Physical Therapy of Cerebral Palsy
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With CD-ROM

Illustrations by Erin Browne, CMI
Cerebral palsy is a lifelong condition that affects the individual, family, and immediate community. Therefore, the goal of allowing the individual with cerebral palsy to live life with the least impact of the disability requires complex attention to the individual and the family. Furthermore, society needs to be sensitive and to accommodate individuals with disabilities by limiting architectural impediments and providing accessible public transportation and communication. The educational system provides the key means for helping the individual prepare to function in society to his or her maximum ability. In many ways, the medical care system probably has the least significant role in preparing the child with cerebral palsy to function optimally in society. However, the medical care system is the place where parents first learn that their child has developmental issues outside the expected norm. It is almost universally the place where parents also expect the child to be made normal in our modern society. In earlier times, the parents would expect healing to possibly come from the doctor, but also they would place hope for healing in religion. As this belief in spiritual or miraculous healing has decreased, a significant font of hope has decreased for parents of young children with disabilities.

The text aims to help the child with cerebral palsy to develop into an adult in whom the effects of the disability are managed so that they have the least impact possible on adult function. This intention is in the context of the fact that the magnitude of improvement in the disability that occurs with ideal management of the musculoskeletal system during growth may be only a small improvement. Probably the more significant aspect of good musculoskeletal management through childhood is helping the child and family to maintain realistic hope for the successful adult life of the growing child. This aim requires the medical practitioner to get to know the child and family and to communicate in a compassionate way realistic expectations of the child’s function. For many reasons, the greatest difficulty in providing this kind of care is the limited time practitioners have to spend with the individual patient. There is also the sense, especially among orthopedic physicians, that cerebral palsy cannot be cured (cannot make the child function normally), and thus it is a frustrating condition with which to work. The physician must maintain a balance between communicating hopelessness to the patient and family; and feeling the need to do something, usually a heel cord lengthening, because the parents are frustrated that the child is not progressing. All medical decisions, including a surgical option, should always consider both the short- and long-term impact. With every decision the medical practitioner should ask, “What will be the impact of this recommendation by the time the child is a mature adult?” This is the most difficult perspective, especially
for young practitioners with little experience. This text is intended to pro-
vide this insight as much as possible.

Another issue is the poor scientific documentation of natural history and
treatment response in cerebral palsy, which has become clearer to me in the
course of writing this book. With little scientifically based natural history
and few long-term studies, much of what is written in this text is expert-
based observation. The goal of writing this is not to say that it is absolute
fact, but to provide the starting point of gathering information with the hope
that others will be stimulated to ask questions and pursue research to prove
or disprove the concepts.

The research, which is of help in treating children with cerebral palsy,
needs to be planned and evaluated with consideration of its long-term im-
pact on the child’s growth and development. All treatment should also con-
sider the negative impact on the child. As an example, a number of moder-
ately good studies have analyzed the impact of wearing ankle orthotics on
the young child. Although the orthotics may provide an immediate benefit
by improving the child’s gait, there is probably no long-term benefit. Thus,
if the child develops a strong sense of opposition to wearing the brace at 10
years of age because of peer pressure, the brace wear cannot be justified on
a cost–benefit analysis.

It is also important to consider the quality of the scientific evidence, rang-
ing from double-blinded protocols to case reports, but it is equally important
not to get hung up on this being the final answer. For example, excellent
double-blinded studies show that botulinum toxin decreases spasticity and
improves gait for a number of months. Therefore, these studies need to be
considered in the context of our goal, which is to give the child the maximum
possible function at full maturity. Because no evidence currently suggests that
botulinum has either a negative or a positive effect on this long-term goal, the
family and physician should decide together if botulinum injection has a pos-
itive cost–benefit ratio, as its effects will last only for approximately 6 months.
In comparison, no double-blind studies show that Achilles tendon lengthen-
ings improve gait three or six months after the surgery, and no such studies
are needed because the goal of surgery is to make an improvement in gait
several years later and to have improvement at maturity. Most important is
that surgery create no disability at maturity. From this perspective, it would
be much more useful to have a good controlled case series with a 15-year
follow-up than a double-blinded study with six months follow-up.

This book should stimulate research that will improve the knowledge base
which is focused on the long-term outcome of treatments. However, just be-
cause the scientific knowledge base is poor does not mean that we should not
apply the best knowledge available to current patients. In addition to research,
an individual professional can best extend his or her knowledge base through
personal experience. This means that the child and family should be followed
over time by the same practitioner with good documentation. By far, my best
source of information has been the children whom I have followed for 10 to
20 years with videotapes every year or two. Practitioner experience is ex-
tremely important for augmenting the relatively poor scientific knowledge
base for musculoskeletal treatment. Careful ongoing follow-up is also crucial
to providing hope for the families and the individuals with cerebral palsy.

How to Use This CD

The CD included with this text is opened with a Web browser. Because the
data on the CD is coded with XML and JAVA, only browsers released after
2002, such as Netscape 7.0, Explorer 6.0 or Safari, will be fully able to access this data. Some of the text in the book is organized in topics and is displayed in the section entitled “Main.” All references on the CD have the abstract available on the CD by activating the link associated with the reference. Cases can also be activated from these references in the Main section. There is also a section called “Cases,” which lists all the cases by name as listed in the text of the book. Following these cases are short quiz questions, which can be used to test understanding or study the material on line. There is also a section called “Quizzes,” which lists the quizzes by name of the cases. These quizzes can be opened and answered referring to the full case descriptions. The answers from the quizzes will be tabulated to keep a running total of correct answers for each session. After a quiz is accessed, it will also change color to remind the reader that he has already reviewed that quiz. The section entitled “Decision Trees” is the treatment algorithms, which are present at the end of each chapter in the book. These decision trees are set up so that area of interest is linked to the text in “Main” for further reading. The section called “Search” is an electronic index to search for specific subjects within the chapter of the section “Main.” Because of space limitations, only individual chapters can be searched at one time. So if you want to search for “crutches,” you first should activate the Durable Medical Goods chapter, and then search. The results of the search allow you to directly link to the area of interest. The section “History” keeps a running history of the areas that have been assessed, so if you want to return to an area you were reading earlier in the session you can open the history and it will allow you to return to that area. The section “About” includes information on the use of the CD and acknowledgments.

In summary, the CD includes videos, case study quizzes, and reference abstracts, which are not included in the book. The book includes significant portions of text not included on the CD, sections on rehabilitation techniques, and a surgical atlas. The book and the CD are intended to complement each other but each can also be used alone.

Acknowledgments

The production of this book and CD was only possible because of an extensive network of support that was available to me. The support of the administration of the Nemours Foundation, especially the support of Roy Proujansky and J. Richard Bowen in giving me time to work on this project was crucial. It was only through the generous support in caring for my patients by my partners and staff, Kirk Dabney, Suken Shah, Peter Gabos, Linda Duffy, and Marilyn Boos, that I was able to dedicate time to writing. I am very grateful for the generous material provided by all the contributors and for the extensive and extremely important role of the feedback given to me by the consultants. In spite of having an extremely busy practice, Kirk Dabney still found time to read all of the Book. With his wide experience, Michael Alexander made an excellent contribution in the editorial support of the section on rehabilitation. The task of writing and editing would have been impossible without the dedicated work of Kim Eissmann, Linda Donahue, and Lois Miller. Production of the CD involved a significant amount of detailed editing and HTML coding, most of which was performed by Linda Donahue. To add a personal touch to the cases, a unique name was assigned by Lois Miller. The CD required a great effort of technical programming to make it work intuitively on all computer formats. Tim Niiler patiently persisted with this frustrating task until it all worked. Videos were masked and formatted by Robert DiLorio. Production of the graphics was a
major effort in understanding the complex material in which Erin Browne excelled. This production would have been impossible without her dedication to understanding the concepts and bringing them to visual clarity. Thanks to Sarah West for modeling for the graphics. I would also like to thank the staff of Chernow Editorial Services, especially Barbara Chernow. Without the long support throughout the evolution of this book by Robert Albano and his staff at Springer, this project would also have been much more difficult. And finally, I am most grateful for the many families and children who have allowed me to learn from them what it is like to live with the many different levels of motor impairments. It is to the families and children that I dedicate this work in the hope that it will lead to improved care and understanding by medical professionals.

Freeman Miller, MD
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Cerebral Palsy Management
Cerebral palsy (CP) is a childhood condition in which there is a motor disability (palsy) caused by a static, nonprogressive lesion in the brain (cerebral). The causative event has to occur in early childhood, usually defined as less than 2 years of age. Children with CP have a condition that is stable and nonprogressive; therefore, they are in most ways normal children with special needs. Understanding the medical and anatomic problems in individuals with CP is important; however, always keeping in mind the greater long-term goal, which is similar to that for all normal children, is important as well. The goal for these children, their families, medical care, education, and society at large is for them to grow and develop to their maximum capabilities so that they may succeed as contributing members of society. This goal is especially important to keep in perspective during the more anatomically detailed concerns discussed in the remainder of this text.

How Different Is the Child with CP?

When addressing each of the specific anatomic concerns, the significance of these anatomic problems relative to the whole child’s success needs to be kept in the proper context. The problems of children with CP should be evaluated in the perspective of normal growth and development similar to any normal children with an illness, such as an ear infection, who need medical treatment. However, keeping the specific problems of children with CP in the proper context is not always easy. The significance of this proper context is somewhat similar to the significance of having a child do spelling homework on Wednesday evening to pass a spelling examination on Thursday. Likewise, practicing the piano is necessary to succeed in the piano recital. Even though each of these acts is important toward the final goal of having a confident, educated, and self-directed young adult who is making a contribution in society, the exact outcome of each event may not be all that important in the overall goal. Often, the success of a minor goal such as doing well on a specific test is less important than a major failure, but the measure of failure or success may be hard to recognize until years later. As with many childhood events, the long-term effect may be determined more by how the event was handled than by the specific outcome of the event.

For children with CP, in addition to all the typical childhood experiences is the experience of their CP treatment. Different children may experience events, such as surgery and ongoing treatment (including physical and occupational therapy), very differently. The long-term impact of these events from the children’s perspectives is often either negative or positive, depending on
their relationship with both therapists and physicians. These children have physical problems, which are the major focus of this text; however, CP affects the whole family and community. These relationships and how the CP affects families and communities are discussed in greater detail in this chapter.

The process of growing and developing involves many factors. One of the most important factors in children’s long-term success is a family caretaker. Likewise, for children with CP, families may be impacted by the CP as much as the children with the physical problems. It is very important for medical care providers to see the problems related to CP as not only involving the children, but also involving the families. Society is realizing more that the education of normal children works best when the family care providers actively participate. Likewise, providing medical care for children with CP must consider their whole families. The outcome for these children will be determined largely by their families, just as the success of normal children’s education is determined by their families. The importance of family does not provide an excuse for medical care providers or educators to become pessimistic if they do not perceive the family is doing its part. In this circumstance, professional care providers still must give as much as possible to each child but recognize their place and limits in the care of these children. Medical care providers who fail to recognize their own limits in the ability to provide care often will become overwhelmed by their sense of failure and will burn out quickly.

Family Impacts of the Child with CP

A healthy liaison should be developed between children with CP, the family unit, and the medical care providers. Cerebral palsy is a condition that varies extremely from very mild motor effects to very severe motor disabilities with many comorbidities. In addition, there are great variations among families. To provide proper care for children with CP, physicians need to have some understanding of the family structure in which the children are living. Because of time pressures, this insight is often difficult to develop. Families vary from young, teenage mothers who may have the support of their families, to single parent families, to families with two wage earners and other children. All the pressures of caring for a child with a disability are added onto the other pressures that families of normal children have. Because most children with CP develop problems in infancy and early childhood, families grow and develop within the context of these disabilities.

Often, the father and mother will react differently or come to different levels of acceptance. It is our impression that these different reactions may cause marital stress leading to high levels of divorce, most frequently when the children are 1 to 4 years old. Although this is our impression, there is no clear objective evidence that the divorce rate for these families is higher than in the normal population. Another high time of family stress is during the teenage or young adult years for those individuals with severe motor disabilities. Often, as these individuals are growing to full adult size and the parents are aging, it becomes very apparent to the parents that this is not a problem that is going away, nor are these young individuals capable of going off to college and making a life of their own.

The response of an individual family varies greatly with the wide variability of severity of CP. Many families develop a stable and very supportive structure for their disabled child. Physicians and other medical care providers may be amazed at how well these families deal with very complex medical problems. For many of these families, however, the medical com-
Complexities have accumulated slowly and are themselves a part of the growth and development phenomena. With multiple medical treatments often provided by many different medical specialists, a high level of stress develops in almost every family.

For the medical professional, continuing to be aware of this stress and listening for it during contact with families is important. Families with less education and limited financial resources may do remarkably well, whereas a family with more education and more financial resources may not be able to cope with the stresses of a child with a severe disability. It is extremely difficult to judge which family can manage and which family will develop difficulty, so it is important not to become prejudiced either for or against specific families. Medical care providers should continue to be sensitive to how the family unit is managing to deal with their stresses. Some families will be seen to be doing well and then suddenly will become overwhelmed in the face of other family stress. This stress may be illness in other family members, financial pressures, job changes, marital stress, and, most commonly, the effects of aging on the parents, siblings, and individuals with CP.

**Care-Providing Community**

Children with CP develop in supporting communities, which vary with each individual child. There are four general segments of these caring communities, with the family or direct caregivers being the primary relationship. This primary relationship is surrounded by community support services, the medical care system, and the educational system (Figure 1.1). The community support includes many options such as church, Scouting, camping,
respite services, and recreational programs. The educational system includes both educational professionals and therapeutic professionals, especially physical and occupational therapists. The focus of this text is to address the medical issues, so there will be no specific discussion of these support services, except to remind medical professionals that other services provide crucial roles in the lives of children and their families. The organization of the medical care system tends to organize around the general medical care and the specialty care for the problems specific to CP.

It is very important for families to have an established general medical care provider, either a pediatrician or family practice physician. Families must be encouraged to maintain regular follow-up with a primary care physician because very few orthopaedists or other specialists have the training or time to provide the full general medical care needs of these children. Standard immunizations and well child care examinations especially will be overlooked. However, most families see their child’s most apparent problem as the visible motor disability and will focus more medical attention on this disability at the risk of overlooking routine well child care. The physician managing the motor disability should remind parents of the importance of well child care by inquiring if the child has had a routine physical examination and up-to-date immunizations. A physical or occupational therapist will provide most of the medical professional special care needs related to the CP. The specialty medical care needs are provided in a specialty clinic, usually associated with a children's hospital.

Cerebral Palsy Clinic

Another way to organize the management of these well child care needs is with a multidisciplinary clinic in which a primary care pediatrician is present. The administrative structure for setting up a clinic to care for children with CP is not as well defined as it is for diseases such as spina bifida. Spina bifida, meningomyelocele, or spinal dysfunction clinics are all well-established concepts and are present in most major pediatric hospitals. These clinics, which are set up to manage children with spinal cord dysfunction, have a well-defined multidisciplinary team. This team works very well for these children because they all have similar multidisciplinary needs ranging from neurosurgery to orthopaedics, urology, and rehabilitation. However, this model does not work as well for children with CP because their needs vary greatly. These needs range from a child with hemiplegia who is being monitored for a mild gastrocnemius contracture only to a child who is ventilator dependent with severe osteoporosis, spasticity, seizures, and gastrointestinal problems. It is impossible to have all medical specialists available in a clinic setting, especially in today’s environment where everyone has to account for their time by doing productive work, described mainly as billable time.

There are two models currently being used in most pediatric centers for the care of children with CP. One model has a core group of clinicians who see the children, often including an orthopaedist, pediatrician, or physiatrist, social worker, physical therapist, and orthotist. The second model consists of families making separate appointments for each required specialist. The advantage of the first model is that it helps families coordinate their child’s needs. The major disadvantage is that it is costly and not reimbursed by the fragmented American healthcare system. The advantage of the second system is its efficiency to healthcare providers; however, there is often no communication between healthcare providers, and the responsibility of coordinating care from many different specialists thus falls to families.
From a practical perspective, considering the cost restriction of the healthcare environment, the best system is some blending of the two clinic models. We use this blended model, and it works for many patients with CP and their families. We schedule outpatient clinics where an orthopaedist and pediatrician share the same physical office space; however, each child is given an individual appointment with each physician. If there are only musculoskeletal concerns, only the orthopaedist is scheduled to see the child. However, if a child also has additional medical needs, the pediatrician is seen before or after the orthopaedic appointment. Orthotics, rehabilitation engineering for wheelchair services, nutritionists, social workers, and physical and occupational therapy are available in very close proximity to this outpatient clinic. If a child had a recognized problem before the clinic visit, appointments would have been made to see any of these specialists. However, if the problem is found at the current visit, such as an orthosis that is too small, this child can be sent to the orthotist and be molded on the same day for a new orthotic. This clinic also has a special coordinator to help parents schedule appointments with other specialists such as dentistry, gastroenterology, or neurology.

This structure is most efficient for medical care providers; avoids duplication of services, such as having a physical therapist evaluate a child who is getting ongoing community-based therapy; and can potentially provide maximal efficient use of the parents’ time. The main problem arising with this system is that it requires cooperation between many areas in the hospital. This model only works if the needed specialists are all working on the same day and are willing to work around each other’s schedules. For example, holding the CP clinic on a day that the dental clinic is closed or the orthotist is not available does not work. Although individual appointments are made with specialists, schedules often are not maintained perfectly, so if the orthopaedic appointment is for 10 a.m. but the child is not seen until 11 a.m., the time of the next appointment with a neurologist, all the schedules are affected. Making this system work requires flexibility by all involved.

One area of efficiency that the medical care system pays little attention to is the parents or caretaker’s time. Most caretakers have to schedule a whole day to take a child to a physician appointment because it means taking the child out of the school, usually driving some distance, seeing the physician, then returning home. This system of actively trying to schedule a number of appointments on the same day allows parents to make use of the whole day, avoiding more days out of work for the parent and out of school for the child.

Coordination between team members is accomplished by weekly team meetings where outpatient children with specific needs, along with pending and present in-hospital patients, are discussed. No matter what administrative structure is used for the outpatient management of children with CP, because of the diverse population and needs, there are always individuals who will not fit the structure. Therefore, an important aspect of providing medical care to this patient population is to have some flexibility in the delivery system.

Family Care Provider and Professional Care Provider Relationship

The specific organizational model for providing care is not as important as the fact that the medical care provided to the child with CP must always be
provided to the family–child unit. This relationship may be somewhat different for educational professionals than for medical care professionals. This discussion focuses primarily on the medical care professional relationship, specifically on the care of the motor disabilities provided by a physician.

The first aspect of treating children with CP is ensuring that the families have heard and come to some level of acceptance that their child has a problem called CP, which is permanent and will not go away. Hearing and acknowledging a diagnosis is a process that requires families first to come to terms with hearing the words and, second, to internalize these words. This process may take many years, with families initially acknowledging that there is a problem, but still expecting a cure soon. In the initial session with families to discuss this diagnosis, it is important that physicians allow plenty of time to answer all their questions, do not demand that they immediately accept the physicians’ words, and avoid definitive words that bring a sense of hopelessness to families. During this discussion with families, there is little role for the use of absolutist terms like “never,” “will not,” “cannot,” “will die,” or “will never amount to anything.” These terms often strike families as extremely cruel and threaten to remove all their hope, which they desperately need. Having time to answer all a family’s questions and allowing them to have their own doubts is important. As the physician relationship develops with a family, especially in the context of a clinic for CP, the families will slowly come to their own realization. However, this process of coming to terms with the diagnosis may be impacted by the circumstances and situations surrounding the etiology.

Family Response Patterns

All families come to terms with their children’s problems in their own way; however, there are several problems that are based on mechanisms surrounding the inciting event or the time of the diagnosis. In general, most families struggle to understand why this happened to their children and who is at fault.

Obstetric difficulties surrounding delivery can be the clear cause of CP. However, many of these birthing problems are probably due to a fetus that was already sick. Nevertheless, the birthing problems often focus the parents on looking for someone to blame, frequently the obstetrician. Some families can come to the point where they can release this need to blame; for others, it may lead to finding a legal solution by way of bringing a legal suit against the individual or organization perceived to be at fault. These legal pursuits are often encouraged by lawyers, and for many families, this only leads to more disappointment when some of the legal efforts are unsuccessful. For families who win legal judgments, there may be some sense of justice; however, the difficulty of caring for a child with a disability continues, and the need to come to terms with why this happened does not disappear by receiving money from a successful lawsuit.

Some parents, who have difficulty dealing with why this happened to their child, will be very suspicious of the medical system and will be perceived as being very difficult. There is a tendency for medical care providers, doctors, nurses, and therapists to avoid contact with these families, which often leads to more stress because the families feel that they are being avoided. This kind of very suspicious family, especially with underlying unresolved anger related to the initial diagnosis, needs to be kept exceptionally well informed and have frequent contact with the senior attending physician.
When a child is hospitalized, it is important to have the attending physician meet with the family frequently and always keep them appraised of changes and expected treatment. This level of communication with families sounds very simple; however, we have seen many families who endured a series of terrible events in hospitals, such as oversights or staff failure to recognize an evolving event that the family already pointed out. When these situations are brought up with staff, such as nurses and residents, there is a tendency for the response to be “they brought it on themselves.” This kind of thinking is unacceptable because lack of contact with the senior responsible medical staff is usually the main cause.

It is important for medical staff to recognize this pattern of behavior in families and respond very consciously by increasing communication and frequent contact. Again, the primary responsibility for this contact rests with the senior treating physician, who must display confidence, knowledge, and control of the situation to comfort the family. These families are very perceptive of physicians and care providers who do not have experience and confidence in dealing with their children’s problems. Often, these families have considerable experience in hospitals and notice when things are overlooked or symptoms are not addressed in an appropriate time (Case 1.1).

Dealing with Blame

Medical care providers must not get into situations where they inadvertently inflame this need to blame someone for the cause of these children’s CP. When parents give their perception of the history of the inciting event, it should be accepted as such without comment. Medical care providers should not tell parents how terrible the person they blame was or anything else that gives the impression that the CP could have been avoided if only this or that were done. This kind of postmortem evaluation of past medical events helps medical practitioners to learn; however, a detailed dissection of long-gone biomedical events to look for a person to blame seldom helps the families to come to terms with their children’s disabilities. By far, most of these families’ “need to find someone to blame” is a stable enduring part of their lives, and if the treating physician acknowledges this need and focuses their concerns on the children’s current care and situation, the blame issue tends to fall to the background.

There is no need for the orthopaedic physician caring for these children’s motor disabilities to get an extensive history of the birth and delivery directed at understanding the etiology of the CP from the families, so long as the diagnosis of CP is appropriate. Instead, the families’ mental energies should be directed at the goal, which is to help their children be all they can be, given the current circumstances. However, trying to convince the parents that they have to give up looking for a cause or a person to blame is also futile. If the parents are totally immobilized and cannot move forward, arranging psychotherapy may be worthwhile; however, most parents will perceive this as another attempt to sweep away the problem of who is responsible.

Another common scenario for the diagnosis of CP is when a parent or grandparent recognizes some slow development in a child. This child was then taken to see the family doctor or pediatrician who reassured the family that they were overreacting. Often, these families end up going to their primary care provider two, three, or four times to hear the same response, that is, that they are just overreacting. The child is a little slow, but there is nothing to worry about. These families often want to lay the blame for the CP upon the
Susan was born after a normal pregnancy and delivery at term and was discharged home from the hospital as a normal newborn. At 3 weeks of age, her grandmother thought that her head looked abnormal, and Susan was taken to a pediatrician where a workup revealed hydrocephalus. A shunt was placed at 4 weeks of age, followed by some complications. After this time, she was noted by her parents and grandmother to be less strong and less interactive. However, she did well, and by age 3 years was crawling, rolling, and talking. At age 3 years, she developed severe seizures and was hospitalized. During this hospitalization, she had a rather severe overdose of antiseizure medication along with other subsequent complications and lost the ability to crawl, roll, and talk. Her parents started pattern therapy when she did not rapidly regain these functions. She also started to develop increased spasticity and had more trouble with her trunk control.

By age 6 years, Susan had an adductor lengthening and was developing scoliosis. She was started in a body jacket to help control her scoliosis, and by age 8 years, she had a painful dislocated hip. After the family searched for several different opinions, they elected to go ahead and have the hip reconstructed. Because Susan had substantial complications with loss of neurologic function on several previous admissions, her parents were perceived as being extremely anxious during the hospitalization. The operative procedure and the recovery phase of the hip reconstruction went very well and the family was very gracious.

By age 9 years, she needed to have additional soft-tissue lengthenings of her right shoulder for a painful dislocation as well as for progressive varus deformity of the feet. The family was less anxious during this procedure than they had been with the prior procedure because they were more comfortable with the staff.

By age 12, the scoliosis had progressed substantially, requiring a posterior spinal fusion. The family was very anxious about this very large procedure. Their anxiety was perceived by some staff as being overreactive; however, considering the history of their experience with past medical treatment, we felt it was appropriate. At the time of the posterior spinal fusion, the shunt tubing was noted to be broken; however, she was no longer dependent on her shunt so shunt repair was not performed.

By age 13 years, she developed more lethargy and a shunt revision was recommended. During this shunt revision, she had severe complications including an infection that required the shunt to be externalized. The external drainage was not controlled carefully enough and, as a consequence, the ventricles collapsed, causing intracranial bleeding. This episode caused substantial neurologic functional loss, so she was now less able to interact socially with her parents on top of her very severe spastic quadriplegic pattern motor disability. In addition, her seizures increased substantially. This episode made her parents extremely anxious about medical treatment, especially about the fear of developing complications and having functional loss.

Shortly after the shunt problems, she was noted on routine medical examination to have a retinal detachment requiring surgery. This surgery occurred without any complications. She continued to have problems with her seizures, and her parents were anxious to have control of the seizures, while at the same time to allow her to regain some of her alertness and contact with her parents, which they much enjoyed.

This family was often perceived by nurses and house staff as being exceedingly difficult to deal with because they were so anxious and always wanted to observe and understand specific treatments and know exactly which medications were being administered. This family was extremely dedicated to the care of their daughter, and the anxieties that they expressed were very understandable considering their history. Often, medical care providers, especially physicians and nurses, were not aware of this history and therefore did not understand the parents’ anxieties. This anxiety tends to make nursing staff and medical staff try to avoid the parents, which just greatly increases their anxiety level. These parents had more than one hospitalization per year on average with their daughter and were very aware of what her proper medical management should be. They were very astute in picking up inexperience in both the nursing and medical staff and would become much more anxious when they sensed this inexperience or discomfort in dealing with their daughter.
physician, believing that this delayed diagnosis is why the child currently is so severe. There is almost no circumstance where a delayed diagnosis will be of any significance. It is important for these parents to have their concerns about the delayed diagnosis acknowledged, but then they must be reassured that this delay did not, in any way, cause their child to have a greater severity of CP. Some of these families will have difficulty developing other trusting relationships with physicians and may call, especially initially, for many minor concerns until confidence in their physician is developed.

Sometimes CP is the result of an accident or event in childhood, such as a toddler with a near drowning, or a child with a closed head injury from a motor vehicle accident in which the parent was the driver. In these situations, the parents often feel a substantial amount of blame for causing their child’s disability. This self-blame and guilt may be even more difficult for a parent to come to terms with than blame focused outward. One response to the inwardly focused blame is to search for extraordinary cures, demand more therapy, or get more devices. This behavior seems to be one of “making it up to the child.” It is helpful to reassure the family that things besides more therapy or more devices, such as maximizing the child’s educational ability, will help the child.

**Giving and Dealing with Prognosis**

Another experience frequently reported by parents whose children were in neonatal nurseries is the comment that the children probably will not survive, and, if they do, will be vegetables. This comment has been reported to us by parents of children who end up with hemiplegia as well as children with quadriplegia. We believe this comment stems from the great difficulty of making a specific prognosis of outcome in the neonatal period. Also, some physicians tell families the worst possible outcome, believing that when the children do better, the families will be grateful for their good luck. However, this explanation almost never has the intended outcome, and much more commonly the families perceive these comments as the physician being incompetent or deceitful. Often, these families will interpret attempts by later physicians to discuss prognosis or expected results of surgery as being too pessimistic. For these families, it is important to be as realistic as possible; however, their optimism may cause some disappointment as their expectations of greater outcomes are not realized. Generally, these families do come to appropriate expectations, but continue to have some negative feelings about their neonatal experience.

An important aspect of giving prognosis or information that is requested by families is to always acknowledge that it is imperfect. Requests to know if a child will walk or sit should be answered as honestly as possible, always avoiding absolutist terms such as “never,” “cannot,” or “will not.”

**Giving the Diagnosis**

Another common problem surrounding diagnosis of children with CP is failure to give the parents a diagnosis. A common example of this is a mother of a 5-year-old who is unable to sit and brings the child to see the orthopaedist to find out why the child cannot walk. The history reveals a normal pregnancy and delivery; however, by age 12 months, the child was not sitting, so the mother starting going to doctors to find out what was wrong with the child. She has seen three neurologists and a geneticist, has had skin
biopsies, muscle biopsies, computed tomography (CT) scan, magnetic resonance imaging (MRI) scan, and many blood tests, but everything is normal. The mother hears from these doctors that they can find nothing wrong with her child; however, what the doctors probably told the mother is that the medical tests are normal and they do not know what caused the child’s current disability.

Families need to be told what is wrong with their child. This type of family is easily helped by explaining that the child has CP. Physicians should clearly explain that even though they do not understand why the child has CP, it is the diagnosis, which they know exactly how to treat. Taking time and providing information to these families will stop the endless and futile search for “why” and allow them to focus on caring for and treating their children. This situation is caused almost entirely by physicians not being clear in communication with parents and the particular aversion by some physicians to giving a diagnosis of CP. This aversion is very similar to wanting to avoid telling a patient that she has cancer, and therefore telling her that she has a nonbenign growth whose cause cannot be explained. In this way, CP is like cancer in that a physician often cannot determine the etiology; however, the treatment options are well defined and should be started immediately.

Medical Therapeutic Relationship to Child and Family

There are many different types of therapeutic relationships that work for families and their children; however, there are some patterns that work better than others. These patterns each have their risks and benefits as well. The major therapeutic relationships in the treatment of motor problems of children with CP include the parents, the physical therapists, and the physicians. The parents will spend the most time with their children and will know them best. Often, the parents recognize developmental gains and day-to-day variability in their child’s function first. Physical therapists will spend the most therapeutic time during treatment with children and will bring the experience of similar children. This in-depth experience with similar children allows therapists to help parents understand the expected changes as well as teach parents and children how to maximize their function. The orthopaedist treating the motor disability will have the least experience with an individual child, but will have the broadest experience with many children to understand the expectations of what will occur. The physician’s experience with each child, however, will be much more superficial and the physician depends on the parents’ and therapists’ observations of the children’s function over time and the variability of function during the day. Recognizing these individual strengths will allow the parents’, therapists’, and orthopaedists’ perception of individual children to be combined to make the best therapeutic judgment.

The Physical Therapist Relationship

The role of the primary treating physical therapist, especially for the young child between the ages of 1 and 5 years, will incorporate the typical role that the grandmother and the general pediatrician play for normal children. In addition, the therapist fulfilling this role must have knowledge and experience
in dealing with children with CP. This role model involves time spent teaching the parents how to handle and do exercises with their child. This role also involves helping the parents sort out different physician recommendations, encouraging the parents, and showing and reminding parents of the positive signs of progress in the child’s development. When this role works well, it is the best therapeutic relationship a family has. The positive aspects of this role are providing the parents with insight and expectations of their child, reassuring the family that they are providing excellent care, and being readily available to answer the family’s questions.

The “grandmothering” role of the therapist has associated risks. One of the greatest risks in our current, very unstable medical environment is that a change in funding or insurance coverage may abruptly end the relationship. An abrupt change can be very traumatic to a family. The therapist must be careful not to be overly demanding of the family, but to help the family find what works for them. Occasionally, a therapist may be fixated on a specific treatment program and believe that it is best for the child; however, the parents may not be in a situation to follow through with all this treatment. The parents feel guilty, and the therapist may try to use this guilt to get them to do more.

The physical therapist in this role as a therapeutic “grandmother” can help parents sort out what medical care and choices are available. The therapist can help parents by attending physician appointments and making the parent ask the right questions, which is often not possible because of funding restrictions. The physical therapist must not give specific medical advice beyond helping parents get the correct information. Therapists with extensive experience should recognize that they have great, detailed, and deep experience with a few children and that generalizing from the experience of one child is dangerous. We have heard therapists tell parents on many occasions that their child should never have a certain operation because the therapist once saw a child who did poorly with that surgery. This type of advice is inappropriate because one child’s experience may have been a rare complication of the operation. Also, there are many different ways of doing surgery. This would be like telling someone to never get in a car again after seeing a car accident. A more appropriate response to the family would be giving them questions to ask the doctor specifically about the circumstance with which the therapist is concerned and has experience.

Another physical therapist therapeutic relationship pattern is the purely clinical relationship in which the therapist thinks the family is incompetent, unreliable, or irresponsible and only wants to deal with the child. Almost invariably, this same therapist next will complain that the family and child never do the home exercise program or that the child is not brought to therapy regularly. This relationship may work for a school-based therapist or a therapist doing inpatient therapy, but it leads to great frustration for both the therapist and family when it is applied to an outpatient-based, ongoing developmental therapy. In this environment, the therapist must try to understand and work within the family’s available resources.

The Physician Relationship

Families of children with CP often have a series of physician relationships and tend to choose the physician with whom they are comfortable, who responds to their needs, and who is able to help them with their child’s problems. As pediatric orthopaedists, many of our patients will report to their schools and emergency rooms that we are their child’s doctors. We strongly
encourage families to have family doctors or general pediatricians to care for well child care needs and minor illnesses. With the changing healthcare payers, some families have changed family doctors every year or two and the physician who cares primarily for the musculoskeletal disabilities of a child often becomes defined as the child’s doctor.

The musculoskeletal problems of CP are well known and are relatively predictable; therefore, a major part of the treatment is educating the family of what to expect. For example, a nonambulatory 2-year-old child who is very spastic has a high risk of developing spastic hip disease. This risk needs to be explained to parents so they know that routine follow-up is important and that, if spastic hip disease is found, there is a specific treatment program. At each visit, this plan is reviewed again. Diligent attention to this individual education process gives parents a sense of confidence about the future and helps prevent the development of a nihilistic family approach that nothing can be done for their child.

Because families usually start to see the CP doctor when the children are about age 2 years, and in our clinic stay until age 21 years, a long-term relationship is developed. Keeping a healthy therapeutic relationship, understanding and taking into consideration the family’s strengths and limits, is important. In addition to helping the family understand what to expect with their child, continuing to support the family as much as possible is very important. One easy way to give the family positive feedback is to focus on the positive things that the child has accomplished, such as better physical functioning, good grades, good behavior, gaining weight, growing taller, and being nicely dressed. There is a tendency for parents to only hear negative things from doctors, such as a catalog of all the things the child cannot do.

Another aspect of the therapeutic relationship is recognizing that this is not a family relationship. Many of our patients are very happy to see us and we enjoy seeing them; however, as they grow and develop, their doctor should be a positive influence but not their main adult role model. These children should not be seen more than every 6 months unless there is an active treatment program such as one following surgery. One goal of the medical treatment of these children should be to have as little direct impact as possible on their normal lives so that they grow up having experiences similar to normal children. To this end, medical intervention should be limited as much as possible and should be episodic so that it more closely mimics normal childhood medical experiences, such as fractures or tonsillitis. Frequent trips to a doctor’s office or to a clinic are also very time consuming for families. There are almost no musculoskeletal problems that need to be monitored more than every 6 months.

Recognizing the strengths and weaknesses in families and trying to work within their limits to provide medical care for children with motor disabilities is important. The medical system is limited to working within the confines of what the families and school environment can provide, especially for children with severe physical disabilities. The state social service protection agencies seldom get involved or are very helpful to families, except in rare dire circumstances.

When the Doctor–Family Relationship Is Not Working

Medical care providers need to understand that personalities are such that one individual can never meet everyone’s needs. This does not mean that as soon as the doctor therapist family relationship becomes difficult, it is not
working. At this time, the relationship needs to be discussed and the physician or therapist should be open about giving the family permission to go to another doctor or therapist. Some families will just leave without saying anything and others will feel guilty about wanting to leave. Physicians and therapists must be honest with themselves because this situation tends to make them feel like a failure. There may be a combined sense of relief that the family left and a sense of failure and anger that the family does not trust their physician or therapist. These are normal feelings that the physician or therapist should acknowledge and not place blame on themselves or the family.

When the Family Chooses Medical Treatment Against the Physician’s Advice

Families may seek a second opinion for a specific treatment recommendation. This desire to get a second opinion should not be seen by the primary treating physician as a lack of faith or confidence. The family may require a second opinion for insurance purposes or, for many families, they just want to make sure they are getting the correct treatment. Usually, getting a second opinion should be viewed as a very prudent move on the family’s part and should be encouraged. Families should be given all the records and support that are needed for them to get a meaningful second opinion. If this second opinion is similar to that given by the primary physician, the family is often greatly comforted in moving ahead. However, there is still variability in medical treatment for children with CP, so depending on the family’s choice of opinions, the recommendations may be slightly to diametrically opposed.

In a circumstance where the recommendation of another physician differs significantly, the primary physician must be clear with the family and place the second opinion in the perspective of their recommendation. Sometimes the words used may sound very different, but the recommendations are very similar. In other circumstances, the recommendation may be diametrically opposed and the primary physician must recognize this and explain to the family the reasons for their recommendation. When recommendations are diametrically opposed, clear documentation, including the discussions concerning the other opinion, is especially important. This situation has a high risk for disappointment. Often, families have great difficulty in choosing between divergent opinions, even when one opinion is based on published scientific data and the other opinion is completely lacking in any scientific basis (Cases 1.2, 1.3). Therefore, a family may base their decision on other family contacts, a therapist’s recommendations, or the personality of the physician.

Physicians must understand that it is the family’s responsibility and power to make these choices; therefore, with rare exception, no matter how medically wrong the physician believes these decisions are, the family must be given the right to choose. Only in rare, directly life-threatening circumstances will a child protective service agency even consider getting involved, and then this involvement is usually very temporary. With a long and chronic condition such as CP, temporary intervention by a child protective agency generally is of no use in interacting with families. With clear documentation of the recommendations, the physician must let the family proceed as they choose; however, we always tell them that we would be happy to see them back at any time. When they undergo treatment against their primary physician’s advice and return, usually after several years, the physician should not make the previous situation a conflict. The family usually feels guilty and may not want to discuss past events. Occasionally, they will come back and
Judy was born premature as one of twins and weighed 1300 g. She was in the neonatal nursery for many weeks. Her development was noted to be significantly delayed early on, and her CP was recognized within the first 2 years of her life. By school age, Judy was not able to walk, but was able to do some speaking, and there was concern about her educational ability. At age 7 years, she was seen by a developmental pediatrician for an educational assessment. This pediatrician thought that she had excellent cognitive ability, but also noted that she was developing significant contractures, and recommended follow-up with a pediatric orthopaedist. However, she was not seen by a pediatric orthopaedist until age 10 years, when she started to develop some pain in the right hip. At this point, she was in a regular school and was complaining of pain in the hip during the school day. An evaluation demonstrated a completely dislocated right hip and severe subluxation of the left hip; however, this hip was an excellent candidate for reconstruction because, at age 10 years, she had substantial growth remaining. Hip reconstruction was recommended to the family and details were given. For reasons that were never quite clear, this family pursued many other options in trying to deal with their daughter’s painful dislocated hip and eventually decided on a treatment that they had located through unknown sources, which consisted of having a spinal cord stimulator implanted in her spinal cord. In addition to the spinal cord stimulator, other alternative medicine treatments were pursued. The hip pain would get better intermittently and then would flare up, requiring her to be in bed for several days. By 14 years of age Judy had periods of relative comfort between bouts of severe pain, until age 15 when the pain became more constant and severe. By age 15 years, as she entered high school with normal cognitive and educational achievements, the pain got so severe that she could no longer sit during the school day. At this point, her parents kept her home in bed and gave her a variety of different pain medications. She was out of school for 1 year, spending most of her time in bed, when her parents finally came back with a request to have her hip reconstructed because they now perceived she could no longer deal with the pain.

At this point, except for getting a brief history, her parents were told simply that reconstruction was no longer possible, and she now required some palliative treatment. Her parents were assured that good treatment was available to get rid of her pain; they were informed of the treatment options, and it was strongly recommended that these options be pursued. Surgery was scheduled emergently and was completely successful in alleviating her pain.

This is an example of a family who for unknown reasons chooses alternative medical treatments instead of well-recognized appropriate medical treatment. This type of behavior may be very difficult for a physician to accept. This family only saw us once when their daughter was 10 years old, and then did not come back for more treatment. In these situations a physician can only make the recommendations, but cannot force the families to follow through with treatment. This girl clearly would have been much better served by a reconstruction at age 10 years; however, the family had complete control. This family’s choice of treatment was not inappropriate enough legally whereby the physician would have gained anything by reporting the family to child protective services or making any other efforts to try to force them to have treatment. There are many different types of alternative medical treatments that families may pursue, some of them performed by a physician, such as spinal cord stimulators, which provide absolutely no benefit to this kind of spasticity or pain. There is nothing that the primary caring physician can do except try to persuade the family and then accept their decisions. However, it is very important to always leave the family the option of coming back when they are ready and then provide appropriate treatment, as was done in this situation.

Six weeks after this girl’s surgery, at which point all her hip pain was gone, the family noted that she was having difficulty sitting because of her scoliosis. They were now very keen on moving ahead and having the scoliosis corrected. This is a circumstance where although the family feels extremely guilty and are often very hesitant to return because of fear that the physician will be angry with them, once the appropriate treatment has been performed and is successful, the family will become very committed to continuing with appropriate medical care.
Rhonda was born following a normal pregnancy and normal delivery. She was perceived to be normal until 18 months of age when her development was noted to be substantially slow and a full evaluation demonstrated an infantile cytomegalovirus (CMV) infection. She continued to make progress and by age 3 years had started walking independently and was speaking. She had low muscle tone with some difficulties with balance. She was doing well in a special education class environment until age 9 years, when she had sudden complete loss of hearing in both ears. An evaluation demonstrated that this hearing loss was in response to the CMV infection. By age 13 years, she had developed severe scoliosis that was making her ambulation difficult. At this point she was quite healthy, and although she had not regained any hearing, she was a full community ambulator. The posterior spinal fusion was performed without difficulty, and the family was told that based on her excellent general health, a fairly quick recovery was anticipated, with her being ready to leave the hospital in approximately 7 days.

However, in the intensive care unit (ICU), on the first day following surgery she became quite hypotensive, requiring a substantial bolus of fluid as well as a dopamine for blood pressure support. Blood pressure support was required for 5 days, and she then developed respiratory problems and was on ventilator support for 5 days. Following extubation, she continued to have pulmonary problems needing positive pressure respiratory support at night. In the meantime, she also developed a mild pneumonia requiring antibiotic treatment. Instead of being discharged from the hospital in 7 days, she was discharged from the ICU to the floor 13 days postoperatively.

During this time, the family became anxious because it was medically difficult to make specific predictions about what to expect. The family was kept informed and, overall, they were able to relax as slow progress was made in the ICU. Each day, the family saw that she was stable or slightly better. Gains were made, such as discontinuation of the dopamine for her blood pressure support, then discontinuation of the ventilator. This progress was followed by needing fewer respiratory treatments as her pulmonary status gradually improved. Being able to see these gains, although slow, gave the family hope and understanding that things were progressively improving.

By postoperative day 10, she had developed some superficial wound separation and very minimal drainage; however, she was afebrile because she was being treated by antibiotics for her pneumonia. The family was informed that this wound opening was not uncommon, especially after having been extremely edematous, and the mild wound drainage was not a concern.

By postoperative day 17, this wound drainage was not decreasing and instead was increasing. The patient was still afebrile, was continuing to make good progress with her respiratory status, and was able to be up walking in physical therapy. However, based on the amount of drainage and the appearance of the wound, it was possible that this could be a deep wound infection. The family was told that the wound did not look good, and that if after 2 more days the drainage did not substantially decrease, a more vigorous exploration would be done. On postoperative day 19, the drainage increased slightly; therefore, a more detailed digital inspection, trying to determine the depths of the wound, was undertaken. The deep fascia was noted to be open at the far superior aspect of the wound, and the family was informed that this was a deep wound infection. The girl needed to be returned to the operating room, and the wound surgically cleaned out, then treated with open packing and dressing changes. At this time the family was told that she would now be in the hospital for an additional 4 weeks on intravenous antibiotics and wound dressing changes, followed with probably 2 weeks of home intravenous antibiotics.

The family was already very anxious about all the complications in the ICU, and now the deep wound infection was another major setback. However, after the parents went home and discussed the significance of this new problem with an understanding of the exact timetable that was required, they were able to make family plans. They came back to the hospital the following day and had more discussions concerning details about the planned treatment. After making plans with the specific information they were given, they shared that they had made arrangements for their other children and were comfortable and relaxed with the plan. They were prepared for the 4 weeks, and the remainder of the treatment was very uneventful.

This case demonstrates how important it is to keep the family well informed as complications are occurring. To give the family the information, the physician has to recognize the complication and develop a clear treatment plan. There is a tendency, especially in situations where there have been multiple complications and the family is very anxious, for the physician to not want to give the family more bad news. Ignoring problems like deep wound infections will not make them go away, and the problem
will continue to be frustrating. When a clear treatment protocol with the expected outcome is outlined, and the family is informed that although this is a substantial setback, it should not compromise the long-term outcome of their child’s treatment in any way. In this specific case, it was equally important to reassure the family that the spine fusion was successful in spite of the current problem and that the rod did not need to be removed.

blame the physician for the problems because they have transferred the blame for the recommendation (Case 1.4). Nothing will be gained by bringing up these past problems with the family, and the focus should be to move on with the problems at hand as they present themselves.

**Recommending Surgery**

For children who have had regular appropriate medical care, the need for specific orthopaedic procedures is usually anticipated over 1 to 2 years, and as a consequence is not a surprising recommendation. We prefer to have these discussions in the presence of the child. For young children, there is no sense that something is being hidden from them. Children in middle childhood and young adulthood can take in as much as possible, allowing us, as their physicians, to directly address their concerns as well. For younger children, those under age 8 years, their main concern is that they will be left alone. We reassure them that we make a major effort to allow the parents to stay with them during preinduction in the surgical suite and again in the recovery room. We also reassure children that their parents will be with them throughout the whole hospitalization. As children get older, especially at adolescence, there is often an adult type of concern about not waking up from anesthesia or having other severe complications leading to death. These individuals may have great anxiety, but have few of the adult coping skills that allow the rationality to say that this surgery is done every day and people do wake up. Some of these adolescents need a great deal of reassurance, most of which should be directed at trying to get them to use adult rational coping skills. If adolescents are having problems with sleeping or anxiety attacks as the surgery date approaches, treating them with an antianxiety or sedative agent is very helpful.

Some adolescents and young adults with mental retardation develop substantial agitation over surgery. Parents of such children are usually very aware of this tendency and may wish to not tell them about having surgery until the day before or the day of surgery. Although this is a reasonable practice for individuals with severe mental retardation who are not able to cognitively process the planned surgery, approaching children who are cognitively able to process the event in this way is only going to make them distrustful of their parents and doctors.

In preparing children and families for surgery, it is important to discuss the expected outcome of the surgery with them. Part of this discussion must focus on what will not happen, specifically that their child will still have CP after the surgery. If the goal is to prevent or treat hip dislocation, showing radiographs to the families helps them understand the plan. They also need to be told what to expect of the procedure from a functional perspective, such as “Will the child still be able to stand? Will the child be able to roll? Will the child’s sitting be affected? Will the child’s walking ability be affected?” For children in whom the surgery is expected to improve walking, showing families videotapes of similar children before and after surgery helps them get a perception of what level of improvement is anticipated.
Patricia was born at 35 weeks weighing 2250 g. She had a relatively normal postnatal course except that she was noted to be very good and slept a lot, even requiring awakening occasionally to eat. However, by 19 months of age, she had significantly decreased tone in her lower extremities and trunk, but had increased tone in her right upper extremity with some spasticity and was diagnosed as a right hemiplegic pattern CP. By age 4 years, she was able to sit but had very spastic lower extremities, which caused scissoring and equinus when she was standing. She was able to sit on a tricycle and pedal. At this time, the parents first heard about dorsal rhizotomies and were very interested in pursuing this method to decrease the spasticity. By age 5 years, she was walking handheld, but scissoring substantially, and the parents were pursuing various opinions concerning the dorsal rhizotomy. By age 6 years, the parents had gotten a recommendation to use a transcutaneous nerve stimulator on the upper right, very spastic extremity. A course of this stimulation was undertaken even though the child objected because of the discomfort, but the parents persisted for several months until it was clear that there was no benefit.

At age 7 years she was able to stand but could not do independent transfers, although she was doing standing transfers with considerable scissoring. She was not able to walk independently without someone guarding her. The parents continued to get various conflicting opinions on the merit of a dorsal rhizotomy from several dorsal rhizotomy evaluation programs. Finally the family decided to have the child undergo a dorsal rhizotomy at age 7 years. After 1 year of intense rehabilitation, the mother was very depressed and angry with herself and with the physicians. After an extensive discussion, the mother volunteered that she was blaming herself and also the physicians, both those who recommended for and against the procedure, for her daughter having undergone a dorsal rhizotomy. She believed the rhizotomy caused her daughter to lose function in spite of an extremely intense amount of physical therapy work and stress over the year following the surgery.

After further discussion, the mother was encouraged and began to see this experience as an attempt by herself and her husband to choose what was right for their daughter. The mother was slowly able to acknowledge how difficult it is for a family to make decisions when there are varying medical opinions about a procedure, especially a new procedure where there are few data available, such as the dorsal rhizotomy in the late 1980s. The mother was able to come to terms with feeling badly about her daughter having the surgery, and she stopped blaming herself and the physicians because she understood that everybody was trying to do what they thought was best with the knowledge they had available at the time. The mother was encouraged to focus forward because, following dorsal rhizotomy, some of the spasticity does return and her daughter probably would slowly regain some of the lost function. The functional loss was specifically identified as the inability for independent stance, for good assisted transfers, and for household ambulation while being held by her hands.

Over the next 3 years, some tone did return and this girl was able to do some minimal standing transfers; however, she has become very heavy, making it difficult for her and her family. She underwent reconstructive surgery of her right upper extremity, which improved her ability to use the right extremity to hold on and assist with transfers. Seven years after the dorsal rhizotomy, she developed a severe kyphosis at the site of the rhizotomy that required a posterior spinal fusion. This development caused her parents some renewed agitation about their daughter having undergone a procedure that they still felt was very detrimental. This combination of the family struggling to deal with their daughter’s disability as she is becoming full adult size, and trying to find past blame for the cause of some of the disability, has made it somewhat difficult for the girl to come to terms with her own disability.

After the posterior spinal fusion, she developed a substantial depression and anxiety syndrome with a period of pain, difficulty with sleeping, and poor appetite. Initially, she was started on amitriptyline to help with the poor diet and sleep. This medication helped by substantially improving her diet; however, she continued with significant amounts of anxiety and the amitriptyline had to be increased over a 2- to 3-month period instead of being decreased. She was referred for a psychiatric consultation for better pharmacologic management of her depression and anxiety. The improved pharmacologic management, as well as some counseling with the parents, has greatly assisted this young woman in making the transition to young adulthood.

This case is an example of parents who try very hard to find the latest and best treatment, and after extensive consultation with conflicting opinions, make a decision that does not turn out well. This decision-making process can inflame the process of coming to terms with the child’s disability further, making the parents feel that they are
A Plan for Managing Complications

Discussion of possible complications is also important; however, the expected outcome should be honestly approached. Some surgeons tend to have very pessimistic expectations with regard to expected outcome and complications. Surgeons with this approach soon overwhelm themselves and their families with their assessment of the poor balance between the expected outcome and the possible complications. Most surgeons who have a large CP practice tend more toward the overly optimistic approach in which the outcomes clearly will be worth the risk of the complications. The risk of an overly optimistic approach to families occurs when there are complications. These families may be surprised and angry and find it difficult to deal with the unexpected. It is difficult for physicians to have the perfect balance, but each physician should be aware of their own tendency. Usually, an honest assessment and feedback from partners will identify which personality trait, either optimistic or pessimistic, a physician tends to use when approaching families. By recognizing this tendency, surgeons can be more sensitive to what families are hearing and make suggestions to moderate this perception.

There are families who for some reason or another have not been obtaining appropriate orthopaedic care for their children. Then, when these children are adolescents, they may come to see a CP surgeon with a painful hip dislocation, severe scoliosis, or other deformities that are in a severely neglected state. Some of these families are surprised to hear that only a surgical procedure will be the appropriate treatment. Some families may be very resistant to surgery and will want to try everything else. These families must understand that only surgery will correct the problem, but the surgery seldom has to occur on an emergency basis. If a surgeon perceives a family’s hesitancy, and attempts to mollify them by suggesting that a brace, injections, or some other modality be tried even though it will provide no long-term benefit, the family will likely hear uncertainty in the physician’s approach.

Families may miss the message completely that only surgery will address the problem when they are appeased by nonsurgical treatment. Giving children temporizing measures to provide relief of pain is appropriate; however, doctors must be clear to families that these measures are only providing temporary pain relief and are not treatments. By giving families a little time with the use of these temporary measures, physicians can develop a relationship with the families. There are situations where medical and psychiatric treatment may be required before the surgical treatment can occur. For all these reasons, it is important to be clear about the required treatment, its expected outcomes, and then to outline the full treatment plan. As this treatment plan is undertaken, the relationship a physician has developed with children and families will allow them to be confident that the recommended treatment can occur in a safe and effective way.
When Complications Occur

When treatment of a child does not go well, the orthopaedist must first recognize this as a complication. The judgment of recognizing a complication is one of the most difficult to develop and some physicians may never do it well. Many complications, especially in orthopaedics, do not present with the drama of a cardiac arrest. In orthopaedics, a more typical example is the presentation of a deep wound infection. Every wound with a little erythema and a mild superficial drainage is not a deep wound infection. However, when a deep wound infection is present, it should be acknowledged as such. These families should be told of the complication and a definitive treatment plan should be described (Case 1.3). For this process to work, physicians first have to acknowledge the complication to themselves. We have seen many physicians who cannot bring themselves to acknowledge the magnitude of the complication. Likewise, we have seen physicians who overreact to relatively minor problems that will resolve if left alone.

Finding a balance requires physicians to be honest with themselves and be aware of their own tendency toward optimistic or pessimistic ends of the spectrum. The optimist tends to see the complication as minor variance of normal, whereas the pessimist tends to be overly concerned that any wound change may be a deep wound infection. By being aware of one’s own tendency, as experience is gained, an approach to diagnosing and acknowledging complications and then making specific treatment plans will be developed. Complications tend to make physicians feel like failures, and a good retrospective evaluation of the treatment course may demonstrate errors of judgment or execution. These errors should be viewed as learning experiences and opportunities to teach oneself as well as others.

A significant number of the case histories in this book are careful analyses of complications that have occurred in our practice. It is important that the approach to analyzing a complication is to determine the exact cause of the complication when possible so that it may be avoided in the future. Saying that “I will never do that operation again” is an inappropriate response to complications. This response comes very close to that of people who say they will never get in a car again after they have had a car accident. Our goal is to always have a complication-free treatment and recovery for every patient; however, we learn the most from careful analysis of our complications and poor outcomes.

Once physicians acknowledge the complications to themselves, the families then need to be told. Families may react with quiet acceptance, frustration, or anger. These feelings are often the same feelings that physicians have about the same complication. If physicians are willing to share some of their frustration and concern about the complications, it often helps families to put the problem in perspective. It is very important to explain to families what to expect from a complication. This explanation should include a detailed outline of the expected treatment plan. If a complication arises that physicians are not comfortable treating, getting a second opinion from, or seeking the help of, another physician is very important. This step should be explained carefully to families. Frequent contact with families is very important, especially if they develop considerable anger and anxiety, because if they feel that the doctor is trying to avoid them, these feelings often increase.

Complications should be managed very much like the initial decision to have an operation. First, specific problems should be carefully defined to families. Next, the range of options and expected outcomes, with respect to the short- and long-term implications, should be placed forward as specifically