Quality of Life for Children with Cancer

A series of modules on pediatric palliative care

This series of modules on palliative care aims to provide essential information to mothers, fathers, and others caring for children with cancer, so that they can provide the best care and take appropriate actions to meet the developmentally appropriate physical, socio-emotional, and spiritual needs of their loved ones, as well as needs arising from the disease itself.

This guide has been developed within the framework of PAHO’s Global Initiative for Childhood Cancer.

ACKNOWLEDGEMENTS

The patients and families who assisted in the development and validation of this material.
PAIN

Pain is one of the symptoms that causes the most distress to both parents and patient.

- Is child experiencing pain?
- How severe is the pain?
- When does the pain occur?

To answer these questions we use certain scales, depending on the age of the child.

If your child is younger than 3 years old, the FLACC scale is used (Figure 1)

If your child is between 3 and 7 years old, the Faces Pain Scale is used (Figure 2)

If your child is over 7 years old and understands numbers, the VAS scale from 0 to 10 is used (Figure 3)

IMPORTANT

Ensuring the quality of life of children with cancer depends on optimal control of the symptoms that cause suffering.

Depending on the course of the disease and the stage of treatment, the indications and management of symptoms may change depending on the care goals that the patient and family have agreed upon with the medical team.
Fever is an increase in body temperature to above normal.

The child is considered to have fever when his temperature is above or equal to 38 °C (wherever it is taken). This can be due to different causes. Whatever the cause, it is important to stay calm and consult your pediatrician or palliative care team.

What should I know?

• What your child’s temperature is.
• How often they get a fever.

USEFUL TIPS

• If your child has a fever, do not cover them up too much.
• Give the medicines prescribed by her doctor.
  Put warm damp cloths on your child or, if possible, bathe them in warm water for 10 minutes.
• Give liquids.
• Bundle them up only if he has chills; This will make them feel better.
• Change the child’s clothes or change the sheets if they are sweating excessively.

If, despite these measures, they continue to have a high fever (above 39°C), contact the health team and follow the instructions given.
# FLACC scale (1 month to 3 years of age)

When using this scale, the scores in each category must be added. (See “Score.”)

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Face</strong></td>
<td>No particular expression or smile.</td>
<td>Occasional grimace or frown, withdrawn, uninterested.</td>
<td>Frequent to constant quivering chin, clenched jaw</td>
</tr>
<tr>
<td><strong>Legs</strong></td>
<td>Normal position or relaxed.</td>
<td>Uneasy, restless, tense.</td>
<td>Kicking or legs drawn up.</td>
</tr>
<tr>
<td><strong>Activity</strong></td>
<td>Lying quietly, normal position, moves easily.</td>
<td>Squirming, twisting back and forth, tense.</td>
<td>Arched, rigid or jerking.</td>
</tr>
<tr>
<td><strong>Cry</strong></td>
<td>No cry (awake or asleep).</td>
<td>Moans or whimpers, occasional complaint.</td>
<td>Crying steadily, screams or sobs, frequent complaints.</td>
</tr>
<tr>
<td><strong>Consolability</strong></td>
<td>Content, relaxed (asleep or awake).</td>
<td>Reassured by occasional touching, hugging or being talked to, distractible.</td>
<td>Difficult to console or comfort.</td>
</tr>
</tbody>
</table>

**SCORING**

- **1-3** Mild discomfort
- **4-6** Moderate pain
- **7-10** Severe discomfort/pain
Wong-Baker Faces Pain Rating Scale
(3 to 7 years of age)

Choose the face that best describes how you feel

0  No hurt
2  Hurts little bit
4  Hurts little more
6  Hurts even more
8  Hurts whole lot
10  Hurts worst

**SCORING**

0  No pain
1-3  Mild pain
4-6  Moderate pain
7-8  Severe pain
9-10  Maximum pain
Visual Analogue Scale (VAS) (for ages 7 and up)

Mark an X on the line to show the intensity of your pain.

NO PAIN

0 1 2 3 4 5 6 7 8 9 10

WORST POSSIBLE PAIN

SCORING

0 No pain
1-3 Mild pain
4-6 Moderate pain
7-8 Severe pain
9-10 Maximum pain
What should I know?

- Pain treatment should be applied according to the type of medication and the frequency indicated by the doctor.
- It is important to keep a clear and precise record of doses of both normal and rescue medications so that your doctor can evaluate the effectiveness of treatment.
- Your doctor will prescribe the most appropriate medication to control your child’s pain. If the pain is severe, you may need opioid medications to control it.
- The most commonly used opioid in palliative care is morphine. Often, those receiving this medication sleep more than usual for the first three days. If the symptom persists, the doctor should be consulted again.

USEFUL TIPS

- Maintain a quiet environment, free of disturbing noises and with relaxing music.
- Always stay with your child when they are in pain.
- Give gentle massages to help with the pain.
- Keep a diary with your child to keep track of pain.

If the pain persists, do not hesitate to call your doctor.
**DIFFICULT BREATHING**

Difficult breathing or shortness of breath causes great distress to both the child and the family; Therefore, **it is important to remain calm so as not to exacerbate that sensation.**

**What should I know?**

- Shortness of breath is also known as “dyspnea.”
- It is important to see whether the skin or lips are purple or pale.
- Notice whether your child makes noises when breathing or has heavy discharge from the nose or mouth.
- Check for blood in the secretions.

**USEFUL TIPS**

- Find the most comfortable position for the child.
- Dress the child in loose, comfortable clothing.
- Change the child’s position to prevent the formation of bedsores.
- Make sure you have adequate ventilation in the room, by opening windows or using a fan.
- Help your child calm down if they become distressed at the feeling of being unable to breathe.
- Show them how to breathe in and out slowly.
- Stay with your child to reassure them.
Adjust your child’s physical activity based on how they feel.

If there are nosebleeds, use dark-colored towels to avoid alarming your child.

Have your child do breathing and relaxation exercises.

Adjust your child’s physical activity based on how they feel.

If the child is unconscious and emits coarse breathing sounds, aspirate only the secretions in the mouth.

If the difficulty persists or increases, do not hesitate to call your doctor.

**CONSTIPATION AND URINARY RETENTION**

Constipation is defined as the presence of dry, hard bowel movements or when one has a bowel movement less than three times a week. Urinary retention occurs when your child is unable to urinate.

**Both constipation and urinary retention may be due to medicines your child is taking for pain, such as morphine.**
What should I know?

- Observe the consistency and pain of bowel movements.
- Assess whether the child:
  - Has diarrhea or leakage of stool.
  - Has urinary retention.
  - Has blood in her stool or urine.
  - Has hemorrhoids.
  - Has pain when urinating or defecating.

USEFUL TIPS

- Provide psychological support to the child if they cannot control the urge to go to the bathroom. Reassure them to avoid panic or embarrassment, since it is part of the disease.
- Clean your child often and use protective creams on areas of pressure and folds to prevent ulcerations or skin lesions.
- Change diapers as needed.
- Watch for urine retention (if you feel something like a balloon above the pubis).
- Increase the child’s intake of foods with fiber (wheat bran, chia, fruits with skin on) and fluids depending on their condition.
- Give gentle abdominal massages.
- Only give laxatives or glycerin suppositories if directed by your doctor.
- Consult the medical team if you feel distressed or cannot handle the child’s situation.
- Tell the health care team if your child is constipated and keep track of their bathroom habits (frequency, amount, and appearance) and if your child has pain.
LACK OF APPETITE

It is common for a child with advanced cancer to have diminished appetite. It is important to understand that the child may want to eat but cannot do so. Therefore, it is essential not to force them; it is better to ask what foods they want to eat. Remember that the child's decline is not due to lack of eating, but to the illness.

What should I know?

• Whether the child is hydrated. To do this, you need to check whether they have dry mouth. You must also observe whether they have wounds that cause pain and prevent eating.
• Whether they have nausea or have vomited.
• If they need help eating.
• If there is pain when the food goes down.
• Feeding tubes should be checked to be sure they are in good condition, properly placed, and do not bother the child.

USEFUL TIPS

Stay calm if your child doesn't want to eat. Try to identify any causes that can be fixed.

Prepare and offer foods your child likes, in small portions, but more frequently (several times a day).

Make feeding schedules flexible to suit the child's preferences.

Avoid strong odors.

If possible, offer your child liquids more often.

Clean your child's mouth before and after eating. If there is nausea or vomiting, follow your doctor's instructions (do not self-treat).

If the child is unconscious, wipe their mouth and lubricate their lips.
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ACKNOWLEDGEMENTS

Silvana Luciani, Chief of Noncommunicable Diseases, PAHO, Washington, D.C.
Mauricio Maza, Liliana Vásquez, Soad Fuentes-Alabí, Karina Ribeiro and Sara Benítez, Noncommunicable Diseases, PAHO, Washington, D.C.
Daniel Bastardo, Medical Content for Patient Outreach, St. Jude Children's Research Hospital.
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The patients and families who assisted in the development and validation of this material.

This guide has been developed within the framework of PAHO's Global Initiative for Childhood Cancer.

PAHO/NMH/NV/cvn4/21–0040
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