



#### Pain

By: The Canadian Virtual Hospice Team

## What is pain?

Pain is one way that your body lets you know there's a problem.

- It's common with most serious illnesses to have some pain.
- Most of the time, pain can be controlled.

Everyone experiences pain differently. For treatment to be effective, friends, family members, and the healthcare provider need to believe what the person in pain tells them. This person knows best what they're going through.

## Types of physical pain

There are three main types of physical pain:

- \* Bone, muscle, and connective tissue (e.g., ligament) pain.
- Organ pain.
- Nerve pain.

Sometimes pain is felt in parts of the body that don't seem connected to the organ with the problem. This is called *referred pain*.

• For example, someone with angina may feel pain in the neck and left arm.

## Bone, muscle, and connective tissue pain

When the bones, muscles, and *connective tissue* are damaged, the pain is usually steady, aching, and felt directly in the area of the problem.

For example, a tumour in the upper arm bone will cause steady aching pain in that area.

#### Organ pain

Pain caused by problems in an organ – such as the stomach, kidney, liver, or heart – may be difficult to pinpoint as the discomfort can be felt in a wider area.

• For example, pain caused by a <u>bowel obstruction</u> is usually felt all over the stomach, making the exact problem area difficult to find.

## Nerve pain

Nerve damage may cause pain or discomfort that's hard to describe since it doesn't always feel like what we think of as "pain." You may have:

- Unpleasant tingling, prickling, burning, squeezing, or crawling sensations.
- \* Sudden pains that come and go quickly, almost like an electric shock feeling.
- Pain that reaches down an arm or leg, along the path of the damaged nerve.
- \* Skin so sensitive that even a gentle touch or the weight of clothing is very uncomfortable.

Most of us have experienced the type of nerve pain that happens when we bump the back of our elbow. We call this the "funny bone" – but it's actually a nerve (the ulnar nerve) that runs behind the elbow. We feel this as an unpleasant tingling sensation down the path of the nerve. Although we might not use the word "pain" to describe it, it's still not something we want to experience frequently.

## Causes

Pain may be caused by many things. In advanced or serious illness, it can be due to:

- \* The underlying illness itself, such as:
  - Pain in cancer, due to a tumour irritating nearby bones or nerves.
  - \* Poor circulation that causes leg pain.
- Problems indirectly related to the disease such as:
  - Stiff joints because illness results in less activity.
- Treatments such as:
  - \* Chemotherapy and radiation.
  - Surgery.
- Problems that have nothing to do with the disease such as:
  - Arthritis that's been present for years.

## Pain and emotions

The experience of pain isn't just physical. There are emotional, social, and spiritual layers that influence a person's experience of pain. This concept was originally described by the founder of modern palliative care, Dame Cicely Saunders.

#### **Emotional**

- Anger feeling, for example, that the cancer causing your pain should have been diagnosed earlier.
- Fear that a new pain means the illness is much worse, and your life is coming to an end.
- \* Sadness the pain is a constant reminder of the losses caused by the illness.

## Social

- \* Feeling alone and isolated, even with other people around you.
- \* Worrying about money, the future, losing your job, and having to depend on others.

## **Spiritual**

- Feeling abandoned by your deity, deities, or other higher power.
- Questioning the meaning and purpose of living and dying.
- \* Fear of the unknown.

# Assessing and diagnosing

To learn more about the pain, your healthcare provider will probably ask questions, do a physical exam, and may order tests. This will help them decide how best to manage the pain.

## Consideration:

keep track of your pain in a <u>daily pain diary</u>. Sharing this information with your healthcare provider will help them to help you.

## Questions

- How bad is your pain?
  - Mild, moderate, severe?
  - Rate your pain on a scale from 0 to 10. Zero means no pain and 10 means the worst possible pain.

<sup>·</sup> Where is your pain?

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- \* One spot or different areas of your body?
- \* Starting in one area and spreading to another?
- \* All over and hard to pin down to any one spot?
- \* Deep down or near the surface of the skin?
- What does it feel like? What words describe it?
  - Aching, throbbing?
  - Burning, tingling, crawling, itchy?
  - Squeezing?
  - \* Stabbing? Like an electric shock?
  - Crampy?
  - Are there areas of skin that are painful when gently touched by your hand, clothing, or water?
- How long does your pain last?
  - \* Is it always there?
  - Off and on?
  - \* Do you only have pain when you move?
  - \* Does it change in how bad it is?
- \* Have you had pain there before, or something like it?
  - \* What happened then?
- What makes it worse?
  - Movement, coughing, deep breathing, certain positions?
- What makes it better?
  - Certain positions, medication, relaxation, massage, imagery?
- \* What medications are you taking now? What medications have you taken before?
  - \* How well are they working?
  - · How often do you take them?
  - What about side effects?
  - Are there other problems?
    - For example, cost, number of pills needed to give relief?
  - What about medications you've taken before?
    - \* Did you have to stop taking them? Why?
- How is pain affecting your life?
  - \* Are you able to walk? Do housework? Work?
  - \* What about sleep?
  - \* What about mood?
    - \* Do you feel discouraged, sad, or depressed? Have you lost hope?
    - Do you worry about what the pain means for example, that the disease might be getting worse?
  - How are your relationships with other people?
    - \* Do you avoid people because of pain? Are you irritable?
  - \* Is it affecting your sex life?

The healthcare provider will usually check for:

- Areas of swelling.
- Loss of muscle.
- Tenderness.
- Weakness.
- \* Changes in sensation.

#### **Tests**

Your healthcare provider may discuss tests to help sort out what's causing the pain and what can be done about it. This will depend on your circumstances, your goals, and your expectations of care. Possible tests include:

- \* X-rays.
  - Pictures taken of the inside of your body using a type of radiation called electromagnetic waves.
- CT scans (Computerized Tomography).
  - \* X-rays taken in a special machine that can look at your body from many angles.
- MRIs (Magnetic Resonance Imaging).
  - Pictures taken of the inside the body using powerful magnets and radio waves.

## Medications and other treatment

## Medications Finding the right medication

There are many effective pain medications. There isn't one medication that is able to treat *all types of pain* – each is used to treat a different kind. Since everyone is affected differently by both pain and medication, it can take time to find the best combination of medication and other treatments.

Good communication between you and your healthcare provider can help speed up the process of finding the best approach.

- Keep track of your symptoms in a daily pain dairy.
- \* Communicate with your healthcare provider regularly for follow-up.

## The medications you're already taking

Your healthcare provider will want to know about all the medications and other supplements you're using, including:

- \* Those that require a prescription.
- \* Those that don't require a prescription (over the counter).
- Vitamins.
- · Herbs.
- Naturopathic or homeopathic prescriptions.

They need this information to safely treat your pain. Not knowing this information might be dangerous for you for many different reasons, such as:

- Your medications might not work well together.
  - A certain herb might limit your prescription medication from working properly or might make the prescription stronger than expected or wanted.
- You might be taking something that:
  - \* Ten't good for you or your particular illness or symptom

- ISHT GOOD FOR YOU OF YOUR PARTICULAR HITLESS OF SYMPTOM.
- Isn't good for the way your illness may be changing or progressing.
- You may have side effects that your healthcare provider won't recognize unless they know everything you're taking.

## Medications used to treat pain

The medications commonly used to treat pain include:

- \* Acetaminophen.
- Anti-inflammatories, including:
  - \* Non-steroidal anti-inflammatory drugs (NSAIDs).
  - Steroids.
- Opioids.
- \* Anticonvulsants.
- Anti-depressants.

## Acetaminophen

## Prescription

Acetaminophen is available over the counter, no prescription needed.

#### Uses

- Widely used for mild to moderate pain.
- \* Works with other pain medications to make them more effective.
- Safely taken together with opioids and NSAIDs.

## Possible side effects

When acetaminophen is used properly, there are few side effects. However, too much can damage the liver so it's important to know:

- There's a maximum amount that's considered safe to take each day.
- \* Some people with certain health conditions should take even less than that amount.
- Acetaminophen is a common ingredient in many cold and flu products.
- \* It is possible to take too much if you use several over-the-counter medications at the same time.

#### Be sure to:

- \* Read product labels carefully to find out if they contain acetaminophen.
- \* Keep track of how much acetaminophen you are taking from all products.
- \* Talk to your healthcare provider about how you're using this medication.

Non-steroidal anti-inflammatory drugs (NSAIDs)

## Prescription

- No prescription is needed for less powerful doses.
- \* A prescription is required for more powerful doses.

#### **Common Names**

- Ibuprofen.
- \* Naproxen sodium.
- · Celecoxib.

#### Uses

• For inflammatory pain such as sprains, arthritis, and some headaches.

## Possible side effects

- Damage the kidneys, especially in older adults who already have kidney problems, or who aren't getting enough fluids and are dehydrated.
  - All NSAIDs can have this side effect.
- Irritate the lining of the stomach and small intestine, causing ulcers.
  - This may result in intestinal bleeding or even more serious complications.
  - \* All NSAIDs can have this side effect.
- Slow the blood's ability to clot (thicken). If blood can't clot, a cut might keep bleeding. This must be considered with people:
  - On chemotherapy.
  - · About to have surgery.
  - \* Who have a higher risk of bleeding for example, those on medication that thins the blood such as heparin, dalteparin, warfarin, and others.

COX-2 inhibitors are medications in the NSAID family that may have less chance of some of the above possible side effects, if at all. However, they have other risks so their use must be considered on a case-by-case basis.

Because of the serious potential side effects of NSAIDS in general, it's important to check with your healthcare provider before taking any that don't require a prescription.

## **Opioids**

## Prescription

A prescription is required for opioids that can effectively treat pain.

## Commonly used opioids

These include:

- \* Codeine.
- Morphine.
- Oxycodone.
- Fentanyl.
- Hydromorphone.
- Methadone.

#### Uses

Opioids are very effective at relieving pain so they are often prescribed for moderate to severe pain.

- They're typically started at a low dose and increased gradually, as needed, a process referred to as titration
- \* The dosage can be increased until the pain is relieved or side effects become a problem.
- \* If side effects become too much:
  - A different opioid can be tried, which is sometimes referred to as "rotating opioids."
  - Other ways of managing pain can be explored. For example, opioids can be combined with other types of medications to help with pain relief.

Research suggests that opioids should not be used for the long-term management of non-cancer pain. To *learn more*, go to: 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain

#### Note the guideline:

Does not address the use of opioids to manage the following:

- Cancer-related pain.
- Opioid addiction or opioid use disorder.
- Acute or sub-acute pain (pain lasting less than 3 months).
- Pain or suffering associated with end-of-life care."

#### Possible side effects

Opioids are very safe when used under the supervision of a healthcare professional. Possible side effects include:

#### Constipation

Constipation is a very common side effect of all opioid pain relievers.

## \* This should never limit the needed use of opioids.

Constipation can be addressed with laxative medications such as:

- \* Stimulants to encourage the stool to move through the intestine.
  - \* For example, sennosides or senna.
- \* Osmotic laxatives to bring water into the bowel and the stools.
  - For example, Lactulose or PEG (polyethylene glycol).
- It's very important to start laxative medications at the same time as opioids, adjusting them so the bowels move at least every two or three days.
- \* To learn more, go to Constipation.

#### Sleepiness

When opioids are started or your current dose is increased, you may feel sleepy.

• This sleepiness usually disappears as the body becomes used to the medication.

#### Nausea

- This is experienced by about one-third of people taking opioids but usually decreases after a few days. Sometimes it's helpful to use an anti-nauseant medication for the first few days.
   For example:
  - Anti-nauseants that don't need a prescription such as:
    - Dimenhydrinate (Note: may cause drowsiness).
  - Anti-nauseants that need a prescription including:
    - Domperidone.
    - \* Haloperidol.
    - Metoclopramide.
    - Ondansetron.

#### Confusion

- This side effect ranges from mental fogginess to bad dreams and hallucinations.
- \* It happens occasionally when by-products of the medications build up in the body.
- \* Contact your healthcare provider if you experience this side effect.
- If the confusion is caused only by the opioid:
  - \* Adjusting the dose may clear this up.
  - \* A different medication may be used if the dose adjustment doesn't help.
- \* To learn more, go to Confusion.

## Slowed breathing

- This is a potentially serious side effect, however, it's extremely uncommon if doses are adjusted in response to pain and under the supervision of healthcare providers.
- It may appear early on as the body adjusts to opioids.

<sup>\*</sup> To learn more, go to Nausea and Vomiting.

- There are other, less common side effects to opioid medications. For example, children may experience itchiness.
- If you experience problems, you feel may be caused by your medication, contact your healthcare provider immediately.

To learn more, go to Common concerns about opioids in palliative care.

## **Anticonvulsants**

## Prescription

A prescription is required.

## Some common names

- \* Gabapentin.
- \* Carbamazepine.
- \* Lamotrigine.

#### Uses

- Anticonvulsants are mainly used to treat seizures.
- \* They can also effectively treat burning, tingling, and stabbing (shock-like) pain related to nerve involvement (referred to as *neuropathic pain*).

#### Possible side effects

These include:

- Confusion.
- Nausea.
- Sleepiness.
- \* Tremors (shaking).

## Anti-depressants

## Prescription

A prescription is required.

## **Common names**

Commonly used anti-depressants include:

- \* Desipramine.
- Duloxetine.
- Nortriptyline.
- · Venlafaxine.
- \* Amitriptyline (this shouldn't be used in older adults).

#### Use

As well as treating <u>depression</u>, these also effectively treat burning, tingling, and stabbing (shock-like) pain related to nerve damage or involvement.

## **Possible side effects**

These include:

- Constipation.
- Nausea.
- Blurred vision.

#### Steroids

## Prescription

A prescription is required.

## Common names

Devamethasone.

• Prednisone.

#### Uses

There are two kinds of steroids: those used to treat inflammation and those used to build muscles. Here, we are talking about steroids used to treat inflammation.

- \* These steroids are used to shrink swelling and relieve inflammation that can cause pain.
- \* They're useful in many situations where pain is caused by inflammation and swelling. For example:
  - Nerve compression.
  - Spinal cord compression.
  - Bowel obstruction.
  - \* Brain swelling.

#### Possible side effects

Steroids may cause a variety of side effects. Some are seen almost immediately, and some are seen after longer term use.

Short-term side effects include:

- Agitation.
- \* Restlessness.
- Interrupted sleep.
- Increased blood sugars.
- \* Increased appetite.
- Increased bleeding if used with non-steroidal anti-inflammatory drugs (NSAIDs).
  - \* NSAIDs are not recommended.
- Thrush.

Long-term side effects may include:

- \* Weight gain.
- \* Muscle weakness.
- Osteoporosis.
- \* Osteonecrosis (extremely rare).

Be sure to let your healthcare provider know if you experience any side effects that are concerning.

## Medications in specialized care settings

## Intravenous (IV) infusions

Lidocaine and ketamine are two medications that are sometimes used when other treatments for pain haven't worked. These medications:

- Are delivered directly into the blood using intravenous.
- \* Are given in a hospital or clinic setting.
- Typically require the involvement of a pain or palliative care specialist.

## How to use your pain medication safely

## Take as needed or as scheduled?

- If you have pain all the time, ask your healthcare provider about taking your medication on a regular schedule.
- If you don't follow this regular schedule, you may find you're always "one step behind" the pain.
  - Someone who takes medication only when they have pain probably uses more than the person who doesn't wait until they have pain, but takes it as scheduled.
- If you're thinking about stopping a medication, talk to your healthcare provider first.
  - \* You may need to lower the dose slowly before you can stop safely

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## Breakthrough pain and breakthrough doses

- Pain that happens between regularly scheduled doses of medication is called breakthrough pain. Extra doses of pain medication can help to treat this.
  - Take the medication your healthcare provider prescribes specifically for these episodes (these are called breakthrough or rescue doses).
  - Keep track of how often you need this quick-acting medication.
- If you often need breakthrough doses more than three times a day, your regular dose may need to be increased.
- \* The starting breakthrough dose is usually about 10% of the total daily dose of regular opioids.
  - For example, if you're taking 200 milligrams a day of regular morphine doses, the breakthrough dose should be at least 20 milligrams.

## One prescriber

• In general, only one healthcare provider should prescribe your pain medication. If this isn't the case, be sure they are discussing your treatment with each other.

## For your use only

- \* Each person responds differently to pain medication so people may have very different doses of the same medication. What matters is that your medication dosage works for you.
- Never take someone else's medication.
- Never share your medication with anyone else.

## Safe storage and disposal of medications

- Be sure your medication is stored safely. Medications may cause harm or death to adults, children, and pets if they're misused or used by accident.
- If you have unused medications you no longer need, take them to your pharmacist to safely dispose of them.
- If you have used pain medication patches, speak with your healthcare provider or pharmacist about how and where these patches should be disposed.

## What to know about a new medication

These are questions to ask your healthcare provider when you're given a new prescription:

- \* How much medication should I take? How often? For how long?
- How long does the medication take to start working?
- If the pain doesn't get better, should I take more medication? How much more?
- What happens if I don't take the medication on time?
- \* Should I take it with food?
- Should I have something to drink with it?
- \* Is it safe to drink alcohol, drive, or operate machinery after taking my pain medication?
- \* Are there possible side effects? What should I do if I have side effects? Can they be prevented?
- \* Will this new prescription work safely with my other medications?

Be sure to read the information sheets that come with your medications. These will answer many of your questions.

## When to communicate with your healthcare provider

Be sure to communicate with your healthcare provider if:

- The medication isn't helping your pain.
- \* The medication doesn't start working when your healthcare provider said it would.
- \* The medication doesn't work for as long as your healthcare provider said it would.

  \* You have pain in between doses of medication.
- \* Dain only occurs with cortain activities (this is called insident pain)

Pain only occurs with certain activities (this is called *incident* pain).

- \* You have side effects that may include sleepiness or nausea that aren't improving a few days after starting the medication or a change in the dose.
- The treatment for a side effect isn't working for example, laxatives aren't relieving your constipation.
- \* The schedule for taking medication isn't working for you.
- Pain interferes with normal activities such as eating, sleeping, working, and having sex.

Your healthcare provider can often help solve these problems by changing the kind, amount, and combination of medication.

## When you can't swallow your medication

Sometimes people who are seriously ill have difficulty swallowing medication. In this case:

- \* Liquid drops may be given under the tongue.
- \* Medication may be delivered into the body by a plastic tube under the skin or into your vein.
- Prescription pain patches may be applied to the skin.

To learn more, go to Help with medications.

#### Other treatments

#### Radiation

High-energy radiation can shrink cancerous tumours, which may lessen pain.

- The shrunken tumours put less pressure on bones, nerves, or internal organs making the pain less.
- It can take up to two weeks to know how effective the treatment was.

Risks of radiation:

- Discuss this with your healthcare provider. The risk depends on:
  - Which part of the body receives the radiation.
  - \* The number of treatments.

## Procedures to block pain signals

Pain signals travel along nerves to the spinal column and then to the brain. It's sometimes possible to block these signals with an injection of pain medications (analgesics).

For more information, discuss this with your healthcare provider.

# **Complementary therapies**

The following relaxation exercises and complementary therapies may help you to manage your pain as well as its emotional impact.

- Acupuncture.
- \* Biofeedback.
- Breathing and relaxation techniques.
  - Including imagery and the pain dial.
- \* Cold therapy.
- Distraction.
- Heat therapy.
- · Hypnosis.
- \* Massage.
- Music therapy.
- \* Transcutaneous Electric Nerve Stimulation (TENS).

If you decide to try a complementary therapy:

Talk with your healthcare provider first in case they have concerns about a certain therapy and your particular health circumstances. For example:

- \* Some herbal remedies may affect how well prescribed medications work.
- Heat therapies are best avoided with certain disorders, such as the skin's reduced ability to feel hot temperatures (risk of burns).
- \* Experiment with the different approaches until a helpful one is found.
  - \* A therapy that works for one person might not work for another.

## What you can do

Living with serious illness can be physically, mentally, spiritually, and emotionally challenging. In this section, you'll find suggestions that might help you to manage these stressful times.

When you are living with illness

## Talk with your healthcare provider

- \* Be honest and let them know if you have any pain or worries about your treatment.
- Show them your pain diary.
- \* Let them know how pain is affecting you physically, emotionally, socially, and spiritually.
- \* The more you communicate and answer your healthcare provider's questions, the better they can help to manage your symptoms.

**TIP:** Keep track of your pain in a daily pain diary. Write down when and where you have pain, treatments and how well they worked. Sharing this information with your healthcare providers helps them to help you.

## Treat pain early

Some people feel they should "be brave" and "bear" pain, but there's no medical reason for this. You don't have to accept pain as part of your disease. In fact, when pain isn't treated, it can cause other problems such as:

- Sleeping poorly.
- Eating poorly.
- Anxiety, fear, and depression.
- Loneliness and isolation when you feel too unwell to be with family and friends.

Treating pain early can help avoid these problems.

Some people feel that getting help for pain is "giving in" to the disease and admitting defeat. Remember that:

- If pain is allowed to take over, you may be giving control of your life to the disease and the pain itself.
- Others won't think you're weak because you admit that you have pain.
- You aren't being a nuisance or making a fuss.

#### Find support

Many people find it helpful to connect with others when they're dealing with illness. These are some suggestions to consider.

- \* Talk with someone you trust, like a friend or family member. Sometimes just talking with someone can help you to feel better.
- \* Ask the healthcare provider to refer you to a counsellor such as a psychologist or social worker. They can offer:
  - Counselling and emotional support.
  - Education.
  - Practical skills to help you manage your symptoms.
- Talk with a spiritual care specialist.
- loin a support group.

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- If you can manage it, join a support group where you can meet with people with the same health concerns.
- Find information online.
  - Canadian Virtual Hospice has information on many topics related to serious illness and palliative care.
- Join online discussion forums such as:
  - Canadian Virtual Hospice Discussion Forums.
  - Cancer Chat Canada.
- Learn more about <u>Programs and Services</u> in your area.

## When someone you care about is living with illness

It can be difficult to watch someone important to you face a serious illness. Helping this person with symptoms such as pain, constipation, nausea, and vomiting can be exhausting. It can also lead to feelings of isolation when others around you don't appreciate the challenge of caring for someone with these symptoms. The following suggestions might help you through this difficult time.

## Find support

Many people find it helpful to connect with others when they're dealing with illness. These are some suggestions to consider.

- Talk with someone you trust. Sometimes just talking with a friend or family member can help you to feel better.
- Ask the healthcare provider to refer you to a counsellor such as a psychologist or social worker. They can offer:
  - Counselling and emotional support.
  - Education.
  - \* Practical suggestions to help with stress.
- \* Talk with a spiritual care specialist.
- \* Ask about a support group for caregivers.
- Find information online.
  - Canadian Virtual Hospice has information on many topics related to serious illness and palliative care.
- Join online discussion forums such as:
  - Canadian Virtual Hospice Discussion Forums.
  - Cancer Chat Canada.
- Learn more about Programs and Services in your area.

## Try complementary therapies

 Various therapies such as relaxation techniques, meditation and yoga can be helpful to manage the stress of illness.

## Take time for yourself

- Choose an activity or something you enjoy. It might be reading, praying, listening to music, watching sports – or something else.
- Regular exercise is important to manage stress. What physical activities do you enjoy? Walking? Biking? Something else?

#### respecting choices

You might disagree with the choices someone makes about treatments and how they live with their illness. Perhaps you feel their choices are unsafe, might cause harm, or risk losing an opportunity to get better. This can be frustrating and upsetting. It's okay to tell this person, respectfully, how you feel about their choices and how they affect you – but remember, everyone has the right to make their own decisions.

If you're concerned this person is no longer able to make good choices, or that their choices may be putting others at risk, speak to the healthcare provider.

Content reviewed January 2023