

Children's Cancer Pain Can Be Relieved

A Guide for Parents and Families



*This booklet is dedicated
to Shaney Banks and all
other children with cancer.*

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Parents and Families*

A Project of the Wisconsin Cancer Pain Initiative
A World Health Organization Demonstration Project

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This booklet is no longer in print, and is now only available in this
electronic version. <http://wiscinfo.doit.wisc.edu/trc>

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Introduction

This booklet provides parents with the facts about pain and its management in children. Parents of children who have cancer can be overwhelmed with questions: Can the cancer be cured? What sort of treatment will be necessary? Will the child have pain? Can cancer pain be controlled?

Thanks to better understanding of the causes of cancer pain and the advances in treatment of cancer and cancer pain, people do not need to worry that the disease will always cause pain. In virtually all cases, pain in children with cancer can be managed and treated successfully. Successful pain management requires that the child, the parents and the health care team communicate well and work closely together.

This booklet contains the facts about successful management of cancer pain in children. It has been prepared by members of the children's committee of the Wisconsin Cancer Pain Initiative, an organization of health professionals working to improve the quality of life for people with cancer.

Questions

1. My child has cancer. Does this mean my child will experience pain like my grandmother did when she had cancer?

Probably not. The cancers that children get are different than the cancers that adults get. While not all children have pain with their disease, they may have pain from the treatments or the side effects of treatments that help cure or control their disease. Treatments such as radiotherapy (use of x-rays to kill cancer cells) and chemotherapy (use of drugs to kill cancer cells) can have painful side effects. Needles placed directly into the vein to draw blood or give medicine, finger sticks to get blood samples, spinal taps, and bone marrow tests hurt.

Whether pain comes from the disease or the treatments for the disease, the most important thing to know is that pain can be treated. Your child's doctors and nurses want your child to be comfortable. The best way to manage your child's pain is to work closely with them.

2. Do infants experience pain?

Yes. The belief that infants do not experience pain is a myth. Even though they are unable to talk about it, infants feel pain. They need to be treated with the same care and concern given to adults in pain.

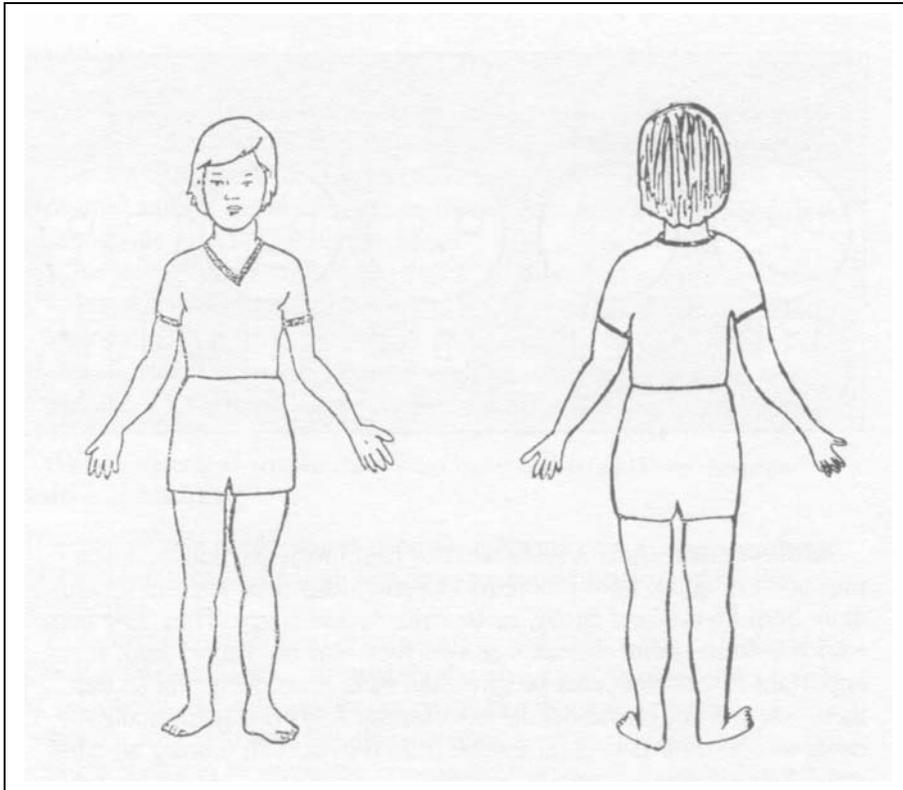
3. How can I tell if my child is in pain?

Infants, toddlers, young children, and adolescents show their pain in different ways. Look for the following pain symptoms:

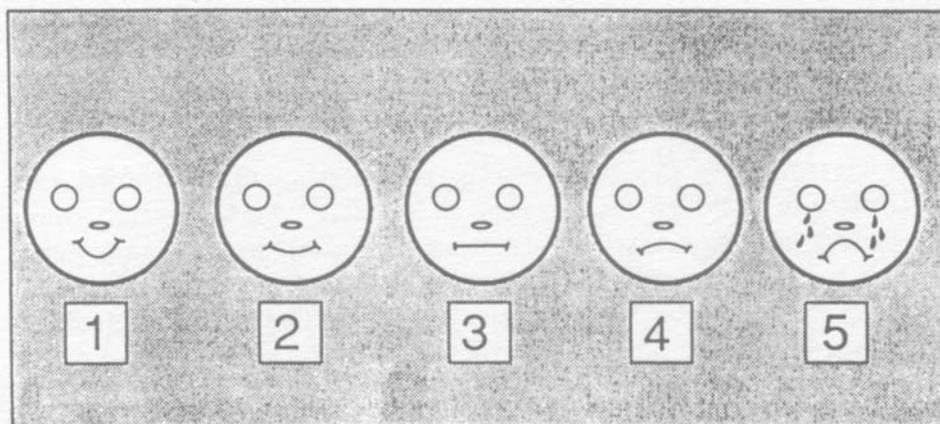
Infants — Infants in pain move less than normally. They may cry more often and be quite irritable. They may look pale and sweaty. They may not eat as well as usual. Infants in pain may cry out if touched or moved. Parents are often able to recognize these signs of discomfort and can help their child's physician and nurse recognize and treat the pain.

Toddlers — Like infants, toddlers with pain may cry more often, be cranky and be less active than usual. Although toddlers can not talk clearly about their pain, they can point to where their hurt is located. When talking to toddlers about pain, use phrases they can understand, like, "where is your owie?" Do not assume you know where your child hurts.

Young children — Since young children can talk, they can discuss their pain. Ask your child to point to the "owie." This will help you find out where your child feels pain. You could also ask your child to color on a body drawing to show just where the hurt is.



Ask how much it hurts. Try using the Five Faces of Feeling (see below) to find out just how much pain your child is feeling. You can also use these faces to find out how much pain the medicines are taking away.



Parents remember this: if young children with cancer say they have pain, they do.

Adolescents — Adolescents react to pain much like adults. They may be very quiet, have problems sleeping, lose their appetites, withdraw from friends and family, or be irritable and angry. They may fear addiction from taking narcotics so that they may not report pain. It is important that adolescents be given

the facts about addiction so that their fear will not create needless suffering. A good way for adolescents to rate their pain is on a scale from 0 to 5, with 0 being no pain and 5 being the worst pain imaginable.

4. Do children always admit to having pain?

No. If children are afraid that admitting their pain means they will have to have a shot or a painful exam, they will often deny they are having pain.

5. My child will complain about pain one minute and the next minute will be playing with toys. Does this mean my child is faking or complaining of pain to get attention?

No. Fortunately, children have a built-in way to help them deal with pain. This is called "distraction." Children can distract themselves from pain by playing with toys or by talking and playing with others. Just because your child can be distracted from pain, doesn't mean that the pain is being faked. Take your child's complaints of pain seriously.

6. What is the best way to treat cancer pain in children?

The best way to treat cancer pain in children is to treat the cancer itself. This treatment may include chemotherapy, radiotherapy, surgery or a combination of these approaches. Unfortunately, as explained earlier, these treatments themselves may hurt or sometimes produce side effects that cause pain.

Many effective pain relieving medicines are available to control most of the pain related to the disease and treatment methods.

In addition to medicines, behavioral techniques can be used to help decrease pain. These will be mentioned in question 17. These techniques can be useful in helping children prepare for painful procedures.

7. What kinds of medicines can be used to relieve cancer pain in children?

The same kinds of medicines used for relieving pain in adults are used for relieving pain in children, but dosages need to be based on the size of the child.

Non-narcotic medicines, such as acetaminophen (such as Tylenol®), relieve mild pain. These are usually the first medicines given to a child for pain relief. Aspirin and similar drugs like ibuprofen (Advil®, Nuprin®, and Motrin®) are almost never used in children with cancer because they can increase the chance of bleeding. Remember that many of the over-the-counter pain relieving medicines contain aspirin, so always ask your doctor or nurse before you give these to your child.

Mild narcotic medicines, such as codeine, offer greater pain relief. Codeine can be given by mouth, and can be combined with acetaminophen.

Stronger narcotic medicines, such as morphine, relieve severe pain. The best way to give these drugs is by mouth, but they can also be given rectally or under the skin by injection into the muscle or into a vein. Intramuscular injections are rarely given because they are painful and there are other ways to give medicines that work just as well.

8. Should I give my child pain medicine on a regular schedule, for example, every three hours; or only when the pain comes back?

For some patients, pain comes and goes. These people may manage their pain by taking medicines as needed when the pain returns. For others with more constant pain, medicines should be taken on a regular schedule, according to the physician's directions, usually every three to four hours. These medicines work best when there is a constant level in the body. Giving medicines at regularly scheduled times or "around the clock" is the best way to get a constant level.

Giving the child medicine before the pain returns also results in better pain relief with fewer side effects. If you wait until pain starts before giving the medicine, your child will probably need a higher dose to become comfortable again.

9. How can I tell if the pain medicine is working for my child?

If your child's pain symptoms decrease after a dose of medicine, you can assume that the pain medicine is working. For example, when an infant's pain is relieved, you'll notice less fussiness or crying. You can ask an older child to rate pain according to the Five Faces of Feeling (page 4). Older children and adolescents may be able to tell you how their pain feels on a scale of 0 to 5, with 0 being no pain, and 5 being the worst pain imaginable.

Most medicines used for severe pain cause sleepiness. So, if your child falls asleep, it is usually a good sign that the medicine is working. However, continuing sleepiness should be brought to the doctor's and nurse's attention.

10. What other things can I do to make sure that my child's pain is under good control?

It helps to write down the questions you have about your child's pain. Write down things you notice about your child's reaction to pain, what makes the pain worse or better and what kind of response your child has to pain medications. For example, record such things as activity levels, constipation, and the effect of positioning during procedures.

Also, ask your child's doctor and nurse how they tell if your child is having pain. Are they using the Five Faces of Feeling, a scale of 0 to 5, or some other way? And, be sure to keep a record of their answers to your questions.

11. What if my child does not like medicines or is afraid to take medicines?

Some children just don't like to take pills, and some don't like the way medicines taste. Also, some children and adults are afraid of pain medicines because of their side effects. These side effects are discussed in detail under question 13.

To solve the problem of a child's dislike for medicines, some pain medicines are available in pleasant tasting liquids. Most pills can be crushed and mixed with small amounts of food or juice, or put in empty gelatin capsules that are available from the hospital or drug store.

12. What if my child throws up the medicine? Should I give another dose?

If your child throws up within a half hour after receiving medicine, or if you see the pills in what your child has vomited, give the child another dose. If it's been longer than a half hour and your child's pain is improved, don't give another dose. If nausea and vomiting continue, call your doctor or nurse.

13. What are the side effects of narcotic analgesics (strong pain medicines)?

Your child may experience constipation, drowsiness, or nausea and vomiting. You should always discuss these and other side effects with the doctor or nurse. These side effects can be treated. They are not a reason to stop giving your child the medicine.

Just a note: to protect children, especially teenagers, they must be warned that driving and other activities (like using power equipment) can be dangerous if they are drowsy from the effects of the narcotic analgesics.

It is important to remember that other medicines (such as medicines for nausea and anxiety) can make this drowsiness worse. Alcohol also increases drowsiness and should not be taken with narcotic analgesics.

What can be done about constipation?

Prevention is the best approach to constipation. It's important to keep track of your child's bowel movements, particularly if your child has had problems with constipation.

Make sure that your child drinks plenty of liquids and eats high fiber foods like fruits and vegetables, whole wheat bread, bran cereal and bran muffins.

If your child does not have a bowel movement after two or three days, the doctor or nurse may suggest a mild laxative such as Naturacil®, Colace®, or Dulcolax®. Some of these products may require a prescription.

What can be done for nausea and vomiting?

First, it's important for the doctor to figure out if the nausea and vomiting are from the pain medication. Other reasons for nausea and vomiting include: poor control of cancer pain; the location of the tumor; chemotherapy; radiation therapy; or other medicines your child might be taking. If nausea is caused by the pain medication, it will usually go away in a few days. If the nausea continues, call your doctor or nurse.

Be sure to include your concerns about side effects on your list of questions for the doctor and nurse.

What if my child seems doped up or "out of it?"

Your child may sleep more for the first 48 hours after getting pain relieving medicines because of sleep lost due to pain. If drowsiness or dopiness continues and it interferes with daily activities, call your doctor or nurse.

14. If my child takes strong pain medicines to control pain, will there be anything to control the pain if it gets worse?

Yes. Many people fear that if narcotic analgesics are used too early they will not be effective if the pain gets worse. This is not true. Your child's pain may not get worse. If it does, a larger dose of the medicine or a stronger medicine can be prescribed safely. Plus, there may be other ways to help control your child's pain so that an increase in the pain medicine will not be necessary.

15. Will my child become a drug addict if given narcotic analgesics?

No. A child in pain needs relief. Once the pain is gone, the child will no longer need pain medicine. At this time, the medicine can be gradually discontinued.

The fear of drug addiction has made people believe that cancer patients will get "hooked" on these medicines and become addicts.

The truth is that addiction is extremely rare when cancer patients take narcotic analgesics for pain. Drug addiction means that a person is taking a drug to get a psychological "high" instead of relief from physical pain.

16. Does the adolescent with cancer pain need special consideration?

Yes. The massive campaign against drug abuse may cause adolescents to worry about becoming addicted to narcotic analgesics. In fact, they may not admit to having pain for fear that they will receive narcotics and become addicted. Adolescents must be reassured that addiction is rarely if ever a problem when they take narcotics for pain. When the pain goes away, they will be able to stop taking pain medicine.

Another special consideration for adolescents is dealing with the psychological suffering that can accompany their disease. Understandably, these young people may be frightened and anxious about their cancer and they may confuse their anxiety with pain.

Peer group pressure is also important in adolescence. Adolescents and their friends must be given accurate information and encouraged to talk openly about cancer, cancer pain and pain medicines. They must realize that a person taking narcotics such as codeine or morphine for pain is not a drug addict and will not become addicted. The pain medicines are a necessary part of the treatment.

17. What other ways are there to control pain and anxiety in children with cancer?

Since children are often very fearful of procedures, it is helpful to explain a test shortly ahead of time. This gives the child some time to accept the idea and practice ways to relieve discomfort. Health care professionals can teach you and your child these ways to help reduce pain and anxiety. Also, children are often less anxious if a parent is with them during a procedure.

Some of the ways to reduce pain and anxiety without medicines include distraction techniques such as play therapy, story telling, and art therapy. Practicing positions to take during a procedure, relaxation, and self-hypnosis are also techniques that can help children who are undergoing uncomfortable tests.

Older children can learn to relax by listening to music or using self-hypnosis. Listening to music by using tape players with head phones has been shown to be very effective in distracting and relaxing young patients.

18. What if my child needs to take pain medicines while attending school?

If your child is having pain and needs to receive medicine while in school, contact your child's school nurse or teacher. Give them information about the need for the medicine, the schedule for taking the medicine, possible side effects, and who to contact if your child has problems.

Arrangements can be made between your child, the teacher and the school nurse so that your child can take pain relievers at the right time without attracting undue attention.

Give the school correct and complete information so that your child's needs are understood and so that "drugs" do not become an issue.

Where to Get Help

AMERICAN CANCER SOCIETY - WISCONSIN DIVISION:
N19 W2450 Riverwood Drive, Waukesha, Wisconsin, 53188

CANCER INFORMATION SERVICE: A toll free cancer counseling service staffed by trained personnel who can answer your questions about cancer and cancer pain. Call toll free, 1-800-4-CANCER.

CANCER RESPONSE SERVICE: An information service sponsored by the American Cancer Society-Wisconsin division. Volunteers answer phones and offer professionally prepared audio and printed materials in response to your questions. Call toll free, 1-800-ACS-2345.

CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION:
National Headquarters, 1901 Pennsylvania Avenue, N.W., Suite 1001, Washington, DC, 20006.

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Mailing address: Wisconsin Cancer Pain Initiative, 4720 Medical Sciences Center, University of Wisconsin Medical School, 1300 University Avenue, Madison, Wisconsin, 53706.

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