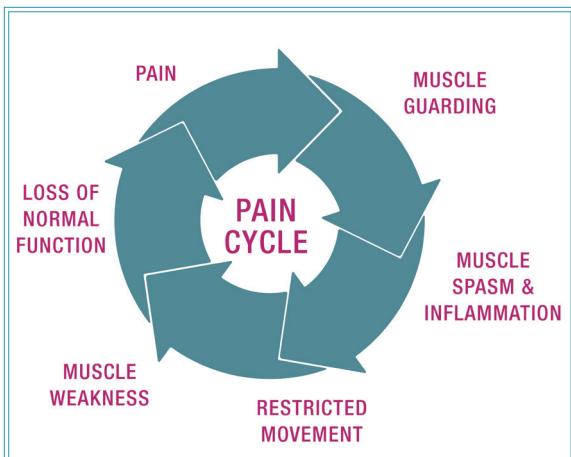


Figure 6

Physical therapists use a range of different types of treatments, often referred to as modalities, to help patients regain range of motion, muscle strength and aerobic endurance. These include stretching, aerobic and strength training exercises, massage, ultrasound, and other treatments.

Occupational therapy focuses on helping patients to perform activities of daily living. For example, in OT, you learn that a baseline level of daily activity is best. A technique called "pacing" is taught, where daily activities are planned in advance, including regular breaks throughout the day, so that you don't do too much in one day and crash the next. OTs may also help you to identify and obtain adaptive equipment that will help you to perform certain tasks at home or at work without increasing your pain. For example, if bending over and putting clothes in the washing machine is painful, an OT may suggest using a small tool that enables you to pick up clothes without having to bend over.

## **Transcutaneous Electrical Nerve Stimulation (TENS)**

TENS is a device that delivers slight electrical stimulation through electrodes placed on the skin. TENS is believed to work by activating a certain type of nerve fiber, which inactivates other nerve fibers that send pain signals to the brain. Sometimes this therapy is used by physical therapists or chiropractors, and if found to be helpful, at-home devices are also available.

## **Spinal Cord Stimulation<sup>243</sup>**

Spinal cord stimulation (SCS) is reserved for patients who do not respond to other less invasive forms of treatment. Careful patient selection is very important for predicting long term outcomes. Currently, chronic low back pain is the only COPC for which a SCS has been FDA-approved (see Table 1 on p. 28). Spinal cord stimulation is thought to interrupt painful nerve signals by “over-riding” them with electrical stimulation. It involves a surgical procedure where small electrodes are implanted next to the spinal cord. Surgeons also implant a stimulator unit under the skin that is programmed remotely by a health care provider. Complications include, but are not limited to the development of scar tissue, movement of the electrodes from their original position, infection, bleeding and pain at the site where the stimulator is placed.

## **Psychological Counseling**

Visiting a psychologist for pain does not mean that your chronic pain is a psychological, rather than a physical, problem. Psychologists can be helpful in identifying the many factors that can worsen pain, as well as pain’s impact on other areas of your life, such as sleep, mood, appetite, relationships, work, and finances. Your emotional suffering and how you respond to chronic pain plays a major role in how well you are able to cope.

There are many approaches to psychological treatment, including:

- Cognitive behavioral therapy (CBT) proposes that we are not merely passive responders to our environment, but active processors of information, who base our responses on our own personal view of reality, which is constantly being revised and updated through sensory, emotional, and cognitive factors. CBT targets negative ways of thinking, feeling and behaving to help us recognize that negative thoughts and feelings about pain are directly linked to behaviors that don’t help us to get better. Unhelpful thoughts are identified and replaced with thoughts about positive functioning, and patients learn that they can control their painful symptoms to an extent by using the skills obtained with therapy.
- Acceptance and commitment therapy (ACT), in contrast to CBT, targets our *responses* to negative thoughts, feelings and behaviors. ACT teaches techniques to address thoughts of pain; minimize one’s sole focus on reducing pain; and engage in a process of letting go and moving towards one’s individual values and goals. It includes elements of ‘mindfulness,’ where we are taught to attend to the present moment without attaching meaning or judgmental

language to thoughts that arise. Thoughts are viewed as transient events, separate from the person, which allows one to deal with difficult thoughts and feelings that might otherwise become barriers to pursuing his or her goals.

- Mindfulness-based stress reduction is a program developed in the 1970s, which uses a combination of mindfulness meditation, body awareness and yoga. Research suggests that it can help to reduce stress, relax and improve quality of life, which can be beneficial in coping with the impact of chronic pain.

## **Complementary Health Approaches**

Some people with chronic pain, including COPCs, may benefit from using complementary approaches, such as chiropractic care, massage, yoga and acupuncture. For additional information on complementary approaches, as well as ongoing research on these approaches, please visit the National Center for Complementary and Integrative Health's website: <https://nccih.nih.gov/health/pain/chronic.htm>.

## **Other Treatments**

This is by no means an exhaustive list of treatments available to manage COPCs, but a summary of therapies that are most common. Your health care provider may recommend other types of treatment depending on your individual condition and any other health issues you may be experiencing. In addition, the pharmaceutical and medical device industry and the medical research community are working to develop new treatments for the treatment of COPCs and chronic pain. To view a list of clinical trials that are currently enrolling patients, please visit: <https://clinicaltrials.gov/>.

## CHAPTER 7: Tracking Progress & Functional Goal Setting<sup>244</sup>

Because no objective measures for pain exist, health care providers often assess progress by asking patients to rate the severity of their pain on a 10-point scale. The fluctuating nature of pain (throughout the day, week, month and year) and the many factors that influence chronic pain (and vice versa) make it difficult for many patients to provide ratings that they feel accurately capture their experience and that are meaningful in managing their chronic pain condition. Further, studies have shown that a pain scale rating and patient's functional abilities do not always correlate, and that a more comprehensive approach is needed to capture the spectrum of issues important to patients, such as sleep, mood, fatigue and their ability to work, exercise and participate in family and social functions.

Clinicians who specialize in the treatment of chronic pain use a variety of tools and questionnaires to obtain this information and work with their patients. One such resource is called Pain Tracker™ from the University of Washington. (see [http://depts.washington.edu/anesth/education/forms/pain/PainTracker\\_PatientVersion.pdf](http://depts.washington.edu/anesth/education/forms/pain/PainTracker_PatientVersion.pdf)) In addition to asking about pain severity, it obtains information on how pain impacts sleep, mood, general activity, pleasure in performing activities and overall enjoyment in life. It also asks about side effects that patients may be experiencing from their medications or other treatments, as well as their satisfaction with the pain treatment they receive.

Functional goal setting is another important part of this tool and oftentimes is utilized by health care providers who treat chronic illness. Setting small attainable goals that you can work towards accomplishing in between visits helps to keep you focused on something positive (i.e., “I took another step towards achieving my goal today.”), rather than focusing on “how bad” you feel each day. Goal setting approaches encourage patients to work on improving quality of their life despite their pain. They have been shown to increase patients’ progress toward mutually agreed upon goals, improve treatment adherence, create a successful individualized pain rehabilitation plan and improve patient-provider communication.<sup>245</sup>

Here’s how the process works. Patients start by selecting a focus area that they think they can improve. Some examples include:

- Exercise (strengthening, stretching, aerobic activity)
- Relaxation/meditation/quieting response
- Social support/social activity
- Meaningful life activities (work, volunteer, social responsibilities)
- Pleasurable activities (hobbies, interests, diversions, distractions, social)
- Attitude/mood/thinking

After selecting a priority area, patients use the SMART goal setting system to help narrow down their focus and set specific goals. (“SMART” stands for: Specific, Measurable, Action-Oriented, Realistic, and Timed.) A well-developed goal allows you to track progress and answer the question, “Did I achieve this goal?” with a clear “yes” or “no” answer. By successfully achieving smaller goals, over time, patients gain the confidence to tackle larger goals in the future.

Next, patients write down their personal SMART goal, and break it down into three small achievable steps, using the 90% rule to assess whether the goal is realistic and achievable. The 90% rule proposes that if you’re not 90% sure that you can reach a smaller goal within two weeks, then you’ve set the goal too high and should scale it back. Even with the best of intentions, the very unpredictable nature of chronic pain can create obstacles. After writing down your three small goals, think about and write down potential obstacles, along with specific steps you’ll take to deal with those obstacles to stay on track.

Here’s an example:

<i>Priority Area:</i>	Exercise
<i>Long-term Goal:</i>	Walk for 20 minutes, 5 days a week
<i>Small Goal 1:</i>	Weeks 1-3: walk for 7 minutes, 3 days a week
<i>Small Goal 2:</i>	Weeks 4-6: walk for 14 minutes, 4 days a week
<i>Small Goal 3:</i>	Weeks 7-9: walk for 20 minutes, 5 days a week
<i>Possible Obstacles:</i>	bad weather
<i>Steps to Stay on Track:</i>	join a gym or plan to walk at the mall when the weather is bad; get a walking partner for accountability, company and encouragement

For additional information on goal setting approaches and a sample worksheet, please visit: [http://www.emergingsolutionsinpain.com/content/tools/patient\\_edu\\_series/FactSheet5.pdf](http://www.emergingsolutionsinpain.com/content/tools/patient_edu_series/FactSheet5.pdf).

# CHAPTER 8: Patient-Centered Care & Shared Decision-Making

Some of us have great relationships with our health care providers. They are attentive and listen to our concerns, take the time to discuss those concerns and other important issues, and work with us as partners, taking our goals and values into consideration. For others, the patient-provider relationship is less than optimal, and we may not have the option of changing providers because of our insurance plan or where we live. In this section, we review aspects of Patient-Centered Care—which is care that is centered on the patient—so that you can evaluate the quality and patient-centeredness of the care you are currently receiving, and address issues that you'd like to improve with your provider.

## Patient-Centered Care<sup>246</sup>

Patient-centered care (PCC) is defined as: "Providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions."<sup>247</sup> It includes listening to, informing and involving patients in their own health care. PCC is not a new concept, but one that has taken some time to be adopted into the health care system.

Using patient focus groups, combined with scientific evidence, researchers from Harvard Medical School, on behalf of the Picker Institute and The Commonwealth Fund, defined eight major principles of PCC. These are referred to as Picker's Eight Principles of Patient Centered Care and are described below. Although originally developed to address medical care provided in a hospital setting, they can be broadly applied to all settings in which medical care is provided. Learning and understanding these principles can help you to evaluate the 'patient-centeredness' of the medical care you are currently receiving and help you to move towards optimal care. As you read through them, take note of which principles are really important to you, as well as the quality of that principle in the health care you're currently receiving.

### 1. Respect for Patients' Values, Preferences and Expressed Needs

Patients are individuals, and individuals are unique. We all have different values, preferences and needs. What is important to one person is less important to another. Therefore, patients should be treated with dignity, respect and sensitivity to their cultural values and individualities, as well as involved in decision-making. Further, because illness and treatment of an illness affect a person's quality of life, medical care should be broadly focused on improving not only one's health, but his/her quality of life. Shared decision-making, which is discussed in the next section, is part of this principle.

This principle is important to me: \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure

My health care needs improvement in this area: \_\_\_\_\_ Yes \_\_\_\_\_ No

## **2. Coordination and Integration of Care**

Patients oftentimes express feelings of vulnerability and powerlessness when faced with an illness. Proper coordination of care can help to alleviate some of those feelings. This includes coordinating not only your office visit, but other aspects of care (e.g., lab tests, medical imaging, physical therapy, long-term care), as well as your interaction with your health care provider's front-office staff, nursing staff and social workers.

This principle is important to me: \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure  
My health care needs improvement in this area: \_\_\_\_\_ Yes \_\_\_\_\_ No

## **3. Information and Education**

Patients often feel that they're not being given all of the necessary information about their medical condition or prognosis. To counter this, health care providers should provide patients with information on their clinical status, progress and prognosis. Further, clinicians should provide information to facilitate patients' self-care and health promotion.

This principle is important to me: \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure  
My health care needs improvement in this area: \_\_\_\_\_ Yes \_\_\_\_\_ No

## **4. Physical Comfort**

Patients' physical comfort has a significant impact on their health care experience. Patients describe physical care that provides comfort, especially when facing acute illness, as one of the most elemental services that a clinician provides. Areas of particular importance to patients include: pain management, assistance with activity and daily living needs, and hospital surroundings and environment.

This principle is important to me: \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure  
My health care needs improvement in this area: \_\_\_\_\_ Yes \_\_\_\_\_ No

## **5. Emotional Support and Alleviation of Fear and Anxiety**

Fear and anxiety can be as (or more) debilitating than the medical condition itself, and therefore need to be identified and addressed in treatment plans. Of particular importance is fear/anxiety over: one's physical status; treatment and prognosis; the condition's impact on the patient and his/her family; and financial impact.

This principle is important to me: \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure  
My health care needs improvement in this area: \_\_\_\_\_ Yes \_\_\_\_\_ No

## **6. Involvement of Family and Friends**

Family and friends play an important role in a patient's experience. Patients report the following as important to them: involving family and close friends in decision-making; supporting family members as caregivers; and recognizing the needs of family and friends.

This principle is important to me: \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure  
My health care needs improvement in this area: \_\_\_\_\_ Yes \_\_\_\_\_ No

## **7. Continuity and Transition**

This principle applies to post-hospital care. Patients express concern about their ability to care for themselves after discharge and the need for more coordination and planning of ongoing treatment and services after discharge from the hospital. Further, they report the need for understandable, more detailed information regarding their medications, physical limitations, dietary needs, etc. They also want to be provided with adequate information regarding access to clinical, social, physical and financial support on a continual basis.

This principle is important to me: \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure  
My health care needs improvement in this area: \_\_\_\_\_ Yes \_\_\_\_\_ No

## **8. Access to Care**

Patients need to know that they can obtain medical care when it's needed. Patients prioritize the following areas: access to the location of hospitals, clinics and physician offices; availability of transportation; ease of scheduling appointments; availability of appointments when needed; accessibility to specialists or specialty services when a referral is made; and clear instructions provided on when/how to obtain referrals.

This principle is important to me: \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_ Unsure  
My health care needs improvement in this area: \_\_\_\_\_ Yes \_\_\_\_\_ No

For a handout that includes questions you can ask your health care provider about patient-centered care, please visit: <http://planetree.org/wp-content/uploads/2015/08/PCCAM-Doctor.pdf>.

## **Shared Decision-Making**<sup>248</sup>

A major component of patient-centered care is shared decision-making. This is a model that enables and encourages patients to actively engage in making medical decisions affecting their health. It operates under two premises:

1. Consumers armed with quality information can and will participate in the medical decision-making process by asking informed questions and expressing personal values and opinions about their condition and treatment options.
2. Clinicians will respect patients' goals and preferences and use them to guide recommendations and treatments.

The aim of shared decision-making is to ensure that:

- Patients understand their options, as well as the pros and cons of those options.
- Patient's goals and treatment preferences are used to guide decisions.

Improved quality of medical consults has been found to positively affect the quality of treatment decision, patient-provider communication and both patient and provider satisfaction. Specifically, research has shown:

- Consumer participation can increase patient satisfaction and lead to better health outcomes.<sup>249 250 251</sup>
- Patients empowered to make health decisions that reflect their personal preferences often experience more favorable health outcomes, such as decreased anxiety, quicker recovery and increased treatment compliance.<sup>252</sup>
- Greater consumer involvement in decision-making leads to lower demand for health care resources.<sup>253</sup>

Although some critics say that patients aren't able or willing to make their own health decisions, there is evidence that patients want more information and greater involvement in decision making in partnership with their providers.<sup>254 255 256</sup> Evidence-based tools, called patient decision aids, can be useful in informing patients and helping them to set their own goals and clarify their values. These tools increase knowledge, improve risk estimates, increase patient's involvement in decisions, and help clarify treatment preferences.<sup>257</sup> Research also suggests that decision aids can increase the quality and depth of discussion between patients and providers; one study found that increased understanding through the use of a decision aid enabled discussion to focus on risk/benefit trade-off, rather than just describing treatment alternatives.<sup>258</sup>

The Cochrane Inventory of Patient Decision Aids uses international standards to rate the quality of available decision aids. The Inventory includes a searchable database, along with a review of the aid standards, which can be found online at: [www.ohri.ca/decisionaid](http://www.ohri.ca/decisionaid).

## Chapter 9: Tips for Improving Communication with Your Health Care Provider<sup>259 260</sup>

Some of us have great communication with our health care providers. For others, there's a lot of room for improvement. You may be hesitant to ask questions or feel as if your doctor isn't fully listening to you. You may have confidence in your provider's competence, but experience communication problems. This is important for obvious reasons, but especially because studies have shown a correlation between effective communication and improved health outcomes. One review of 20 studies found that the quality of communication in the history-taking segment and discussion of the management plan was found to influence health outcomes, including pain control.<sup>261</sup>

There is increasing awareness that quality doctor-patient communication is one of the key elements in effective health care. To improve communication with your health care provider, consider the following tips.

1. Use a journal or mobile app to help you track your pain and organize pertinent health information. Keeping a diary of your symptoms and treatment can be very helpful in identifying patterns that either help you to feel better or worse. In addition to tracking the intensity of your pain, it can be helpful to track your sleep, mood, fatigue, stress, exercise/activity, or anything else that impacts your pain (and vice versa). In addition, in a health journal, you can include the names of, and contact information for, your health care providers, names/doses of your medications, as well as questions for your health care provider. There are many mobile apps, specifically designed for people with chronic pain or chronic illness, that you may consider using.
2. Prepare for your appointments. Write down your questions ahead of time and bring them with you to your appointment. Recognizing that your provider's time is often limited, list the most important questions first. You can also prepare for your appointment by doing some research and educating yourself about your condition.
3. Research your insurance and prescription benefits. Doing so will help you in making choices about covered/uncovered services, therapies and medications. It's better to know ahead of time, rather than having to follow-up with your doctor's office after your appointment to request an alternate medication or service if it's not covered. Make sure to bring this information, along with your insurance card, to your appointment.
4. Bring someone with you to your appointment. Even if you have a journal and have prepared a list of questions and concerns, your appointment may be rushed, and depending on how well you're feeling that day, come with high emotions. It's always helpful to have a source of support when you go to your appointments. He/she can be a second set of ears, as well as help you to think of questions to ask or remember details that you forget.
5. Take notes or, if possible, record your visit. Studies show that people are only able to retain a small percentage of the information shared with them during a medical

visit. Taking notes will help you to remember your clinician's responses, advice and instructions. If you have someone come with you to your appointment, he/she could take notes for you. If your health care provider agrees, record the visit so that you can hear specific information again and/or share it with family members or friends.

6. Be open and honest. It can be detrimental to withhold information, such as other medical conditions you may have, allergies, and/or substances you may be using, from your provider. With very few life-threatening exceptions, the information you share with your provider is confidential and protected by privacy laws. In order to provide you with an accurate and thorough medical assessment, as well as determine the best course of treatment, your provider needs to have a complete picture of what is going on with you physically and emotionally. So be open and honest. Share everything, even little things that you might think are unimportant or embarrassing, because these often provide useful clues.
7. Make sure to share information on all of your medications, supplements and health practices. Patients often only report information on their prescription medications, but vitamins, supplements, herbal remedies and other therapies and health practices can adversely interact with another treatment, resulting in serious side effects. Make a list and bring it with you to your appointment.
8. Ask questions! It's normal to have questions about your condition, recommended treatments, how to take medications and other things. If you have questions, make sure to ask them before you leave the office. If your provider doesn't have enough time to address all of your questions, ask to be contacted by phone or whether a nursing assistant is available to go over that information with you. Also be sure to ask how your provider prefers that you contact the office with questions in between appointments.
9. Ask about expected results. Many different types of medications are used to treat chronic pain. It can often take weeks to months to gradually increase the doses of these medications to an effective level. Some of these medications can have substantial side effects as well, so it's prudent to ask questions about what you should watch for and what you should do if you begin to experience any issues. Likewise, with some other treatments, like physical therapy, it may take many sessions before you begin to notice any change in your pain levels. It's normal to ask questions about how long it may take to experience a significant effect, side effects that you might experience, and what to do if you experience an adverse event.

Your provider has medical knowledge and experience, but you know your body better than anyone else. Exercising these principles can help you to establish better partnership with your provider, so that you are both working on the same goal – improving your health and quality of life.

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