CANSA
Cancer Association of South Africa

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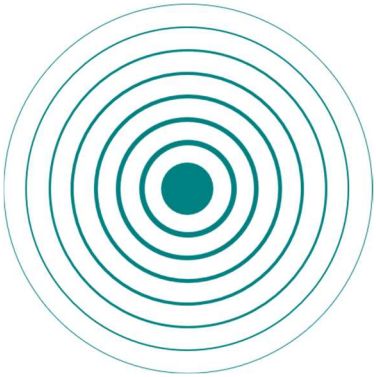
CANSA
At Home Pain Guide



In collaboration with

PALPRAC

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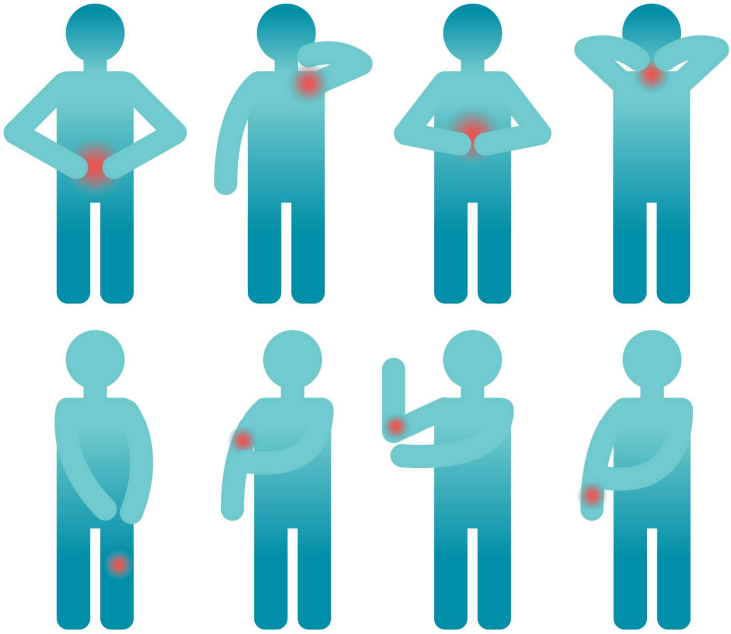

What is pain?

Pain is an unpleasant sensation that varies from mild to extreme discomfort. It can be concentrated in one area or cause distress all over. Pain can feel worse if you are worried, tense, lonely, afraid, sad, or searching for spiritual answers to the big questions in life.

Pain is a frequent complication of cancer, but it is also linked to many other serious illnesses.

Why do we want to treat pain?

Pain affects many areas of life. Sleeping patterns, mood and energy levels can all be disrupted by pain. It might make it difficult for you to do the things you love or need to do, and it affects the quality of the time you spend with others. In general, living with pain makes life harder.

Everyone has the right to have their pain treated effectively, and you will have to work closely with your healthcare professional to find an effective pain treatment plan.

Myths about pain

- *My pain is not bad enough to take pain medications.*

  While the decision to take medication or not remains with you, experience tells us that people have a much better quality of life when their pain is controlled. Sometimes, simple non-medical treatments are enough. In other circumstances, medications are needed, and their strength depends on the intensity or severity of your pain.

- *When my pain is bad, I use whatever pain medication I have in the cupboard.*

Not all pain can be managed in the same way, and some medications might even be harmful to you. It is important to have your healthcare professional assess your pain and discuss your options with you, so that you can agree on a pain treatment plan that works specifically for your needs.

- *I am worried about becoming addicted to the medications.*

  If you are being treated for cancer-related pain, you will not become addicted to the medication.

- *If I start with strong medications too soon, they won't work later on.*

  The type and dosage of medications might have to be adjusted in the future as things change with the status of your cancer but starting treatment when you have pain will not make medication ineffective later.

- *Morphine is only used when people are dying.*

  Morphine is used effectively for cancer pain, no matter which phase of the journey you are in. Your doctor will prescribe morphine if your pain is moderate to severe, and if other medications like paracetamol and tramadol have not been effective in treating your pain.

- *I am allergic to morphine.*

  Very, very few people are truly allergic to morphine. Some of the common morphine side effects such as itchiness might be wrongly misinterpreted as an allergy.

What is causing your pain?

In someone with cancer, pain can be caused by:

- The cancer itself
- The cancer treatments and side effects
- Other things, like an infection

What to do if you have pain?

- **Ask for help**: tell your family or friends; get advice from a qualified healthcare provider.
- Try these **simple things** to help relieve the pain:
  - **Take a warm** shower or bath or use a hot water bottle or warm washcloth. Heat relaxes muscles; this can help reduce pain and give a sense of comfort.

Be careful not to burn yourself or cause tissue damage by applying too much heat to the area you're treating.

- Gently **massage** the area.
- **Use a cool** cloth: cooling the skin and muscles can soothe pain, especially pain that comes from inflammation or swelling.
- **Try relaxation techniques**: breathing slowly and deeply will help quieten the mind and allow your body to relax.
- **Engage in enjoyable activities:** keeping busy with something you enjoy will distract your mind and decrease your awareness of pain.

- Use a **pain diary**: this information will help your medical team to understand your pain, as not every day is the same.
- **Consider these questions** when talking to your healthcare professional about your pain:
  - What kind of pain do I have? Is it burning, sharp, dull, or throbbing?
  - Where is it located, and does it spread anywhere?
  - Does it come and go, and how long does it last?
  - What makes it worse and what makes it better?
  - How does it affect my functioning?
  - What do I believe about my pain?
  - What impact does it have on my loved ones?

These pictures might help you explain the pain intensity better:

Image credit: https://wongbakerfaces.org/

Your healthcare professional will need to complete a pain assessment and then prescribe pain medication according to the type of pain you are experiencing and its intensity. The "face" or number above that you use to describe your pain will result in a different prescription. For example, if your pain level is 6/10, the doctor might prescribe tramadol – but if your pain is at a level 8 or more, the doctor may prescribe morphine.

Treating pain

Psychological, social, and emotional approaches in pain management

Pain affects all areas of your life. That's why there are teams of different professionals available who can assist you in learning to manage pain better.

Here are a few ways they can help:

Expert information: As provided in this booklet, reading through the available information on pain management will help you to understand what you're going through and help you communicate with your health professionals about your experience of pain.

Skills training: Whether this is performed personally or in a group, learning the skills to reduce stress and manage pain adds to your quality of life. Being able to modify your thoughts and emotions will help you along your pain management journey. Techniques and exercises based on Cognitive Behavioural Therapy (CBT), Acceptance & Commitment Therapy (ACT) and Mind-Body therapies are used by psychologists, social workers, physiotherapists, and occupational therapists. An example is the Empowerment Pain Program (PEPP).

Mind-Body therapies: These emphasize the power and ability of the mind (or thoughts) to influence physical health and wellbeing. Examples include guided imagery, mindfulness, meditation exercises and hypnosis.

Music, art, movement, and drama:

These fields are used by therapists to help reduce stress and pain, as well as create a comfortable space to explore your thoughts and emotions related to pain and illness and help you become more in touch with your inner self.

Small groups also help with feelings of isolation and distress and enable you to share your experiences with others in a similar situation.

Spiritual counselling: This form of therapy provides supportive care and a confidential, non-judgmental space to discuss beliefs, emotions, and ideas about your illness. The counsellor will also assist you and your family in describing the meaning and impact of the pain experience and is interested in your community of faith.

Psychosocial counselling: This includes individual, couple & family counselling as you navigate your unique experience of pain management. Psychosocial counselling deals with the behavioural and social results of chronic pain, as well as related emotional problems like depression and anxiety. In psychosocial counselling you may also discuss fatigue and sleeping patterns, stigma, and social isolation, coping strategies, your living and work situation and family and social support. Counselling programs preferably include your support system, such as a partner, family members, or caregivers.

In couple's counselling, relational and sexual difficulties can be discussed. Pain influences relationships within families and can create social problems related to the perception of pain in the family, as well as in the community. Dynamics within couple and family relationships can shift as the role of the patient becomes complicated by illness and pain.

Using pain medication

Understanding the use of pain medications:

The simple measures described above are often helpful in easing cancer-related pain but are usually not enough to control the pain completely. After hearing about your pain experience in detail and doing a thorough examination, your doctor will often need to prescribe pain medication as well.

- **Understanding what doctors think about when prescribing pain medications:**
    - The type and severity of your pain and the most probable cause of your pain
    - Other illnesses you may have and the medications you are currently taking
    - The type of medications you have tried previously: they might want to increase the dose, add something, or change the medications altogether

- The side effects you have previously experienced
- Avoiding a mix of too many medications at the same time and keeping it simple
- The fact that oral medications are preferable and as effective as injections
- The other treatments that might help, such as physiotherapy or counselling

- **General guidelines in using pain medications:**

  - The type of pain medication prescribed will depend on the type and severity of your pain, as described above
  - The names of medications can be confusing, as each pharmaceutical company might have a different name for the same thing

- **Use pain medicines as prescribed:**
  Cancer-related pain is often either constant or frequent during the day. For this reason, it makes sense to take the medicine at **regular intervals,** as prescribed (e.g. every 4 or 6 hours), instead of waiting for the pain to come back before taking the next dose. This will avoid unnecessary suffering.
  Sometimes, depending on the type of pain you have, your doctor might prescribe a combination of medications. It is useful to keep a pain medication chart to avoid confusion or forgetting to take a dose.

- **Understand what side effects** to expect and what to do about them: most medications have side effects that are irritating. Some will pass after the first few days and others can remain a problem. There is a solution to most of them - ask your healthcare professional for guidance.

- **Know what to do if the pain medication is not effective:**

  - Your doctor needs to prescribe additional medication for you to take if you have pain, despite taking medications regularly as prescribed (this is called “breakthrough medication”). This might be more of the same medication, or an alternative medication.

- It is important to know who to contact if your pain is not controlled.

Using oral morphine:

Oral morphine is a strong painkiller which is given to someone with high (severe) levels of pain and needs to be actively managed.

Morphine should always be given by the mouth (orally) and by the clock (regularly, every 4 hours). Your healthcare provider will prescribe how much morphine you should use. Take care to follow these instructions precisely.

Morphine comes in two forms - tablets and syrup. The tablets are taken twice a day (12 hours apart). The syrup is taken every 4 hours - this is not an overdose! The syrup starts to work quickly (within 15-20 minutes) but only lasts in the body for 3-5 hours, which is why doctors recommend taking it every 4 hours.

Because it works quickly and effectively, we will concentrate on the syrup in this booklet. If you find it difficult to take medication every 4 hours and your pain is well controlled, talk to your healthcare provider about changing to morphine tablets.

With either the syrup or the tablets, it doesn't matter whether you eat or not before taking morphine. Taking morphine will not cause damage to your kidneys, liver, or stomach.

How much and when to take your morphine:

1. Take the dose prescribed, every 4 hours, by the clock.
2. Take an extra half dose (half of the 4-hourly dose) in between as needed. This dose can be repeated at any stage between the 4-hourly scheduled doses. This extra dose is called the breakthrough dose.
3. Continue taking the prescribed 4-hourly dose by the clock. (For example: 6am, 10am, 2pm, 6pm, 10pm, 2am).
4. At the end of the 24-hour period, add up all the doses taken and then divide by 6. That gives you the new 4-hourly dose schedule.

   For example, if the 4-hourly dose is 10ml and 4 extra doses of 5ml have been taken, the total after 24 hours is 80ml (6 x 10 plus 4 x 5 = 80). The new 4-hourly dose is now 14ml (80 divided by 6, rounded up to the next whole number, which is 14ml). The breakthrough dose is now 7ml.

5. Sometimes healthcare providers recommend taking a double dose at bedtime/10pm, and then skipping the 2am dose. This allows you to sleep better without waking up for medication. Talk to your doctor to see if this is the right option for you.

How to measure out a dose of morphine:

1. Pour a small amount of the morphine liquid from the bottle into a cup.
2. Draw up your dose into a syringe (no needle) to measure out the correct amount.
3. Drop the liquid into the mouth using the syringe.
4. Return any unused morphine from the cup to the bottle.

It is important not to stop your morphine suddenly. Always discuss changes to the dosage with your healthcare provider.

Side effects:

Morphine sometimes causes some of the following side effects:

- **Nausea** - this usually goes away after the first few (3-4) days but can be unpleasant. Medicines can be given to control it.
- **Constipation** - your healthcare provider will prescribe various treatments to ensure that you continue to have regular bowel movements.

- **Dry mouth** - take regular sips of water to help ease this.
- **Drowsiness** - this usually lessens after a few days, but if it persists or gets worse, the dose can be adjusted by your healthcare provider.
- **Sweating or muscle jerks** - tell your healthcare provider if you experience either of these side effects.

If the pain is getting worse, inform your healthcare provider so that the dose can be increased, or additional medicines can be added to your treatment.

There are **other pain medications** available that work as effectively as morphine (they are the same class of drug, called an opioid). They are also taken on a regular schedule rather than only when the pain comes. The side effects are also similar to morphine.

Ask your doctor to write down the medication's name and the way you need to use it here:

Name of medication:

_____

_____

How often do I take it:

_____

What can I take if I still have pain despite taking my medication as prescribed: _____

_____

What do I take for the side effects:

_____

_____

_____

Consider using a pain chart to keep track of what you have taken and when. Here is a simple example:

Time	Sunday		Monday		Tuesday		Wednesday		Thursday		Friday		Saturday	
	Name of medicine	✓												
6am														
10am														
2pm														
6pm														
10pm														
2pm														
Extra														

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How CANSA can help

Free **Tele Counselling** per appointment on 0800 22 66 22 in English, Afrikaans, isiXhosa, isiZulu, siSwati, Sesotho and Setswana

Facebook Support Groups:
@CANSA Survivors – Champions of Hope
@CANSA Caring for the Caregivers

iSurvivor and **iSurvivor MBC** for Metastatic Breast Cancer patients – two 16-week email support programmes