

**My Child Has Cancer:
A Parent's Guide to
Diagnosis, Treatment, and
Survival**

Della L. Howell, M.D.

PRAEGER

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The Praeger Series on Healing and Managing Injury and Disease
Julie K. Silver, M.D., Series Editor

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**Westport, Connecticut
London**

Library of Congress Cataloging-in-Publication Data

Howell, Della L., 1973–

My child has cancer : a parent's guide to diagnosis, treatment, and survival /
Della L. Howell.

p. cm. — (Praeger series on healing and managing injury and disease,
ISSN 1940–5804)

Includes bibliographical references and index.

ISBN 978–0–275–99601–7 (alk. paper)

1. Cancer in children—Popular works. I. Title.

RC281.C4H69 2008

618.92'994—dc22 2007048298

British Library Cataloguing in Publication Data is available.

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reproduced, by any process or technique, without the
express written consent of the publisher.

Library of Congress Catalog Card Number: 2007048298

ISBN: 978–0–275–99601–7

ISSN: 1940–5804

First published in 2008

Praeger Publishers, 88 Post Road West, Westport, CT 06881

An imprint of Greenwood Publishing Group, Inc.

www.praeger.com

Printed in the United States of America



The paper used in this book complies with the
Permanent Paper Standard issued by the National
Information Standards Organization (Z39.48–1984).

10 9 8 7 6 5 4 3 2 1

For Clay, Will, Emily Grace, and Rachel

CONTENTS

Series Foreword	ix
Introduction	xi
Abbreviations	xv
Chapter 1: Cancer and Children	1
Chapter 2: Types of Cancer, Part I—Leukemia	5
Chapter 3: Types of Cancer, Part II—Lymphoma	19
Chapter 4: Types of Cancer, Part III—Brain Tumors, Neuroblastoma, and Kidney Tumors	27
Chapter 5: Types of Cancer, Part IV—Bone Tumors and Muscle Tumors	39
Chapter 6: Types of Cancer, Part V—Rare Pediatric Cancer Diagnoses	49
Chapter 7: Telling the Child	61
Chapter 8: Procedures at Diagnosis, in Therapy, and After Therapy	69
Chapter 9: Chemotherapy and Taking Medicines	85
Chapter 10: Radiation Therapy	101
Chapter 11: Stem Cell and Bone Marrow Transplants	109
Chapter 12: Common Side Effects	117
Chapter 13: Complementary and Alternative Medicine in Cancer	131

Chapter 14: Choosing Among Potential Treatments	139
Chapter 15: Understanding the Medical System	145
Chapter 16: Understanding Clinical Trials	155
Chapter 17: Asking Questions, Finding Answers	163
Chapter 18: Helping Family Members and Friends	169
Chapter 19: When Cancer Treatments Stop Working	173
Conclusion	179
Appendix: Resources for Children, Adolescents, and Parents Dealing with Pediatric Cancer	181
Notes	189
Index	191

SERIES FOREWORD

Pediatric hematologist/oncologist Della Howell writes in the opening pages of this book about one of her favorite words—*children*—and one of her most dreaded—*cancer*. Combining these two words is the subject matter for her professional life and the content of this wonderful guide for families.

Ideally, one would never use *children* and *cancer* in the same sentence, but in fact the incidence of pediatric cancer is increasing (though survival rates are too, fortunately). Serious illness is not just reserved for adults—kids can get cancer, and when they do, their families face the overwhelming task of getting the information they need to successfully navigate the health care system, seek out appropriate treatment, and help their child physically and emotionally recover as well as possible.

Where to begin? Dr. Howell has written just the guide in *My Child Has Cancer: A Parent's Guide to Diagnosis, Treatment, and Survival*.

In a thoughtful, thorough, and highly readable book, Dr. Howell guides readers through the diagnosis and treatment phases and offers strategies to help them cope. Between the lines, readers will find a sincere and empathic woman who is an expert in both the science of pediatric oncology and the support that families need to face this difficult journey.

Dr. Howell is a mother, wife, physician, and accomplished pianist. She has much to offer the families of children diagnosed with cancer in this important book. The future for pediatric oncology looks brighter and brighter,

but the journey is still long and very difficult. In this guide, Dr. Howell helps to pave the way.

Julie K. Silver, M.D.
Series Editor

INTRODUCTION



A four-year-old girl sits on a hospital gurney in the emergency room. She seems scared and a little overwhelmed by all of the lights and noises of the hospital. Her dark brown eyes have a sense of sadness as she sits there, very still and quiet. She stares at the floor, rarely looking at my face. The girl's mother is there with her, standing beside the gurney, stroking her daughter's curly brown hair, keeping strands away from her face.

As I close the curtain, the mother's attention turns towards me with a look of mild concern. I start to ask questions: How long has the girl been sick? Why did she come to the emergency room? Has she been healthy in the past? What are her symptoms? The mother tells me that Sara is there because she was having knee pain and fevers. She has never been sick before. The emergency room doctors told the mother that there was a problem with Sara's blood tests. Unfortunately, I already know that there is a problem—that's why I am seeing Sara.

I am a pediatric oncologist, so I specialize in taking care of children and adolescents with cancer. I received a phone call only minutes before, telling me that a young girl's lab tests showed leukemia. I already know some of the child's symptoms and health background, but I need to talk to Sara's mother before breaking the life-shattering news that her daughter has cancer.

We start talking about the blood test and the specific things that the other doctors noted. Then I tell her that I am very concerned that her beautiful young daughter has leukemia. She starts sobbing uncontrollably. I have no idea what

to do—should I keep talking? Should I get someone else for the mother? Should I just leave? It is so hard to know that you are responsible for giving such horrendous, unbelievable news to a family that, up until now, has been “normal.”

After she has a chance to compose herself and spend time with Sara, I try to prepare them for what will happen next. More blood tests. Hospital stays. Procedures. Medications. I’m not sure that she has heard a word that I’ve said, but I had to start somewhere. I try to talk to her in a manner that I would want to be addressed. I always try to put myself in the minds of the people that I’m speaking to, staying empathetic, considerate, never rushing. They deserve to have the undivided attention and compassion of the person who can help make the cancer go away. As far as I am concerned at this moment, Sara is the only patient in the world. Sara and her mother deserve nothing less than my best.

Children. This is one of my favorite words. I think of children and I can’t help but smile. Their innocence, their carefree nature, the way that they say whatever comes to their minds—these are all wonderful things in a world that, at times, seems filled with trouble.

Cancer. This is one of the most dreaded words I know. It strikes fear in most peoples’ hearts. Yet, almost everyone has been affected at some time in life by cancer, whether through a parent, a friend, or their own personal experiences.

In an ideal world, the words *children* and *cancer* would never share a sentence. Unfortunately, children can and do get cancer, and when this happens, a family’s world is shattered. How could someone so innocent get such a devastating disease? When a child is given this diagnosis, the family bears the burden for the rest of their lives. It affects not only the child’s physical health, but the emotional health of the child, parents, siblings, extended family members, friends, classmates, and teachers. It places a strain on relationships both within the family and outside the family.

The family of a child with cancer very quickly forms a relationship with the medical community—doctors, nurses, hospitals, clinics, and pharmacies. This relationship should be a strong one, one that can be a source of support for the family and the child during one of the most difficult times in their lives. I truly love being a part of that community, working closely with these children and their families, helping them through some unbelievably difficult moments.

People often ask how I can do this job—how I can treat and take care of children with cancer. “It must be so depressing.” “I couldn’t bear to see all

those sick children.” “How are you able to sleep at night?” I always tell them that I am privileged to take care of some of the best patients and families possible, and I couldn’t imagine working anywhere else. These patients are *my* patients. The children, their families, and the hospital staff work together to get the children through one of the worst times in their lives. In many instances, I don’t just feel like their physician; I feel like a member of their family. We all have the same goal—a cure.

In 1998, in the United States there were 12,400 children and adolescents younger than 20 years of age diagnosed with cancer. Almost 2,500 children and adolescents died of cancer during this same year. The incidence of pediatric cancer has increased significantly since the mid-1970s. However, thanks to wonderful advances in modern medicine, the survival rates have also improved during this time. Despite the improvement in survival as a whole, cancer is still the most common cause of disease-related mortality in these age groups, so even more work is needed to come up with the ideal cure for all types of cancer.

But until that cure is discovered, families hunger for information when a loved one is diagnosed with cancer. It is a frightening disease that can be devastating. I know this not just as a doctor, but as a cancer patient. I was diagnosed with metastatic carcinoid cancer of the small intestine in late 2006, just a month before the youngest daughter of my three children turned one. Hearing that I had a type of cancer with no truly effective treatment was very difficult to handle, but I actually received strength when I thought of my patients and their struggles. These children face tremendous obstacles in their fight against cancer. If they could take on the war, so could I.

While there are many resources available, the information can be fragmented, complicated, or not detailed enough for family members. In this book, I attempt to provide accurate, in-depth information for parents and other family members of children or teenagers with cancer. The book is also meant as a resource for those who just want to learn more about the journey that begins when a child or young adult is found to have cancer. In the book, I cover areas such as the differences between cancer in children and cancer in adults; treatment of cancer, including chemotherapy, bone marrow transplant, and “alternative” therapies; and coping with some of the future struggles met by children who have completed therapy for cancer.

I am honored to work in this field of medicine. I have been given the opportunity to work with some of the most compassionate healthcare workers, strongest families, and sweetest children in the world. While we don’t

always win our battles with cancer, I leave work every day believing that I have been able to make a real difference in the life of a child and in the lives of their family members.

It is my hope that this book will bring you information and understanding. And with this understanding, each reader will find strength.

ABBREVIATIONS

6-MP	mercaptopurine
6-TG	thioguanine
AFP	alpha-fetoprotein
ALCL	anaplastic large cell lymphoma
ALL	acute lymphoblastic leukemia
AML	acute myelogenous leukemia
ANC	absolute neutrophil count
ARA-C	cytarabine
B-HCG	beta-human chorionic gonadotropin
BMT	bone marrow transplant
CAHCIM	Consortium of Academic Health Centers for Integrative Medicine
CAM	complementary and alternative medicine
CBC	complete blood count
CML	chronic myelogenous leukemia
CNS	central nervous system
COG	Children's Oncology Group
CSF	cerebrospinal fluid
CT	computed tomography
DMSO	dimethyl sulfoxide
DNA	deoxyribonucleic acid
DO	doctor of osteopathy
EBV	Epstein Barr Virus
ECG/EKG	electrocardiogram
ER	Emergency Room
ESR	erythrocyte sedimentation rate
FAB	French-American-British

FDA	Food and Drug Administration
FNA	fine needle aspiration
GBM	glioblastoma multiforme
GVHD	graft versus host disease
HCC	hepatocellular carcinoma
HIV	Human Immunodeficiency Virus
HLA	human leukocyte antigen
HVA	homovanillic acid
IM	integrative medicine
IRB	Institutional Review Board
IV	intravenous
JPA	juvenile pilocytic astrocytoma
LDH	lactate dehydrogenase
LVN	licensed vocational nurse
MD	medical doctor
MDS	myelodysplastic syndrome
MIBG	metaiodobenzylguanidine
MRI	magnetic resonance imaging
NCCAM	National Center for Complementary and Alternative Medicine
NCI	National Cancer Institute
NHL	non-Hodgkin lymphoma
NIH	National Institutes of Health
NRSTS	non-rhabdomyosarcoma soft tissue sarcoma
PACU	post-anesthesia care unit
PET	positron emission tomography
PFT	pulmonary function test
PICC	peripherally inserted central catheter
PICU	Pediatric intensive care unit
PNET	primitive neuroectodermal tumor
RN	registered nurse
SCT	stem cell transplant
TBI	total body irradiation
TPN	total parenteral nutrition
VMA	vanillylmandelic acid
VOD	veno-occlusive disease
WBC	white blood cell
WHO	World Health Organization

Chapter 1

CANCER AND CHILDREN

WHAT IS CANCER?

Simply put, cancer is an abnormal growth of cells. Cells are the building blocks for our body; there are many different kinds of cells within our bodies, and the type of cancer depends on the type of cell from which it started. For example, leukemia (cancer of the blood) usually comes from white blood cells, while sarcomas (a type of solid tumor) originate from muscle cells. The name of each type of cancer gives you a clue about where the cancer is located and which type of cell is responsible for its growth.

Cancer cells develop because of a change in a normal cell's DNA (deoxyribonucleic acid). DNA is essentially a genetic code for an individual. It helps determine the individual characteristics for each person. The normal cells in a person's body divide rapidly and duplicate the DNA in a very intricate process. Billions of cells are dividing in our bodies on a daily basis, and errors will occur. Fortunately, the body has a built-in repair mechanism to fix these errors, so usually these mistakes don't cause problems in the body. The problems occur when the errors go unnoticed. An "abnormal" cancer cell gets through the natural checks and balances of the body and is allowed to divide and duplicate its own abnormal DNA, eventually leading to the disease of cancer. Cancer cells grow and divide more quickly than our body's normal cells, so the cancerous growth overtakes the normal growth, leading to symptoms.

Why Does Cancer Happen?

What allows the error to happen? What truly causes cancer? There are several theories on the subject, but sadly, no one has all the answers. Scientists are fairly confident with the generalization that DNA is the source of the problem, but there are many potential reasons for abnormal DNA. Some believe that viruses are to blame for most cancers, but it's hard to accept that this is the whole answer. If a particular virus is the sole reason for a certain type of cancer developing, then why don't more of those in close contact with those who have cancer also develop cancer? Usually, when a virus hits a family with cold symptoms or gastrointestinal upset, many people who share close quarters become sick with the same type of infection. This is not the case with cancer.

Genetics in Cancer

Others think that the genes we inherit are to blame, and in some cases, we know that this is true. People who have many relatives in their family with particular types of cancers, such as brain cancer, bone cancer, or breast cancer, are oftentimes more likely to get cancer themselves. However, this does not explain all incidences of cancer, because there are many people who develop cancer who have no family members with cancer. Our bodies have some genes that are considered "tumor suppressor" genes, and we may have others that are called "proto-oncogenes." Tumor suppressor genes do what their name says—they suppress the growth of tumors, or cancer. If these genes become defective, they can't do their job, and a person is more likely to develop cancer. Proto-oncogenes are genes that in basic terms actually lead to the formation of cancer ("proto" can be combined with other words to mean that word's ancestor; and "onco" is a word for cancer—think "oncologist"). If a person has inherited one of these proto-oncogenes from a parent, then he has inherited a "genetic ancestor for cancer." This leads to the belief that these people are therefore more likely to develop cancer than those who have a more normal genetic background.

Cancer and the Environment

Another theory is that environmental exposures lead to the development of cancer. Smoking and radiation are two examples of environmental exposures that are associated with increased risks of cancer. However, of two separate individuals who have the same amount of cigarette exposure or radiation exposure, one might get cancer, while the other might not. What makes one

person more likely to get cancer than the other? Unfortunately, there is no answer to this question, yet.

Cancer Comes from a Combination of Factors

A more likely explanation is a multifactorial one, as was first presented by Dr. Alfred G. Knudson in the Knudson hypothesis—multiple “hits” on the body are required for a specific individual to get cancer. Perhaps a virus provides one “hit” on a person’s body, making a subtle change in that person’s DNA. Then, an environmental exposure such as smoking gives the second “hit,” leading to another small change in that same person’s DNA. And if that same person has bad genes (a brother with a brain tumor, an uncle with bone cancer, a mother with breast cancer), this is the final “hit” required to make this person develop cancer.

Adults Versus Children with Cancer

When most people think of cancer, they may think of an older relative or friend who had breast cancer, lung cancer, colon cancer, or prostate cancer, which are four of the most common types of cancer in adults (Table 1.1). Adults are often not completely healthy when they get cancer; they may have

Table 1.1 Estimated Yearly Incidence of Cancer in Adults and Pediatric (<20 years of age) Patients

Adults ¹		Children/Adolescents ²	
Type of cancer	Incidence	Type of cancer	Incidence
Skin (non-melanoma)	>1,000,000	Leukemia	3,250
Prostate	234,460	Brain tumors	2,200
Breast	214,640	Lymphoma	1,700
Lung	174,470	Neuroblastoma	650
Colon and Rectal	148,610	Wilms’ tumor	500
Melanoma	62,190	Osteosarcoma	400
Bladder	61,420	Rhabdomyosarcoma	350
Non-Hodgkins Lymphoma	58,870	Thyroid carcinoma	350
Endometrial	41,200	Melanoma	300
Leukemia (All)	35,070	Retinoblastoma	300

Sources: 1) American Cancer Society: Cancer Facts and Figures 2006. Atlanta, GA: American Cancer Society, 2006. 2) Cancer Incidence and Survival among Children and Adolescents: United States SEER Program 1975–1995.

heart disease, diabetes, or other chronic medical problems that predispose them to having infectious complications, fatigue, or chronic pain. Adults are often unable to tolerate intense cancer treatment regimens because of poor baseline health.

Pediatric cancer is quite different from adult cancer. The most common types of cancer in children are leukemia, brain tumors, neuroblastoma, and Wilms' tumor (more details about these diseases will be covered in the next chapter). Children are usually in good health prior to presenting with cancer symptoms and only rarely have to deal with chronic medical problems during their cancer treatment. They can tolerate intense treatment regimens much better than their adult counterparts.

Another important difference between adult cancer and pediatric cancer is the concept of "survival." Somewhere between 70–80 percent of all pediatric cancer patients will become long-term survivors, with definite variability according to the type of cancer. Unfortunately, adults usually don't fare as well. However, when looking at terms like "five-year survival" from cancer, which is a major landmark for most adults dealing with cancer, this statistic is not as exciting for children.

Imagine a 70-year-old man who develops lung cancer and a 3-year-old girl who develops leukemia. Five years for the man with lung cancer gets him to a more acceptable length of life; five years for the young girl doesn't even get her to fourth grade. The focus on truly lengthening the life of children who are afflicted with cancer guides a lot of the therapies for pediatric cancer. Physicians are more aggressive in treatment and want to actually cure the patient of the disease so they can have a long and fruitful life. For adults, sometimes the best treatment is something that doesn't cause a lot of side effects but merely gives a good quality of life with a shorter extension of time.

Chapter 2

TYPES OF CANCER, PART I—LEUKEMIA

In these sections, the focus is on the individual types of cancer that commonly affect children. Details on the specific therapies used to fight cancer will be discussed in detail in a later chapter.

LEUKEMIA

My son James was always such a healthy boy—never sick, never absent from school. He had never seen a doctor except for routine “physical” visits. When he started running fevers, I thought that he just had a virus like most children. A couple of days later, he was still having fevers and seemed so tired. He didn’t want to play. He didn’t want to go outside. This was not my child. A family friend told me that she thought he looked “pale.” He was also having nosebleeds and these little red dots on his skin. When I took him to the pediatrician, she recommended that we get some blood work on James. An hour after the blood was taken, she called us back into the office, sat us down, and said that James had leukemia. I didn’t know what leukemia was. I just knew it was bad. I was even more shocked when the Pediatrician said that leukemia was cancer. My son can’t have cancer, I thought. Cancer is for old people. Cancer kills people. My son can’t die. People with cancer lose their hair and feel sick and are miserable. Over the next few days, James saw many different doctors and had many tests. Some were painful, some were simple. I came to learn more about leukemia, and I realized that this was something that James could and would beat! He is now 2 years into his treatment and overall doing well.