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CANSA At Home Guide for Children with Pain

In collaboration with



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Hospice Care for Children



ACKNOWLEDGEMENTS

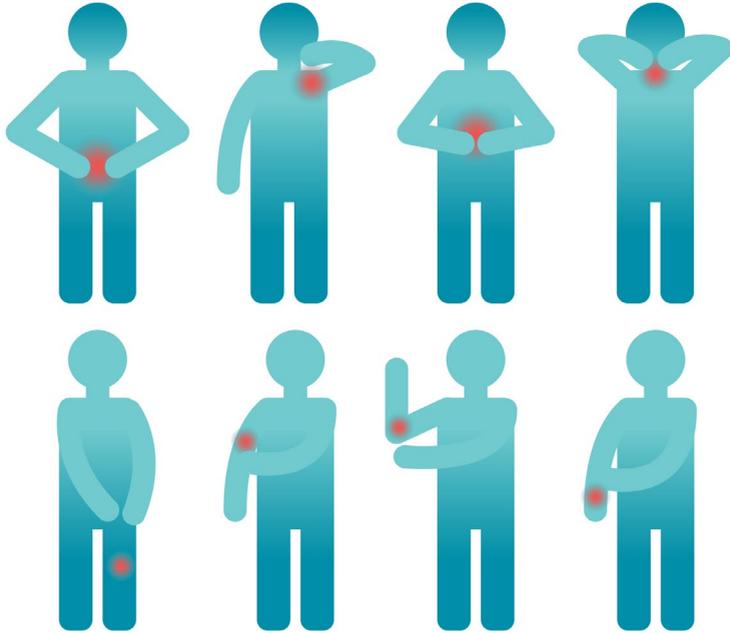
Dr Julia Ambler, MBChB (UCT), MRCGP (UK), Dip Pall Med (Cardiff), DCH (SA)

Tracey Brand, BSocSci (SW), MSW (Clinical Practice)

Tracy Rawlins, Registered Professional Nurse, Midwife and nurse educator, Dip Pall Med (UCT)

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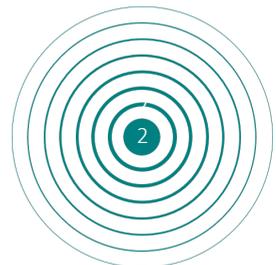


What is pain?

Pain is an unpleasant sensation that varies from mild to extreme discomfort and distress. It can be concentrated in one area or feel like it's all over the body.

Why do we want to treat pain?

Pain affects so many areas of a child's life. Sleeping patterns, moods and energy levels can all be disrupted by pain. It affects the quality of the time a child spends with others and it makes it more difficult for a child to cope in general. Children can feel as if they are being punished by pain, and this can



increase anxiety and distress. Severe ongoing pain can also affect a child's appetite, growth and development.

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 plan for your child.



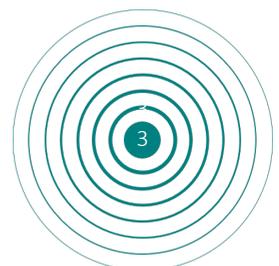
Myths about pain

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

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 cases, medications are needed, and their strength depends on the intensity or severity of the pain.

- *When my child's 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 are harmful to children. For example, children under 12 should not be given aspirin. It is important to have your healthcare provider assess your child's pain, and to agree on a pain treatment plan that works specifically for them.





- *I am worried that my child will become addicted to the medications.*

If your child is being treated for cancer-related pain, he or she will not become addicted to the medication.

- *If I start giving my child 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 child's cancer but starting treatment when your child has 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 your child is in. Your doctor will prescribe morphine if your child's pain



is moderate to severe, and if other medications like paracetamol have not been effective in helping treat your child's pain.

- *My child is 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 my child's pain?

A child with cancer can experience pain caused by:

- The cancer itself
- The cancer treatments and side effects
- Blood tests and investigations
- Normal conditions affecting children such as infections or teething



What else might worsen the pain?

Pain is not always purely physical. Emotional pain is likely to worsen the child's experience of physical pain. Fear, anxiety, boredom, and isolation are all emotions that children with cancer might experience, and these are exacerbated by pain.

How will I know that my child is in pain?

At times this might be very obvious, your child may complain or cry. At other times, your child may continue to play but be in pain, so you might not recognise that they are hurting. The way your child expresses their pain will depend on their age and stage of development. Children can only really start to say that they are in pain or that "it hurts" from about 2 years old, and only describe how the pain feels from about 5 years old. Look out for some of the following signs which may indicate that your child is in pain.



Physical signs of pain may be:

- Sweating
- Shallow breathing
- Change in behaviour – more hyperactive or withdrawn than usual, more clingy
- Change in appetite
- Crying or moaning
- Grinding of the teeth
- Tensing the body
- Restlessness or lying very still

Talking about pain:

Because all children with cancer will experience some form of pain in their cancer journey, it is a good idea to talk to them about it. A calm discussion helping them to understand that they might feel discomfort at times - and that you as their parent or caregiver would like to ease that - might make them more comfortable to tell you about their experience.

Ask them questions such as:

- Are you feeling pain (or use your family word for pain)?
- Where are you feeling the pain?
- How bad is it? (Depending on their age and ability to communicate, you could use a pain scale. See below.)
- Can you tell me what it feels like? (If they struggle you could help them find the words – for example, “Is it sharp like a knife or burning like fire?”)
- You could also ask them to draw a picture of their pain.



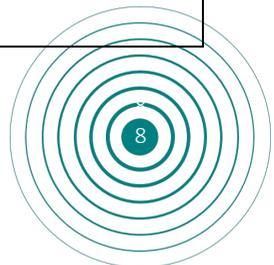
Using Pain Scales:

The following are examples of tools you can use to assess your child's pain.

FLACC Scale:

- For use in children under 3 years or older, non-verbal children
- Evaluating each item, add up the scores and arrive at a total score/10.
- If your child scores >6/10, the child is likely to be in pain.

Item	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, clenched jaw, quivering chin
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking, or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability (can the child be calmed?)	Content, relaxed, no need to console	Reassured by occasional touching, hugging or "talking to", distractible	Difficult to console or comfort



The Faces Scale: For the older child

Faces PAIN SCALE – REVISED (FPS-R) for children over age 3

Point to the face that shows how much you hurt.



0



2



4



6



8



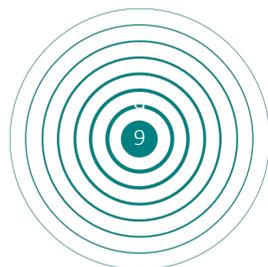
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These faces show how much something can hurt. The left-most face shows no pain. The faces show more and more pain up to the right-most face – it shows very much pain.

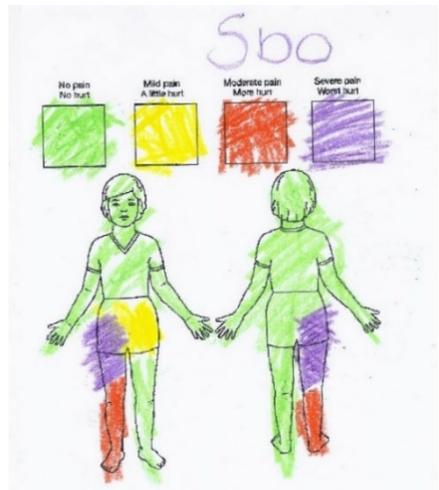
The Eland Body Tool: For the older child

After discussing with the child several things that have hurt him/her in the past:

1. Present eight crayons or markers to the child. Suggested colours are yellow, orange, red, green, blue, purple, brown and black.
2. Ask the following questions, and after the child has answered, mark the appropriate square on the tool (e.g. severe pain, worst hurt), and put that colour away from the others. For convenience, the word “hurt” is used here, but whatever term the child uses should be substituted. Ask the child these questions:



- "Of these colours, which colour is most like the worst hurt you have ever had (using whatever example the child has given), or the worst hurt anybody could ever have?" Which phrase is chosen will depend on the child's experience and what the child is able to understand.
 - Some children may be able to imagine much worse pain than they have ever had, while other children can only understand what they have experienced. Of course, some children may have experienced the worst pain they can imagine.
 - "Which colour is almost as much hurt as the worst hurt (or use example given above, if any), but not quite as bad?"
 - "Which colour is like something that hurts just a little?"
 - "Which colour is like no hurt at all?"
3. Show the four colours (marked boxes, crayons, or markers) to the child in the order he has chosen them, from the colour chosen for the worst hurt to the colour chosen for no hurt.
4. Ask the child to colour the body outlines where he hurts, using the colours he has chosen to show how much it hurts.



5. When the child finishes, ask the child if this is a picture of how he hurts now or how he hurt earlier. Be specific about what earlier means by relating the time to an event, e.g. at lunch or in the playroom.

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How do I manage my child's pain?

Firstly, children are very sensitive to their parent's emotional state. Stay calm and don't panic.

We can manage pain by using medication, but we can also do other things to relieve pain, such as:

- Distract the child with music, art, stories, toys or games
- Help the child find a comfortable position using pillows or cushions
- Help the child to relax by doing some deep breathing, or rub, massage or stroke the child
- We can use a warm water bottle or a heatable wheat bag to soothe aches. Be careful not to burn the child!
- Small babies may benefit from swaddling – i.e. wrapping them snugly in a blanket
- Breastfeeding can reduce the experience of pain



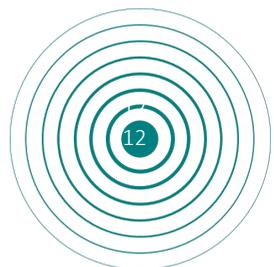


How do I use pain medication?

Your child does not need to experience pain. Chat openly to your child's doctors about pain and the prevention of pain, particularly for procedures such as blood draws and drips. The doctors can prescribe cream that you can apply to the skin to numb it an hour before the procedure.

Also make sure you understand each of the medications prescribed. The names of medications can be confusing as each pharmaceutical company might have a different name for the same thing; e.g. Panado and Calpol are both paracetamol. Having many medications at home can be overwhelming, so ask questions before you go home.

Most medications are prescribed according to your child's weight, so try to keep a record of this from each hospital visit. The pain medications prescribed will depend on the severity of the pain that your child is experiencing. It is important to understand that often we need to use a combination of medications to adequately control the pain.



Below are the more commonly used medications for cancer pain.

Paracetamol

This is the most simple, commonly used medication for pain and fever, but can be dangerous in overdose or children with liver disease. The correct dose for your child's weight can be given every 6 hours by the mouth.

Aspirin

Children under 12 years of age should not have aspirin at all.

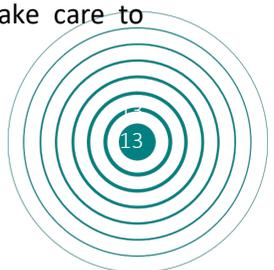
Ibuprofen

This is an excellent reliever of pain and fever. It is described as an anti-inflammatory, which means it will relieve pain associated with swelling and irritation of the tissues. Unfortunately, it can cause irritation to the stomach, so your child should eat something first. We usually recommend that it is taken every 8 hours as needed.

Morphine

Pain that cannot be relieved by paracetamol and Ibuprofen will need to be treated with stronger medication, such as morphine.

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.



How much and when to give your child morphine:

Give the prescribed dose to the child every 4 hours. This means giving the prescribed 4-hourly dose by the clock. (6am, 10am, 2pm, 6pm, 10pm, 2am).

Give 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.

If you have had to add in an extra breakthrough dose in that 24-hour period, then add up all the doses taken and divide by 6. That gives the new 4-hourly dose.

For example, if the 4-hourly dose is 1 ml and 4 extra doses of 0.5 ml have been taken, the total after 24 hours is 3 ml (6×1 plus $4 \times 0.5 = 8$ ml). The new 4-hourly dose is now 1.4 ml (8 divided by 6, rounded up to next whole number, which is 1.4 ml). The breakthrough dose is now 0.7 ml.

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 child's mouth using the syringe.
4. Return any unused morphine from the cup to the bottle.



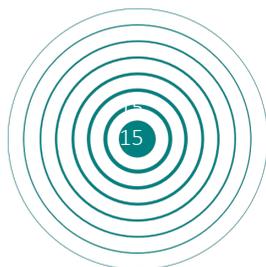
It is important to never stop your child's morphine suddenly. Always discuss any changes to the dosage with your healthcare provider first.



Side effects:

Morphine sometimes causes some of the following side effects:

- Nausea – this usually goes away after the first few days and fortunately is not common in children. If it is a problem, medicines can be given to control it.
- Constipation – this is a very common side effect, and you should be giving your child a medication such as lactulose daily to prevent this.
- Drowsiness – some parents find this quite scary when morphine is first started. It is normal and lessens after a few days of giving the morphine regularly.
- Itchy skin – unluckily some people get an itchy skin as a side effect. You will need to let your doctors know.



- Difficulty passing urine – this is a very rare side effect, but if it happens to your child and they are not able to pass urine at all, after drinking enough fluid, you will need to see a health professional as soon as possible.

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 child’s treatment.

Other medications that can treat pain:

Sometimes pain has a specific cause. For example, the cancer may be causing pressure on a nerve, causing nerve pain or pain from swelling and inflammation around the tumour. Your doctor may need to prescribe a different medication over and above the medications already prescribed.

- For nerve pain the doctor may prescribe medicines such as anti-depressants or epilepsy medication
- For swelling and inflammation the doctor may prescribe corticosteroids
- For stomach cramps the doctor may prescribe an anti-spasmodic medication such as Buscopan

To read more on children’s pain and get some practical advice on how to treat it, follow this link to download “How to Become a Pain Investigator”:

<https://cansa.org.za/pep-talks-training-for-cansa-staff-on-pain-in-children/>



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How CANSA can help children and families affected by cancer

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