

MAKING CANCER LESS PAINFUL

A Handbook for Parents



Authors

Patrick J. McGrath PhD
G. Allen Finley MD FRCPC
Catherine J. Turner RN MN

Table of Contents

Preface

Introduction

Does cancer have to be painful?

Purpose of this handbook

What causes pain in cancer?

Pain From Disease

Pain From Procedures

Pain From Treatment

Pain Management

Palliative care

Whose job is "Pain Management"?

What Is pain?

How can we control pain?

Psychological methods

Pain medications

Needles

Continuing Pain

Taking medicines

Physical methods

Help with painful procedures

Fingerpricks

Venipunctures

Spinal Tap or Lumbar puncture

Bone marrow aspiration and bone marrow biopsy

Central venous access

Parents need help too

Where to go from here

Medical terms

Relaxation instructions

Dedication



This book was written as part of a comprehensive pain management plan at the Oncology Unit of the Izaak Walton Killam Children's Hospital. We believe that parents should take an active role in the management of their child's cancer pain, but are often not given the information they need to participate. Families working together are a vital aspect of pain prevention and treatment, and giving parents the knowledge is the best way to ensure quality pain care.

A companion book for professionals is currently being written. Although we acknowledge the contribution of many professionals and lay colleagues, we are responsible for any errors that remain. The opinions expressed are those of the authors and may not reflect the opinions of our colleagues, sponsors, or institutions.

We wish to dedicate this book to all the children and parents who have taught and inspired us.

Patrick McGrath
Allen Finley
Cathy Turner

Halifax, March 1992



Introduction

Does Cancer Have to be Painful?

Many people believe cancer is a very painful disease. If your child has cancer, you may be concerned that he or she will suffer a great deal of pain. Until recently, this often happened. Fortunately, what we now know about pain, and how to control it, means that children's cancer does not have to be painful. In fact, an important goal of treating childhood cancer is to eliminate as much pain as possible. With the help of doctors, nurses, and other people caring for your child, almost all pain can be reduced or eliminated.

Purpose of this Handbook

This handbook was written for parents of children with cancer. Our main goal is to teach parents about pain and how they can help their child deal with pain from cancer.

It is difficult for parents when their child is first diagnosed with cancer. They are often in a state of shock, feel numb, and do not know how to help their child. This book gives suggestions for ways you can help and an overview of pain management ideas. The first part of the book talks about things that may cause pain in childhood cancer. The next sections discuss what is known about how to prevent and reduce children's pain. The last part of the book describes the best ways to treat pain from specific procedures a child may have.



We suggest you read this book from start to finish, as soon as you are able. There is a lot of information in it, but much of what you read in the first part of the book will become clearer after you have read all the sections. Keep the book handy. Re-read it as different situations come up for your child. We think you will learn something new each time you read it.

Sometimes this book uses medical terms you may not know. Some of these are defined when you first read them. For words not defined in the book, we've made a glossary of medical terms at the end. If there are other words or ideas you don't understand, your child's nurse or doctor can help.

Parents can play a role in the management of their child's illness. One of the reasons we wrote this book is to help parents feel more comfortable about being involved in the treatment of their child's pain. We hope you will talk to the doctors and nurses about the things in this book. The more we all know about pain control, the more we will be able to help the child who has pain from cancer.

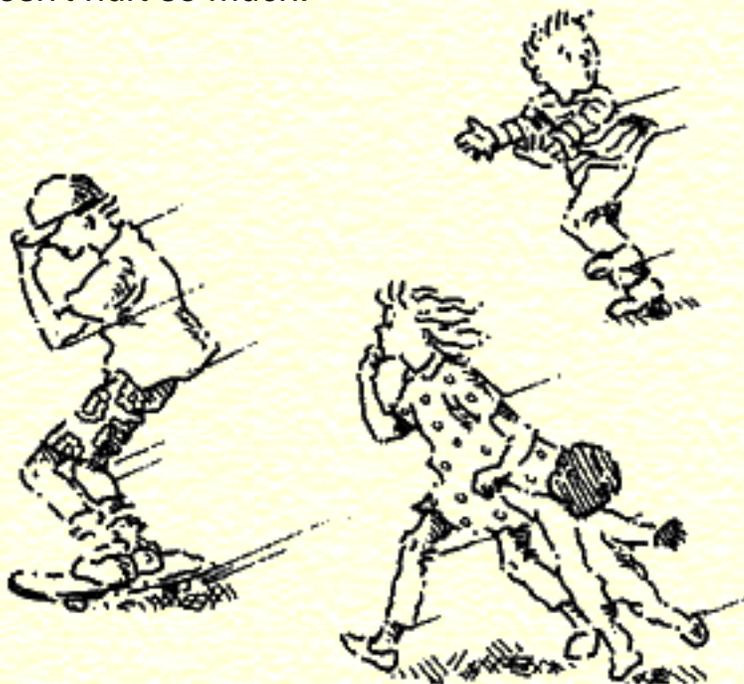


What causes pain in cancer?

There are three sources of pain in childhood cancer: **pain from disease**, **pain from procedures**, and **pain from cancer treatment**. Sometimes, procedures and treatment for cancer are more painful than the disease itself. This can be difficult for parents and children to understand. But we can work with you and your child so it doesn't hurt so much.

Your child may have other distressing symptoms such as nausea, vomiting, itching, tiredness, or depression, and controlling them is very important. Talk to your child's nurse or doctor about how to make these problems better.

Children with cancer can also have the "normal" headaches, tummy aches, or other aches and pains that many children have.



PAIN FROM DISEASE

Many children have some pain before cancer is diagnosed. It is often pain that brings a child to the doctor. Disease pain is almost always due to pressure from the cancer cells on a part of the body. As these cells are removed with treatment, the pain usually disappears.

Disease pain may come back if the cancer cells return. This pain is usually short-lived, because the next cancer treatment will get rid of the cells that are causing the problem. It is important to know that new pain does not necessarily mean the return of your child's cancer. The pain may be from something else.

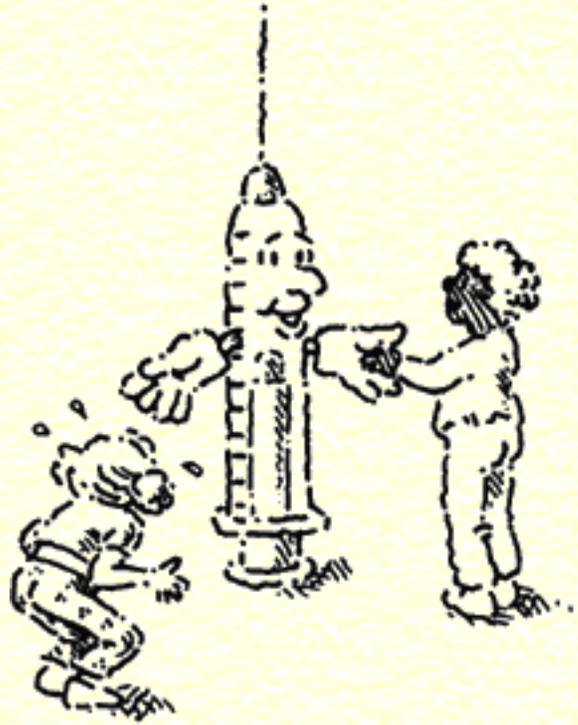
PAIN FROM PROCEDURES

Children with cancer require frequent needles to check how well the treatment is working. Such needles include finger pricks, heel pricks, venipunctures (needles put into a vein), lumbar punctures (spinal taps), bone marrow aspirations (needles into bone), and access to internal central lines.

Until recently, it was not unusual for children with cancer to be very afraid of needles. Many say that needles are the worst of part of having the disease. Fear makes pain a lot worse, and, in the past, children have suffered a great deal from these procedures. The good news is that there are now many ways we can reduce this type of pain.

PAIN FROM TREATMENT

Pain can also come from cancer treatments. Sometimes, getting better hurts! For example, a needle in the leg muscle or the bottom can cause pain when the needle goes in the skin, and a stinging kind of pain as the drug is injected.



In some cases, side effects from cancer drugs may seem worse than the disease itself. For example, some cancer drugs may cause short-term nerve damage, which can be painful. Other drugs can cause constipation and tummy pain. Some treatments (both drugs and radiation) can also cause painful sores in the mouth. Fortunately, treatment pain can now be controlled.



Pain management

Palliative Care

Most children are successfully treated for cancer. However, some will die from the disease. In these cases, the child and the family will be helped and supported with palliative care.

The main focus of palliative care is to make sure the child is comfortable, enjoys life as much as possible, and is able to die peacefully. Pain that may occur when children are dying can be well-managed. For example, pain may come from a tumour moving into bones or other organs or pressing on nerves. Such pain can be treated with strong pain medicine such as morphine, radiotherapy to shrink the tumour, or surgery. In many cases, the child can receive pain treatment at home with help from doctors and nurses by telephone, home visits, and outpatient visits.

Whose job is "Pain Management"?

The answer is everyone's. Parents, children, and health professionals all have a job on the "pain management team". This team works best when all members share information and ideas with each other.

ROLE OF THE PARENTS

Parents have an important role in pain management: as experts, as coaches, and as advocates or spokespersons for their child. While this may seem overwhelming at first, the suggestions in this book will help.

Parents as experts:

First, parents are experts about their own children.

As a parent, you probably know more about your child's feelings and expressions than



anyone else. This means you should be asked how he or she might react to an event, before it happens. You should also be involved in decisions about how your child's pain is managed. You should feel free to offer your opinions and ideas, even if not asked. This is a new thing for many parents. With time, you will become more comfortable talking with the doctors and nurses about your child.

Parents as coaches: Second, parents can be the best coaches or teachers of ways to deal with pain. Parents know their children best and have close emotional bonds with them. Therefore, they are able to help their child deal with new and difficult situations. It is important to know that you can be with your child during most procedures. Children usually want a parent with them to talk in a soothing voice, hold their hand, or rub their forehead. You know best how to comfort your child. You may have already used some of the suggestions in this book; you may want to try others. The staff can also give you ideas to help your child with painful procedures.

Parents as advocates: Third, parents are advocates (someone who speaks on behalf of another) for their children. Parents have the right and responsibility to make sure their child's pain is well-managed. This means you may have to speak out for your child. As we've said, you should be able to discuss your ideas and your suggestions for changes in pain management with the hospital staff. In particular, if you see that something is not working, make sure someone knows. A good person to talk with first is the nurse, since he or she will be with your child the most.

ROLE OF THE CHILD

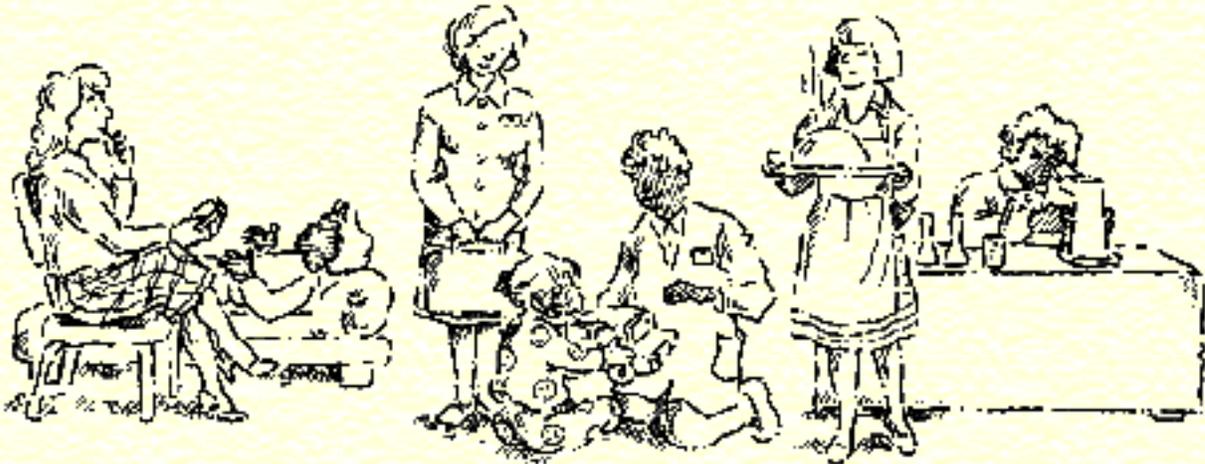
Children have two main roles in pain management: as co-directors and as experts.

The child as Co-director: Your child should be involved as much as possible in deciding how pain will be managed. The age of the child will affect how much he or she is able to do this. Teenagers can be very active in managing their pain, while infants will have little direct participation. Increasing a child's sense of control decreases pain and increases co-operation. But there are limits to this control. For instance, children as young as 3 years old can be asked which finger they want "pricked", but they cannot be allowed to decide whether or not the

fingerprick will be done. Teenagers, on the other hand, can decide whether the side effects of a pain medicine are worth its pain-relieving effects.

The child as Expert: Only your child knows how much pain he or she is feeling. When a child says something is painful, he or she should be believed unless there is a very good reason not to. Children also know what they prefer. For instance, some like to watch as a needle is inserted, while others may want to look away.

ROLE OF THE HEALTH PROFESSIONAL



Health professionals have three main roles. First, they are Experts in the treatment of your child's disease and the control of symptoms such as pain. Second, they should be Teachers, educating you and your child about disease, pain, and treatment choices. Third, they should be Caregivers, providing support and assistance to parents and children.

For the newcomer to the hospital, there can be a confusing number of people in white coats. The following list describes who these people are, and what they do. If you wish to see any of these people, talk to your child's nurse or doctor. He or she should be able to arrange it for you.

Nurse: the person who provides day-to-day care for your child. Nurses have the most contact with patients and make many decisions about their care. They give medicine, watch your child's condition, and give valuable emotional support. Nurses can also help you understand treatment choices for your child. They are readily available and can answer most of your questions. If they cannot answer a question, they will refer you to someone who can help.

Oncologist or Hematologist/Oncologist: a doctor who specializes in the treatment of cancer. He or she will direct the medical treatment of your child's cancer and discuss treatment choices with you and your child.

Anaesthetist (or anesthesiologist): a doctor who specializes in the

control of pain during surgery and at other times.

Psychiatrist and/or psychologist: doctors who specialize in the mental, emotional, or behavioural adjustment of children and families. In many clinics a psychologist or psychiatrist is routinely asked to see families who have a child with cancer. Finding out that your child has cancer is very difficult, and these doctors are trained to help people during difficult times. Consulting with a psychologist or psychiatrist is NOT a sign of mental illness or of family problems. These doctors may also be able to teach you and your child more about pain control.

Social worker: a professional who specializes in the emotional and social adjustment of children and families. Often, a social worker is assigned to each family to help them during their illness.

Physiotherapist: a professional who specializes in exercises to keep muscles strong and flexible. Physiotherapists can often help with pain that comes from muscles and nerves.

Occupational Therapist: a professional who specializes in maintaining your child's abilities in activities of daily living, play, and school.

Nutritionist: a professional who helps your child get the best possible nutrition, in order to improve healing and maintain strength.

Child life specialist: a professional who encourages children in learning, play, self-expression, and family involvement while in hospital.

Chaplain: a member of the health team who helps children and families deal with the spiritual and emotional aspects of their lives. The chaplain may be of a specific denomination or may serve several denominations.

Clinical pharmacist: a hospital pharmacist who monitors the use of drugs to improve the effectiveness and safety of treatment.

Technical personnel: technologists who take blood samples and X-rays and test blood and other samples.





What is pain?

We all know "pain" is a hurt that we feel, however, only recently have we begun to understand how pain works.

Most parts of our body, both inside and out, have "pain receptors". When these are activated by pressure or damage to body tissue, a pain message is started. The message passes along our nerves to the spinal cord (in the backbone), and then to the brain. Our brain "reads" the pain message, and we feel pain.

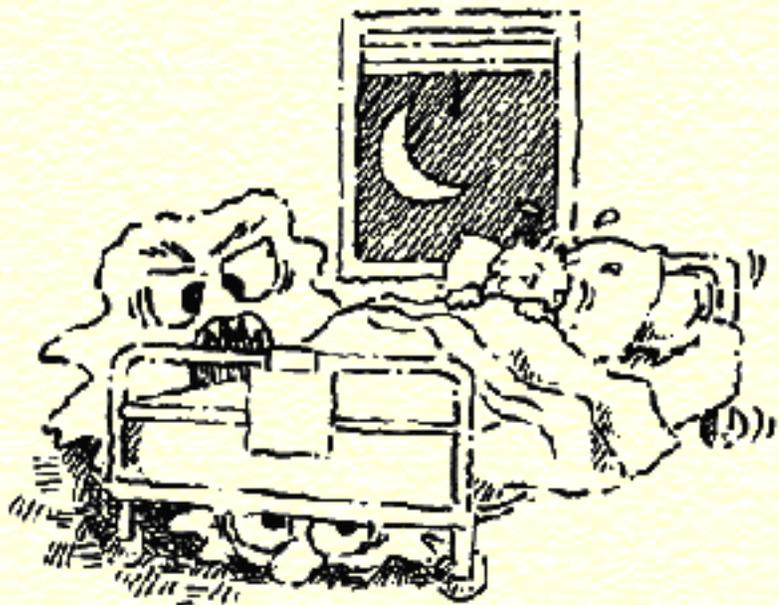
The pain system is very complex, with "switches" or "pain regulating centres" found where the pain starts, in the spinal cord, and at several places in the brain. These switches can affect how much of the pain message the brain actually reads.

Pain is also a very personal thing. Each person is different. For example, the same physical damage can cause very different amounts of pain in different people. As well, the same procedure can cause a different amount of pain each time it is done.

WHAT MAKES PAIN WORSE?

We know that some things make pain worse. Controlling any or all of these can help a child have better pain control.

Anxiety, depression, and fear: No matter how they are caused, negative emotions can make pain worse. If a child has had a bad experience with poorly managed pain, he or she will fear a procedure more and have more pain. Similarly, if a child believes pain is a "bad sign", or that a



procedure or treatment is not going to work, pain will be more severe. Fear and anxiety spread easily, and children whose parents, brothers, or sisters show these emotions are likely to have worse pain.

Lack of control: Children who think they have no control are likely to feel more pain. For example, kids who say "I feel like a pin cushion that everyone just sticks" suffer more than children who have been given some choices and control.

Exhaustion: A child who is exhausted by other symptoms, such as nausea, fatigue, or shortness of breath, will have worse pain.

Unfair expectations: If parents or medical staff encourage extreme levels of bravery (such as never crying), or encourage a lot of complaining, children are likely to have a more difficult time.

Surroundings: Dull or inappropriate surroundings, such as a room with no toys, or baby toys for a 10 year old, will make pain stronger. In the same way, pain is often worse at night when little is going on.

HOW CAN PAIN BE MEASURED?

It is important to have a consistent way of measuring pain. That way, we can tell when pain is getting better or worse.

The best way to measure pain is to ask children how much pain they feel. Three ways to help children describe their pain are listed below. With children less than 4 years old, it is harder for them to tell us how much pain they are having. In these cases, we need to watch for changes in their behaviour.

Pieces of hurt : A child is given five poker chips or small stones and asked how many "pieces of hurt" they feel. It is explained to the child that one piece means a little hurt, two pieces mean more hurt and all five pieces mean the most hurt. This method is useful with children over 4 or 5 years of age.

FACES scales: The FACES scale shown below can be used with

children over 5 years old. The child is asked to point to the face that best matches how much pain or hurt he or she is having. If you use this scale, it is helpful to enlarge the faces to about 6 cm (2 1/2 inches) high.



[Pain 1990; 41:139 -50 - reproduced with permission from the authors and Elsevier]

0 - 10 scale: A simple way to measure pain is to ask an older child (8 years and above) to rate their pain from 0 to 10. Zero is "no pain" and 10 is pain "as bad as it can possibly be".

Behavioural measures: Changes in how children act may be a clue that they are in pain. Behaviours that suggest pain include crying, fussing or being irritable, avoiding people, sleeping poorly, having a "pain" face, holding or protecting a body area, not being easily comforted, not eating well, not playing, and not being able to pay attention.

Behavioural changes do not always mean a child is in pain. Sometimes, the behaviour means something else, such as hunger, cold, or fever. On the other hand, a child in serious pain may show little response and just be very withdrawn and quiet.

Children differ in the way pain affects their behaviour. Because of this, parents are often able to see changes that mean pain more readily than a doctor or nurse. Although behavioural change is not a perfect way to tell if there is pain, for young children it may be the only way we have.

CULTURAL ISSUES

Culture is made up of the traditions and values of a society. Different families have different cultures because of their own heritage and this is important in pain for many reasons. For example, some cultures promote "being strong" while other cultures promote "expressing oneself". These may result in different responses from children.



How can we control pain?



Pain lets us know something is wrong. Once we know what is causing the pain, it serves no useful purpose and should be eliminated. It is not "weak" to have help with pain. In fact, sometimes being "strong", or not talking about pain, prevents doctors and nurses from knowing about a problem. Children with cancer should be protected from pain as much as possible. Pain takes energy that is better used to fight disease and to do more normal things like playing.

There are many ways we can help control pain. These are described in the next sections of the book. But first, there are three important principles for treating pain:

1. TREAT PAIN BEFORE IT OCCURS

We know ahead of time that some things will be painful. In these cases, it is better to treat or prevent the pain before it begins. "An ounce of prevention is worth a pound of cure". For example, "freezing" the skin with a local anaesthetic will help prevent needle pain. Giving pain medicine regularly, around the clock, is better than giving it only when it is needed. (The latter is sometimes called "giving medicine p-r-n"). Giving medicine regularly prevents pain from coming back before the next dose and helps keep the child pain-free.

2. PLAN AND COMBINE PAINFUL PROCEDURES

When possible, painful procedures should be combined to reduce their effect on the child. For example, if a child is to have conscious sedation (see the section on Pain Medications) for a bone marrow aspiration, other painful procedures can be done at the same time. If possible, the child should also know when a procedure is to be done. If a child knows he or she is to have a bone marrow aspiration at 2:00 pm, there is no need to worry about it until then. For most children, it is more of a worry not to know when a procedure will be done or to have the time changed



without being told.

3. USE MULTIPLE TREATMENTS AGAINST PAIN

Pain control methods fall under three general headings: psychological methods, methods using medications, and physical methods. The following sections describe choices within each method.

Because pain is so complex, it is best stopped by using several methods at the same time. For example, a child having a lumbar puncture will find it helpful to combine relaxation techniques with a local anaesthetic. A later section of this book (Help with Painful Procedures) describes specific methods that are useful for procedures your child may have.



Psychological methods

Parental Behavior

Child Behavior

Summary

Parental Behavior

SHOW CONFIDENCE

Children can tell how confident you are about their pain management. In fact, children say parents are their greatest source of strength when dealing with pain. But they can also react to parents' anxiety about pain.

Understandably, parents can feel overwhelmed by their child's illness and the pain they think he or she may have to endure. If this is the case, it is best to ask for help to deal with the situation. Your own doctor, one of the doctors caring for your child, or the nurse can tell you what resources are available.

GIVE EXPLANATIONS THE CHILD CAN UNDERSTAND

Children need to know what is happening to them. They should be given explanations about what they will feel, hear, and smell in a way they can understand. A young child will need a different explanation than a 16 year old. For example, younger children are often helped by using a doll to show what is to be done, but adolescents may respond better to diagrams.

INDIVIDUALIZE THE APPROACH

Each child is an individual. Something that helps one child may not help another. Some children like to know exactly what is going on during a procedure. Others want only a few details. Some children like to know things long before they happen, while others like to find out closer to the time. As a parent, you will have a good idea how your child might react. Older children and adolescents should be asked directly what they prefer. And in all cases, careful observation will make many preferences clear.

BE HONEST

It is always a mistake to lie to a child about pain. Children who are wrongly told a painful treatment or procedure won't hurt will have little trust the next time. Children's fears and pains should also be accepted. For example, you could say: "I know this medicine stings when it goes in." Follow this with some help, for example: "...but if you take a breath and blow out slowly, it may hurt less."

GIVE POSITIVE FEEDBACK

Children respond well to praise. Co-operative behaviour should be encouraged. Statements like: "I was pleased to see you trying to stay still" or "It was good you told the nurse exactly how you were feeling" can be helpful. Minor misbehaviour should be ignored, although, at times, a no-nonsense approach may help the child co-operate. Even children with

serious illness need expectations of "good" behaviour. Small rewards, such as stickers, food treats, or a special activity, can help a child with painful procedures. Rewards should also be given for effort. Painful procedures are difficult, and the child who is trying to co-operate should have as much recognition as the child who is able to achieve it.

NEVER USE MEDICAL PROCEDURES AS A THREAT

When a child misbehaves, it is not fair to threaten him or her with a needle. This interferes with the child's sense of trust and can make behaviour worse.

GIVE SOME CONTROL TO THE CHILD

Children can be allowed to control some aspects of their treatment. As we said before, the feeling of being in control reduces pain. Even very young children can be allowed to decide some parts of their treatment, for example: whether to sit on your lap or a chair, which finger to have pricked, and/or whether to have a bandaid.

Child Behavior

USE PLAY



Play is an essential part of every child's life. Play is the way a child explores his or her world and becomes part of it. Play also helps children express feelings and "work through" issues that concern them.

Children who are sick can still play, although some children may need more help in their play. Most games, toys, and books can be brought to the bedside.

Small hospital furniture and medical supplies with dolls are especially good for helping children act out fears and anxieties. Medical play can also help us discover misconceptions a child has about his or her disease or medical treatment. Likewise, drama, art, music, writing, poetry, and puppetry can all help children talk about their illness and gain control over painful

experiences.

Child-life specialists are specially trained to help your child enjoy playing while in hospital. They can also help you with ideas to help your child with play activities.

USE RELAXATION AND IMAGERY

Anxiety and tension can make pain worse. First, it is more difficult and more painful to put a needle in a tense muscle. When a child is relaxed, veins are easier to find and bruising is reduced. Second, anxiety increases pain by opening "pain switches" in the brain. Anxiety also stops the brain from blocking the feeling of pain. Finally, anxiety uses up needed energy, decreases rest and sleep, and tires the child. All of these make it more difficult to cope with pain.



Relaxation is a useful way to combat pain.

Regular relaxation exercises can, and ideally should, be started before a specific problem has occurred. We suggest, for example, that relaxation techniques be learned in the first couple of weeks, or as soon as possible after the initial diagnosis. That way, you and your child will know how to use these techniques when they are really needed.

Some helpful relaxation techniques are described below. In addition, there is a script at the end of the book which presents three types of relaxation exercises. As always, the doctors and nurses caring for your child should also be able to help you and your child find the best approach.

Different forms of relaxation are better for different ages. **Babies** relax with rocking, cuddling, sucking on a sweetened soother, gentle stroking, soothing talk, and lullabies. For instance, a heel- or fingerprick will be less painful if a baby is cuddled and has a soother.

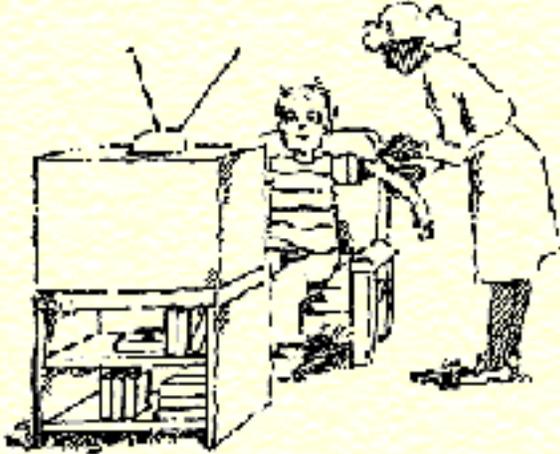
Toddlers and **preschoolers** relax with many of the techniques used for babies. They also enjoy stories, and often love hearing the same one over and over. A favourite teddy bear or blanket is often comforting. Listening to or singing a familiar song may also relax them.

School-aged children often enjoy cuddles and a gentle massage by parents. Reading may relax some children, while for others it can be a chore. Children over 10 years may be able to learn formal muscle relaxation. In addition, "pleasant imagery" (such as recalling a favoured activity), or taking deep slow breaths, may help relax them. The script that comes with this book describes both pleasant imagery and muscle relaxation for this age group.

Most **teenagers** can readily learn muscle relaxation and deep slow breathing. Many of the techniques used with younger children (cuddles, being read to, massage) will also comfort an older child. Adolescents will also have comfort objects, such as a favourite sweater, a small stuffed toy, or a good luck charm.

The stress of having a child with cancer is considerable and many parents find it helpful to learn relaxation methods for their own use.

USE DISTRACTION



Distraction is especially helpful for short pain, such as pain from fingerpricks. All ages of children can be distracted with music, action videos, or TV. For some, music through earphones (such as a Walkman→) is particularly useful.

Babies can be distracted by dramatic talking: "Oh Mary we are just going to do this as quickly as we can." Showing a baby something interesting, such as a

squeaky toy or anything bright and moving, will help take their attention off the painful procedure.

Preschoolers and **early school-aged children** can be distracted with a pop-up book or a detailed and interesting picture book. Blowing bubbles and party blowers are also great for this age group.

Older children and **adolescents** can be distracted by conversation. Talking to them about past, present, or future events will help take their mind off the procedure.

TEACH SELF TALK

Children and adults talk to themselves. "Self talk" can be calming and helpful for some children, while for others it may cause more anxiety.

Some examples of useful self talk include: "This will be over soon", "I can handle this", "It's tough but I am doing well", "This will help me in the long run". Children above about 6 years of age can be coached during a procedure to say calming and relaxing things to themselves. After about age 10 years, children can learn to do this even when a "coach" is not there.

Older teenagers can learn a more sophisticated strategy. Called ADAPT (after the first letter in each step), this approach is as follows:

Acknowledge the negative feeling or thought.

Describe to oneself what statements or thoughts are causing the negative feeling.

Assess if the thoughts are helpful.

Present alternatives to the thoughts.

Think praise: Give yourself a pat on the back for a better way of thinking.

TEACH PROBLEM SOLVING

Older children and adolescents can learn what makes their pain worse, and what makes it better. Measuring pain and keeping a record of the ratings is helpful for problem-solving discussions. By comparing previous ratings, the child and parent or nurse can figure out what helps pain and what makes it worse. Brainstorming can then be used to find new ideas to help reduce the pain.

Summary

Infants 0-1 year: Rocking, stroking, patting, use of soother, food, distraction, music, soothing talk, new or favourite toy.

Toddler 1-3 years: Rocking, stroking, patting, use of food, distraction, music, soothing, self-talk, favourite stories read by parent or on tape.

Preschool and School-aged: Self talk, relaxation exercises, control, distraction, music or stories on tape.

Adolescent: Problem solving, self talk, relaxation exercises, control.



Pain medications

This section describes the use of medicines to control pain. The source of the pain helps determine the best way to treat it.

Needles

Continuing Pain



Needles

Children with cancer have many needles that cause pain for a short time. Some small quick needle procedures tend to be well tolerated once distraction and other coping strategies are learned. Some procedures also require drug treatment to reduce or eliminate the pain.

If possible, more painful procedures (such as bone marrow biopsies or lumbar punctures) should be done in a place other than the child's room. The child's room should be kept as a safe haven, where the child knows pain will not be inflicted.

EMLA® is a local anaesthetic cream which works very well when needles are given into tissue just under the skin. It is put on the skin before a procedure is done and works to numb or "freeze" the area so the needle is not felt. For example, starting an intravenous catheter, placing a needle in a Port-a-Cath®, or inserting a needle for a blood sample or cancer medicines can be much less painful with EMLA®. Many children can also have a lumbar puncture (spinal tap) quite comfortably with EMLA®.

EMLA® contains two very well established and researched drugs, lidocaine and prilocaine. These are blended in a way to make them more effective than each one by itself. EMLA® is applied in a thick "blo" at the spot where the needle will go in, at least one hour ahead of time (90 minutes for dark-skinned patients). It should NOT be rubbed in. It is then covered with an airtight bandage and the time is written on the dressing. This airtight bandage helps the medicine go further into the skin and freeze the deeper areas. The doctor or nurse then removes EMLA® and cleans the area before the needle is given. Children who have had a large number of needles without EMLA® may find it doesn't work perfectly at first, because they expect to have pain with their needles.

If you are applying EMLA® yourself, the package comes with detailed instructions. Your child's nurse can also help you, or answer questions you have about applying the cream.

For bone marrow aspirations and biopsies and some lumbar punctures, two other methods of pain control are required: local anaesthetics by needle and sedation.

Local anaesthetics by needle can be injected into deeper tissue first, so that the needle used for these procedures will not hurt. In this case, EMLA® is also used to make the local anaesthetic needle pain-free.

Sedation (especially "deep sedation" or "conscious sedation") is very helpful for children during more painful procedures. The goals of sedation are to

have the child pain-free and comfortable for the short time of the procedure and awake as quickly as possible when the procedure is finished. Different combinations of drugs can be used intravenously (or occasionally by mouth) to do three things: reduce pain from the procedure, reduce anxiety or worry, and help the child forget unpleasant parts of the procedure. Intramuscular medications for sedation are not usually helpful. Two types of drugs are used in conscious sedation: a drug to remove anxiety and memory of the procedure (e.g. midazolam or diazepam); and a strong analgesic or anaesthetic (e.g. ketamine, fentanyl, alfentanil, morphine, or meperidine).

When this type of sedation is used, an anaesthetist, another physician, or a specially trained nurse carefully checks the child's blood pressure, pulse, breathing, and oxygen saturation during the procedure. Every child has a somewhat different response to sedative medications, so the anaesthetist will carefully adjust the dose to make sure the child is comfortable.

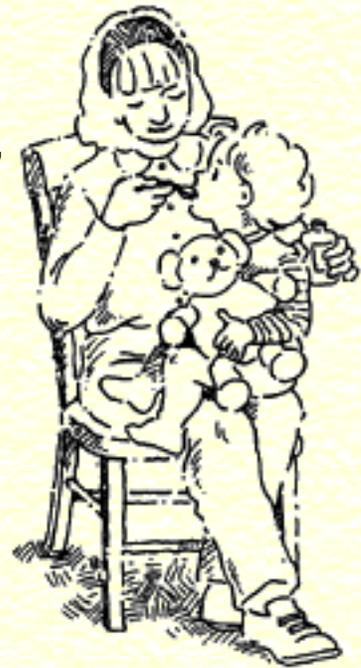
Occasionally, it may be better to have a procedure done in the operating room under general anaesthesia. This may occur if several procedures are to happen at the same time, or if a child is very sick. General anaesthesia is no more dangerous than other types of sedation, and in some hospitals is used for all bone marrow biopsies.

Continuing Pain

Children may also have pain from cancer that goes on for a long time (days, weeks, or months). This pain may be caused by growth or spread of the disease, or by side effects of treatment. The first step is to find out what is causing the pain, then to do everything possible to reduce or eliminate the pain.

Medicine for continuing pain should be given regularly, to prevent the pain from coming back. Once pain gets out of control, it is harder to stop. It is important not to wait for the pain to return; if medicine is given before the pain is bad, it will work better and less will be needed.

In most cases, medicine for continuing pain can be given by mouth. This is the easiest, safest, and least expensive method. For mild pain, the first medicine tried is usually acetaminophen (Tylenol® , Panadol®), or a similar drug, given every four hours around the clock. In some cases, a longer acting drug (such as naproxen) can be given two or three times a day. If an acetaminophen-like drug isn't enough, a mild opioid or narcotic (such as codeine) can be given every four hours with acetaminophen. More severe pain may need a stronger medicine. Morphine is the most commonly-used strong pain medication, and is effective in most cases. It should usually be given every four hours around the clock, although sometimes a slow-release preparation such as MS-Contin® can be given twice a day. Occasionally, other similar drugs, such as hydromorphone (Dilaudid®), are used instead.



Pain from damaged nerves may be treated with other drugs, such as anti-convulsants like carbamazepine (Tegretol®) or anti-depressants like amitriptyline (Elavil®).

Different children will need different strengths of medicine. In almost every case, we can find the right level for each child. It is important NOT to give your child extra pain medicine on your own. For example, pain remedies that you can buy off the shelf. If you think your child is not getting enough pain medicine, be sure to talk to the doctor or nurse about it.

Many parents are frightened when morphine is suggested for their child. They think morphine is only used when children are about to die. Children may be treated with morphine at any stage of their disease, if they have strong pain. The use of morphine or other strong pain medicines has everything to do with how much pain a child has. It has nothing to do with his or her chance of survival.

Some parents worry about side effects of morphine, including addiction, constipation, nausea, itchiness, and sedation. Children who are on morphine gladly stop taking the drug once it is no longer needed. If morphine is stopped suddenly, a withdrawal reaction may occur because the child's body has become dependent on the drug. The child will become jittery, sweaty, and grumpy. That is why we reduce morphine slowly once the drug is no longer needed. Addiction is an excessive craving for a drug even if it is not needed for pain relief. This does not happen when morphine is given for cancer pain.

Unless prevented, constipation will occur in almost all children who take codeine or morphine for more than a few days. Constipation must be treated before it begins. Stool softeners such as Colace® and lactulose and bowel

stimulants such as Senokot® are very helpful, and should be given routinely whenever opioid drugs are used.

Nausea can occur with morphine, but usually goes away in a few days or is easily treated with medications. Itchiness, if it occurs, also tends to go away in a few days. If not, there are drugs that may help stop the itch.

Some children may be sleepy the first few days they are on morphine. Sometimes they are just catching up on sleep they have missed. Sleepiness is rarely a problem once the right dose is found, and children can take morphine for months and be very alert. In addition, children whose pain is well-controlled with morphine are able to sleep better at night, because they are in less pain. In the rare cases when drowsiness is a problem, a stimulant drug may be given.

A concern of some parents is that their child will become used to morphine's effects. They worry that if morphine is used too early in the disease, it will not work well later on. Some children may need a larger dose of morphine after they have been on it for a while, but there is no upper limit to the amount of morphine that can be used. Giving a larger dose is not a problem.

In summary, when used properly, morphine is a safe, effective drug.



Taking medications

Many children, especially those under 5 years, find it hard to swallow pills. This is usually because they have never had to do it. Most children with cancer need pills at some time, and it is best to teach them how to swallow a tablet or capsule before they really need it.

The following steps can be used to teach children how to swallow medicines, including pills:

1. Keep a calm and positive attitude.
2. Be honest about any unpleasant taste, and always tell your child if medicine is mixed with food or drink.
3. Show the child how to swallow pills calmly and quickly. Demonstrate by placing a tablet or capsule well back in the centre of the tongue. Take a sip of a drink, then tip the head back and swallow. This can be followed with another drink.
4. Learning to swallow pills should be done in small steps, with success at every stage. For example, have your child practice with a very small cake decoration. When the smallest size can be swallowed with no problem, a slightly larger size may be tried. Then work up to the size of pill your child has to take. It is best to work in short sessions (5-10 minutes) several times a day over a few days. If this does not work with your child, talk with the hospital staff.
5. Reduce distractions and interruptions during medicine-taking times. For example, close the door, pull the curtains around your child's bed, and turn off the television.
6. Some children like to play "beat the clock". Use a one or two minute time limit, then have a small treat.
7. If the child gags or vomits, be calm and clean up any mess in a matter-of-fact way. Let the child settle for 10 or 15 minutes, and try again.
8. Give plenty of praise. Use specific praise such as "Oh good! You

swallowed it right down."

9. Some pills may be easier to swallow if they are broken in halves or quarters. Ask the nurse whether this can be done with the pills your child is taking.
10. Arrange for something pleasant, such as getting a sticker or playing with a favourite toy, right after the medicine is taken.

When taking pills is too hard, a liquid form may be available. Liquid medicines can be given on a spoon, from a tiny cup, or with a mouth syringe. They may be taken "straight", or may be able to be mixed with a small amount of favourite drink or "chased" with a drink or food. As well, some pills can be crushed and given on a spoon with ice cream, yoghurt, or applesauce. Others can be dissolved in liquid. If your child has trouble swallowing pills, be sure to ask the nurse if any of these ideas can be tried. But remember, don't trick the child. Let the child know what is happening.

Some children may not be able to swallow medicine because of sores or other disease in their mouth or throat. In these cases, pain medicine can be given by continuous intravenous infusion. This method can also quickly control severe pain. It is very reliable, but may be a little inconvenient since an intravenous pump is needed.

Sometimes a special computer-controlled device, called a Patient Controlled Analgesia (PCA) Pump, is used to give a small dose of intravenous medicine when it is needed. Older children can usually control this device themselves. With younger children, the pump is controlled by a nurse or parent. The computer is set ahead of time so that too much drug cannot be given. PCA is ideal because the right amount of drug can be given exactly when it is needed. It also helps the child feel in control and know that their pain will be looked after right away.

Another approach is to give morphine or similar drugs subcutaneously (just under the skin) on a regular basis. This can be more convenient than continuous intravenous infusion, especially when the child is at home. A tiny needle is placed anywhere on the body and is easily changed by the child, parent, or visiting nurse. The needle is usually changed twice a week.

A patch (like a bandaid) is being developed to give a strong analgesic called fentanyl through the skin. When available, it will give a steady dose of the medicine without any needle and may be helpful for some children.

With some unusual pain problems, an anaesthetist will inject local anaesthetics to block specific nerves or use an epidural catheter to place a strong analgesic close to the spinal cord. Both these methods can control very severe pain.



Physical methods

A number of physical methods can be useful in controlling some types of pain. Often a physiotherapist or occupational therapist is the best person to teach these techniques.

Transcutaneous Electrical Nerve Stimulation (TENS): TENS is a pain control method which uses gentle electrical impulses to block pain. A pocket-sized device is connected by wires to two or more small sticky pads which attach to the skin. TENS is used for a variety of pain problems, but may be most useful for "phantom" pain following an amputation.

Vibration: Vibration, either by gentle tapping or by some other mechanical means, can also block pain.

Massage: Gentle massage or stroking can be very calming and soothing for a child, especially the affectionate touch of a parent. There are many specific methods of massage, but it is best to do what your child finds most effective. Massaging and cuddling your child will often make you feel better, too.

Heat and cold: Both heat and cold may relieve pain, although care must be taken not to accidentally burn or freeze the child's skin. Brief cold stimulation on the skin may reduce pain from a needle. Note, however, that heat or cold should NOT be used after injection of chemotherapy, since it will change the absorption of the drug. As with all our suggestions, be sure to ask your child's nurse or doctor first whether you can use this method to help relieve your child's pain.



Help with painful procedures

So far we have looked at various methods to relieve a child's pain. This section applies these ideas to specific procedures your child may have and gives more information about the different procedures.

Fingerpricks

Venipunctures

Spinal Tap or Lumbar Puncture

Bone Marrow Aspiration and Bone Marrow Biopsy

Central Venous Access

FINGERPRICKS

Fingerpricks are used to obtain a small amount of blood for tests. A small blade or lancet is used to make a tiny cut or puncture in the skin. The finger is then squeezed gently to make blood come out.

Specific methods of pain control for fingerpricks are:

Explanation: The reason for the procedure should be explained.

Play: For younger children, anxiety may be reduced by doing a pretend fingerprick on a doll. Other types of play may be useful for older children.

Distraction: Distraction geared to the child's age and interests may work very well.

Relaxation: If the child can relax, the fingerprick will be easier and less painful.

Problem solving: With the help of a parent or health professional, older children and adolescents can work out the best strategy for their own situation.



VENIPUNCTURES

Venipunctures involve placing a small needle into a vein, usually in the hand or arm. These are done to get a small amount of blood for tests, to give medication, or to give liquid to prevent dehydration. A venipuncture needle may be left in the vein for only a few moments, or it may be left in for several days (in which case, a soft plastic intravenous catheter is usually used).

To do a venipuncture, the doctor or nurse first looks closely at the child's hand or arm to find the best vein. A tight band (tourniquet) may be placed around the child's arm to make the veins easier to see. Once the best vein is found, the

skin over it is cleaned with an alcohol swab. The needle is then put through the skin into the vein. If the needle is to stay in the vein for awhile, it will be taped in place. A small board may also be taped to the child's arm or hand to decrease movement of the needle. Without pain-control techniques, venipunctures are painful for most children.

Explanation, play, distraction, relaxation, and problem-solving can be used as described above. In addition, EMLA® cream can make most venipunctures pain-free and is used routinely in some cancer clinics.

SPINAL TAP OR LUMBAR PUNCTURE (LP)

The brain and spinal cord are washed by a liquid called "spinal fluid." Sometimes a sample of this fluid is needed to find out the child's diagnosis or treatment progress. At other times, spinal taps are done to put chemotherapy medicine right into the spinal fluid.

The doctor will have your child lie on his/her side, with knees bent up and chin touching the chest. The child's back is cleaned with a special antiseptic soap. A small needle is put into one of the spaces between the child's vertebrae (the small bones down the centre of the back) and into the spinal fluid.



Spinal fluid usually comes out drop by drop, and is collected in small bottles that are sent to the lab for testing. Medicine may then be slowly injected through the same needle. The needle is removed and a bandaid is placed over the area.

Explanation, play, distraction, relaxation, and problem-solving can be used as described above. In fact, many children can manage spinal taps well with just these techniques and EMLA®. Injected local anaesthetic is often used and can be quite effective, but may sting during the injection unless EMLA® is used as well.

Children who are very anxious may find conscious or deep sedation is the best way to manage spinal taps.

BONE MARROW ASPIRATION AND BONE MARROW BIOPSY

Bone marrow is a soft gel in the middle of bones where white blood cells, red blood cells, and platelets are made. A sample of bone marrow may be needed to see if it is making the right types and amounts of blood cells. Usually marrow is taken from the hip bone with a special bone marrow needle. The child lies on his or her side and is properly positioned by the nurse. The doctor puts on gloves and cleans the area with an antiseptic soap. The needle is placed into the bone and a syringe is used to take marrow out. Sometimes a small piece of bone is also taken (bone marrow biopsy). The procedure is painful unless appropriate pain-control steps are taken.

Specific methods of pain control for bone marrow procedures are:

Explanation: The reason for the bone marrow aspiration and how the procedure will be done should be explained.

Play: For younger children, anxiety may be reduced by doing a bone marrow aspiration on a doll. Adolescents may wish to write a story or poem, or draw a picture about the procedure.

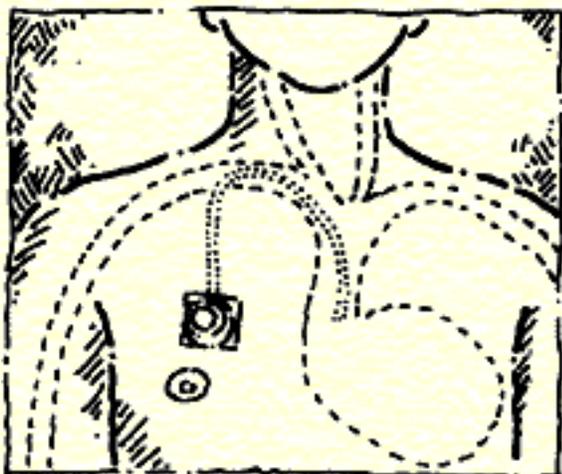
Relaxation: Children and adolescents who have practised relaxation, and can do it well, may find it very effective in relieving anxiety.

Problem solving: Older children and adolescents can problem solve with a parent or health professional to find the best strategies for their own situation.

Local anaesthetic: An injected local anaesthetic should be used to numb the deeper tissues. EMLA® should also be used to prevent pain from the needle and the burning feeling as the local anaesthetic goes in.

Conscious or deep sedation: Since bone marrow procedures can be frightening and painful, children should be offered conscious or deep sedation. Some older children may decide to stay awake during bone marrows. In these cases, relaxation, distraction, EMLA® , and local anaesthetic may be sufficient.

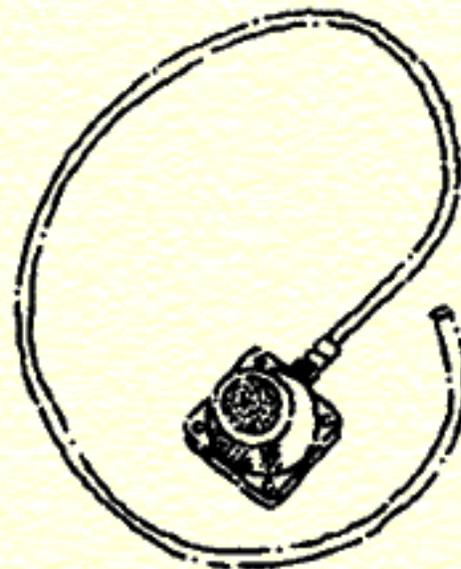
CENTRAL VENOUS ACCESS



When children need frequent intravenous medicines, blood products, and blood tests, it becomes harder to find a usable vein. Fortunately, there are new ways to easily access a child's veins. These are known as "central venous access lines" or "central lines". A central line is a permanent intravenous tube or catheter which can stay in place as long as it is needed. There are two main types of central lines. One type is entirely under the skin (an "internal" line) and the other has tubing outside the skin (an

"external" line). Both have a long thin tube that reaches the large vein that goes to the heart.

Internal lines (such as the Port-a-Cath®) cannot be seen once they are under the skin. The internal line is placed in the upper part of the child's chest by a surgeon in the operating room while the child is under general anaesthesia. In order to use the internal line, a needle is put through the child's skin into a reservoir (see diagram). To prevent infection during the use of the internal line, the skin over it will be washed with an antiseptic soap. The nurse or doctor will wear surgical gloves and often use a face mask. The needle may be kept in for only a few moments, or for several days. If the needle is to stay in, a special dressing will be used to cover the needle. Once the needle is in place, it is not painful.



If the needle going through the skin causes pain, EMLA® and the other methods described for venipunctures should be used.

External central lines have tubing outside the skin (usually on the child's chest). To use this type of line, a needle is placed through the end of the tubing. This is not painful.



Parents need help too

Parents who have children with cancer are under tremendous strain. It is very easy for parents to become run down, exhausted, and feel very alone. Many parents say they were able to help their children because they were able to take care of themselves and accept help from others.

Parents often find that other parents of children with cancer are an important source of strength.

Candlelighters is an international parents' organization with local groups at most children's cancer treatment centres. Candlelighters' aim is to support and educate parents. They have regular meetings and publish a newsletter. Many parents find Candlelighters a valuable resource to help them deal with their child's cancer. The name and phone number of a contact person for your local Candlelighters group is available from your nurse.



Although it may be very difficult to leave your child, a few hours away from the hospital (shopping, going for a walk, having a coffee) can be a tremendous relief. Exercise and eating regularly can also help parents stay on top of things. Many parents find that talking with their clergyman or with a social worker, psychologist, or psychiatrist makes it easier to cope.

Friends and family members are often the most valuable source of help for you in your child's fight with cancer. Sometimes, parents do not wish to impose. However, friends and family usually want to help and can be a great support. They may not know what to do. Some may feel uncomfortable with your child's diagnosis. You may need to "break the ice" and talk to them about your child or suggest ways they can help. For example, they may be able to babysit, run errands, cook a meal, or sit with your child in hospital while you go for a walk.

Hospital volunteers may also provide help for parents. A volunteer can read or play with a child while you take a break.



Where to go from here

This handbook has described what can be done to control pain in children with cancer. Its purpose is to give parents a better understanding of both new and tested ways to make children with cancer more comfortable.

But what should parents do if their child is suffering pain and they feel not enough is being done?

There are three steps that may be effective in these cases. First of all, tell the nurse or doctor what you are concerned about. Ask what more can be done for your child. You may want to ask about specific pain control methods. There are several possible reasons why these aren't being used, including the following:

- Your child's case is different and needs a different approach.
- The service or product isn't available. It may be difficult to obtain services such as anaesthesia or psychology in your unit.
- Some of these approaches are very new and your unit may not be aware of them yet.
- Something has been missed. People who work with children's cancer are very concerned about their patients, but they are not perfect. Drawing attention to a problem may be all that is needed to correct it.

If you are still unhappy with your child's pain control, ask for a specific time to discuss pain. Don't try to catch people on the run. Make a list of your concerns. Try to be clear about your concerns, without being angry or hostile. You and the staff are all on the same side.

The second step is to get together with other parents, perhaps through your local Candlelighters group. Contact professionals who know about pain control. Invite experts to talk to your group, and invite local health professionals to attend. Read about the latest in children's pain. Learn everything you can.

Third, work with the doctors and nurses to make changes. Decide what changes are needed and develop a plan for action. Your lobbying of the hospital administration, insurance companies, or politicians may help the clinic get the resources it needs to provide better pain relief.

We sincerely hope this book helps you and your child manage pain from cancer. As we said at the beginning, keep it handy. You will find it helpful to re-read different parts over the course of your child's treatment.



Medical terms

acetaminophen (e.g. Tylenol®): a drug used to control mild pain and fever. It comes in a liquid, chewable tablets, or caplets.

addiction: drug-seeking behaviour that occurs after the drug is no longer needed. Contrary to popular belief, this is not a problem if drugs are given for pain.

amitriptyline (e.g. Elavil®): this drug is most widely used for depression. When used in smaller doses, it is often useful for pain, especially pain related to nerve damage.



analgesic: a drug that reduces pain, a pain killer.

Aspirin® : a mild analgesic rarely used with children.

Broviac® : a type of external central line.

carbamazepine (e.g. Tegretol®): an anti-epileptic or anti-convulsant drug that is often used to treat pain due to nerve damage.

catheter: a tube which is inserted into a body cavity such as the bladder or into a vein. It is used to add or remove things from the body.

central venous access line (CVL): a long catheter that is inserted into a large vein and can stay in place for an extended period of time. It is used to give drugs or to take blood samples. External lines (e.g. Broviac®) are outside the skin while internal lines (e.g. Port-a-Cath®) are under the skin.

codeine: a mild opioid analgesic that is useful in mild or moderate pain. It may be combined with acetaminophen.

conscious sedation: an anaesthetist (or other specially trained doctor) uses powerful drugs to abolish pain, while the child is still awake. The child has no memory of the procedure.

diazepam (e.g. Valium®): a minor tranquillizer often used to reduce anxiety.

deep sedation: an anaesthetist (or other specially trained doctor) uses powerful drugs to abolish pain. The child is asleep for a few minutes.

dependence: If an opioid drug like morphine is taken for more than a few days, and stopped suddenly, the child will feel anxious, irritable, or sick. This is because the body has become used to, or dependent on, the drug. If the drug is reduced gradually these problems do not occur. This is not the same as addiction, which almost never occurs in cancer pain treatment.

EMLA® : a mixture of two local anaesthetics, lidocaine and prilocaine. When combined in a cream these drugs are able to numb the skin and prevent or reduce pain from needles and other minor procedures.

epidural: An anaesthetic drug (like lidocaine or bupivacaine) or an opioid (like fentanyl or morphine) is put into a part of the spine near the spinal cord to cause numbness or to control pain in a specific part of the body.

fentanyl (Sublimaze®): a strong, short-acting opioid drug used in general anaesthesia and deep sedation.

general anaesthetic: an anaesthetic that affects the whole body. It may be given by mask or by needle to cause the child to go to "sleep" for an operation or other procedure. A specially-trained doctor (an anaesthetist or anesthesiologist) administers the anaesthetic and stays with the child the whole time he or she is asleep.

hydromorphone (e.g. Dilaudid®): a strong opioid that is used in the same way as morphine.

ibuprofen (e.g. Advil® , Motrin® , Nuprin®): a non-steroidal anti-inflammatory drug (NSAID) used for mild or moderate pain.

IM (intramuscular): IM injections are usually given in the leg or buttock and are used for some chemotherapy treatments. IM injections should not be used for pain control.

IV (intravenous): literally, into the vein. IV's are used to give medication or liquids. Intravenous lines can be kept in for days or longer.

ketamine (Ketalar®): a short acting anaesthetic that is used in conscious or deep sedation.

lidocaine (e.g. Xylocaine®): a local anaesthetic that is used to make the skin numb. Sometimes it is put under the skin by a small needle. It is also one of the drugs in EMLA® .

local anaesthetic: a drug that numbs a specific area of the body. It may be given as a cream (EMLA®) or by needle. The anaesthetic is placed on or in a specific area of the body to cause a loss of feeling around that area only.

lorazepam (e.g. Ativan®): a minor tranquillizer used to reduce anxiety.

meperidine (e.g. Demerol®): an opioid that is widely used for post-operative

pain. It is not advised for long term use because the by-products of this drug may be toxic.

midazolam (Versed®): a very short-acting sedative drug used in conscious sedation.

morphine: an opioid analgesic drug widely used in the management of severe pain. It is safe, has many uses, and is inexpensive. Morphine can be given intravenously, subcutaneously, or by mouth. Its effects usually last 3 or 4 hours. Sustained-release pills (e.g. MS-Contin®) that last 8 to 12 hours are available. In some areas, methadone is used instead of sustained-release morphine.

naproxen (e.g. Naprosyn®): a non-steroidal anti-inflammatory drug used for mild or moderate pain.

narcotics: (see **opioids**)

nitrous oxide: "Laughing gas" can sometimes be used for painful procedures. It is available in pre-mixed canisters or can be given by means of an anaesthesia machine.

NPO: or "nil per os", means nothing should be given by mouth.

NSAID: Non steroidal anti-inflammatory drugs (like naproxen or ibuprofen) are often used in treatment of arthritis and are particularly useful for some types of bone pain.

opioids: all drugs that are similar to morphine. Commonly used opioids include meperidine, fentanyl, morphine, codeine, and hydromorphone.

oxygen saturation: the amount of oxygen in the blood. This is a good measure of how well a child is breathing.

PCA (Patient Controlled Analgesia): a computer-controlled infusion pump that allows the patient to control the amount of pain medication he or she receives.

PO: or "per os" means the drug is taken by mouth. Port-a-Cath® : a type of internal central venous access line.

Pulse oximeter: a machine that measures the oxygen saturation (see above). A pulse oximeter should be used to check the child during and after deep sedation or conscious sedation.

PR: or "per rectum" means that the drug is taken as a suppository or gel placed in the rectum.

prilocaine: a local anaesthetic that is one of the drugs in EMLA® .

PRN: or "pro re nata" means "as needed". Unfortunately, that often means

that pain medication is not given until after the pain recurs.

Q4H: every four hours. regional anaesthetic block: the injection of a drug into a nerve or the spinal column to relieve pain.

respiratory depression: a decrease in the number of breaths and the depth of breathing. It can be a side effect of strong analgesics such as morphine.

S/C (subcutaneous, pronounced "sub Q"): "under the skin".

tolerance: Children may become tolerant to morphine or another opioid and may require a larger dose after they have been taking the drug for a prolonged time.



Relaxation instructions

There are three sets of relaxation instructions that follow. The first set has both a tension phase and a relaxation phase. The second uses imagery and the third is a breathing exercise.

These types of relaxation are probably best for children ten years or older. Younger children may relax better by involvement in their favourite stories. The relaxation instructions should be spoken in a slow, quiet voice. It is best to learn the instructions so that they flow smoothly. It is OK to vary the instructions to suit your child. The instructions can be tape recorded and then played back at a convenient time. Children can learn relaxation and then apply it when needed.

These relaxation instructions are available on audiotape from Dr. Pat McGrath, Department of Psychology, Dalhousie University, Halifax, Nova Scotia, B3H 4J1, for \$5.00.

WHAT TO DO

Find a comfortable place for you and your child to relax. Choose a chair that will support your child's body, or a bed or couch. Ensure that you will be free from interruption or distraction. Have your child settle and then begin. If your child fidgets or feels uncomfortable, stop and try again at some other time. Do not try to force your child to follow the instructions. You can't make someone relax.

Loosen any tight clothing or shoes and make sure you have a light blanket (in case your child gets cold during relaxation). Make sure your child does not cross his or her legs or arms (they might "fall asleep"). It is fine if your child's body twitches during the relaxation. If he or she feels uncomfortable, you should stop the relaxation exercise. If your child laughs or seems self-conscious, just continue and the feeling will probably pass.

WHAT TO SAY

Relaxation with imagery

Let's use your imagination to help you relax. Start by imagining being in a very pleasant and happy mood. Imagine that you are doing something you really like. Imagine what you can see, what you can feel, and what you are doing. You can close your eyes if you wish.



Breathe in deeply and then breathe out slowly relaxing your lower arms and your hands. Your arms and hands may be kind of heavy and tingly. You feel peaceful and relaxed. Allow your arms and hands to loosen and relax more and more. Let your arms and hands relax from your elbows to your fingers. Just let go. Enjoy the calm, relaxed feeling.

Now pay attention to relaxing your upper arms and shoulders. Notice where there is some tension. Let the muscles become loose and relaxed. Try to smooth out and calm the muscles in your imagination. Be calm and peaceful. Notice how pleasant it is to relax your muscles. Just let go of any tension in your arms and shoulders.

Pay attention to the muscles in your neck and face. Relax these muscles. Let them become loose and heavy. If you can, you may want to rest your head on the pillow or couch. As you relax your face, your mouth may open. That is fine. Breathe slowly and calmly. Now pay particular attention to your forehead. Relax and smooth the muscles of your forehead. Relax your forehead as much as you can. Relax your jaw. Let all the muscles in your head and face relax and loosen. Let these muscles become heavy and calm.

Think again of the very pleasant thing you were thinking about at the beginning of this exercise. Imagine you are totally relaxed and happy. Enjoy this memory.

Now, focus attention on the muscles of your chest. Loosen the muscles of your chest. Try and make your breathing smooth and slow, calm and peaceful. Breathe in relaxation, breathe out tension.

Relax your stomach and abdomen. Notice the difference between tension and relaxation. Imagine all of your tension escaping as you relax.

Let the muscles in your upper legs become relaxed and peaceful. Feel that your legs are relaxed. Allow your legs to sink into the chair or bed. Your legs are becoming calm and relaxed. Relax your lower legs and feet. Let the

muscles become calm and peaceful. Let them become very relaxed.

Imagine the warm peaceful feelings of relaxation gradually moving through your body and loosening all your muscles. Allow all your tension to disappear. Breathe in relaxation, breathe out tension.

Let the warmth move through your head. Relax all the muscles in your head and face. Allow the warm feeling of relaxation move through your neck and shoulders. Relax your shoulders. Allow the warm feelings of relaxation to move throughout your back muscles. Let the warm feelings of relaxation move down your spine. Let the warm relaxing feeling fill your legs and move into your feet. Imagine that the tension is just gradually draining away. Let the tension disappear gradually as you relax. Breathe slowly and deeply. Allow yourself to be calm and peaceful, warm and relaxed. Let all your muscles become heavy and loose. Enjoy the calm gentle feelings of relaxation.

You are calm and relaxed and feel very confident and peaceful. Just enjoy these feelings for a few moments. Gradually come out of this relaxation as I count backwards from 5. Five, four, three, two, one. You will feel good as you open your eyes. Open your eyes, stretch if you wish. Good, now just enjoy the pleasantness of the situation. Relax. Enjoy every moment of it.

Tension and relaxation

Move so that you are as comfortable as you can be. Take a deep breath and exhale slowly. Now do it again, breathe in and slowly breathe out.

Relax all of you muscles as best you can. Focus your attention on your right hand. Squeeze the hand into a fist. Tighten all the muscles and hold the tension for five seconds. Notice the tension. Study the tension. Now relax. Relax your hand as much as you can. Notice the difference between tension and relaxation.

Now create tension in your left hand. Tight, tight (hold for five seconds). Notice the tension; study it. Now relax, release the tension in the hand. Let go and release the muscles in your hands. Let your hands become totally relaxed.

Tense your right arm by pushing it down on the chair or bed. Hold it for five seconds and study the difference between tension and relaxation. Now relax. Loosen the muscles and enjoy the warm relaxing feeling.

Now tense your left arm by pushing it down on the chair or bed. Hold it for five seconds and study the contrast between tension and relaxation. Relax. Calm and loosen the muscle in your arms. Enjoy the peace and tranquillity of relaxation.

Tense your shoulders by thrusting them forward. Hold the shoulders in this position for five seconds and notice the muscles in your back and shoulders

stretching and tensing. Release and relax. Loosen your muscles and allow your shoulders to drop. Allow the tension to leave your shoulders and allow the warm pleasant feeling to move into your arms and shoulders.

Tense your shoulders by thrusting your shoulders back and noticing the tension. Hold the tension and then release and relax. Finally tense your shoulders by moving and lifting them up and holding them for five seconds. Release, relax, deepen the relaxation by breathing deeply and slowly. Your hands, arms, and shoulders now will form a ring of relaxation.

Concentrate now on your face. Create tension by scrunching up your face and hold it for five seconds. Notice the tension spreading throughout your face and scalp. Relax and let all the tension disappear.

Clench your teeth and notice the tension in your jaw. Hold it and study how the tension and tightness spreads. Loosen, relax, and let go. Let your jaw go slack. You can let your mouth open if that is comfortable. Breathe slowly and deeply. Relax.

Now create tension in your neck. Be careful not to cause yourself any pain. Turn your head to the left as far as comfortable. Notice the tension in your neck and back. Hold it for five seconds and then return your head to the resting position. Next turn your head in the other direction. Hold the tension for a few moments and then relax. Finally, create tension by pushing your head onto your chest. Hold the tension and then relax.

Focus attention on your breathing. Create tension by taking a deep breath and holding it. The tension will spread gradually. Allow the tension to build until it is mildly uncomfortable. Then breathe out. Breathe deeply and slowly for three breaths. Imagine that you are breathing in through the bottom of your feet. Breathe out through your mouth or nose. If you begin to feel dizzy, breathe more slowly.

Now create tension by exhaling all your breath. Hold it for a few moments and then breathe in. Resume normal breathing and breathe deeply and slowly. Each time you exhale, try to breathe out any tension.

Cause tension in your abdomen by pulling in the muscles and holding them. This will curtail your deep breathing and tension will increase. Relax, loosen the muscles, and enjoy slow and relaxing breathing. Create tension by pushing your stomach out and holding it for five seconds. Relax, loosen your stomach muscles, allow the muscles to become calm and peaceful. Enjoy the calm feeling.

Tense your right leg by pushing it down on the bed or chair. Study the tension in your upper and lower leg. Do not tense your foot. Hold the tension for five seconds and then let go. Relax, let go, enjoy the feeling of relaxation spreading through your leg.

Now repeat the same procedure with your other leg. Tense your left leg by pushing it down on the bed or chair. Study the tension in your thigh and your calves. Do not tense your foot. Hold the tension for five seconds and then let go. Relax, let go, enjoy the feeling of relaxation spreading through your leg.

Finally, make some tension in both of your feet by pointing your toes towards your head. Do not cause too much tension or you may cause cramping and pain in your feet. Relax your feet, legs and thighs. Let the relaxation move into your abdomen and back. Notice the warm pleasant feelings of relaxation. Breathe deeply and slowly. Allow the relaxation to move into your lungs and chest. Relax your shoulders and neck. Relax your arms and hands. Now deepen your relaxation by trying to loosen any remaining tense areas.

Now, let's use your imagination to deepen the relaxation. Create in your mind a very pleasant and relaxing scene. Perhaps it would be lying on a beach or walking through a forest. Imagine the calmness in your body as you enjoy the sounds and smells of your created scene. Feel the refreshing air and enjoy the calm relaxed peaceful feeling that you have throughout your body. Feel the warmth of the sun on your head and allow the warmth to spread throughout your upper body. Feel the warm relaxing feeling spread throughout your entire body. Imagine that your body is actually a bag of sand and allow it to totally relax and mould to the chair or bed.

You are calm and relaxed and feel very confident and peaceful. Just enjoy these feelings for a few moments. Gradually come out of this relaxation as I count backwards from 5. Five, four, three, two, one. You will feel good as you open your eyes. Open your eyes, stretch if you wish.

Good, now just enjoy the pleasant feelings. Relax. Enjoy every moment of it.

Relaxation by deep breathing

Just relax and if you wish close your eyes. Now, take a deep breath, try to breathe in as much air as possible. Hold it for a few seconds. Now, let your breath out very, very slowly. As you let out your breath, relax all of your muscles.

Now, breathe in again, slowly and deeply. Breathe in relaxation. Slowly, breathe out and let tension flow out. Relax your face, arms and shoulders. Enjoy the warmth of the relaxation.

Take another deep slow breath. Fill your lungs. Relax and breathe out. Relax your chest and tummy. Allow calm and peacefulness to replace any tension.

Now breathe in again as if you are breathing in through the bottom of your feet. Slowly. Slowly. Slowly. Relax your legs and feet. Pause for a few moments and then breathe out slowly. If you begin to get dizzy breathe more slowly.

Breathe in again, deeply and slowly. Try and relax some part of your body that is a bit tense. Breathe out slowly. Release all tension. Relax and enjoy being peaceful.

Begin breathing normally but continue to increase your relaxation with every breath. Open your eyes and enjoy how you feel.



Author notes

Patrick McGrath is Professor of Psychology, Pediatrics, and Psychiatry and Co-ordinator of Clinical Psychology at Dalhousie University. He has a long-standing interest and experience in pain research and treatment.

Allen Finley is a Staff Anaesthetist at the IWK Children's Hospital and Assistant Professor of Anaesthesia at Dalhousie University. He has a special interest in research and clinical management of paediatric pain.

Cathy Turner is the Clinical Nurse Specialist for the Hematology-Oncology Service at the IWK Children's Hospital. She has been involved in the development of the pain management program for pediatric cancer patients.



Dedication

This book was produced by the Oncology Unit of the Izaak Walton Killam Children's Hospital in Halifax, Nova Scotia, Canada, and was made possible by an educational grant from ASTRA PHARMA CANADA INC. We thank all those professionals and parents who assisted in its preparation, including:

Mickie Al-Molky	Judy Mathews
Judy Beaver	Linda McAlpine
Dorothy Barnard	Barbara McCully
Heather Beaudoin	Gillian McNeill
Diane Britton	Annette Penney
Estelle Forbes-Doucet	Allan Pyesmany
Paula Forward	Judith Ritchie
Nancy Gee	June Roach
Cathy Hamdullahpur	Anita Unruh
Bea Hanisch	Staff of the IWK Hospital Child Life Dept
Darlene Joyce	Staff of the IWK Hematology-Oncology Unit
Lois LaRoche	

We would also like to thank our colleagues in other centres who gave us advice and encouragement, including:

Charles Berde	Ada Rodgers
Jo Eland	Peter Rowe
Gerri Frager	Neil Schechter
Angela Miser	Barbara Shapiro

We owe a special debt of gratitude to Brenda McBean Cochran of BMC Health Associates for valuable assistance with editing of the text.



Copyright information

© 1992 McGrath, Finley, Turner

ISBN 0-9696071-0-5

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, xerographic, recording or otherwise for commercial purposes without the written permission of the authors. It may be distributed or copied freely to patients, parents, students, and hospital staff provided that no fee is charged for such distribution and that appropriate credit is given.

Illustrations : Elizabeth Owen

Publication design and layout : Jay Rutherford Rutherford/Owen Design & Illustration

Text composition in ITC Cheltenham Book and Franklin Gothic Demi

Printed in Halifax, Nova Scotia, Canada March 1992

Canadian Cataloguing in Publication Data

McGrath, Patrick J. (Patrick John), 1948-

Making Cancer Less Painful

"This book was produced by the Oncology Unit of the Izaak Walton Killam Children's Hospital in Halifax, Nova Scotia"

ISBN 0-9696071-0-5

1. Cancer Pain - Prevention.
2. Cancer Pain - Treatment
3. Pain in children.

I. Finley, G. Allen, 1954-

II. Turner, Catherine Joan.

III. Izaak Walton Killam Children's Hospital. Oncology Unit.

IV. Title.

RC281.C4M33 1992 618.92'994 C92-098597-1