

CHAPTER 2

COPING IN THE EARLY YEARS

(Ages 5-6 Years)

When I turned six I began to realize that I was somewhat different from the other kids. They could run with no problem, while I would have to slow down and quit before too long. Also, while riding my bicycle, it would be really tough to get up hills; and sometimes about half way up I would have to get off and walk, or else turn back. I could tell at times that they would use this to their advantage. If they did not want to hang around with me, they would just take off running recognizing that I would not be able to keep up with them. While I realize that sometimes they did it out of meanness, there were other times that I was not being as friendly as I should, and I do not blame them for wanting to get away from me. My reaction was to call them every name that I could think of, and this would just reinforce their feeling of justification for treating me the way that they did.

The times when they would do this were somewhat frustrating and puzzling to me. In retrospect I now recognize that it did not hurt my feelings – it just made me mad. That is, I tended to blame them for their meanness as opposed to anything inherently deficient within my own realm. It was *their* behavior here that seemed abnormal. Some 25 years later I recognize that this type of behavior is a common characteristic of young people in general. The cases of the persecution of the “different,” regardless of what that difference is, are very well documented, and we have all experienced it first hand. Such behavior would not be that problematic if it were just restricted to children. However, it seems that many if not most, humans never mature out of this. It reflects their own personal lack of self-esteem, which necessitates that they build themselves up at the expense of others.

Neither is this characteristic restricted to humans. It is well known that a crippled chicken, for example, in a chicken house will be physically assaulted by the others to the point of death – just because of the weakness of the unfortunate to defend themselves. While this might serve a natural purpose in preserving the health of various species, you would think that humans would have matured beyond this clearly animalistic tendency. It is clear, however, that we have not.

The major point that I am trying to make is that reality dictates that children left to themselves *will* behave in this manner naturally. Whether it is a taught characteristic or one that is learned is irrelevant at this point – it is all too pervasive to just think that it will go away by ignoring it. It seems clear that children need to be **taught** the respect that they should have for people who have limitations, or, for that matter are in any way *different*. Their ridicule of those less fortunate to exalt themselves is a reflection of their own insecurity, which is probably an inherited trait from those whom they observe. On the other hand, coming to the defense of one who is less fortunate, and identifying with that person’s humbling circumstances, requires a tremendous amount of self-confidence, which most children seem to lack. (I would use the popular term “self esteem,” but what is promoted as self esteem and taught in many schools

today is nothing but the type of self exaltation which is the root cause of the problem, not its solution. If you want to test the character of a young person, place him with three of his closest friends in the presence of a handicapped child of the same age for a few hours and observe the results.)

One approach toward producing a more positive attitude on the part of normal kids is to intentionally subject them to those who are handicapped, and provide instructions on the proper attitude that they should have. This introduces several difficulties, not the least of which is that our general society does not have a consistent and positively healthy approach to this issue. Kids tend to emulate the adult society, and the stigma of handicaps that pervaded the dark ages has not altogether vanished. There is still the lingering question: “is this the fault of the person, or this person’s parents?” (See John 9:2.) That the victim is not at fault is a most critical and difficult fact to convey. It is most often met with natural denial, for if no one is at fault, then it could equally likely happen to them; and they have something to be thankful for that they probably would much rather take for granted. So we have some deep-rooted psychological problems to overcome here.

A second problem lies with the handicapped person(s) to which these children are going to be intentionally “exposed.” Personally, I do not relish being part of any kind of a freak show, and I am sure that I speak for most other handicapped individuals in this regard. I want to be viewed as contributing to society for my own intrinsic worth, not *just* because I am handicapped. I say “just” here because obviously being handicapped is part of what makes me different and unique – that I will not deny. Further, it is our uniqueness that contributes to our intrinsic worth; so, in many ways my value as to what I can contribute is enhanced by my handicap. (For example, I could not write this book if I were not handicapped.) Each handicap has a tremendous downside, which tends to be the focal point of society. However, each handicap produces some added potential to the victim enabling him or her to excel, not only *despite* of the handicap, but often *because* of it.

A third problem that this introduces is one of stereotyping. The variation within handicapped individuals has the same range that it does within the population in general. We know that some of the most physically blessed in our society self-destruct in bitterness. The plight of drugs in our athletes and movie/music super-stars is so predominant that examples do not even need to be cited. Now, if the most blessed of our society self-destruct, why not the persons who (most would say) have a very good reason to be bitter with their lot in life. Thus, to expose children to one, or a few, handicapped persons could be counterproductive in producing within them a hasty generalization as to what *all* handicapped people are like, what they want, and how they want to be treated.

On the positive side, however, there is much to be said for dealing with reality head on. This is true not only for the children who have no idea as to how to behave in the presence of a handicapped peer, but also for the handicapped child. If any degree of normalcy and contribution to society (which is the essence of self-esteem) is to be reached, the handicapped child will also have to learn how to deal with normal kids. This can be part of the process, and serving in this capacity can be an honorable and noble thing that builds a sense of purpose and self-esteem. It

does not have to be demeaning. However, this process has to be handled very carefully and professionally by those who know the personalities of all of the individuals involved – the normal and the handicapped – so that there will be no surprises. Any handicapped person will not do. It must be someone who has the desire and the ability to present a mature view of the realities of handicapped life and the range of how handicapped people want to be treated by society.

As for kids with MD, this would not be feasible, since generally the first 4-6 years of life are quite normal. I can see, however, that if a young person with MD had a very positive experience with another handicapped individual, and learned that life does not end when you are confined to a wheelchair, that this could play a very positive role in their acceptance of the inevitable. It could help tremendously in their making provisions to get on with that part of life that might be enhanced by the handicap. *However, this must be presented to a young person in a very subtle way* – not hidden as much as disguised. For example, to even infer to a young person with MD that this is going to be *your* fate would tend to rob them of the enjoyment of the high degree of normalcy that they have at that age. So, this should not be presented as his/her future prematurely. Rather they should be treated themselves as the “normal” kid at this point and learn how to treat the handicapped, and how the handicapped want to be treated. The preparation of the MD child should be no different from the training of the normal child as to their relationships with the handicapped. In essence, we do not know who will become a Christopher Reeve in the future, so everyone can certainly profit from this experience – the normal, the handicapped, and the future handicapped alike.

In all of this the most important aspect to get across (and which launched this parenthetical discussion) is the fact that handicapped people *want* to fit in. All people are different. Some are ugly, some are too tall, some are too short, some are fat, some have freckles, and we could go on ad infinitum. Whenever *any* of these physical characteristics is used by a segment of the society (usually those who are most insecure in their own humanity) to divide and persecute, the results are catastrophic to everyone in our society. So, there are broader implications in this training as well, and perhaps the handicapped need not be singled out. Perhaps if the training is in terms of total toleration of our uncontrollable differences, then the handicapped persons would not be in such a minority situation. This is somewhat of an oversimplification, since it is also necessary to communicate the *special* needs of handicapped and how they should be addressed, but this is something that should be at the foundation of all such programs to address these needs. While it is the desire of everyone to fit in, we do not all contribute in the same way, and it is our uniqueness that, as likely as not, provides the niche for our maximum contribution.

My response to the first assaults by my friends was to withdraw into myself. I might attempt to visit another neighbor, or I would just go home and get involved in something else that did not involve others at all. Then there was always Missy; I could count on her to be around. While our relationship was one of mutual persecution at this point, it was an excellent retreat from the slings and arrows of those who did not know or understand me as “one of them.” There is something within each human that enables us to adapt to the situation no matter how devastating it might appear. As they say, life goes on, and the alternatives to getting on with it

are not that inviting. However, I have known many who have taken other alternatives and grown quite bitter over it; and we will address these in due time.

If I could not do things with the other kids, I would find something else to do – like climbing a tree or riding my bicycle. I enjoyed the company of others as long as I got some degree of respect, but I did not find being alone a major curse. As a young person it is not difficult to create friends (and enemies) in one's mind; and in your mind, they are under complete control. It is a healthy outlet to a point – but I feel that I had enough healthy contact with others my age to keep my individual play from becoming unhealthy. And I hasten to add that, while there were bad experiences that tend to be placeholders in my memory, there were many good times as well. For the most part my friends accepted my minor shortcomings, even though at times they thought I was a little weird.

At times they would ask questions, and the only answer I could give them was the answer that my parents gave me to these same questions. (They had prepared me well, and for that I am grateful.) I would explain to them that my muscles were weak. While they were somewhat bewildered at such an explanation, it was more than sufficient for children of this age. Sometimes they would complain (like when I would climb up to the top of a tree and then be unable to get down), but they would gladly help me out of my difficulties, and their actions spoke louder than their words. Parents should realize the tremendous positive effects that their children can have when they befriend someone who is different and do not allow it to hamper their friendship.

I have given some thought as to whether I was better off effectively evolving into my disease (as I did) or just being born with it full-blown, as is the case with several of my friends. Actually, for the individuals themselves it tends to be a moot point, since there is nothing that can be done about it. However, from the point of view of parents and those who take care of handicapped children, this might be an important point.

My impression is that individuals who are positive in their outlook generally feel thankful for their situation, regardless of what it is. For example, I have a close friend who was never able to walk as I was – she effectively had her handicap from birth. She feels thankful that she did not have something and then have to part with it. To her, it would be much more traumatic to have to go through that. Having been through that myself, on the other hand, I can assert that I am certainly glad to have had a relatively normal first five or six years. It enables me to relate to other children with whom I now have contact and appreciate their zest for life. Probably the most traumatic adjustment that I had to make was in not being able to ride my bicycle anymore, but this happened very much later, after I was confined to a wheelchair.

Along these lines, the most significant thing about MD is that it allows time for adjustment. It steals your capabilities from you so slowly that you do not notice that they are gone. There is a definite grieving period, but also a continuous adaptation that makes it easier from those who lose all of their capabilities at the same time. For example, as I was forced to use the wheelchair more and more over a period of two or three years, it got to be like a second

home, almost like an extension of my body. We will discuss this process more as we get to it in later chapters.

I am grateful for the “normal” years that I had. However, I am convinced that the most difficult experience must be for those who have no idea that there might be a problem, are living perfectly normal lives and then suddenly, without warning lose it all. For example, Christopher Reeve has my greatest admiration, since he seems to have withstood the loss of all (or almost all) of his physical abilities in a heartbeat, waking up after his accident to find himself completely paralyzed. In my mind, this would have to be the toughest way to be introduced to a handicap, and it would be the hardest thing to overcome. (By *overcome*, I mean to be able to mentally adjust to live a happy and productive life; I do not mean to necessarily obtain physical normalcy.) Even with such a traumatic event occurring, however, the human will *has* the ability to overcome these problems and move on, as has been so amply demonstrated by Christopher Reeve. This man must be seen as one of the major heroes of our day by his demonstration of the power of the human will to overcome all obstacles.

As I mentioned, MD is a disease that begins to show some significance affects in the 6-7-age range. For example, sometimes when I would walk around the neighborhood it would feel like my leg was going to fall out from under me. But for the most part, this was not a major problem at this stage of my life. It consisted of mainly not being able to run and ride as fast, and occasionally falling down. It could be classified as a minor annoyance, not a major catastrophe. When you have MD and use your muscles too much, they begin to ache. I recall one occasion in which my sister had been invited to a birthday party to be held at a skating rink, and I got to go along. I put on the skates and, like everyone else, spent the afternoon skating around the rink. This was the very first time that I had tried on roller skates, so I spent most of the time picking myself up off of the floor. The thing that I can recall so vividly, however, is that when we had finished the afternoon, all of my muscles ached, especially those in my legs. I went home, took a quick bath, and went straight to bed without a second thought about it – despite the fact that it was still daylight outside. My young muscles were probably the physical equivalent to someone who was forty or fifty years old as far as endurance and recovery are concerned. Parents should be especially aware of this, since kids, especially in the “party” environments have a very difficult time keeping themselves from over-doing it.

While this places a considerable responsibility on parents, I am not about to pretend genius as to how they can effectively control a child of five or six who wants to join in the fun with the other kids. It would seem rather cruel and arbitrary to the child if you just jerk him/her out in the midst of having the time of his/her life. Perhaps it is better to allow them to find out for themselves. As I recall the skating event, I recognize that it did me no physical harm. I am sure that my parents were worried, but in this case the greatest love might have been to leave well enough alone. The problem is that there is a point at which intervention will be required, i.e., when that point comes where a failure to intervene will cause physical damage and might aggravate the condition. In this regard, parents need to stay in very close touch with the child’s doctor to determine when this will occur. In addition, if at all possible, the child should share this responsibility as much as possible. This too is an extremely difficult call to make in that children mature at radically different rates. Further, reasoning which makes complete sense to a

child when in the company of just Mom and Dad gets quickly thrown to the wind when the fun begins.

But I can recall a positive side at this stage in my life as well. Being different brought special attention, and this is something that all children crave. Missy and I were as competitive as most siblings – probably on the upper edge of the distribution. Both of us were always looking for something that would make us different to get the edge on the other. For me, MD was one thing that tended to focus additional attention on me. Sometimes I wonder about kids that are constantly getting hurt (some call it accident prone), and feel that in many cases they are willing to take the short term pain for a much larger perceived benefit – attention. In my case, of course, it was not under my control, and it was more like a long-term pain for the benefit of the immediate attention. You have to remember as well that the downside delay of even a few years seems like an eternity to a kid.

To elaborate further, I can recall my parents giving me a whistle to wear around my neck in case I fell down and could not get up. Well, the whistle was kind of a pain always flopping around and everything. And I figured: what's the sense in having this great attention-getter if you could never use it? So (I can recall once quite vividly -- there might have been other times), I fell down on purpose just so I could “blow the whistle.” Similarly, another time they gave me a bell to place on my nightstand in case I was to fall out of bed or something. That very night, sure enough, I just happened to get too close to the edge and fell right out of bed. Unable to get up I availed myself of the benefits of the bell. Fortunately, this incident occurred before my parents had gone to bed (only a few minutes after I got in bed), so they were not too annoyed. In retrospect, I can see that I was not putting anything over on them. However, not wishing me to be intimidated into not calling for help, they went along with my wolf-crying tactics. This sounds kind of trivial at this point, but such things tended to give me a positive outlook in turning an otherwise really rotten-developing situation into an advantage.

The early visits to the doctors were not all that bad either. I had the normal apprehensions at this point about the ones who stick you for blood or give you shots. A major transition came, however, when I began seeing a specialist in Birmingham. He never did any of these things, as I recall, since he was primarily concerned with fitting and adjusting the braces and then getting on to the other therapeutic treatments that would follow. I got to look forward to Missy and my getting a day off from school and taking that hour-long trip into the city. Having supper at MacDonald's across the street was also something that kids look forward to – and we were not exceptions. Having all of this centered on me made me unique and gave me my own separate identity. The doctor had recommended that I get used to the braces and walk with them regularly. This resulted in Mom taking Missy and me to the Mall almost every afternoon for a while, which was another great plus.

The main purpose of going to Birmingham to see the MD specialist was to see if he could offer a treatment of the disease. As we all know, there is no cure for the disease itself. However, at this time no one had alerted me as to the seriousness of the disease, and I really did not care to inquire myself about it. I did not even know what the name of the disease was at this point. (I am appreciative that this was one concern that I did not have to worry about at this time.) The

specialist pointed out that the objective of the treatments was to keep me walking just as long as possible so as to put off the consequences which occur when you become wheelchair bound. One of the first things that he recommended was exercise that would help stretch the muscles in my arms legs and ankles. If they stay stretched and relaxed, that would keep me walking even longer, and I would get more use out of the muscles. The main problem that MD patients develop is that their heels begin lifting off the ground, which makes patients so afflicted have to walk on their toes. Of course, the toes are not going to take that pressure for very long, putting the patient into a wheelchair much earlier than necessary.

The MD specialist had a couple of recommendations in this regard: (1) have surgery to stretch the tendons (which is what my cousin opted for), or (2) wearing braces with weights at the bottom of the heel to keep the foot flat. This latter option is the one that my parents thought best for me. So I wore orthopedic shoes with the braces and weights connected to the bottom of them. The first pair was too small, giving blisters on the back of my ankles, causing excruciating pain, especially at night

So the attention advantage was ironic in that it cuts two ways. When I would wake in excruciating pain and have to call out to get my parents to adjust the braces, I would gladly have exchanged the special attention for a good night's sleep. However, after a couple weeks of this, Dad and I drove back to Birmingham and they fitted me with a larger pair of shoes. (I wore the braces for two or three years.)

While this was truly a major downer, I did not perceive of wearing the braces as some great curse. While the pain was not worth it (when there was pain), the braces gave me an identity of my own, which was an advantage the majority of times when the pain was just a minor inconvenience. Once I got used to them, the braces became part of me – just like slippers or regular shoes. I understand that this is how many people actually get attached to their crutches or canes, and there is a grieving process when they are so fortunate as to be forced to give them up. In my case, the shedding of the braces was such a non-event that I cannot recall when I stopped wearing them – probably around age 7. At that time there was a transition since I began only wearing them at night. I remember when I began to outgrow them and we had to take them back to Birmingham. They cut the toe of the shoes out so that my toes could stick out.

Tree climbing with the braces was a major problem. Most kids shimmy up and then walk up the limbs like a strange ladder. My approach was to grab a lawn chair or something else to boost me up before I could get up. Sometimes the kids would get tired of this and abandon me. Again, however, this was the same type of temporary setbacks that most kids have. While it bothered me at the time, I also remember fully recovering from it the next day, so that we had no problem picking it up where we left off the previous day.

The slow onset of MD allowed for some physical victories as well in these early years. I recall a visit to a friend of mine in our neighborhood (I will call him Johnny). This was during the summer and we went out after dinner to play. There was a big pear tree out back and we went and picked up a few ripe ones for dessert. It was a big tree and the ground was covered with them. We started tossing them around, one thing led to another, and we began throwing

them at each other. My aim, of course, was not nearly as sharp as anyone else, and I had real problems in scoring any direct hits. I would really prefer to avoid such a game, and after a few token throws I withdrew behind a tree to a purely defensive position. This led to the accusation of “chicken” several times, which had the same effect on me as it would on any kid. As we were heading back to the house, Johnny ran on ahead and hid. He did not realize that I still had a pear. Just when we came close to the house, he jumped out from behind a tree and yelled “chicken” just one too many times. I hauled back and delivered the pear over about a ten yard span right to the tip of his nose, which immediately started to bleed. Naturally I was scared to death, so I ran straight home.

He got his parents and soon they were over at our house. I was expecting the worst from Mom and Dad, but I cannot recall ever being punished. I am not sure why they cut me the slack, but always felt that it was because it was an accident (of sorts), and everyone was engaged in the game. The fact that I recall this as a major “triumph” is indicative of the need that most kids have to be able to defend themselves. I am certainly not an advocate of violence, but *all* kids have to grapple with this problem at some time or another, and the handicapped are not immune.

The most definitive negative impression at this time was one time when a friend was visiting at our house. We were sitting on the floor playing with our matchbox cars. Every time that I would get up to get something else; I would use the foot of the bed to help me climb up to a standing position. After this occurred about three or four times, he asked me: “Why do you always have to climb up on the bed to get up?” This is really the first, or at least the most traumatic, time that it hit home that there was something different about me. Not that he was being mean – he readily accepted the “weak muscles” explanation, and we went about our games. It is interesting that an encounter with our peers often is much more of enlightenment as to reality than is the weighted and well-rehearsed words of our authority figures. Even with such an abrupt collision with reality, however, I recall that I was having far too much fun at the time to begin feeling sorry for myself. That is as it should be – childhood is not to be wasted worrying about a future that may never be.

Some of my friends would go out of their way to be nice about it, but this had as much of a negative as a positive effect. For example, some of them would give me a head start in our races but then come back later and brag to others about it. Rather self-serving benevolence to be sure. All such things began to impress upon me that I had a problem that was far broader than the physical weakness of my muscles. There was a weakness in the dedication of my friends that was far more difficult to cope with. After all, what was the big deal in having to use the bed to get up, or not being able to run quite as fast? Those things were not the problem – I could deal with them. But how do you get people to understand that you want to be accepted as an equal and not given special consideration. Perhaps this is impossible. And more importantly, if they are going to help they need to do it out of real concern for my problems and not just to give them some future advantage at my expense.

As an example, I can recall on occasions going to a movie with some of the kids at church. I never heard them say how great they were, or how inconvenienced they were because they had done this “charitable” act. If this were their attitude, I would rather have gone to the

movies by myself or with my family. No, they seemed (because they were) genuinely enjoying my company, and I theirs', and I would recall them commenting on what a fun time we had on these occasions. Now, perhaps there was some inconvenience in this, and perhaps they would rather have done this with someone who was not handicapped. By I must say *perhaps* because I never knew either by what they said or their reactions to me. It seemed as though they were enjoying my company not *just* to make me happy, but that they were sharing in the overcoming of my physical shortcomings and enjoying the benefits of this as well.

I recognize that half of this has to do with the attitude of handicapped individuals, since we can make such interactions either relaxed fun or very tense situations. One prime contributor to this is to keep things light – be willing to crack a joke when the inevitable happens and your handicap gets in the way of something. This is generally a psychological, not a physical, problem. No one minds taking an extra couple of minutes to help, or to put forth a helping hand – in fact, that is what they want to do. If everyone can have a little laugh in the process, so much the better. The environment is there, since there is no better set-up to a good laugh than a little tension. So when it occurs and no one exactly knows what to do, interject a little humor and make the situation work for you. A little exaggeration (“no problem, just exercising my security system”), or something unexpected (in a deep voice: “your breakfast sir” when its spilled all over the floor) – use your imagination. It has to be spontaneous and fitted to the situation to be effective, but practice makes perfect.

Of course, it is quite difficult to expect this of a child of six, whether s/he is handicapped or not. A child of six cannot hope to change the nature of the other children, and in most cases even one's own character is not in control at this point. This job can only be accomplished over a long period of time primarily by parents, and secondarily by society as a whole through schools, churches and other institutions. Parents have primary responsibility, and they should recognize that their children will inherit their disposition and their personality traits. If they see themselves as victims, so will the child. If they see themselves as blessed, so will the child. If they are bitter at life, so will the child be, regardless of circumstances. If they make a habit of humbly laughing at themselves, so will the child, regardless of the circumstances.

The parents of the disabled child might also find themselves to be quite vulnerable, since it is impossible that others can fully identify with them and their children. When the inevitable rejection does occur, it should be explained as something that cannot really be prevented in this stage of our society's maturity –but that many are working on it, and perhaps one day the victim can help in this effort. In the meantime, I strongly recommend that parents have alternative activities with the family, and cultivate several activities that involve the child alone. This will go a long way toward getting their minds off of these things until a degree of maturity in the child is achieved at which time they can get out of their fantasy world and have some effect upon themselves and others. We cannot expect children to be crusaders at this point in their tender lives. While isolation is not the answer, neither is confrontation. A balance is essential to preventing total despair and maintaining a healthy degree of hope.

My cousin Kevin, who was a year older than I sort of blazed the trail for me, since the disease was more advanced in him. There might be some question as to whether this played to my advantage. It was not a matter of choice: Kevin was my cousin, and since MD is a hereditary condition, it is probably not uncommon for those afflicted with the disease to have close relatives who share their fate. Parents who have children with MD where there are no close relatives similarly afflicted have a choice as to whether to expose or shield the child from others who have this same disease. This would be highly variable with the personality of the child, and I do not pretend to have a general answer. However, in my case I feel that this type of exposure can cut two ways. It can serve to allay unwarranted fears in some children, while in others it will do just the opposite. If the “friend” is older, coping well and not really too much further advanced in the disease, the friendship will certainly bring hope. For children this age, time seems endless; thus, if it’s a “big kid” (four years or so older) who shares similar symptoms but is not that much further ahead in the disease’s advancement, the friendship can bring hope. On the other hand, I strongly discourage it if, in fact, the friend is in significantly worse condition, for all that this can do is to scare a child whose sensitivities to such things cannot be understood by most adults. Older kids can be insensitive, and if they think that they are doing the younger one a favor by talking about being confined to a wheelchair (or other negative outcomes of the disease) this can be quite negative.

This is a strange dilemma, since with MD and many other diseases, chances are high that the older child will encounter some rough times and even die. It is not a matter of dealing with objective reality at this point – it is a matter of keeping the fears aside long enough to allow the young person to enjoy his/her childhood. Some people believe that they should be brutally “honest” with their child. I strongly disagree with this approach, since it usually leads to unwarranted and totally unjustified fear. It is never right to lie; however, there is no reason that the entire truth needs to be revealed in all of its gory details. Would you take the newspaper and read all of the horrendous evils that people are perpetrating on one another to a young child just because it is reality? Would you describe all of the details of rape and child abuse? There are some things that they certainly need to know about these things, but there are others that they should best learn about when they can handle it. It is wrong to deny young people of their childhood just because they have special problems. My feeling is that it is best to keep the young as innocent as possible, but build confidence by not hiding what is the obvious when it manifests itself. “Sufficient unto the day is the evil thereof.” Take it one day at a time using love and good common sense – it works out best if questions are answered accurately and realistically as they come up.

Do not volunteer unnecessary detail. Wait for the appropriate questions, and then be prepared to deal with them in a straightforward manner. The truth does not have to be uncomfortably forced; it might not even be received with the same perception as that given, thus making the attempt a failure to actually convey the truth. For example, if a description of a future event leads the child to overreact with fear, no useful objective information will be conveyed. This requires great wisdom and judgment on the part of parents and other care providers, which is what we are hoping that the information in this book will promote.

In my case, this was as much a function of Kevin's personality as it was of mine. Kevin had a very positive outlook on life, and this had the effect of enabling me to enjoy my childhood despite the many pains and inconveniences with which I was afflicted. Of course, neither one of us was aware of the extent to which we were affecting each other – we were just kids having a good time. The fact that we had MD in common made it one less thing that needed explaining to each other, and this established a kinship that was difficult to establish with most normal kids.

It might be difficult to find a "friend," as was the situation with my cousin. However, your local MD Association (MDA) or other related support organization will be glad to help. The information that I am presenting here is from the perspective of one who has been through it first hand. I recognize that this is not the most objective perspective, and I advise you to take whatever advice the psychologists that you have available to you can give you. Ultimately, however, the decision as to the extent of and type of involvement with others will be the parents' responsibility, and I believe that the perspective that I have given will be valuable in this regard.

Before we leave this subject, one other option is summer camp. Recognize that this is the same problem or opportunity for handicapped kids as it is for normal children. Some will enjoy it whatever is thrown at them; others will hate it regardless of how much they are catered to. Homesickness is not a function of disability; it is more a function of environment and innate personality. My personal recommendation is not to "force" the kids to have fun. If it is meant to be, they will find new friends on their own with the appropriate encouragement, of course.

As I got to school age, there were times when I found it more and more difficult to keep my balance and I fell down quite often. One day when I was visiting two of my friends (who were brothers) and I was at that stage where I was falling down a lot. They had this black poodle, and every time that I would fall down, that thing would jump on top of me and start licking me in the face. I am a great dog lover; but few people like to be licked in the face by a dog. So, each time I fell down, I would look to be sure that that little dog was not coming after me. After a while, however, we recognized that the dog had been bothering me just a little too much, so I kicked at the dog not realizing that I would actually hit it. But I did, and when he squealed, my friend's father asked me if I had kicked the dog. I told him it was an accident; but I am still not sure that it was.

These mixed remembrances are probably quite characteristic of these early years. Few children do not have some perceived shortcoming that tends to focus their greatly exaggerated concerns. I probably did not, at this stage, fully recognize that in my case these perceptions were as real and as devastating as they were. But most other children do not recognize how unreal and insignificant their concerns are either. So, feeling wise, these early years were not without redemption. That pup bothered me, but I could kick him away if I wanted to.

I remember one particular occasion when things were really not going at all well for me. Strangely, the major problems had nothing to do with MD, but I was doing the normal "feeling sorry for yourself" cycle that most young people go through. As I recall it had to do with Missy spending the night with one of her friends, leaving me, on one of those rare occasions, without her to fight with. Well, after all of this, I can remember going in and interrupting Dad, who was

in bed reading. I feel for him, because there was not much that he could do to answer the question of “why me?” He smiled a reflective but concerned smile pressing his lips together, and said: “I understand.” He knew as I did that there was no way that he could really understand, but that was of secondary importance to providing the assurance that someone was there when I needed help. The point is that MD has little to do with it in the mind of a child. All children need such support, and they are disabled without it more than the effects that MD can ever produce.