Chronic Pain

Survivors sometimes experience ongoing pain after cancer treatment. Knowing what the causes are and being able to describe your symptoms to your health care team can help you manage chronic pain.

Chronic Pain: Detailed Information

This information is meant to be a general introduction to this topic. The purpose is to provide a starting point for you to become more informed about important matters that may be affecting your life as a survivor and to provide ideas about steps you can take to learn more. This information is not intended nor should it be interpreted as providing professional medical, legal and financial advice. You should consult a trained professional for more information. Please read the Suggestions (http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Physical-Effects-of-Cancer/Chronic-Pain#s#) and Additional Resources (http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Physical-Effects-of-Cancer/Chronic-Pain#AR#AR) documents for questions to ask and for more resources.

Many cancer survivors experience pain during their treatment. Most find ways to manage it with the help of their health care team. However, there are some who may continue to have pain after their treatments have ended. Their chronic (also called persistent) pain may be mild or severe and may affect the quality of life. The good news is that there are now many ways to treat pain that can greatly reduce or even eliminate most pain.

Be sure to tell your health care team if you are having pain—even if they do not ask about it. Pain should not prevent you from going about your daily routine and doing the things in life that are important. There are many ways to manage pain and lessen the effect it has your life. Work with the members of your health care team to set goals for pain control. You should not have to live your life in pain.

Why do some survivors experience chronic pain?

Not every survivor will experience chronic pain. However, some do, and the cause may vary. For example, chronic pain can result from treatment of cancer or because the cancer has metastasized or spread to other parts of the body. Survivors who had breast, prostate, lung or colorectal cancer may have pain because cancer has spread to the bones. Bony metastases are the most common cause of pain in advanced cancer.
Peripheral neuropathy, due to injury to nerves, may result from treatment with chemotherapeutic agents. This can cause pain, tingling, burning, numbness or weakness that usually begins in the hands or feet. Most of the time, the pain caused by peripheral neuropathy will go away when cancer treatment stops. However, if the nerves become permanently damaged, the pain will persist. Chemotherapy medications may cause peripheral neuropathy such as Taxol, Vincristine, Taxotere, and Cisplatin.

Steroids taken as part of cancer treatment may bring a risk for chronic bone pain. They can cause the bones to grow weaker leading to osteoporosis that may lead to fractures that can cause pain. Talk with your health care team if you took steroids during your cancer treatment to find out if you might be at risk of chronic pain.

Radiotherapy and surgery can also lead to a variety of acute and chronic pain problems. Studies have shown that unrelieved acute postoperative pain is a major risk factor for delayed recovery and the development of chronic pain problems.

**What do the members of the health care team need to know?**

Be sure to tell your doctor or nurse if you experience a new pain or the pain changes and feels different to you. Let them know right away if you develop painful swelling (lymphedema) in an arm or leg. Contact your health care team right away if you feel pain, numbness, tingling or a burning sensation in your hands or feet. Also, let your doctor know if your current pain medications stop working or are not working as well as they once did.

If you have pain problems, contact your doctor or other members of your health care team right away. It is important to get the best treatment possible. If pain becomes severe, it can become more difficult to manage. Keep a record of your pain. Take this information to your appointments with your doctor.

**Tell your doctor if you have:**

- New or different pain
- Long-term or constant pain
- Pain that continues after treatment
- Pain that feels different than what you have had before
- Pain and swelling in an arm or leg
- Pain, numbness, tingling or a burning sensation in your hands or feet

Give your doctor enough information to correctly assess your pain situation. Many doctors ask patients to rate their level of pain using a pain scale. A rating of zero means no pain. A rating of 10 stands for the highest level of pain. This method gives the doctor a better idea of the level of discomfort.
Pain can affect your ability to sleep, eat, work and spend time with loved ones and friends. Tell your doctor how the pain is affecting your life. Describe how it interferes with your activities. Relief from pain can positively affect your overall health, strength and ability to heal properly. A doctor may try several methods to find what works best to relieve your pain.

When you talk with your doctor about pain symptoms, he or she should ask questions. Tests should be done to identify the cause of the problem. It is important that the members of your health care team listen to you.

Be certain that your doctor has the experience and skills to treat your specific condition. You deserve to receive good pain care. Some nurses and doctors specialize in managing pain, such as physiatrists and anesthesiologists. If you think your doctor is not having success treating your pain, ask for a referral to a pain specialist.

The American Pain Foundation provides important information about pain care and support. They have also developed a Pain Care Bill of Rights as a patient guide. Call their toll-free number (1-888-615-7246) or go online www.painfoundation.org.

**Pain Relief Treatment Options**

Stress can make pain worse. It can also lessen the effect of medications. Sometimes a doctor may recommend counseling to help a patient cope. This may lessen the pain. It may also help improve the effectiveness of the pain medication.

Other types of treatment may be used along with pain medications to provide relief. These methods are called complementary, alternative or holistic medicine. They include massage, acupuncture, biofeedback or hypnosis.

Some health care professionals are not aware of many types of complementary therapies. Others might think that these methods do not work. To learn more about these types of therapies, contact the National Cancer Institute at their toll-free number (1-800-422-6237) or go online to www.cancer.gov/cancertopics/factsheet/therapy/CAM.

Talk with your doctor if you are interested in adding another method of treatment. Your health care team also needs to know about supplements and herbs that you want to try. Some types of therapies or alternative treatments could affect the cancer treatment that has been prescribed by your doctor.

**What can be done to manage pain?**

There are things your health care team can do to help reduce or eliminate pain. Good pain management requires that you work together with your health care team.
Medications

Cancer pain is often treated with one or more medications. If you have concerns about taking certain treatments, discuss these with your doctor and pharmacist. Your health care team will want to address your concerns while effectively treating your pain.

There are many medications to treat pain. Work with your doctor to find the best treatment for your situation. Ask about long-term usage and side effects such as an allergy or other reaction. The following list provides examples of how varying levels of pain may be treated with medications:

- For mild pain, medications such as acetaminophen (such as Tylenol) or non-steroidal anti-inflammatory drugs (NSAIDs) may provide relief. Some of these drugs such as ibuprofen or naproxen can be purchased without a prescription.
- For moderate pain, medications that combine an opioid (sometimes called a narcotic) such as hydrocodone or oxycodone with acetaminophen or aspirin may be needed. Vicodin and Percocet are examples of these combination drugs. The dose of these combination drugs is limited by the toxicity of the acetaminophen or aspirin.
- For severe pain, medications that contain an opioid only (sometimes called a narcotic) such as morphine, oxycodone, fentanyl or methadone are usually needed.
- Adjuvant medications may be important for the treatment or management of neuropathic pain that is generally caused by a problem (such as a lesion) in the nervous system. These are medications with primary uses for other conditions, but are sometimes effective for certain kinds of pain. Examples include the antidepressants Elavil and Cymbalta. Always talk with your doctor about the possible side effects of medications.

Other Treatment Options

Pain medications are almost always needed when pain levels are moderate or severe. However, other treatments can bring comfort and reduce the stress that can actually make the pain experience worse.

For some types of pain, heating pads, hot or cold packs, and massage may be soothing and help reduce the pain level. Biofeedback is a method that uses the mind to help with pain. Breathing exercises, relaxation, visualization, meditation, or imagery may also be effective. Sometimes, talking with friends, laughing, or listening to music might be a helpful distraction from pain.

For severe pain, a technique called a nerve block is sometimes considered. This procedure may involve injecting a substance, such as alcohol, directly into or around a nerve or around the spine. This to block the nerves from sending pain signals to the brain so that the pain will not be felt. Extreme cold or heat is now sometimes used in nerve blocks instead of drugs or chemicals. A nerve block can cause temporary muscle paralysis or numbness in the affected or surrounding area.
Nerve blocks may work to control pain for people who have advanced cancer or very painful nerve conditions. However, there may sometimes be serious complications. Nerve blocks are not recommended for people with certain medical conditions. Talk with your doctor about the benefits and risks before any treatment to decide what is best for your situation.

Every survivor is different and each responds differently to pain management strategies. Open communication with your health care team can help you decide together what will work best to manage your pain.

This document was produced in collaboration with:
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Works Cited


Chronic Pain: Suggestions

The suggestions that follow are based on the information presented in the Detailed Information (http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Physical-Effects-of-Cancer/Chronic-Pain#d#d) document. They are meant to help you take what you learn and apply the information to your own needs. This information is not intended nor should it be interpreted as providing professional medical, legal and financial advice. You should consult a trained professional for more information. Please read the Additional Resources (http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Physical-Effects-of-Cancer/Chronic-Pain#AR#AR document for links to more resources.

Always prepare for appointments with members of your health care team.

- Use a notebook or journal, such as the LIVESTRONG Guidebook, to write down information about your pain.
- Write down pain information such as a description of the pain level, when the pain occurred, how long it lasted, and what worked (and did not) to provide pain relief.
• Talk to your health care team about the benefits and risks of medications and other treatments prescribed for pain.
• Keep track of any medication you take for pain including the name, dosage and any reactions you may have.
• Ask your health care team about alternative or complementary therapies.
• Bring pain information to your appointment along with all of your medication bottles.
• Be certain that all of your health care providers are aware of the medications you are taking, including vitamins and over-the-counter medications.
• Take notes during medical appointments, and write down your next appointment date.
• Bring extra copies of important documents with you to give to the health care team (or email, fax or mail these documents in before the appointment).

Talk to your health care team about medications and treatments that are prescribed for pain. Medications are commonly prescribed by physicians to help control pain. It is important to understand as much as you can about the medications you are taking. Ask questions about medications such as:

• What is the name of the medication?
• How much should I take (dosage and strength)?
• When should I take this medication?
• Should I eat before I take it?
• Does this medication have any side effects?
• Will this medication interfere or react with other medications I take?

Ask your doctor questions about pain medications, such as:

• What pain medications are available for this type and stage of cancer?
• Are there likely to be side effects to the treatment prescribed for pain?
• Could there be interactions with other medications?
• Do you recommend any other treatments?
• Are there any concerns about trying different treatments?

Give your doctor specific information about your pain, including:

• Where the pain is located
• How much it hurts (mild, moderate or severe)
• When you experience the pain
• What seems to lessen or increase the pain
• How often you have pain
• How long the pain lasts
• How much any current pain medication helps
• Whether the pain affects your ability to sleep, eat or do daily activities
Ask yourself questions to find out whether your pain is being managed well such as:

- Are your reports of pain are taken seriously by your health care team?
- Has your doctor told you what may be causing your pain?
- Have you been told about all of the pain treatment options?
- Do you understand the benefits and risks of each treatment option?
- Are you involved in decisions about managing your pain?
- Have you been referred to a pain specialist for pain that is ongoing?

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- Have you been referred to a pain specialist for pain that is ongoing?

Keep track of all medications, over-the-counter medicines, and vitamins or supplements that you take:

Some of the things that may help you include pill dispensers, lists, and asking a family member or friend to help you keep track of what you are taking. Ask your health care team about complementary or alternative therapies.

Complementary or alternative therapies can be used along with medications to help you manage your pain. Some complementary therapies you may want to discuss with your health care team:

- Acupuncture
- Aromatherapy
- Art
- Dance
- Diet and nutrition
- Herbs, vitamins and minerals
- Music
- Meditation
- Reflexology
- Tai Chi
- Yoga
- Massage
- Spiritual care
Chronic Pain: Additional Resources

LIVESTRONG Navigation Services
LIVESTRONG.org/Get-Help

Online: Complete an intake form through the LIVESTRONG website.
Phone: 1.855.220.7777 (English and Spanish)
Navigators are available for calls Monday through Friday, 9 a.m. to 5 p.m. (Central Time). Voicemail is available after hours.

LIVESTRONG offers assistance to anyone affected by cancer, including the person diagnosed, loved ones, caregivers and friends. The program provides information about fertility risks and preservation options, treatment choices, health literacy and matching to clinical trials. Emotional support services, peer-to-peer matching and assistance with financial, employment and insurance issues are also available. To provide these services, LIVESTRONG has partnered with several organizations including Imerman Angels, Navigate Cancer Foundation, Patient Advocate Foundation and EmergingMed.

American Cancer Society (ACS)
www.cancer.org

Email: Submit questions in English or Spanish from the "Contact Us" page.
Phone: 1-800-227-2345
TTY for deaf or hard of hearing callers: 1-866-228-4327

The American Cancer Society (ACS) offers information about many of the challenges of cancer and survivorship. You can search for information by cancer type or by topic. ACS provides a list of support groups in your area. You can join online groups and message boards. Some information on the website is available in Spanish, Chinese, Korean and Vietnamese. ACS specialists can answer questions 24 hours a day by phone or email.

The American Pain Foundation
www.painfoundation.org

Email: info@painfoundation.org
Phone: 1-888-615-7246

The American Pain Foundation is an independent nonprofit 501(c)3 organization serving people with pain by providing information, advocacy, and support. The APF mission is to improve the quality of life of people with pain by raising public awareness, providing practical information, promoting research, and advocating removing barriers and increasing access to effective pain management. The APF provides information that can be used to discuss pain concerns with your doctor.
U.S. Institutes of Health - National Cancer Institute (NCI)
www.cancer.gov

Online: Online assistance is available in English or Spanish through the LiveHelp instant messaging system. This service is available Monday-Friday, 9:00 a.m. to 11:00 p.m. (EST).
Email: Send an email through the "Need Help?" section of the website
Phone: 1-800-422-6237
TTY for deaf and hard of hearing callers: 1-800-332-8615
Information specialists answer calls Monday-Friday, 9:00 a.m. to 4:30 p.m. local time.

The National Cancer Institute's website provides accurate information about the challenges cancer can bring. You can search for information by cancer type or topic. You can find information about treatment, financial and insurance matters. You can also learn how treatments in development work and search for a clinical trial in your area. This site also has a good dictionary of cancer terms, drug information and other publications. Cancer information specialists can answer your questions about cancer and help you with quitting smoking. They can also help you with using this Web site and can tell you about NCI's printed and electronic materials. The knowledgeable and caring specialists have access to comprehensive, accurate information on a range of cancer topics, including the most recent advances in cancer treatment. The service is confidential, and information specialists spend as much time as needed for thorough and personalized responses.

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