

A Child in Pain

What Health Professionals Can Do to Help

Leora Kuttner, PhD

Foreword by Lonnie Zeltzer, MD

Afterword by Neil L. Schechter, MD

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List of Contributors

Stefan J. Friedrichsdorf, MD

Medical Director, Pain Medicine & Palliative Care, Children's
Hospitals and Clinics of Minnesota, Minneapolis, MN, USA

Helen W. Karl MD

Associate Professor of Anesthesiology
University of Washington, School of Medicine
Former Director of Pain Medicine
Seattle Children's Hospital, WA, USA

Jonathan Kuttner, MBBCh, Dip. Sports Med. FACMM

Musculoskeletal & Pain Specialist
Auckland, New Zealand

Carl L. von Baeyer, PhD

Professor Emeritus of Psychology &
Associate Member in Pediatrics
University of Saskatchewan, Saskatoon, Canada

Preface

A Child in Pain: What Health Professionals Can Do to Help is designed to help pediatric health professionals of all disciplines gain understanding and skill in how to approach and treat children's pain, and how to help children make sense of and deal with their own pain. Pain is the most common reason for children to seek a medical consultation—and sometimes a common reason for avoiding it. Unaddressed fears and anxiety complicate pain management and recovery. A central theme in this book is the examination of children's fears and anxieties that accompany their need for pain relief, and the communication skills and words that will allay these fears.

Pain is now recognized as a major health problem in its own right. Pain, however, has a history of being one of the least understood and one of the most neglected domains of health care, particularly for children. In this book I have placed a strong emphasis on children's experience of pain and pain treatment, and on their self-expression of their concerns. Wherever possible, children are quoted in the book so that we gain a more nuanced appreciation of their needs. The quotes are from children in my practice or in my documentaries. If the former, their names and identifying factors have been changed to protect their identity. Throughout the book the term *children* includes teenagers, and covers ages three to nineteen. As well, in pediatric medicine today, parents have gained their rightful place as an integral part of their child's care (the term *parent* includes *carer*). This book also demonstrates how health professionals can guide parents to help their child through acute pain, procedures, or chronic pain.

As a clinical psychologist with more than 30 years experience in pediatric pain management, I want to sharpen the focus on behavioral, emotional, and relational aspects of pain management, while simultaneously working with the essential and traditional contributions of physical and pharmacological treatments in our health care system. Affectionately termed the "3Ps," the integration of all three aspects of treatment forms a fundamental principle in this

book. The integration of psychological, physical, and pharmacological methods goes hand in hand with our prevailing biopsychosocial model of care. Today a child's pain (particularly the more complex and chronic pains of childhood) cannot be properly appreciated or treated without applying a biopsychosocial model that incorporates all aspects of the child's world. Dealing with only one aspect of pain and neglecting the other contributing stressors would now be regarded as providing sub-standard care. Explaining why pain may be occurring, how the brain is "the mastermind" of the pain system, what the child can do to manage or resolve the pain, and how medication and the child's efforts can provide comfort, is now part of state of the art care. With this as a central tenet, I provide examples of, and discussion on, how to navigate this biopsychosocial spectrum of care with greater facility. As fourteen-year-old Jeremy says in the book, "A mind is a terrible thing to waste!"

Today, in the first part of the 21st century, there is still a great deal that we need to do to address and relieve children's pain and suffering. To meet this I've drawn from evidence-based literature to provide direction. Our challenge is to bridge the gap between knowing and doing. This book is another in a series of efforts that our international pediatric community has made to close the gap between what we know and what we do.

Our knowledge in pain medicine has mushroomed over the last three decades. On many fronts remarkable progress has been achieved in understanding and developing capacities to assess, treat and relieve children's pain and suffering. This includes basic science research on nerve and brain functioning, technological advances in imaging, and new delivery systems for medications. We have developed new analgesics and anesthetics, and there has been a burgeoning of research into determining the efficacy of psychological, physical, and pharmacological approaches to treating pain. Studies and meta-reviews have examined efficacy with recommendations on how best to apply treatments to relieve different types of pain. Pain services in children's hospital are proliferating, and there is growing collaboration between the many disciplines within the hospitals to develop standards of care and protocols to manage acute, procedural, and chronic pain. Pain

management has become a collective pursuit across disciplines—and this is welcomed.

A Child in Pain: What Health Professionals Can Do to Help is addressed to all disciplines, in its valuing of the professional-patient relationship and in the language used to allay anxiety, address fears and promote relief and well-being. The book is organized into three parts: Part I explores our scientific understanding of pain as a part of children's development. It addresses the physiological processing of pain, how to assess it, and how to explain it to children who are fearful, anxious, and in pain. Part II explores pain treatments themselves, their efficacies and how to combine them for therapeutic impact. Part III uses this understanding to help translate knowledge into clinical practice in three domains of pediatric medicine: the physicians' practice, the dental practice, and in the hospital. Within the extensive References at the back of the book, key resources are identified with an asterisk.

I have found it a rewarding and extraordinary privilege to belong to a vigorous, dynamic, resourceful, and generous international pediatric pain community. We've shared, learned from each other, collaborated, and inspired each other. We have worked together, critiqued each other's endeavors, and matured as practitioners and researchers. My hope is that this book supports and benefits those of you entering and participating in this deeply meaningful and worthwhile field.

Chapter 1

Pain in Children's Lives

"Pain is when it hurts."

5-year-old boy

As children and teens grow and explore the world, they experience many falls, illnesses, and hurts of one kind or another. They turn to their parents to find relief from pain. Too often parents feel anxiety and fear, not knowing what to do in the face of their children's pain, and turn to pediatric professionals for the expertise and guidance to provide their child with sufficient relief. Pediatric health professionals at all levels of care need to know how to provide this necessary help.

Fortunately today many breakthroughs in scientific research have increased our understanding and treatment of childhood pain. The goal of this book is to make this information easily accessible to those working directly with children. With a knowledge of the most effective therapies and treatment combinations in conventional and complementary medicine, professionals can help children and their parents to better manage minor and major pain from injuries and illness. Instead of minimizing, misunderstanding, or dismissing a child's pain, a skilled professional can provide prompt pain relief and empower the child to cope. This requires a combination of helping the child to understand and interpret the pain sensations and to develop coping skills, as well as being aware of the treatment options to ease the pain.

Pain is part of growing up. Young children frequently fall and scrape themselves as they learn to walk, run, climb, and ride a bicycle. This is a time of developing co-ordination and skill and, as a consequence, learning about pain and suffering. Research has shown that preschool children during play, experience an average

of one 'owie' or 'boo-boo' every three hours (Fearon, McGrath, & Achat, 1996). Children encounter accidents at home, in parks, in cars, and on the playground at school. They may experience pain when they get a tooth filled at the dentist's office or when they have an injection at the doctor's office. Some children and adolescents struggle for years with painful diseases and hospital treatments.

This chapter discusses the role that pain plays in the human body, the relationship between pain and the brain, and types of pain. A few widely held attitudes or misconceptions about pain have prevented parents and health care providers from dealing promptly and appropriately with children's pain. At the end of this chapter I review and debunk misconceptions about pain.

The Protective Value of Pain

Pain is protective. It provides vital information to guide us in the use of our body, informs us about its condition, and helps us survive and remain intact. As health care professionals, part of our responsibility towards children is teaching them to respect pain signals and to learn how to interpret and cope with them. We know from interview studies on children's concepts of pain that they seldom mention any beneficial aspects of pain, such as pain's diagnostic value, its warning function, or its role in determining whether treatment is effective (Abu-Saad, 1984*a,b,c*; Ross & Ross, 1984*a,b*; Savedra, Gibbons, Tesler, Ward, & Wegner 1982). Children need to know that pain is their personal safety-alarm system, interpreted by the brain in a highly rapid and sophisticated way. Pain messages quickly tell us if there is something wrong with our organs, muscles, bones, ligaments, and tissues, all of which are interwoven with nerve fibers and pain mediators that rapidly carry pain messages to, from, and within our brain. Children need to be informed that part of the sophistication of pain is that memory, emotions, previous learning, beliefs, stress, endocrine and immunological processes, as well as the current meaning of pain, all factor into how the pain message is experienced.

In its healthiest form, short-term acute pain is protective, alerting and preventing damage to one's body. As David, aged four and a half, discovered: "You've got to listen to your stomach when it's hurting, 'cause if you don't, your stomach will get upset!" David knew this firsthand; for five days he had had stomach pains and gastric spasms and had been throwing up. The pain signals had taught him that if he continued eating the tuna sandwich his well-intentioned mother had given him, his stomach might send it back again. Recovering from a gastrointestinal virus, David had come to respect the signals he was receiving from his stomach: to eat only what his stomach could handle and when to stop. Because his actions helped settle his pain and nausea, and because he was being listened to – although he was only four and a half – he learned to manage his own recovery, and set the stage for dealing effectively with the experience of pain in the future.

Children learn about their bodies when we encourage and teach them to pay attention to their body's messages and sensations. They learn to interpret the different pain signals and determine what gives the best form of relief. This learning is refined over a lifetime. Even very young children can be taught to share their pain sensations so that we can determine what is going on, their severity, and what will be most effective in helping the pain to go and stay away.

The value of pain is poignantly evident when we encounter children born with one of the rare conditions of insensitivity or indifference to pain (Nagasako, Oaklander, & Dworkin, 2003). Throughout their lives, these children are at great risk of damaging their bodies, particularly their eyes, hands, fingers, joints, and feet. Pain is disabled by their genetic condition and does not protect them. It does not alert them to stop an action that will cause injury, or prompt them to call for help when they experience the early pain signals of a medical crisis such as appendicitis. These children continue to walk on sprained ankles and damage the tips of their fingers and their legs; frequently they require artificial protection such as braces and guards. By school age, these children have already sustained significant and often irreparable damage to their limbs.

Tools for a Child's Own Report of Pain

Many tools can be used with children of different ages to obtain their self-report of pain (Stinson, Yamada, Kavanagh, Gill, & Stevens, 2006). Six tools are suggested here: Pieces of Hurt Tool, a Body Map to draw in the location of pain, a Faces Scale, a Verbal Numerical Rating Scale, a Ladder Scale to measure pain severity, and a Pain Diary.

Pieces of Hurt

The Pieces of Hurt tool is ideal for young children and easy to use. It consists of four red poker chips that are shown to the child, representing “just a little hurt” (one chip); “a little more hurt” (two chips); “more hurt” (three chips); “the most hurt you could ever have” (four chips). There is no zero. Ask the child, “How many pieces of hurt do you have right now?” Clarify the child’s answer by words such as, “Oh, you have a little hurt? Tell me about the hurt.” Record the number of chips selected. Reportedly, children without pain will say they don’t have any. There is data supporting the use of this tool with preschool age children for acute procedural and hospital-based pain (Stinson et al., 2006). Note that after use with one child, the chips require cleaning.

Body Map

Children aged five and older can use the body map tool. It is not a quantitative measure, but it assists health care professionals to see accurately where a child feels pain. Presented with a body outline, such as the one shown in Figure 4.2, the child is asked to shade or color in the places that hurt. Older children can be asked to use a different color for each different kind or severity of pain, such as mild, moderate and severe pain, but the coloring should not take more than a couple of minutes. Repeating the process over time will show changes. Using the body map, children often identify areas of pain that are not detected by other methods.

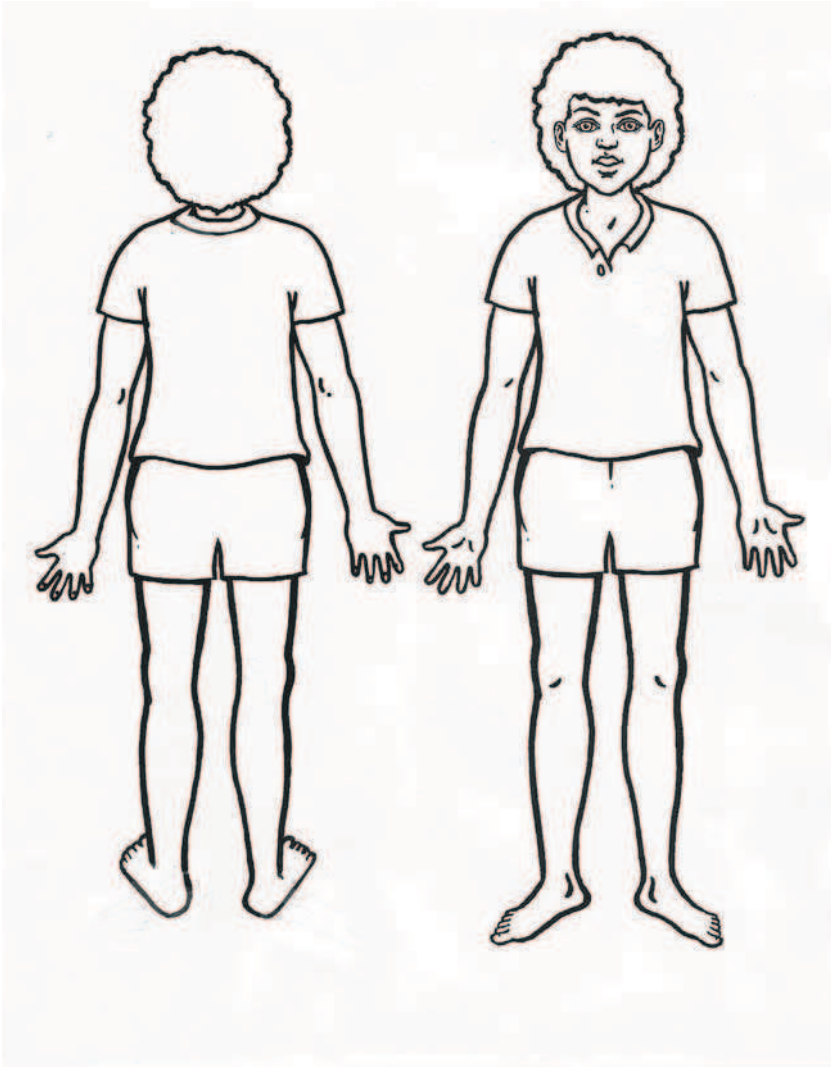


Figure 4.2. Body Map

Ask the child to shade or color in the places that hurt on both front and back body maps. Children can use a different color for each different kind or severity of pain, such as mild, moderate and severe pain. This measure can be repeated at subsequent assessments.

[The Body Map may be modified and reproduced freely.]

Faces Pain Scale – Revised

Some three-year-olds, many four-year-olds, and most children five years and older can use the Faces Pain Scale – Revised to indicate how severe their pain is (Hicks et al., 2001). In the following instructions, say ‘hurt’ or ‘pain’, whichever seems right for a particular child. The health care provider or parent shows the pictures in Figure 4.3 to the child and says, “These faces show how much something can hurt. This face (point to left-most face) shows no pain. The faces show more and more pain (point to each from left to right) up to this one (point to right-most face) – it shows very much pain. Point to the face that shows how much you hurt [right now].”

The numbers are not shown to the child. Write down the number for the chosen face, so ‘0’ = ‘no pain’ and ‘10’ = ‘very much pain.’ Do not use words like ‘happy’ and ‘sad’. This scale is intended to measure how children feel inside, not how their face looks.

Verbal Numerical Rating Scale

The verbal numerical rating scale (NRS) has the great advantage of needing no paper, pencil, nor other equipment. The child can be asked for a rating, and can respond by saying a number or just holding up fingers to show the number. This scale is considered suitable for most children aged eight years and up (von Baeyer, Spagrud, McCormick, Choo, Neville, & Connelly, 2009). The parent or health care professional can say, “I’d like you to tell me a number to show how much pain you’re in right now. We’ll use numbers from 0 to 10. Zero would mean that you have no pain or hurt, and 10 would mean that you have the worst or most pain.” Write down the number the child selects, and repeat the question at regular intervals to track the pain over time.

Note that this method requires not only the ability to count, but also some ability to estimate quantities using numbers, and sometimes may need previous experience in using a pain ladder scale (see Visual Analogue Scales Figure 4.4) to become familiar with the requirements.

Blowing Away the Pain, or the 'Red Cloud Technique'

Age: Ten months and older.

Pain: Acute, brief pain from scrapes, falls, or injections; anticipatory anxiety and pain associated with medical treatments.

Time: 2 to 10 minutes or for the duration of the pain.

Tell the child to 'blow out the pain', or alternatively, pretend that the pain is a big red cloud and blow it out! Demonstrate this by blowing out in a steady, slow, long breath, adding that pain leaves the body this way. Encourage the child to blow out with you over several deep breaths with a good pause after three or five breathes to ensure the child does not hyperventilate.

"Breathe out as if you're blowing candles out and empty your lungs. Now you'll find yourself breathing in... and let's blow the red cloud out! This gives your body the immediately instruction to let go the pain on each out breath. It feels good, and you start feeling better. Continue with this breathing until you start feeling the tension leave your body. Good!"

Provide the child with information on how breathing this way benefits the body:

"When you breathe more deeply and regularly, your muscles stretch and this expands your ribs. Your spine lengthens, easing tension and stretching and helping the pain to release and tightness to go. Let's do it. Close your eyes and after five cycles of breath when you feel some change you can tell me about it."

This simple method can be used for many types of pain and can even be taught to pre-verbal young toddlers as young as ten to twelve months. Most one-year-olds adore blowing out candles! Toddlers and younger children depend heavily on their parents' involvement to engage and sustain any breathing technique. For this reason, have the parents join in so that they mirror and support their children's efforts. Children aged six and older can easily learn to regulate their breathing. Children with recurrent pain

report that blowing away the pain when it recurs helps to contain their anxiety as well as settle their pain. “It helped to cool the pain,” said a nine-year-old. Breathing methods can be used during procedures when a child has to remain still for two to ten minutes (Power, Lioffi, & Franck, 2007), such as, for an injection, intravenous access, laceration repair, or a cast setting. Children can use breathing to stay calm during X-ray, CT, a bone scan, and other assessments, or during more prolonged aching pain. When analgesics are given prior to the procedure, blowing away worries and fears will help settle the child until they take effect. Breathing techniques give the child a constructive job to do while the procedure takes place – being still is not a natural state for most awake children!

Nine-year-old Seanna had mastered blowing out as her preferred way of ridding herself of scary feelings and distress during spinal taps, part of her treatment for leukemia. After she was discharged from hospital, she feared that she might forget how to do her blowing, her mainstay. So she practiced daily, in case she had to return into hospital. She was determined to ensure that she could cope. “All I need to do is to return to my blowing, and I know I’ll get through!”

Blowing Bubbles

Age: One year and older.

Pain: Acute, brief pain, as from a scrape, fall, injections, or IV starts.

Time: Before and for the duration of the pain.

This is an all-time favorite simple pain and anxiety reducer. It’s versatile, entertaining, a great tension breaker and the child feels back in charge – you can’t lose! Bubbles, party blowers, or pinwheels are all eligible, as they can be used to sustain and regulate the child’s breathing to reduce pain and anxiety, while adding an element of fun. Children love to blow colorful bubbles of different sizes and watch them travel across the room. In an otherwise

anxious or uncertain situation, children will respond to an inviting challenge: “See how far you can blow this bubble!” “I wonder how many twin bubbles you will blow this time while I look at your veins,” or “Can you catch a bubble and blow even more bubbles from it while I wash your skin clean? I wonder how many more it’ll make?” Throughout this purposeful activity, instead of being gripped by fear and pain, the child has a job to do – breathe and produce bubbles – and so gains a sense of success and competence.

Children are individuals. Some children become totally absorbed in this task, find relief with bubble blowing, and want to continue blowing long after the acute pain has ceased. Others may refuse to blow, may reject the bubble wand, or choose to blow out without bubbles. It is the child’s pain, and the child should decide what works and how to participate in the process. Do not feel defeated and throw the method out just because it hasn’t worked on the first occasion – remain flexible. At the next procedure the child may surprise everyone by spontaneously blowing or requesting the bubbles – I’ve seen this happen on more than one occasion. Give children the opportunity to learn and to choose the method they want. (When bubbles aren’t handy, an inventive colleague shows the child how to blow gently on a pretend candle, first on his finger and then on the child’s finger to make the flame flicker but not go out!)

Relaxation

There is considerable evidence for the benefit of relaxation for children’s pain management for abdominal pain (Brent, Lobato, & LeLeiko, 2009) and for painful procedures (Power, Liozzi, & Franck 2007; Uman et al., 2008). Children who experience pain enjoy relaxation. Twelve-year-old Kevin trained himself to relax ‘by becoming a wet noodle!’ for his recurrent medical procedures. Once begun, the relaxation process will lead the child into a gradually deepening state of rest characterized by increased feelings of warmth and comfort. Many physiological changes naturally occur when one is relaxing. Pain, such as gastrointestinal pain, may lessen and achy muscles may soften as the relaxation progresses.

This comprehensive book is designed to help health professionals of all disciplines who work with children gain understanding and skill in how to approach and treat children's pain, and help children understand and cope with their own pain. Pain is the most common reason for children to seek a medical consultation – and sometimes the most common reason for avoiding it. This book examines children's fears and anxieties that accompany their need for pain relief, and gives health professionals communication skills and words to calm these fears. Without doubt, this volume will become a standard on pediatric pain management for many years to come.

"Like a breath of fresh air, Dr. Kuttner brings clarity, authority, and evidence to this crucially important area of pediatrics. She allows the patient's voice to be heard, grounds her advice in what is known about best practice, but remains sensitive to the needs of the health professionals, who are only trying to help. Bravo!"

Christopher Eccleston, PhD, Director, Centre for Pain Research, The University of Bath, UK

"Dr. Kuttner has provided simple, clear guidance for health professionals of every discipline, with just the right balance of research made real by countless patient stories that bring it to life. It will be required reading for students and residents rotating through our clinic. There is no other book that fills this niche – easy to read, yet packed with practical advice and strategies that every pediatric clinician can use every day."

G. Allen Finley, MD, FRCPC FAAP, Professor of Anesthesia and Psychology, Dalhousie University, Medical Director, Pediatric Pain, IWK Health Centre, Halifax, Canada

"This is a unique and marvelous book. By reading this book, we can better understand the complexity of pain, and can find numerous ways to improve the pain of a child. This book is a must read for all professionals who work with children, and should be translated into many languages in order to help the children in whatever country they live."

Chantal Wood, MD, Paediatrician and Pain Care Specialist, Unité d'Évaluation et de Traitement de la Douleur, University Hospital Robert Debré, Paris, France

"I had to review this book while experiencing intense stomachaches and trying to figure out with what end I should address the toilet. Let me tell you something, this book really helped me understand what children go through! Buy it!"

Laurence I. Sugarman, MD, Clinical Associate Professor in Pediatrics, University of Rochester School of Medicine and Dentistry, President, American Board of Medical Hypnosis



Leora Kuttner, PhD is a pediatric clinical psychologist who specializes in children's pain management. She is a Clinical Professor in the Pediatric Department of the University of British Columbia and BC Children's Hospital, Vancouver, Canada. Dr. Kuttner has authored, *A Child in Pain, How to Help, What to Do*, a book for parents, and has also co-produced and directed award winning film documentaries on pediatric pain management, *No Fears, No Tears, No Fears, No Tears – 13 Years Later*, and *When Every Moment Counts*.

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